“You have to sometimes be like a bulldog”: Filial Caregiver Experiences Supporting their Parents During the Transition from Hospital to Home in Ontario

by

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ABSTRACT

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During older age, many people experience hospitalization, and during the transition from home, family members are often depended upon to provide support. Often these family members are filial caregivers, yet limited research has examined their experiences caring for their parent during this period. Eighteen filial caregivers from Southern Ontario were interviewed about their experiences caring for their parent during their parent’s transition from hospital to home, and a thematic analysis was conducted. The analysis contextualized caregivers’ experiences by examining how caregivers described the healthcare system, and the concerns they had about their parent’s care. The analysis also examined the activities that caregivers performed to support their parent during the transition from hospital to home, and the challenges they encountered in doing so. Specifically, the analysis suggests that caregivers did not always have the capacity to support their parent because they did not have access to necessary information or resources, and in some cases, may not have had the authority to intervene in their parent’s care. In such instances, their
parent’s well-being could be compromised. However, caregivers actively worked to overcome these barriers, and advocated to gain access to resources and information that would improve or maintain their parent’s well-being. Findings suggest that increased attention to the role of caregivers is needed, and examining what they can reasonably be expected to do given the structural conditions under which they provide support.
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# Table of Contents

**ABSTRACT** ................................................................................................................................. ii

**Acknowledgements** ..................................................................................................................... iv

**List of Tables** ............................................................................................................................... ix

**Chapter 1: Introduction** ................................................................................................................ 1
  Care Transitions ............................................................................................................................... 3
  Overview of the Dissertation ........................................................................................................... 5

**Chapter 2: The Context of Caregiving** ......................................................................................... 7
  The Ontario Healthcare System ...................................................................................................... 8
  An ‘Apocalyptic Demography’: Perceived Challenges for the Canadian Healthcare System .......... 9
  Increasing Reliance on Family Members to Provide Support in Older Age ..................................... 10
    Perceptions of responsibility in the healthcare system. ................................................................. 15
    Preferences of older adults. ............................................................................................................ 19
  Financial and Employment Benefits to Support Informal Caregivers ............................................. 20
    Tax credits. ................................................................................................................................... 21
    Compassionate care benefits. ........................................................................................................ 22
    Family caregiver leave. .................................................................................................................. 23
  Profile of Informal Caregivers in Canada ......................................................................................... 24
    Characteristics of informal caregivers. ........................................................................................ 24
  Consequences of Informal Caregiving ............................................................................................. 26
    Employment and the economy. ..................................................................................................... 26
    Financial strain. ............................................................................................................................. 28
    Health and well-being. .................................................................................................................. 28
    Family dynamics. ......................................................................................................................... 29

**Chapter 3 Summary** ..................................................................................................................... 29

**Chapter 3: Caregiving during the Transition from Hospital to Home** .......................................... 31
  Factors that Limit Caregiver Capacity to Support Patients ............................................................ 31
    Information. ................................................................................................................................. 32
    Training. .................................................................................................................................... 35
    Respite. ...................................................................................................................................... 36
  Activities Performed by Informal Caregivers During the Transition from Hospital to Home .......... 37
    Direct care work. ......................................................................................................................... 39
    Advocating on behalf of patients. ............................................................................................... 41

**The Current Study** ...................................................................................................................... 48

**Research Questions** .................................................................................................................... 48
List of Tables

Table 1 Overview of themes and codes developed.......................................................... 66
Chapter 1: Introduction

People are currently living longer than ever before. Medical advancements, safer working conditions and public health measures have contributed to extended lives (Levine, 2004). Indeed, by the year 2036, the proportion of the Canadian population aged 65 years and older is expected to double to represent 23-25% of the total population (Statistics Canada, 2012). This rapid increase is largely attributable to the baby boom population (those born between 1946 and 1964) entering the 65+ year age bracket (Statistics Canada, 2012).

This demographic shift will have implications for the healthcare system as the increasing number of older adults will result in a higher usage of healthcare resources. Many older adults experience good or excellent self-reported health (Statistics Canada, 2014) and older age is certainly not synonymous with dependency; however, in general, older age is associated with increased prevalence of chronic illness marked by decreased mobility and functioning (Public Health Agency of Canada, 2010). Across an individual’s lifespan, healthcare dollars are therefore more likely to be spent nearer the end of life (Canadian Institute for Health Information, 2005).

Although in older age some individuals may never experience a medical emergency, acute episodes of medical crisis arising from complications associated with chronic illness or injury often result in hospitalization (Statistics Canada, 2008). After hospitalization, many older adults require formal and/or informal assistance (Kropf & Cummings, 2017). Increasingly, owing to limited health care resources and an aging population, the Canadian health care system depends on the family and friends of older adults to provide the bulk of assistance to older adults in community settings (Health Canada, 2002).
These family and friends are commonly referred to as ‘informal caregivers’. Informal caregivers are, “individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical or cognitive conditions. They can be primary or secondary caregivers or part of an informal network of multiple informal carers such as siblings who share caring responsibilities for a parent” (Canadian Research Network for Care in the Community, 2011, p.1). Statistics Canada further clarifies this definition noting that caregivers are defined as, “individuals providing help or care to someone with a long-term health condition or physical or mental disability, or to someone with problems related to aging.” (Sinha, 2012). Within the gerontological literature, additional categorizations are often made to differentiate individuals providing care to spouses (i.e., spousal caregivers), from individuals providing care to parents (i.e., filial caregivers), though both terms can be subsumed under the broad category of ‘family caregiver’

Within Canada, filial caregivers comprise the largest group of caregivers of older adults (Sinha, 2013).

Informal caregivers can also be distinguished from formal caregivers. Formal caregivers are paid to support care recipients. However, as will be described within this dissertation, the activities that each perform are often similar. Informal caregivers are frequently called on to perform clinical activities comparable to those provided by formal caregivers that may be beyond their skill capacity, such as dietary management, wound care, and ambulation to name but a few (Schumacher et al., 2000). Additionally, informal caregivers often work to navigate the healthcare system without adequate training or specialized skills, and these roles are often thrust upon them without preparation or support (Coleman & Berensen, 2004).

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1 Family caregivers (including spousal and filial caregivers) are also classified as informal caregivers.
Although the care provided by informal caregivers can remain relatively stable, and caregiving often does not have a discrete beginning, acute medical episodes that require hospitalization may prompt more intensive caregiving (Kane, Reinardy, Penrod & Hucks, 1999). The transition from hospital to home represents a period during which patients and their families are particularly vulnerable (Murtaugh & Litke, 2002), and is therefore an important period to investigate within the lives of caregivers. Within the Canadian context, little research has focused on this period, particularly as it is experienced by filial caregivers. Therefore, the major aim of this study was to examine the experiences of filial caregivers during the transition of their parent from hospital to home.

**Care Transitions**

A primary focus of this dissertation is the transition of patients from hospital to home. Schumacher, Jones and Meleis (1999) provide a theory of transitions in older age, and describe common characteristics of such transitions. According to Schumacher et al., in the broad sense, transitions are triggered by events that require significant changes to daily life, including the development of strategies to address new life circumstances. Transitions are also characterized by the passage of time, and the end point of a transition is distinguished by the establishment of stability. Transitions often demand modifications to expectations, the reformation of established routines and the development of knowledge and skills. Additionally, transitions may not take place in isolation. For example, when an individual experiences a health crisis that initiates a state of transition, their children may experience a simultaneous transition as they assume the role of caregiver.

The characteristics of transitions described by Schumacher and colleagues (1999) are illustrative of the nature of *care* transitions. Care transitions refer to, “the movement patients
make between health care practitioners and settings as their condition and care needs change during the course of a chronic or acute illness,” (Coleman & Boult, 2003, p. 556). Settings can include hospitals, long-term care homes, the patient’s home or the home of their caregiver, as well as primary and specialty care offices (Coleman, 2003). While continuity of care is frequently promoted as an ideal of care transitions, often patients and family caregivers are the only common thread (Coleman, Mahoney, & Parry, 2005).

A significant and common transition that may be experienced by older adults and their families is a transition from hospital to home after experiencing an exacerbation of a chronic illness (or the onset of chronic illness), injury, or an acute episode of illness. Indeed, when older patients no longer require acute care in a hospital setting, the majority (76.8%) are discharged home (Canadian Institute for Health Information, 2012a) rather than to other settings such as long-term care facilities. During care transitions from hospital to home, a shift in the responsibility for care moves from health care professionals to family members (Giosa, Stolee, Dupuis, Mock & Santi, 2014; Lowson et al., 2013; Wiles, 2003) and family members often experience worry attributable to lack of preparation (Bull, 1992). Throughout a family caregiver’s tenure, this period has been described as stressful and frustrating for caregivers, particularly when they are new to the caregiving role (Grimmer, Moss & Falco, 2004).

Hospital stays for older adults are generally shorter than ever before, resulting in accelerated discharges for which families and patients are not prepared (Bauer, Fitzgerald, Haesler & Manfrin, 2008; Lafortune, Huson, Santi & Stolee, 2015; Weaver, Perloff & Waters, 1999). Discharge planners are often at a disadvantage with little time to gather appropriate information to inform a high quality discharge plan (Franco, Kane, & Pothoff, 1997). Furthermore, patient and family input is often underrepresented (Byrne, Orange & Ward-Griffin,
2011; Lafortune et al., 2015), though such input is often necessary to ensure successful and integrated transitional care (Allen, Hutchinson, Brown & Livingston, 2016).

The body of literature on care transitions is growing, with a particular focus on the transition from hospital to home. Within this literature, there is a focus on the needs and actions of family caregivers within the home care environment, presumably because scholars have recognized that the shift from institutional care to home care has placed increasing responsibility on caregivers. However, as will be suggested by the analysis presented in this dissertation, filial caregivers in particular also provide extensive support during the period of hospitalization as well.

**Overview of the Dissertation**

Chapter 2 provides a broad overview of the context in which caregivers are providing support to family members, with a focus on demographic changes, perceptions of responsibility for care, and structural shifts within the healthcare system that have had implications for the role of family caregivers. The chapter concludes with a presentation of the current profile of family caregivers in Canada, and the consequences associated with caregiving. In Chapter 3, the focus of examination narrows, and a literature review about the activities that family caregivers perform during the transition from hospital to home is presented. Challenges are highlighted, and emphasize that caregivers do not always have the information, training or support to be able to care for their relative during this period. In Chapter 2 and Chapter 3 the term ‘caregiver’ broadly refers to family caregivers. However, because the primary focus of this dissertation is on filial caregivers specifically, I note where cited findings distinguish filial caregivers from other groups of family caregivers.
Chapter 4 presents a detailed description of the procedure implemented to collect data, the participants, and the method of analysis. Chapters 5, 6, and 7 are analytic chapters where empirical findings are presented. Chapter 5 “Caregiver Descriptions of the Ontario Healthcare System” examines filial caregiver perceptions of the healthcare system and situates their experiences in the broader institutional context that governs transitional care. Chapter 6, “Caregiving Activities” examines the support that filial caregivers provide to their parents during the transition from hospital to home and the difficulties they encounter in doing so. Chapter 7, “Caregivers as Advocates” examines how filial caregivers respond to the care environment and the ways that they attempt to overcome perceived inadequacies in their parent’s care. Throughout the chapters, the terms caregiver and participant are used interchangeably to denote filial caregivers, and the terms healthcare professional and healthcare provider are used to refer to individuals in healthcare administrative roles or those providing direct, formal care to patients.

In Chapter 8, I reflect on my experiences throughout three phases of research for this study: the pre-research phase, the data collection phase, and the data analysis phase. I discuss how the trajectory of this study changed based on practicalities of conducting research in a real world setting, and describe my relationship to the research. In Chapter 9, the final chapter of this dissertation, I discuss the findings, the strengths and limitations of the study, and possible avenues for further research.
Chapter 2: The Context of Caregiving

The purpose of this chapter is to provide an overview of the current context in which care takes place in older age, highlighting two major institutions: the healthcare system and the family. Although this study focuses on a very specific period in a caregiver’s tenure (i.e., the transition from hospital to home), it is important to recognize that informal caregiving is situated in a broader political, social, and economic context (Levine, 2004), and the transition from hospital to home does not represent a termination of contact with the healthcare system. As we seek to understand the experiences of filial caregivers, we must acknowledge that their experiences can only be understood within this broader and longitudinal context (Wiles, 2003) and that informal caregiving demonstrates the connection between personal lives and public issues (Hankivsky, 2004; Pavalko, 2011). Specifically, although the challenges that family caregivers experience are often personal, caregivers and recipients of care are located within larger systems and institutions that garner public attention. These institutions have changed over time and many of these changes have resulted in increasing reliance on families to provide care to older relatives.

Within this chapter, informal caregiving in older age is discussed at a general level, focusing on support offered by family members. Family is often broadly defined, but generally includes spouses, adult children, and siblings. Given that the focus of this dissertation is on filial caregivers, research findings and policy level discussions that pertain directly to filial caregivers are distinguished where relevant.
The Ontario Healthcare System

The Government of Canada (2017) provides a broad overview of the Canadian healthcare system. Canada has a publically funded healthcare system where purported medically necessary healthcare services are provided to Canadians based on need, rather than on ability to pay. Healthcare is governed at the provincial and territorial level and each province and territory has its own health insurance plan funded through tax revenue. Provincial and territorial health insurance plans must meet standards set out in the federal Canada Health Act, including the up-front coverage of medically necessary hospital and physician services. In Ontario, eligible residents receive healthcare cost coverage through the Ontario Health Insurance Plan (OHIP).

The Ministry of Health and Long-Term Care (MOHLTC) governs healthcare in Ontario. The MOHLTC sets strategic directions for the healthcare system, determines funding structures, develops legislation and policies, and monitors the system’s performance. In 2006, Local Health Integration Networks (LHINs) were established in the province to transfer administrative responsibilities from the provincial to the local level in recognition that healthcare is best governed locally. A total of 14 LHINs exist within the province and each is responsible for “planning, coordinating, integrating and providing funding to local health service providers to create a system that is person-centred, integrated, and sustainable” (Waterloo-Wellington LHIN, 2014, para. 2). More specifically they are accountable for long-term care homes, hospitals, Community Care Access Centres, Community Support Services, Community Health Centres, and Addictions and Mental Health Agencies. They do not carry responsibility for physicians, Public Health agencies, laboratories, ambulances or provincial drug programs (Waterloo Wellington LHIN).
An ‘Apocalyptic Demography’: Perceived Challenges for the Canadian Healthcare System

Providing care to aging parents is certainly not a new phenomenon (Montigny, 1997; Pavalko, 2011). However, increasingly scholars have described changing demographic and social trends that have introduced informal caregiving as a pressing matter for political discussion (Betts, 2014; Pavalko, 2011). Although it is evident that a greater number of healthcare dollars are spent in older age, the mere demographic shift alone (i.e., an increasing number of individuals over the age of 65) does not account for the increase in healthcare spending (Montigny, 1997; Williams et al., 2016). Montigny (1997) states that other independent factors also contribute to these rising costs, including the development of new and often costlier technologies, a purported propensity to over-medicate, and the rising price of pharmaceuticals. Nevertheless, the financial implications associated with a greater number of Canadians living into older age has in part contributed to alarmist reactions among policy makers, the media, and gerontological researchers who construct the aging population as a crisis (Estes, 2011). For example, in a qualitative analysis of media accounts of older adults in a national Canadian newspaper, Rozanova, Northcott and McDaniel (2006) found that older adults were constructed as ‘burdens’ to both their families and the healthcare and social security systems. Such a categorization is not unique to media accounts. Such language is also widely used by policy makers where aging populations are also described as “tsunamis” or “tidal waves” (Stephens & Flick, 2010), reflecting an impending crisis.

Despite the perceived contemporary uptake of these characterizations by the public (including the media and researchers), this type of discourse is not new. As early as the 1890s, the Ontario provincial government was engaged in debates about the financial burden of supporting dependent older adults (Montigny, 1997). Such debates continue and have largely
influenced healthcare policy and reform, and defined state and familial responsibility related to
the care of older adults requiring support. Within these debates, the construction of older adults
as a burden to the healthcare system often underlies arguments that are used to support the
retrenchment of public funding for programs and services (Betts, 2014).

**Increasing Reliance on Family Members to Provide Support in Older Age**

Owing to limited health care resources and demographic shifts toward an older
population, the Canadian healthcare system increasingly depends on the family and friends of
older adults to provide the bulk of assistance to older adults in community settings (Expert
Group on Home and Community Care, 2015; Hankivsky, 2004; Health Canada, 2002;
OACCAC, 2015). This largely reflects a historical shift of state responsibility to family
responsibility to care for older adults in need of support, and this trend has been noted across
developed nations (Allen, 2000; Bauer et al., 2008; McKeever, 1999; Skinner & Rosenburg,
2004; Wuest, 2000).

In mid-19th century Ontario, notions of being a good neighbor were prevalent and concepts of
individuality and self-reliance that currently dominate Western culture were limited. (Montigny,
1997). Montigny notes that within such a context, families were not expected to bear sole
responsibility for older relatives who required care and support, but rather care was perceived to
be a communal responsibility, with municipal governments also providing a great deal of
financial assistance to older citizens. However, when the economy slowed in the late-19th
century, Montigny explains that there was an increasing perception among policy makers that
older adults were draining the treasury as a result of their reliance on public assistance funding.
As a consequence, social welfare spending was reduced which meant that few older adults
received any publically funded assistance, and strict eligibility criteria was enacted within public
institutions (e.g., poor houses, asylums) that limited the number of individuals admitted. As a consequence of these policies, families were required to provide a greater amount of financial assistance to support their older relatives.

More recently, formal changes to health care delivery have further increased the role that families play in caring for older relatives (OACCAC, 2015). According to Health Canada (2012), healthcare services and their delivery have changed in the period since inception of universal healthcare in Canada. The increased prevalence of chronic conditions among the Canadian population poses challenges for the healthcare system which was originally developed to respond to acute, episodic conditions (Rajakulendran, MacIntosh, Salah & Khayat, 2014). With limited healthcare resources, economic downturn, and the constant need to provide more care to more people, there has been a shift from reliance upon hospitals and institutions, to home and community care (Canadian Healthcare Association, 2009; Health Canada, 2010).

The reliance upon home and community care is illustrated by examining system level restructuring in response to particular fiscal environments. During periods of economic prosperity, greater public health care expenditures are often made to support older adults, though such periods are temporary and are often followed by retrenchment of services and supports. For example, during the 1950s and 1960s, more than 500 nursing homes were built province wide but the demand for institutional care rapidly outpaced available funding (Williams, 1996). Therefore, during the 1970s the Home Care branch of the formal provincial healthcare system was established as a cost-saving alternative to institutional forms of care. This branch of the healthcare system provides publically funded care to individuals who require care at home or in the community (Ontario Homecare Association, 2008).
The shift in system reliance to home care is further evidenced by examining provincial health care statistics. Over the past several decades, the number of overnight stays in the hospital has decreased and alternative services provided at home and in the community has grown (Health Canada, 2012). Furthermore, over the last 12 years the number of individuals receiving services funded by the Community Care Access Centres (CCACs)\(^2\) within the community has increased by 101% (OACCAC, 2015), and since 2008 the number of patients discharged to home care services after a hospital stays as increased by 42% (Intellihealth, 2015). Additionally, since 2009, the number of older Ontarians being admitted to long-term care homes (commonly referred to as ‘nursing homes’) has decreased by 26% (Government of Ontario, 2012). Although absolute figures are not publicly available, it is likely that these statistics represent large shifts in healthcare delivery.

This move to home and community care is referred to as *deinstitutionalization* (Flood, 1999), and is attributable to a number of factors. Technological advancements related to medical care have enabled individuals to recover in their homes rather than in hospital (Health Canada, 2010). Prior to such advancements, individuals often remained in the hospital until they were fully recovered (Kripalani, Jackson, Schnipper & Coleman, 2007). Returning patients to their homes before they fully recover (or what has been colloquially been termed “quicker and sicker”) has meant that family caregivers are increasingly required to perform medical tasks such as wound care, catheter maintenance, maintaining and monitoring medical machines, and administering medication that were previously performed by professional healthcare providers.

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\(^2\) At the time this dissertation was written CCACs arranged for care within the home and community context by determining eligibility for publically funded services, and connecting individuals with appropriate resources. Since the time data was collected, CCACs have been subsumed under the Local Health Integration Networks. Therefore, although the organization is no longer referred to as the CCAC, because this was the term used at the time of data collection, this is the term that is used throughout this dissertation. A more detailed description of CCAC services is provided in the Methods Chapter.
Although some policy makers argue that relying on family members to provide care is merely “returning care work to its rightful place,” (Hankivsky, 2004, p.114), in their paper submitted to the Law Commission of Canada, Armstrong and Kits (2001) remind us that, “our grandmothers never cleaned catheters or checked IV tubes, they did not examine incisions or do much wound care” (p. 26). This shift has been referred to by some scholars as the “trivialization of high-tech care” in that family caregivers are assumed to have the knowledge and skills to perform tasks that are highly complex and specialized (Guberman et al., 2005).

Additionally, fiscal expenditures on healthcare have slowed over the past 35 years, particularly as they relate to hospitals. Although hospitals still receive the largest share of the healthcare budget (29.4% in Canada in 2014), on average, hospitals are currently receiving the lowest funding since the economic recession of the 1990s (Canadian Institute for Health Information, 2014). Traditionally, during periods of economic recession governments have exercised fiscal restraint on hospital expenditures. For example, during the economic recession of the 1990s, a number of hospitals were consolidated and beds were closed across the country (Canadian Institute for Health Information, 2014). With limited budgets, hospitals were forced to enact cost saving measures that additionally drove the shift to home and community care. A recent report from the Canadian Institute of Health Information (2015) shows that Ontario’s spending on hospitals is the lowest in the country at $1,396 per capita compared to the national average of $1,750.

Budgetary restrictions within hospitals have consequences for the qualifications held by healthcare providers and potentially the quality of care they deliver. The Registered Nurses
Association of Ontario (2015) (RNAO) reports that, on average, from 2005 to 2014 the proportion of Registered Nurses employed in hospitals has decreased while the proportion of Registered Practical Nurses has increased. RNAO explains that Registered Practical Nurses have less extensive training compared to Registered Nurses which makes them less suitable to increasingly complex patient needs. This context, they argue, compromises patient safety, resulting in adverse patient health outcomes.

With a shift in focus to home and community care, the provincial government has increased funding to this sector. Specifically, since 2003/2004, the government has increased funding to CCACs by roughly 5.6% per year (Expert Group on Home and Community Care, 2015). However, funding to CCACs still only accounts for only 6% of the overall healthcare budget (Expert Group on Home and Community Care, 2015). At the same time, the number of clients receiving services from the CCAC has increased by 101% (OACCAC, 2015). As such, CCACs must provide care and services within a fiscally restrained environment and representatives have noted that funding to the home care sector is inadequate (Ontario Human Rights Commission, 2001).

CCAC support is also governed by service maximums which restrict the number of hours of professional support offered within the home (including retirement facilities). For example, the CCAC’s Client Services Policy Manual (2007) states that 1) personal support services (e.g., personal hygiene, activities of daily living) cannot exceed 80 hours of service within the first 30 days of service and 60 hours within any subsequent 30-day period, and 2) registered nurses’ service cannot exceed more than 43 hours of service within a week, or support cannot exceed 53 hours of service per week if provided by a registered practical nurse. Personal support services may be provided in “extraordinary circumstances”, where the client’s requirements exceed the
service maximum, for a period of up to 30 days. Such circumstances might include situations in which family caregivers are ill or clients are waiting for alternative arrangements. However, the provision of additional services is contingent upon an assessment by a CCAC Care Coordinator and is therefore not guaranteed, nor is the provision of the service maximums. This means that each client who is eligible for services may not qualify for the service maximum (ARCH Disability Law Centre, 2013). In summary, if we examine the maximum provision of personal support services, we can see that within the first 30 days, clients are eligible to receive approximately 3 hours of service per day, while within any subsequent period they are eligible to receive a maximum of 2 hours of service per day. Within this environment, families are therefore increasingly called upon to support their older relatives (Expert Group on Home and Community Care, 2015; Health Canada, 2002; OACCAC, 2015).

**Perceptions of responsibility in the healthcare system.** Increasing caregiver responsibility can also be realized through the expectations of formal service providers regarding the role of informal caregivers. For example, among a sample of nurses, occupational therapists, social workers and physiotherapists from Quebec who participated in an interview study, much discussion focused on the activities that they expect family caregivers to perform when caring for an older relative (Guberman, Lavoie, Pepin, Lauzon & Montejo, 2006). Service providers expected family caregivers to monitor their family member’s medical condition, initiate services when necessary, and provide service providers with the information about the patient (i.e., older adult). Service providers also expected family caregivers to develop nursing level skills and engage in rehabilitative efforts with their relative during periods when professional homecare services were not available.
Similarly, findings from a study that took place in Southwestern Ontario suggest that homecare nurses expect that family caregivers will learn the necessary skills to care for their older relative, and nurses often delegate tasks to family caregivers over time as their skills grow (Ward-Griffin & McKeever, 2000). However, caregivers are not always willing to partake in technical activities related to the care of their relative (e.g., giving injections) because they are overwhelmed and sometimes perceive the task to be too difficult. According to Guberman and colleagues (2006) such findings suggest that service providers’ expectations reflect system wide values that place the majority of the responsibility on families.

Providing care to a family member requiring support may be viewed as a normative aspect of family relationships, and some family members may prefer to be involved in the care of a relative. Indeed, research suggests that family members who have been involved in a relative’s care for an extensive period of time experience challenges relinquishing control over their relative’s care (Allen, 2000; Lowson et al., 2013). However, the provision of familial care becomes problematic when it exceeds the capacity of the family (Levine, 1999), particularly within a context where family caregivers lack the skills required to support an older relative (Glazer, 1990). As I will explain in the next chapter, research suggests that the tasks required of family caregivers often outpaces their capacity, particularly during the transition from hospital to home.

As discussed, current healthcare structures are largely reflective of increased responsibility of informal caregivers in the care of older relatives requiring support. Two policies that embody the responsibility placed on informal caregivers of older adults warrant consideration: Aging in Place and Home First. These policies have been implemented by governments to support individuals as they age. However, critical scholars argue that many of
the policies enacted to support older individuals place the majority of the responsibility on family caregivers by redefining state responsibilities (Montigny, 1997; Skinner & Rosenberg, 2004; Williams, 1996).

**Present policy: Aging in Place.** In response to demographic shifts towards an older population, globally there has been a push to implement *Aging in Place* policies. Such policies are intended to ensure that older adults can remain safely in their homes or communities, as long as possible regardless of their age or ability level (Morely, 2012). Such policies are fiscally desirable because home care expenditures are significantly less than those incurred by institutionalized care (Betts, 2014; Lecovich, 2014). For example, in Ontario it is estimated that the provincial government incurs a cost of $45/day for home care services, $135/day for a long-term care bed, and $450/day for a hospital bed (Health Care Ontario, 2016).

Such policies also reflect the preferences of older adults, many of whom wish to remain in their homes (OACCAC, 2015). These preferences are held by both older adults in good health, as well as those experiencing physical or cognitive declines; when support is necessary, most older adults express a desire to receive such support within their own homes (American Association of Retired Persons, 2000). Remaining within one’s own home promotes a sense of familiarity and maintenance of social connections (Wiles, Leibing, Guberman, Reeve & Allen, 2011), as well as the maintenance of identity, well-being and a sense of independence and control (Cutchin, 2004).

Although such policies have clear benefits, in order for implementation to be successful, care both in, and by the community are essential (Chui, 2008). Care in the community refers to the provision of care within a community that an older adult is familiar and comfortable with, and one to which they feel a sense of belonging. Care by the community denotes a willingness on
the part of fellow community members to care for and support older adults. Very often this means that the support of family members is required (Ontario Non-Profit Housing Association, 2016; Tang & Lee, 2011). Therefore, such policies are dependent upon the intensive involvement of informal caregivers, many of whom report having little choice in providing care (Grimmer et al., 2004).

Present policy: Home First. Home First policy embodies the emphasis that the healthcare system places on home and community care, and relates specifically to discharges from hospital. Within this policy, earlier hospital discharges are promoted, with the most desirable discharge destination being the patient’s home (i.e., the place that the patient lived prior to hospital admission) (CCAC, 2015). During the hospital stay, a home care plan is developed in collaboration with medical professionals (e.g., doctors, nurses, therapists, etc.), a CCAC Care Coordinator, the patient and their family. The homecare plan is implemented by a CCAC Care Coordinator and includes publicly funded services required by the patient to promote optimal recovery (e.g., personal support, physiotherapy, nursing, speech therapy, social work, dietary advice, equipment and supplies). Upon discharge the patient receives the documented services, and, as their health improves, service hours decrease (CCAC, 2014).

This policy is intended to provide benefits for both patients and their families, as well as the healthcare system. For patients and their families, there is a reduced risk of hospital acquired illness, maintenance of health within a familiar environment, as well as the opportunity to reflect on future healthcare decisions, including the possible admission to a long-term care facility, in a comfortable environment. Benefits for the healthcare system include a greater availability of hospital beds, as well as the prevention of premature admission to long-term care facilities, thus leaving space for those who cannot safely be supported in the community (CCAC, 2015).
Although *Home First* programs provide desirable benefits, shorter hospital stays often mean that older adults have not returned to the same level of health and functionality as prior to the acute episode that resulted in hospital admission (Bauer et al., 2008; Weaver, Perloff & Waters, 1999). Therefore, they often require intensive care, some of which must be provided by family caregivers (Advocacy Centre for the Elderly, 2011; Armstrong & Kits, 2003; Williams, 2012). Indeed, often underlying such policies is the assumption that family members will provide care, often without consultation with them about their willingness to do so (Dow & McDonald, 2007). As will be discussed in the following chapter, caregivers still play extensive roles in the care of their older family members after discharge which suggests that even when publicly funded services are offered, they are still responsible for the bulk of the care. As an illustration, Kane and colleagues (1999) describe the intensive nature of the care and support that family caregivers provide to older adults during the period after hospitalization. Specifically, on average, during the first two weeks post-discharge, caregivers provide 42 hours of care per week to their relative. This figure decreases at the 6-week point to 26 hours, still indicating an intensive level of care.

**Preferences of older adults.** Throughout this discussion, emphasis has largely been placed on understanding the responsibility of the state and families with respect to the care of older adults who require support. However, the preferences of older adults are also important to acknowledge (Van Haitsma et al., 2013). As individuals age, they are more likely to require some type of assistance (Pinquart & Sorensen, 2002). This assistance can come in many forms including buying groceries, transportation, bathing, dressing, taking medication, and nursing to name but a few. Some older adults are entirely capable of performing these tasks independently,
but among those that do require support, the preferences for the source of support is an important consideration.

The preferences of older adults have received only recent attention within the literature. Mair, Quinoes and Pasha (2015) suggest that generally, when there are high state expenditures on healthcare (e.g., the existence of universal healthcare), older adults are more likely to express a preference for state-based care over family-based care. This preference is augmented for older adults who experience chronic health conditions that may require more intensive support over the long-term (Mair et al., 2015; Pinquart & Sorensen, 2002). While the reasons for preferences of formal care over informal care have not been directly explored, Mair and colleagues suggest that older adults who have chronic conditions may have concerns about their family’s capacity to support them in the long term, and about the strain that caregiving may place on family relationships. Despite this finding, reports suggest that there is often limited use of formal services among older Canadians who require assistance, with the bulk of support being provided by family caregivers (Statistics Canada, 2009).

Financial and Employment Benefits to Support Informal Caregivers

In general, families have always provided care and support to their older relatives, and some policy makers view their increasing involvement as a natural shift. However, when we examine the publicly funded supports available to caregivers, and the consequences associated with caregiving, we can see that such a shift becomes problematic (McKeever, 1999).

Within the federal Canadian and provincial Ontario homecare system, services are often aimed at addressing the needs of patients, with little direct support offered to caregivers (Guberman et al., 2006). The federal and provincial governments do offer some support to family caregivers and this support is important to acknowledge. However, while this support is
available, eligibility criteria are strict and research demonstrates that caregivers are often not aware of these benefits (Sihna, 2012). In the following sections I provide an overview of these publicly funded supports.

**Tax credits.** Home Care Ontario (2015), advocates for increased tax credits for family caregivers who supplement publicly funded professional care with private home care services. The underlying basis of this argument is that any lost tax revenue would be balanced by the avoidance of re-hospitalization when families are unable to cope, which is significantly more costly than home care services.

On a federal level such arguments have been accepted to a degree. The Canada Revenue Agency offers tax credits for individuals caring for a dependent with an impairment in physical or mental functions, and dependents can include parents. To provide an example of how this tax credit applies to filial caregivers specifically, in order for filial caregivers to claim the tax credit, their parent must be dependent on them because of a physical or mental impairment, and their parent must have little or no income themselves. Individuals claiming this tax credit must have a signed statement from a medical practitioner describing the nature of the impairment and its expected duration. In 2016, individuals could claim $2,093 to reduce their payable federal income tax, and receive an additional $314 provided that their total credits were not more than their total income tax payable (Canada Revenue Agency, 2016). Despite the availability of this tax credit, the financial difference it makes in the lives of family caregivers is limited. Because a tax credit is an amount deducted from federal income tax owing, families do not receive cash payments and low and middle income caregivers receive little benefit (Torjman, 2015).
**Compassionate care benefits.** Informal caregivers who are also employed can apply for Compassionate Care Benefits offered through the federal government’s Employment Insurance. These benefits are available for individuals providing care or support to a family member who is at risk of dying within 26 weeks. Within this context “care or support” is classified as:

- Providing psychological or emotional support; or
- Arranging for care by a third party; or
- Directly providing or participating in the care

Individuals are eligible to apply if:

- They can demonstrate their weekly earnings have decreased by more than 40%, and
- They can demonstrate that they have accumulated 600 insured hours of work in the last year, and
- They can provide medical documentation that the person they are caring for is at risk of death within 26 weeks

Individuals are eligible for approximately 55% of their average insurable earnings up to a yearly maximum of $50,800. The maximum amount an individual can receive is $537 per week for 26 weeks and is taxable by the Canada Revue Agency as income (Government of Canada, 2016).

Scholars argue that eligibility criteria for this benefit excludes segments of the workforce including those employed part-time, seasonally or casually (Flager & Dong, 2010; Prince, 2015). For example, if an individual works part-time they may not have accumulated the number of hours necessary to be eligible. As a consequence, individuals in these situations may face the difficult decision of giving up paid employment to care for their relative (Prince, 2015).
Additionally, the necessity of submitting paperwork stating that death of their loved one is imminent has been described as particularly harsh and poses additional barriers for individuals with low incomes who may not be able to afford the fee associated with doctor’s notes (Flager & Dong, 2010; Williams, Crooks, Giesbrecht & Dykeman, 2009). Furthermore, Flager and Dong (2010) note that such a requirement also poses a risk to individuals with low incomes should their application be denied, and invested money lost without obtaining the desired benefit.

**Family caregiver leave.** At the provincial level, all Ontario employees (e.g., full-time, part-time, contract, etc.) caring for a family member are eligible for an 8-week (per calendar year) family caregiver leave. This leave is unpaid but offers job protection regardless of the length of time an individual has been employed by their organization. To be entitled to this leave, employees must produce a medical certificate obtained from a qualified health practitioner stating that the care recipient has a “serious” medical condition (specifying the medical condition is not necessary). Employees must inform their employer in writing that they will be taking this leave of absence. When employees take this leave they are entitled to the same rights as employees taking parental or pregnancy leave. This means that employers cannot fire or penalize employees in any way for taking this leave. They are however not required to pay an employee. This leave is governed by Ontario’s Employment Standards Act, 2000 (Ministry of Labour, 2015).

The uptake of formal unpaid leaves of absence is relatively low. Employees have expressed concerns that making use of these policies could generate damaging perceptions about their commitment to their job (Ontario Human Rights Commission, 2005). Furthermore, although the Employment Standards Act (2000) states that employees cannot be penalized in any way for taking the leave, some employees may be hesitant to take such leaves because they
believe that they could still negatively affect their careers in the long-term (Ontario Human Rights Commission, 2005).

**Profile of Informal Caregivers in Canada**

It is evident that the healthcare system relies substantially on caregivers to support their older relatives. However, clarification is necessary to understand precisely who informal caregivers are, the support they provide, and the consequences of providing care. Such a clarification provides additional context in which to understand the extensive role that informal caregivers play in caring for older adults, and why conducting research with this diverse group is particularly important. The support that caregivers provide, particularly, during the transition from hospital to home, is extensive and is therefore presented in detail in the following chapter.

**Characteristics of informal caregivers.** There is no single descriptive profile of family Canadian caregivers. However, data have been collected through the General Social Survey\(^3\) that identifies common patterns. Most family caregiving takes place in the context of caring for older parents or parents-in-law. In 2012, 48% of Canadian family caregivers reported caring for a parent or parent-in-law (Sinha, 2013). Often these filial caregivers are parents themselves, engaging in both child care and parent care in a situation of “double dependency” (Brody, 2004). These individuals are often referred to as the “sandwich generation” because they experience pressure associated with balancing their parental, marital, employment and filial caregiving roles and responsibilities (Cantor, 1983; Raveis, Karus, & Siegel, 2000). The majority of Canadian caregivers (54%) are also female (Sinha, 2013). Indeed, informal caregiving is often gendered,

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\(^3\) The General Social Survey is conducted by Statistics Canada. In 2012 23,093 Canadians were surveyed, with 29.7% living in Ontario (The Change Foundation, 2016a).
and Brody (2004) describes informal caregivers as “women in the middle” because it is generally daughters who provide care to their parents, while also providing care to their own children.

Given that the healthcare system increasingly relies upon filial caregivers, concerns have been raised about the availability of caregivers to support their aging parents (Taylor & Quesnel-Vallee, 2016). Over time, a number of demographic and social trends have influenced the availability of filial caregivers. These include smaller family sizes and greater participation of women in the workforce. As mentioned previously, members of the baby boom generation are entering the 65+ age bracket, and with aging comes the greater likelihood that they will require some type of support. Compared to their parent’s generation, baby boomers generally have fewer children. Baby boomer’s parents had 3.1 children on average, while baby boomers themselves have 1.6 children on average (Statistics Canada, 2015). This has contributed to fewer available filial caregivers, raising concern among policy makers.

Changing trends in the Canadian workforce have also contributed to concerns among policy makers about the availability of informal caregivers, presumably including the availability of filial caregivers. Currently, the vast majority of Canadians aged 25-54 participate in the workforce. As of 2014, 91% of men and 82% of women aged 25-54 were employed in the workforce. The high percentage of women participating in the workforce today reflects significant changes in the gender composition of the workforce over the last 65 years. In the early 1950s approximately 25% of women aged 25-54 were workforce participants. (Statistics Canada, 2016). While previously women may have been able to devote much of their time to caring for a parent, increased workforce participation has rendered such an option untenable. Although societal norms for women’s workforce participation have changed, the expectation for
them to provide informal support has not (Pavalko, 2011). Subsequently they are placed in a context of competing roles and demands.

**Consequences of Informal Caregiving**

The extensive role that family caregivers play in supporting older relatives can have both positive and negative consequences (Kramer, 1997). Within the literature, detrimental consequences have received much greater attention and include consequences associated with employment, finances, health and well-being, and family dynamics. However, positive experiences associated with caregiving have also been reported and include feeling a sense of purpose associated with the caregiving role, the mastery of skills, developing a closer relationship with the care recipient (Dellman-Jenkins, Blankemeyer & Pinkard, 2000), and finding support from friends, family and neighbours (Cheng, Mak, Lau, Ng & Lam, 2016). In the following sections I discuss some of the negative consequences of caregiving and draw attention to experiences of filial caregivers specifically where data exist to illustrate the consequences of caregiving in their lives.

**Employment and the economy.** In 2012, approximately 35% of the Canadian workforce was providing informal care to an older friend or family member; the number of individuals providing care to a parent represent a large portion of this figure (Employer Panel for Caregivers, 2015). In general, informal caregiving can have particularly negative consequences for employees, and such consequences are likely prevalent among filial caregivers. Employees who provide informal care are more likely to be late or absent (and as a consequence incur lost wages) and often demonstrate lower productivity compared to employees who do not provide such care (Employer Panel for Caregivers, 2015). They are also less likely to participate in professional development opportunities, travel for work or work overtime hours (Employer Panel
for Caregivers, 2015). Across Canada, informal caregivers often reduce their work hours, turn down paid employment and even quit their jobs to provide care (Employer Panel for Caregivers, 2015). Among filial caregivers specifically, approximately 10% report that caring for a parent has prevented them from holding employment (Turcotte, 2013). These negative consequences can also directly impact businesses and the Canadian economy. In 2012, it was estimated that businesses experienced a $1.3 billion loss in productivity owing to all caregiver absences\(^4\) (Chenier, Hoganson & Thorpe, 2012).

Despite the pervasive negative implications of informal caregiving on the workforce and economy, few employers have any formal policies in place to support informal caregivers. In 2014, a report was commissioned by the federal government to determine workplace practices that support caregivers (Employer Panel for Caregivers, 2015). A total of 114 organizations from across Canada participated in the consultation. Although most organizations do not have formal policies in place, many do promote flexibility in their approach to support, with some offering flexible working arrangements to their employees (e.g., changing hours, working from home, paid sick leave, re-distribution of workloads). However, the degree of flexibility offered was reflective of the resources and size of the organization, such that smaller organizations could not accommodate caregivers the same ways larger ones could. Findings from this report suggest that although there are innovative approaches to accommodation offered at some organizations, most employers do not have an awareness of the magnitude of informal caregiving, and consequently informal caregivers may not receive adequate support.

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\(^4\) Absences referenced here refer to all absences for caregiving, which may include childcare, parental care, spousal care and care to other family members or friends.
Financial strain. Beyond lost wages, Canadian caregivers often incur additional costs in the course of caring for a relative. Examining the financial strain experienced by filial caregivers specifically, data collected by Statistics Canada show that in 2012, 7% of filial caregivers reported financial strain associated with caregiving. The median out of pocket cost of caring for a parent in 2012 was $890 with at least 18% of filial caregivers spending over $2000 per year to care for their parent. A total of 5% of filial caregivers incurred costs associated with professional or rehabilitation services, 5% incurred costs hiring people to help with daily activities, 9% spent money on specialized devices or equipment, 11% spent money on prescription and non-prescription drugs, 12% incurred costs associated with dwelling modifications and 54% incurred costs associated with transportation, travel and accommodation (Turcotte, 2013).

Many older adults and their families are connected with the CCAC, and this is particularly true after hospital discharge. As discussed, services provided through the CCAC are publicly funded, but there are also restrictions placed on the services patients can receive (Long-Term Care Act, 1994). When government funded services are inadequate, private services are also available. However, these services are often costly. For example, median costs for personal care (e.g., bathing, dressing) are estimated to be $25.95/hour, $50.50/hour for skilled nursing, and $120/hour for physiotherapy (Sun Life Assurance Company of Canada, 2015).

Health and well-being. A large proportion of filial caregivers experience psychological distress associated with caring for a parent. Turcotte (2013) reports that among filial caregivers responding to the 2012 General Social Survey, 60% reported feeling worried or anxious about caregiving responsibilities, 42% reported feeling angry or irritable, 36% experienced sleep problems, 21% reported feeling unhappy or depressed, 18% reported feeling alone or isolated,
and 14% experienced a loss of appetite. Furthermore, 22% reported that their overall perceived health suffered, and 6% even sustained injuries related to caregiving.

The mental health of informal caregivers more generally is not only detrimental to their wellbeing, but is also associated with the health of care recipients. Research suggests that when informal caregivers experience depression or difficulty coping, care recipients are at greater risk for bed sores, falls and declines in physical abilities (Elliott & Pezent, 2008). Furthermore, when informal caregivers are at risk for clinical depression or experience physical health problems, harmful behaviour (e.g., abuse) is more likely to take place (Beach, Schulz, Williamson, Miller, Weiner & Lance, 2005).

**Family dynamics.** Although family can be a source of comfort and support for caregivers, it can also be a source of conflict. Family conflict in relation to the care of an older adult can manifest in different forms including disagreements regarding (a) the nature of the illness and care needs, (b) a family member’s action or inaction in helping with the care of the care recipient, and (c) a family member’s action or inaction toward the primary caregiver (Pearlin et al, 1990). Although family conflict can occur for both spousal and filial caregivers, filial caregivers are more likely to experience family conflict, specifically among siblings (Semple, 1992).

**Chapter Summary**

Informal caregivers are increasingly relied upon to provide care to older relatives within the context of population aging. The shift from state to family responsibility is illustrated by healthcare restructuring that has placed an emphasis on community and home care over institutional care, and policies such as *Aging in Place* and *Home First* that are largely dependent upon the intensive involvement of informal caregivers. There are a number of negative
consequences associated with caregiving including economic losses, threats to physical and mental well-being, and family conflict, and these consequences are experienced by filial caregivers specifically. This chapter has been necessarily broad in focus so as to situate the study in the broader social, political and economic context. The following chapter narrows this focus to a specific period within a caregiver’s tenure (i.e., the transition from hospital to home), and demonstrates the specific forms of responsibility caregivers assume to support their aging relative.
Chapter 3: Caregiving during the Transition from Hospital to Home

The previous chapter provided an overview of the context in which family caregivers support their relatives. The focus now moves to the literature specifically on caregiving during the transition from hospital to home. The shift to a greater reliance on family for the care of their older relatives described in the previous chapter has been documented globally (Keefe & Rajnovich, 2010), so for the present chapter I incorporate studies with an international focus to provide a more robust overview of activities that caregivers are involved in during the transition from hospital to home. Additionally, the research on the experiences of filial caregivers during the transition from hospital to home is limited, so throughout this chapter I discuss family caregivers more generally. However, I also highlight where studies distinguish filial caregivers from other types of family caregivers.

As I show in this chapter, relevant studies suggest that caregivers assume multifaceted roles and often have a considerable responsibility for ensuring the safety and wellbeing of their family members during the transition from hospital to home. I first review the literature on the needs of caregivers, which suggests that family caregivers do not always have the capacity to support their older relatives because they have limited access to the resources that are necessary. I then present an overview of the activities that caregivers engage in to support their relative and the ways in which they work to secure information and resources that act to support their relative’s care.

Factors that Limit Caregiver Capacity to Support Patients

Within Ontario, the healthcare system has explicitly been described as unsupportive of family caregivers during the transition from hospital to home (Giosa et al., 2014). Indeed, for older patients and their caregivers, the transition from hospital to home is often characterized by
confusion, inadequate preparation, miscommunication, and fragmentation in care (Coleman, Smith, Frank, Min, Parry & Kramer, 2004). During the transition from hospital to home, family caregivers experience a number of challenges that may limit their capacity to provide appropriate care and support to their relative. Largely these challenges occur because caregivers do not have access to necessary information, training or resources to meet the needs of their relative. The literature suggests that caregivers are often required to perform tasks that formal care providers have traditionally executed (Guberman et al., 2005; Levine, Reinhard, Feinberg, Albert & Hart, 2004). Therefore, while caregivers face increasing responsibility to perform tasks similar to those once performed by healthcare professionals, their limited access to information, training, and resources constrains their ability to provide the same quality of care. In the following sections, I briefly discuss the most commonly identified factors that limit caregiver capacity to support patients during the transition from hospital to home.

**Information.** During care transitions, poor information sharing between healthcare providers and family caregivers can compromise patient safety (Bauer et al., 2009; Bull, Hansen & Gross, 2000). Indeed, caregivers often view health related information about their relative as imperative to their ability to provide care (May, Ellis-Hill & Payne, 2001). A well-documented finding is that family caregivers, including filial caregivers, often leave the hospital with little information to prepare them for their caregiving role (Bull, 1992; Bull & Jervis, 1997; Docherty et al., 2008; Driscoll, 2000; Dunbrack, 2005; Elliott, Forbes, Chesworth, Ceci, & Stolee, 2014; Graham, Ivey & Neuhauser, 2009; Robinson, Pesut, & Bottorff, 2012; Shyu, 2000), and both patients and their caregivers have been found to be dissatisfied with the information they receive related to home care (Driscoll, 2000). Canadian caregivers report that they are sometimes not even aware of the type of information that is deficient, and caregivers may not know what
questions to ask to obtain such information (Dunbrack, 2005; Glenney, Stolee, Sheiban & Jagal, 2013). Furthermore, caregivers may not be aware of who is responsible for particular aspects of their relative’s care when a multitude of healthcare providers are involved (Dunbrack, 2005; Lafortune et al., 2015; Levine et al., 2004; Toscan, Manderson, Santi & Stolee, 2013; Zakrajsek, Schuster, Guenther & Lorenz, 2013). In Ontario, Community Care Access Centres (CCACs) contract homecare services out to over 1,500 private agencies, and different agencies may be involved in care over time which compounds the difficulty caregivers express related to understanding and navigating the overall system (OACCAC, 2015).

After their relative has been discharged from hospital, caregivers often require information related to their relative’s diet, wound care, health complications, medication regimen, and mobility issues (Driscoll, 2000), as well as when and how to provide personal care (e.g., hygiene, dressing, feeding) (Grimmer et al., 2004). This information may not be provided by healthcare professionals at the time of discharge, or be provided, but through a means of communication that does not facilitate understanding (Kripalani, Jackson, Schnipper & Coleman, 2007). Giosa and colleagues (2014) report that miscommunication errors between hospital staff and Ontario caregivers are prevalent, particularly when information is provided only in verbal formats rather than a written format that can be retrospectively consulted. Findings from a study situated in Southern Ontario suggest that caregivers often desire information in a simple written format (Elliott et al., 2014). However, Foust, Vuckovic and Henriquez (2012) caution that written information too can be overwhelming for caregivers and question caregivers’ ability to interpret and understand the written information.

Caregivers similarly report a deficiency in the provision of information within the hospital setting (Giosa et al., 2014). Healthcare professionals may have limited time available to
spend time with family members (Glenny et al., 2013) and members of the healthcare team may have differing abilities to provide information. For example, while caregivers view nurses as valuable sources of information, physicians are generally viewed as definitive sources of information, particularly because they have foremost authority over patient care (Higgins, Joyce, Parker, Fitzgerald & McMillan, 2007). However, research suggests that within the hospital setting, physicians are minimally accessible to caregivers both because of limited time, and because nurses may act as gatekeepers, screening requests for meetings with attending physicians (May et al., 2001).

Glenny and colleagues (2013) explored the reasons why poor information sharing is prevalent between healthcare providers and family caregivers by interviewing members of each group involved in care transitions of older hip fracture patients in Southern Ontario. Their findings suggest that healthcare providers generally did not provide information proactively to caregivers. Rather, caregivers had to actively seek information from service providers. Healthcare providers perceived this non-standardized process for information sharing to be acceptable, while caregivers perceived it to be indicative of poor quality care. Glenny et al. (2013) suggest that the discrepancy in perceptions about the acceptability of this information sharing arrangement between healthcare providers and caregivers might be attributed to their respective access to information. While healthcare providers can fill information gaps by accessing patient information through medical charts and staff meetings, caregivers do not have access to these resources.

Adequate information helps caregivers to successfully manage their relative’s condition through identification of symptoms, as well as a necessary response, including the knowledge about when professional intervention is necessary (Boise, Heagerty & Eskenazi, 1996).
However, although caregivers may view access to information as important, the provision of such information should not be viewed as an avenue through which to place more responsibility on caregivers for the safety of their relative.

**Training.** Compounding informational needs, family caregivers, including filial caregivers, often perceive a lack of training for life at home after hospital discharge (Giosa et al., 2014; Graham et al., 2009; Shyu, 2000). For example, in a study based in Taiwan, filial caregivers reported little available training to assist care recipients after hospital discharge (Shyu, 2000). Lack of caregiver training is associated with detrimental outcomes for patients during care transitions, but this is often not widely appreciated by healthcare professionals (Coleman, 2003). After discharge, family caregivers provide extensive support to their relatives. Such support may include assistance with Instrumental Activities of Daily Living (IADLs) which refer to activities that are generally necessary to function within a community setting (e.g., shopping, doing laundry, cooking, taking medication, transportation, managing money, using the telephone, performing housework), and also with more basic activities described as Activities of Daily Living (ADLs) (e.g., bathing, using the toilet, dressing, feeding, movement throughout the home). Although providing assistance with some of these activities may appear unproblematic, assistance with others requires training that is not always available to caregivers (Toscan, Mairs, Hinton, & Stolee, 2012). For example, caregivers may have to assist their relative with bathing which may require appropriate training on how to lift their relative (Levine et al., 2004).

Adding further complexity to the caregiving environment, family caregivers may also be called on to perform “skilled nursing-level care such as catheter care or feeding tube maintenance” (Graham et al., 2009, p. 27). Despite the complexity of these tasks, family caregivers often receive little training with respect to the execution of this care (Graham et al.,
Additionally, informal caregivers in Ontario have expressed feelings of being excluded from important conversations and decisions related to their relatives’ care, despite their necessary involvement in implementing care plans (Giosa et al., 2014; Lafortune et al., 2015). As a result, caregivers may be conscripted by healthcare professionals to perform duties that they are not capable of executing (Health Canada, 2010; Levine, Halper, Peist & Gould, 2009).

**Respite.** Respite is an important need among family caregivers, particularly when the caregiver co-resides with the care recipient (Boise, Heagerty & Eskenazi, 1996). Respite services are designed to provide caregivers with time away from caregiving responsibilities within the home environment, and are particularly important to sustain caregiver well-being (Dunbrack, 2005; Schmall, Cleland & Sturdevant, 2002). Indeed, the use of respite services can help to avoid “burn out” that may be associated with extensive caregiving over time (Petrovic, 2013), but caregivers may require information about how to obtain such services or supports (Grimmer, Moss & Falco, 2004). Despite the promising benefits of respite programs, such services may not always be effective (Lund et al., 2014), which suggests that current respite arrangements may not be sufficient.

Caregivers often consider continuity in home service providers (specifically personal support workers) to be important so that new workers do not constantly have to be briefed about individual circumstances, and so that continuity in relationships is sustained (Dunbrack, 2005; Wiles, 2003). When there is little service continuity, family caregivers may be obligated to act as care managers, ensuring that important aspects of their relative’s individual circumstances are not overlooked (Dunbrack, 2005; Lafortune et al., 2015). This means that even when personal support workers are scheduled to provide respite to caregivers, the relief experienced by caregivers may be diminished when they are required to consistently orient new workers to the
home environment (Sims-Gould & Martin-Matthews, 2010a). However, although family
caregivers express a desire for a continuity in service providers, within the current healthcare
context, this is not always possible given that organizations providing homecare support often
experience high worker turnover owing to low wages and irregular hours (CRNCC, 2010).
Additionally, caregivers often have little choice in the scheduling of formal supports within the
home despite the finding that having choice with respect to when service providers will visit the
home is associated with better service effectiveness (Steffansson, Pulliainen, Kettunen,
Linnosmass & Halonen, 2016).

It is important to acknowledge that family caregivers often provide extensive support to
their relatives, and they may require their own sources of support. Therefore, appropriate respite
services that support caregivers and patients are important within the context of increasing
caregiver responsibility.

Activities Performed by Informal Caregivers During the Transition from Hospital to Home

Recent reviews on successful care transitions have tended to focus on what activities
healthcare professionals can engage in to limit any detrimental consequences to patients (e.g., re-
hospitalization, injuries, death) (Abrashkin et al., 2012; Arora & Farnan, 2008; Sims-Gould,
Byrne, Hicks, Khan & Stolee, 2012). However, both healthcare professionals and patients
acknowledge the importance of informal caregivers during this period (Bradway et al., 2011;
Coleman & Williams, 2007; Shyu, Chen, & Lee, 2004; Driscoll, 2000; Zakrajsek, Schuster,
Guenther & Lorenz, 2013). Given that there has been an emphasis placed on the importance of
providing care within the community (Allen, 2000; Bauer, Fitzgerald, Haesler & Manfrin, 2008;
Canadian Healthcare Association, 2009; Health Canada, 2010; McKeever, 1999; OACCAC,
2015; Skinner & Rosenberg, 2004; Wiles, 2003 Wuest, 2000), an environment in which
caregivers are intimately involved and relied upon, understanding the activities that caregivers are engaged in to support their relative becomes increasingly important. This understanding is imperative because it is clear that their capacity to support their relative is often limited because of insufficient support within the healthcare system.

In reading the following sections it is important to recognize that few studies have examined the specific experiences of filial caregivers during the transition from hospital to home in Ontario. Their experiences are important to investigate for two reasons. First, they represent the largest group of caregivers in Canada (Sinha, 2013) and many report psychological distress associated with caring for a parent (Turcotte, 2013). Second, research suggests filial caregivers experience caregiving differently from other caregiving groups such as spouses due to the nature of their relationship with their parent (Bastawrous, Gignac, Kapral & Cameron, 2015; Byrne et al., 2011). Therefore, it is important that their experiences are clearly delineated from the experiences of other caregiving groups.

Furthermore, the vast majority of studies related to the transition from hospital to home have tended to focus primarily on the experiences of patients and caregivers after hospital discharge (i.e., when providing care in the context of the home environment). Yet, as Schumacher and colleagues (1999) explain, any type of transition is initiated by an event that necessitates modifications to daily life. Consequently, hospital admission and care is implicated in the transition from hospital to home and for some caregivers, caregiving is triggered by their parent’s hospitalization. Therefore, further research that examines the experiences of filial caregivers while their parent is hospitalized is important in order to capture experiences across the full range of care environments involved in the transition from hospital to home.
Direct care work. The dominant paradigm of caregiving research suggests that the main activities family caregivers perform after their relative is discharged from hospital include assisting older adults who possess particular physical or cognitive limitations with direct care work including help with Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs) (Levine et al., 2004). Feldman and Kane (2003) describe ADLs and IADLs as two of the most important research concepts within the field of long-term care and as concepts they possess an extensive history. Research on ADLs and IADLs was initiated in the 1950s to identify functional abilities of older adults, and in the 1960s measurement tools were developed to assist medical practitioners in assessing patient capabilities as they related to ADLs and IADLs (Levine et al., 2004). In the 1980s and 1990s the utilization of IADLs and ADLs measures shifted from research on patients to research on caregivers, and the ways in which they supported care recipients with IADLs and ADLs. Underlying assumptions of such research included the notion that caregiver activities directly reflected care recipient’s limitations (Levine et al., 2004).

However, contemporary research from both Canada and abroad challenges this paradigm by providing evidence that family caregivers, including filial caregivers, engage in a significantly broader range of activities that are not adequately represented by a focus on IADLs and ADLs (Byrne et al., 2011; Giosa et al., 2014; Levine, Feinberg, Albert & Hart, 2004; Schumacher, Stewart, Archbold, Dodd & Dibble, 2000; Shyu, 2000). Family caregivers have consistently been found to provide social and emotional support to older adults (Byrne et al., 2011; Chappell & Funk, 2011; Herron & Skinner, 2013; Lowson et al., 2013; Rittman, Boylstein, Hinojosa, Hinjosa & Haun, 2007) which is particularly relevant in the context of the transition from hospital to home because social isolation has been found to contribute to delayed hospital
discharges (Landeiro, Leal & Gray, 2016). With changing locations of care, high-tech care and pain management tasks that were once largely associated with hospital stays now figure prominently within the homecare environment (Levine et al., 2004). Caregivers must contend with medical equipment such as heart monitors and respirators, and manage care recipient pain without adequate knowledge of medications. Levine et al. (2004) note that while medication management was once considered a simplistic task, with the development of an ever growing amount of medications and prescriptions, the task has become increasingly complex.

**Problem solving.** When caregivers experience challenges related to caring for an older relative, research suggests that caregivers engage in self-directed activities to meet their own needs and the needs of the care recipient, such as information seeking and accessing resources. In an American study with mother-daughter caregiving dyads, Bull (1992) found that caregivers undertake problem solving strategies to “find out what works”. These strategies included piecing together health related information and asking questions of family members and friends. Indeed, recent findings suggest that family caregivers are likely to access their family and friends for health care information when informational needs are unmet by professional care providers during the discharge process (Cumbler, Carter, & Kutner, 2008; Graham et al., 2009; Plank, Mazzoni, & Cavada, 2012). Similarly, Byrne and colleagues (2011) found that spousal caregivers in Canada reported sorting through multiple sources of information, searching for new directions, and learning through experience as central problem solving strategies in response to insufficient information provision by healthcare providers.

Caregivers are also immersed within a formal and complex healthcare system that requires navigation to obtain resources, and monitoring to ensure that current resources and care are sufficient (Lowson et al., 2013). Wiles (2003) suggests that from the perspective of family
caregivers, the homecare system in Southern Ontario can be difficult to navigate, and many caregivers express confusion over eligibility requirements for services. Within this environment, caregivers monitor the care provided by formal service providers and attempt to navigate the system by determining which services are available, and advocating and negotiating for more services to improve their relatives’ care. Similarly, Wuest and Stern (1990) note that family caregivers who are unfamiliar with the healthcare system engage in a process to “learn the rules” (e.g., understanding how referrals work) to obtain control within the system and gain access to additional resources.

Advocating on behalf of patients. Advocating has also been well-documented as an activity that family caregivers, including filial caregivers, engage in as their relative transitions from hospital to home (Bull & Jervis, 1997; Byrne et al., 2011; Coleman & Williams, 2007; Ghazzawi, Kuziemdky & O’Sullivan, 2016; Gibson, Kelly & Kaplan, 2012; Grimmer, Moss & Falco, 2004; Levine et al., 2004; Wiles, 2003). However, despite wide acknowledgement of the importance of caregivers advocating for the patient during the transition from hospital to home, this form of caregiving work is only tangentially examined by scholars. It therefore warrants further consideration. In the following paragraphs I review the role of caregivers as advocates more broadly within the healthcare system, rather than focusing specifically on the transition from hospital to home. I do this to provide a broader discussion of the role of patient advocate, as this has only more recently been identified as a caregiving role within the literature.

Defining advocacy. Advocacy is a term that is utilized across disciplines, including law, social work, psychology, sociology and medicine. Generally, the meaning is consistent, although the processes through which advocacy takes place may vary considerably. Cohen (2004) broadly describes advocacy as, “adopting a stance, advancing a cause or attempting to produce a result
on behalf of an interest of a person, group or cause” (p.9). From this definition it is evident that advocacy can be a politicized process whereby individuals and organized groups attempt to produce change at the institutional or policy level, but can also refer to smaller scale efforts where advocates represent or protect individuals by focusing on specific cases (Earp, French & Gilkey, 2008).

Within the context of caregiving specifically, advocacy has been defined as “work that attempts to create resources, recapture resources that have been lost, and/or correct for problems in those services currently at hand” (Litt, 2004, p.628). Caregivers and care recipients are immersed within institutional environments and in relationships that govern the distribution of resources. Consequently, the experiences of family caregivers can only be understood within the context of the institutional environments and systems in which they are immersed (Allen, 2000; Wiles, 2003). The hospitalization of a relative necessitates contact with the healthcare system, and even after discharge caregivers may have sustained contact by interacting with homecare staff, pharmacists, nurses, occupational therapists, and physicians. These healthcare professionals often possess control of the resources necessary to ensure high quality care, and may be viewed as resources themselves (Romanow, 2002).

**Types of patient advocates.** Patient advocates are individuals who represent patients by speaking and acting on their behalf (Baldwin, 2003), and patient advocacy has been described as foundational to patient safety and care (Schwartz, 2002). Advocating for patients has been described as important because patients are considered vulnerable individuals by virtue of their ill health and limited health literacy (Bu & Jezewski, 2006; Mallik, 1997). A number of groups involved in patient care have been identified as patient advocates including nurses, professional advocates (i.e., individuals who receive training specifically to be a patient advocate), and family
caregivers (Schwartz, 2002). Much research that has discussed patient advocacy has identified nurses as primary patient advocates, and nurses have enjoyed a long history of patient advocacy dating back to the 1970s (Hewitt, 2001). Indeed, the nursing profession has formally defined advocacy as an integral part of their role in the healthcare system, and as a result, advocacy has been an important focus in the nursing literature (Earp et al., 2008). While nurses certainly work to support patients, and emphasize that understanding the patient’s unique situation is important to patient advocacy (Vaartio, Leini-Kilpi, Salantera & Suominen, 2006), limited time and communication with patients may prevent nurses from collecting information that can inform such an understanding (Negarandeh, Oskouie, Ahmadi, Nikravesh & Hallberg, 2006).

Professional advocates have also been cited as important representatives in patient care. Professional advocates can be hired privately (Integrity Healthcare Consultants, 2015), and provide fee for service support, or may work within hospitals. Fee for service advocates work directly for individuals and their families, providing services such as research, attending medical appointments, and assisting with system navigation (Katsarov, 2017). Professional advocates working in hospitals are hospital employees and provide publicly funded services. Established as a requirement under the Excellent Health Care for All act, all Ontario hospitals have a staff member filling a formalized patient advocate or patient representative role. While the responsibilities and processes associated with this role may vary between hospitals, generally patient advocates can be found within the patient relations unit of each hospital and work with patients and families to address concerns regarding care provided within the hospital. While this appears to be a valuable role, access to patient relations representatives is often described as a last step in any grievance process. To highlight a local example, Grand River Hospital, located in Kitchener, Ontario, encourages patients to first share their concerns directly with members of the
healthcare team. If further assistance is required, or if concerns could not be addressed directly by an individual providing care, then patients may contact the clinical manager of their unit, or the patient relations office. This process is similarly described in other Ontario hospitals’ Patient Relations information handbooks.

From the above example, it is clear that family members and patients may also engage in patient advocacy, by communicating directly with members of the healthcare team. Further, extensive research points to advocating on behalf of a patient as a caregiver activity during the transition from hospital to home. However, in-depth examinations of caregivers advocating on behalf of patients are largely absent from the caregiving literature, particularly among studies of filial caregivers. What little research has been conducted on the topic has focused on identifying some of the reasons why caregivers advocate, the processes they engage in to advocate on behalf of a relative, and some of the facilitators and barriers associated with advocating on behalf of a relative experiencing ill health. An overview of this research is presented in the following sections.

**Reasons for caregiver advocacy and ways of advocating.** A limited number of studies have investigated why and how family caregivers advocate. According to Neufeld, Harrison, Stewart and Hughes (2008), advocacy often develops as a response to non-supportive interactions with healthcare professionals (e.g., when healthcare professionals challenge their authority as caregivers, when ineffective support is offered by healthcare professionals, or when expectations of support are not met by healthcare professionals). From interviews with Albertan caregivers providing care to children, adult relatives with cancer, or an older family member diagnosed with dementia, Neufeld et al. found that to advocate for their relatives, caregivers used a number of strategies. These strategies included monitoring their relative’s condition or
environment, educating themselves or others by accessing resources or sharing information about their relative with their care team, and negotiating or fighting for additional resources or the attention of healthcare professionals. Similarly, Wuest (2000) reported that in response to system failings such as failure to help, provision of inadequate help, or even making things worse, women caregivers, including those caring for children and older relatives diagnosed with dementia, work to harness resources by confronting healthcare professionals and assertively advocating for more resources.

Other studies have found that caregivers may act as advocates by providing information to physicians about the care recipient’s situation and history, and may even question the appropriateness of physician recommendations (Hirsch, Forlizzi, Hyder, Goetz, Stroback & Jurtz, 2000). Several researchers have demonstrated that both filial and spousal caregivers in the United States and Ontario advocate by confronting and challenging healthcare professionals to ensure that their relative receives appropriate care, or when they perceive the current level of care to be inadequate (Bull & Jervis, 1997; Byrne et al., 2011; Lowson et al., 2013).

Advocacy has been linked to caregiver perceptions of patient safety (Rathert, Brandt & Williams, 2011). Drawing upon data obtained through focus groups with family caregivers in the United States, Rathert and colleagues argue that caregivers perceive particular institutional arrangements to detract from patient safety. For example, participants expressed concerns about the large number of healthcare professionals involved in their relative’s care because they felt that it meant their relative was not a priority for the healthcare professionals, and thus compromised patient safety. Allen (2000) similarly suggests that within the hospital environment, caregivers’ concerns are focused on the needs of their relatives, while nurses must
attend to the needs of a larger group of patients. Therefore, caregivers advocate to make known the needs of their relatives to healthcare providers.

**Barriers and facilitators to advocating.** Few studies have identified barriers and facilitators to advocacy among individuals caring for their parents, or among individuals caring for older adults more generally. Gilkey et al. (2008) suggest that family members and friends in particular have an important role to play “in asserting patients’ rights, preventing adverse drug events or other medical errors, and helping patients understand and follow treatment regimens” (p. 19). Therefore, they argue that family members and friends should be encouraged by healthcare professionals to become engaged in a patient’s care. While this model of patient advocacy suggests that family members should be recruited to become involved in patient advocacy, in many circumstances they often find themselves engaged in advocating without professional prompting (Petronio, Sargent, Andea, Reganis & Cichocki, 2004).

Given the importance of advocating, and the observation that caregivers tend to find themselves acting as patient advocates with little preparation and possibly low health literacy, understanding the facilitators and barriers to advocacy is an important avenue of investigation. A small number of studies point to barriers within the hospital environment that may impede caregivers’ advocacy efforts. When relatives are hospitalized, experienced caregivers face a loss of control over their relative’s care and often feel undervalued by healthcare professionals (Bloomer, Digby, Tan, Crawford & Williams, 2016). Similarly, when older adults are hospitalized, caregivers who previously maintained the structure of the care recipient’s care, may be consigned to a subordinate position, whereby they are no longer be viewed as a caregiver but instead merely as a relative by hospital staff (Lowson et al., 2013). Irrespective of how caregivers are perceived by hospital staff, challenging healthcare professionals about aspects of
their relative’s care requires considerable confidence and assertive abilities. Some caregivers may be intimidated in such an environment which limits their ability to ask questions and demand greater assistance (Toscan et al., 2012). In an Ontario based study, Wiles (2003) identified the worries some caregivers have about being perceived as aggressive when advocating for formal services (i.e., services from the CCAC), but view this as necessary to ensure their relative receives appropriate care.

In an ethnographic study of expert caregivers (i.e., caregivers who have been providing care over a long period of time, and who possess a strong sense of responsibility for their family member’s care) and nurses in a hospital ward in the United Kingdom, Allen (2000) argued that caregiver advocacy efforts are not always accepted by nurses because they challenge the normative lay-professional relationship. When family caregivers advocated for their relative, nurses perceived this action as a criticism of their professional expertise and this sometimes caused tension between nurses and caregivers. Therefore, advocacy efforts were not always accepted by nurses within the hospital environment, and nurses rarely solicited the involvement of family caregivers. Consequently, the hierarchical arrangement of the hospital setting, in which nurses occupy a position of greater power than family caregivers, can inhibit caregivers from effectively advocating for their relative (Lowson et al., 2013).

Although all of these studies provide insight into some of the reasons why family caregivers advocate, the ways that they advocate, and the barriers they face in advocating, none have specifically focused on filial caregivers, and few have discussed this caregiver activity during the transition from hospital to home. Additionally, with two notable exceptions (see Byrne and colleagues, 2011 and Wiles, 2003) studies identifying advocacy as a caregiver activity were not situated in Ontario. As mentioned in the previous chapter, the structure of the
healthcare system varies between provinces, and between countries so it cannot be said that experiences identified in the literature are representative of those caregivers providing care in Ontario. Therefore, the experiences of advocating among filial caregivers in Ontario during the transition from hospital to home requires further examination.

**The Current Study**

The current literature has established a strong foundation that encourages further study of caregiver experiences during the transition from hospital to home. Factors that compromise the ability of caregivers to support their relatives are well identified in the literature, and researchers are beginning to examine the vast array of activities that caregivers engage in to support their relatives during the transition from hospital to home, and in the context of caregiving more generally. Through the current research, I sought to fill some important gaps in the transitional care literature. It is important to further examine 1) filial caregiver experiences across the environments implicated in the transition from hospital to home and 2) the reasons and processes associated with filial caregivers advocating on behalf of care recipients.

**Research Questions.** As mentioned, the objective of the current research was to explore filial caregivers’ experiences during the transition of their parent from hospital to home. Specifically, the purpose of this study was to better understand the activities that they engage in to support their parents within an environment where resources are limited and their capacity to provide care is often challenged. Three broad questions guided data collection and analysis:

1) How do filial caregivers perceive the healthcare system? In what ways do their perceptions influence their actions when caring for a parent?

2) How do filial caregivers support their parent’s well-being during the transition from hospital to home?
3) When filial caregivers experience challenges caring for their parent, how do they obtain resources necessary to support their parent’s well-being?
Chapter 4: Methodology

This chapter describes the partnerships that were formed to make this study possible, the ethics approval process, participant recruitment, participant characteristics, data collection, and data analysis procedures.

Establishment of Partnerships

The establishment of partnerships was a significant aspect of this study that allowed me to maximize recruitment, and connect with healthcare professionals who could provide detailed information about the healthcare system, and more specifically about the transition from hospital to home. I first established a relationship with the Waterloo-Wellington Community Care Access Centre and then Grand River Hospital. A brief overview of each organization is presented in the following sections, including a description of the way in which a connection was established.

Waterloo-Wellington Community Care Access Centre. Community Care Access Centres (CCACs) work extensively with caregivers so I therefore believed that they could be an excellent organization through which to recruit caregivers. CCACs are institutions located across the province that provide information and connect individuals with professional support services at home and in the community. CCAC staff provide referrals, programs, and services to individuals of all ages and abilities, including older adults. Individuals can become patients of the CCAC through multiple avenues. These include self-referrals, referrals from family and friends, and referrals from medical professionals. These referrals may be made while an individual is living in the community or when individuals are admitted to hospital.
CCACs are funded by Local Health Integration Networks (LHIN) through the Ministry of Health and Long-Term Care, and as such, services provided by the CCAC are covered by the Ontario Health Insurance Plan (OHIP). The Ministry of Health and Long-Term Care (2015) provides the following overview of services offered by the CCAC:

- Identify care needs
- Explore the options best suited to needs and personal situation
- Determine eligibility for government-funded services and settings
- Gather information about local providers
- Provide information on how services are delivered
- Arrange for delivery of government-funded home and community support services
- Apply for admission to programs, supportive housing or long-term care
- Apply for wait-lists

The provision of these services is managed by Care Coordinators. These staff members are health professionals with expertise in “nursing, physiotherapy, occupational therapy, social work and other health care-related fields” (LHIN, 2018, para. 1). These individuals work in hospitals, physician offices, communities and schools, and are assigned to an individual once they become a patient of the CCAC. To determine a care plan (e.g., the services required by each patient), Care Coordinators assess patients using the Resident Assessment Instrument (RAI). The RAI is a standardized assessment tool that is intended to comprehensively cover the health areas of clinical, mental health, psychosocial and physical functioning (InterRAI, n.d.).

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5 Since the time data collection took place the CCAC and LHIN have merged. The description provided in this section is intended to provide an overview of the organizations as they were at the time of my interaction with them.
Assistance is provided to support individuals during care transitions, such as the transition from hospital to home. In the context of transitions from hospital to home, patients are the CCAC’s client though Care Coordinators often have extensive contact with caregivers as well. Once care needs are assessed, staff members create a care plan in consultation with patients and their caregivers (Waterloo-Wellington LHIN, 2017). Discharge planning takes place within the hospital, usually led by a CCAC Care Coordinator.

The Waterloo-Wellington CCAC (WWCCAC) provides service to the region in which the University of Guelph is located. Therefore, I contacted the WWCCAC Executive Director in February 2015 to discuss the possibility of forming a partnership. She invited me for a meeting during which I described my study and we discussed how the findings could be useful to the CCAC. Almost immediately she supported my study and within weeks the WWCCAC Board approved the study because it aligned with their goals. As part of Waterloo-Wellington CCAC’s Strategic Plan for 2016-2019, five “success factors” were identified to chart a path for achievement of their mission: “partnering to provide equitable access to high quality, individualized, coordinated care in the home and in the community” (WWCCAC, 2016, para. 6). These success factors include:

1. Outstanding Service Delivery
2. Inspired People and Culture
3. Effective Partnerships and Relationships
4. Performance Excellence
5. Communication and Engagement
Many of these success factors are aligned with particular aspects of this study. To achieve Effective Partnerships and Relationships, the CCAC has committed to identifying “new partnership opportunities with non-health organizations to bring new ways of thinking to the organization”. To achieve Performance Excellence the CCAC strives to use service delivery statistics and qualitative data to improve care and the delivery of services. Finally, to achieve Communication and Engagement, the CCAC is committed to including a range of perspectives in their decision making, including those of patients, caregivers and community partners.

As will be discussed in Chapter 8, I did not recruit caregivers through the WWCCAC for logistical reasons. However, I was still granted permission to interview Care Coordinators who proved to be a valuable resource to me. Ultimately, I recruited a number of participants through Grand River Hospital so a partnership with the hospital was also necessary and valuable.

**Grand River Hospital.** Grand River Hospital (GRH) is located in Kitchener-Waterloo, approximately 32 kilometres from the University of Guelph. A partnership was established with the Medicine Unit of GRH in November 2015 by inviting the Clinical Manager of Medicine to be a member of the research team. To be permitted to conduct research through GRH, a local investigator must be a member of the research team and Clinical Manager of Medicine was not only willing to join the research team, but also expressed a great interest in the study.

The Medicine Unit includes three sub-units, two of which were involved with recruitment for this study. General Medicine houses 32 beds for patients who have acute conditions that require diagnosis, stabilization and treatment. Individuals receiving care in this sub-unit are adults and older adults. Acute Care of the Elderly houses 12 beds for patients over the age of 65 who may have unique needs related to aging.
Research at the GRH is governed by the Tri-Hospital Research Ethics Board (THREB). The THREB serves GRH, Cambridge Memorial Hospital, and St. Mary’s General Hospital, all located within the Kitchener-Waterloo region of Ontario. The THREB makes decisions about the ethical acceptability of research involving patients and staff members of the hospital.

**Ethics Approval and Research Data Agreement**

Ethics approval for the study was first obtained from GRH’s administrative review board. This board is responsible for reviewing the financial, resource, and contractual implications of studies associated with the hospital. Researchers are required to describe the hospital resources that their study will require, including personnel and any chart review. Researchers are also required to attend the administrative review board meeting to present their project and answer any questions the board may have. The Clinical Manager of Medicine and I attended this meeting on December 1, 2015, and administrative approval was obtained which granted permission for the study’s ethics application to be submitted to the THREB for full board review.

The Clinical Manager of Medicine and I attended the THREB meeting on January 6, 2016, to present the project and answer questions related to the ethical implications of the study. Final ethical approval was granted on February 3, 2016. After speaking with the head of the THREB an ethics application was submitted to the University of Guelph’s Research Ethics Board (REB) while waiting for final approval from the THREB. Approval was obtained from the University REB on April 5, 2016. An amendment was submitted to the University of Guelph REB when changes to the recruitment protocol were made that would also allow me to recruit caregivers through the community, after recruitment efforts at Grand River Hospital yielded few participants. This amendment was approved on December 7, 2016. Please see Appendix A for ethics approval certificates.
There were a number of ethical issues that I addressed throughout this study. Here I highlight two that were pertinent to studying caregivers of older adults. In helping participants make an informed decision to participate, I stressed that our conversation would remain confidential and that their participation in the study would not affect the standard of care that their parent would receive. This was particularly important in the context of caregiving because at the time of participation, a number of caregivers’ parents had been hospitalized again and/or had ongoing contact with members of the healthcare system. Further, to ensure that informed consent was an ongoing process, during the interviews I asked participants if they would like to stop the interview when they became visibly upset. However, this only happened in two instances and participants indicated that they would like to proceed with the interview. Although there are certainly other aspects to the informed consent process, these two pieces were particularly salient given that I was interviewing caregivers.

Another major ethical issue involved in this study was my role as a researcher, and any duty to report elder abuse. Prior to ethics approval I had a number of conversations with representatives from the Grand River Hospital, the CCAC and the University of Guelph REB. All agreed that I did not have a duty to report elder abuse because I was not classified as a healthcare professional (who have a discretionary duty to report elder abuse). Particularly, they emphasized that because my role was that of researcher, it was instead my duty to protect participant confidentiality. Nevertheless, we all acknowledged that some caregivers could be experiencing particular distress (which could lead to elder abuse) and it would be useful for me to inform all caregivers of the resources available to them. Therefore, in consultation with a CCAC representative, I created a resource list that I provided to participants prior to beginning the interview.
Recruitment

As mentioned, the central objective of this study was to explore filial caregiver experiences during the transition of their parent from hospital to home. To meet this research objective, I recruited both filial caregivers and Care Coordinators from the WWCCAC. Given that filial caregiver experiences are immersed within a formal and complex healthcare system, I chose to interview Care Coordinators to provide additional context based on their extensive experience with family caregivers during the transition from hospital to home. Subsequently this meant that they provided insights into filial caregiver experience (albeit from a different perspective), and also helped me to understand particular aspects of the healthcare system with which I was unfamiliar. Within my analysis, the data Care Coordinators provided are selectively drawn upon where their perspectives provided additional context to the caregivers’ experiences.

Care Coordinators. The Research Planning Manager from the WWCCAC sent an invitation email to all Care Coordinators in June 2016. This email included a letter of information which described the study and asked interested Care Coordinators to contact me directly. No responses were received. The Planning Manager then sent individual, personalized emails to Care Coordinators and received responses from four in October 2016. After receiving consent to share their contact information, the Planning Manager provided me with their email address and I then set up individual interviews at a place and time convenient to both parties.

Filial caregivers. Caregivers were recruited through GRH and through my own social network. The original recruitment plan included only recruitment through GRH. However, as will be explained below, because of resource limitations, recruitment through GRH was initially slow to start and few caregivers consented to participate. Therefore, I also recruited through my own social network and through websites to supplement hospital recruitment methods.
**GRH recruitment.** In order for hospital staff to recruit participants for the study I believed that staff buy-in was important to the success of the project. They would be devoting parts of their already busy days to assisting me so I wanted to share as much as I could with them about the study, and address any concerns they might have. I therefore conducted a recruitment training session on May 31, 2016, which was attended by four Unit Managers. This session was intended to provide a broad overview of the study, including eligibility criteria and the process for recruiting patients\(^6\) and their filial caregivers. Unit Managers advocated for discharge nurses to be involved in the identification of appropriate participants given their intimate knowledge of patient files (which include caregiver information). The Clinical Manager of Medicine and I agreed that this would be appropriate so the Unit Managers then shared the information about the study to the nurses working in their corresponding Units. To complement the presentation, I also created a recruitment binder so that anyone involved in recruitment would have access to information about the study and recruitment process.

Recruitment in the hospital officially began in September 2016. Between September 2016 and February 2017 I visited the hospital three times to assist the nurses in identifying eligible caregivers. During the first two visits I spent time with a discharge nurse in one of the discharge lounges. During my first visit she explained that it was difficult to recruit caregivers because they often do not visit the discharge lounge on the day of discharge (instead they may wait in the hospital lobby). She therefore had no opportunity to interact with them to ask if they would be interested in participating. We determined that it would be fruitful for me to visit the hospital and recruit participants myself because I would be able to leave the discharge lounge and speak with

\(^6\) Originally, I intended that patients would participate by consenting to release their discharge plan to me. Ultimately this was not possible because staffing resources at the hospital were too limited to devote to the lengthy consent procedure.
caregivers in the lobby. However, both times I visited, there was no one being discharged who matched the study eligibility criteria.

In November 2016, a Medicine Flow Resource Nurse began leading the recruitment process. Her role at GRH is to maximize the flow of medicine unit patients from time of admittance in the Emergency Room through to discharge. This is done through collaboration with physicians, the allied health team, and nursing staff and through daily review of each patient’s care plan and ultimate discharge destination plans. In December 2016, she provided me with the contact information of eleven caregivers. Of these eleven individuals, only two consented to participate. This was concerning to all parties involved in recruitment, including the Clinical Manager of Medicine and the Medicine Flow Resource Nurse. Therefore, we had a meeting to consult about alternative methods of recruitment. The Medicine Flow Resource Nurse described her current method of recruitment which involved approaching patients and asking for consent to provide their son or daughter’s contact information to me. If they consented, the Medicine Flow Resource Nurse provided their phone numbers to me and I contacted them to provide them with some more information about the study and to ask if they would be interested in participating.

I found that often caregivers seemed to be confused by my request when I called them and they ultimately declined participation. Still others declined to participate for other reasons (which are described in detail below), and some could not be reached. Because this method of recruitment had been relatively unsuccessful, the Medicine Flow Resource Nurse suggested that after receiving consent from the patients to contact their caregivers, she would contact them herself to see if they would be willing to speak with me. She felt that they may be more comfortable receiving a call from a hospital staff member, compared to an external researcher. If
they agreed, then the Medicine Flow Resource Nurse would provide me with their contact information and I would call them, provide them with additional information about the study and ask if they would be interested in participating. This method was more successful and I attribute this to 1) the Medicine Flow Resource Nurse directly contacting caregivers, rather than asking patients who may have made incorrect assumptions about their son or daughter’s willingness to be contacted and 2) interested caregivers were already expecting the call from me, so they were more receptive to my request. Through this method 36 caregivers were recruited and 10 participated in the study. Of the 26 individuals who did not participate, I could not reach fourteen (I generally called twice and left a message where possible), and the other 12 declined participation for reasons explained in detail below.

**Community and social network recruitment.** Due to low participant numbers from GRH, beginning in January 2017, I posted recruitment ads on Facebook (which were shared multiple times by my Facebook friends), Kijiji and Craigslist, placed a hard copy ad on the bulletin board of the Guelph Volunteer Centre, and also contacted family and friends to ask if they knew of anyone who was providing care to a parent who had recently been in the hospital. From this method of recruitment I interviewed eight participants, one of whom was recruited through Kijiji, and the others through my social network.

**Reasons for Declining Participation.** As mentioned above, not all participants who initially expressed an interest in the study agreed to participate. It is important to report the reasons why they did not participate because it provides a more comprehensive picture of the lives of filial caregivers. The reasons they provided for declining participation generally related to having limited time, or to changes in their personal lives. Some caregivers had already taken time off work to care for their parent and felt that they could not devote time to participating
because they had work to catch up on. Others were overwhelmed by their caregiving responsibilities, and in a minority of cases, the individual’s parent had passed away since the time they were discharged. The reasons for declining participation are important to highlight because they illustrate that discharge from the hospital can then lead to any number of outcomes for patients (institutionalization, death) and demonstrate that some caregivers may have reached capacity in relation to the time they have to devote to new activities.

**Participants**

Care Coordinator participants were 4 individuals with diverse educational and employment backgrounds. One had a background in occupational therapy, another was a social worker, and two were registered nurses. These Care Coordinators had been in their current position with the CCAC for three to four years, but had up to 30 years of experience working in home care and/or hospitals.

Eighteen filial caregivers (male n=5, female n=13) aged 22 to 67, with an average age of 46 participated in the study. The majority of participants were married or living with a partner (n=11), and a roughly equal portion of the sample were single (n=4) or divorced (n=3). More than half of participants (n=10) reported completing college or university, and two held post-graduate degrees. Three participants had completed high school, and three reported completing some college or university (with two participants stating that they were currently enrolled in a university program). Ten participants disclosed their annual family income, and reported a range of $5,000 to $251,000. The majority of participants (n=10) were working full-time, three were working part-time, three were retired, one was on maternity leave, and one reported being on long-term disability leave. Most participants did not have dependent children (n=13). Although participants were not directly asked to state their nationality, a number shared the country where
they were born (or where their parents were born) and responses included Hungary, Germany, Jamaica, India, and Canada. Three participants reported that they immigrated to Canada during their adult years.

Most participants provided support to one parent (n=14). There was a roughly equal distribution of caregivers providing support to their mother7 (n=10) and to their father (n=8). Their parents ranged in age from 60 to 97, with an average age of 82. Eight participants reported that their parents lived with them, 7 parents lived in their own homes, two parents lived in a nursing home at the time of the interview and one parent lived in a retirement home at the time of the interview. Participants reported a number of reasons that their parents were hospitalized including falls (n=5), cancer related complications (n=2), abdominal pain (n=2), infections (n=5), “mild” stroke (n=1), diabetes related complications (n=1), kidney failure (n=1). One participant could not report the precise reason that her mother was hospitalized because a diagnosis was not made, but did report that her mother experienced dizziness and shortness of breath. I was unable to obtain discharge records for the purposes of this study, and I was therefore unable to confirm the reasons for hospitalization. The length of hospital stay ranged from one night to 35 days, with an average length of stay of 11 nights. One participant was unable to report the length of time his father spent in the hospital because he had been in the hospital on six separate occasions during the previous six months, and reported that the time was “blending together”. A minority of participants’ parents were diagnosed with dementia (n=4).

Within the sample, 10 participants reported that they had been providing support to their parent for a number of years, though often their parent’s recent hospitalization prompted more

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7 Note that one caregiver was providing support to her grandmother who had been involved in raising her as a child.
intensive support. For the other eight participants, their parent’s recent hospitalization mobilized them as caregivers for the first time in their lives. Indeed, some caregivers described not knowing how poor their parent’s health was and their hospitalization served as a “wakeup call”.

Half of all of the caregivers participating in the study had some kind of assistance from other siblings (n=9) and this appeared to be particularly important in supporting their parents. Given the vast array of activities they engaged in, they described splitting tasks with siblings. Six participants reported that they had siblings, but that these siblings were not involved in the care of their parent because of geographic distance or, as one female caregiver with brothers observed, “all of the care falls on the women”.

**Data Collection Procedure**

Interviews took place between October 2016 and April 2017. Most caregiver interviews took place in participant’s homes (n=14), with a smaller number taking place over the phone (n=4). One Care Coordinator interview took place in person in the Discourse, Science and Publics Lab at the University of Guelph, two took place over the phone, and one was conducted at a local hospital.

Participant consent was obtained over the phone or in-person immediately prior to the start of the interview. I explained the purpose of the study, highlighted important points on the consent form, and answered any questions they might have. Given that caregiving has the potential to be a distressing experience, I felt that it was important to emphasize to caregivers that although I was a Psychology student, I was not clinically trained and therefore was not in the position to offer therapy. This was important to draw attention to as it was possible that some participants may have viewed the interview as a therapeutic encounter, owing to the sometimes
stressed and emotional experience of caring for a parent. I provided all caregivers with a resource list (see Appendix B) that they could consult should they have any concerns.

A copy of the consent form was provided to all participants and I gave a $10 Tim Hortons gift card to all caregivers to thank them for their participation, immediately prior to the start of the interview. Caregivers were also asked to complete a demographic questionnaire before the interview began (see Appendix C). Within this demographic questionnaire, participants were asked to report gender, but all participants reported sex. Therefore, within this document, participant sex, rather than gender is reported. I then began the caregiver interview sharing some information about myself (e.g., my educational background, my interest in the topic of caregiving) and the main focus of the study. The interview guide for caregivers is presented in Appendix D, and questions generally focused on participants’ experiences pre-hospitalization, during hospitalization, and post-hospitalization to capture the process oriented nature of transitions over time (Schumacher et al., 1999).

I began the Care Coordinator interviews explaining the purpose of the study, my educational background and interest in caregiving, and the role of the WWCCAC in my study. The interview guide used with Care Coordinators is presented in Appendix E, and questions generally focused on their experiences with family caregivers and their perceptions of the challenges family caregivers experience. The interview guides were used as a reference but I asked questions in an organic way to allow participants to direct the conversation.

Interviews lasted between 40 and 90 minutes. All interviews were recorded using two audio recorders (one was used as precaution to ensure that recorder malfunction would not result in the loss of data). I stopped data collection among caregivers once I felt there was sufficient overlap in the conversations I had with participants. I stopped data collection with Care
Coordinators once I was made aware by the WWCCAC Project Manager that their work schedules would not permit them time to participate in the study.

Since I had visited the hospital on a number of occasions I also kept field notes that documented my observations of the hospital environment. These notes did not have any specific focus, and they therefore provided a broad overview of my observations to serve as a reminder as I entered the writing phase of my dissertation.

**Transcription and Data Analysis**

Audio files were transcribed verbatim into a Microsoft Word file, and in this document, “I” denotes interviewer and “P” refers to participant. All participants were assigned pseudonyms to ensure confidentiality. I transcribed each of the interviews myself and made notes as I did so to document my thoughts about the data as they occurred. Following transcription, I verified all transcripts to ensure accuracy, and made edits accordingly.

I read and re-read the data through a number of times prior to creating any codes. This allowed me to familiarize myself with the data and to make analytic notes that would help me to develop a coding structure. Multiple codes were then created using an inductive approach and interview excerpts related to each code were copied and pasted into a Microsoft Word document. I utilized the heading function to organize each code. For example, I named the code “monitoring” using Heading 1 which would allow it to be easily searchable and accessible in the document. Participant numbers were retained throughout so that I could refer back to the original transcript if necessary. I reviewed the data categorized under each code for relevance, and data were moved within the document or removed entirely if I felt it was not appropriately categorized. Codes were sometimes re-named as data were reorganized. Analytic notes were made throughout this process.
I utilized a thematic method of analysis (Braun & Clarke, 2006). Following guidelines proposed by Braun and Clarke, I looked for patterns across the list of codes and organized them by sorting them into broader themes. Themes largely represented the activities that caregivers reported participating in during the transition from hospital to home, and the ways that they described the Ontario healthcare system. I then examined the validity of the themes by returning to the complete data set to determine if they helped to tell a coherent narrative that was representative of what participants shared during the interviews. During this process I coded (or re-coded) additional data that were missed during my initial coding process. Themes were named in a way that directly connected them back to the research questions and included advocating, descriptions of the Ontario healthcare system, and caregiver activities. Sub-themes were also created to assist in the analysis. For example, under the overarching theme of descriptions of the Ontario healthcare system, sub-themes included deteriorating, overburdened, surprise with positive experiences. A complete list of themes, sub-themes and codes are presented in Table 1.

The analysis continued by engaging in an interpretive process whereby I considered the relevance and importance of data extracts coded under each theme, and attempted to explain the implications of the patterns for caregivers and the broader healthcare system (Braun & Clarke, 2006). My analysis in the following three chapters is organized largely around the overarching themes and sub-themes, and not the codes that I used to construct those themes.
Table 1 Overview of themes and codes developed

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-theme</th>
<th>Codes</th>
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<tbody>
<tr>
<td>Descriptions of the Ontario Healthcare System</td>
<td>Falling through the Cracks: Deteriorating</td>
<td>• Fragmented</td>
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<tr>
<td></td>
<td></td>
<td>• Discontinuity in care</td>
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<tr>
<td></td>
<td></td>
<td>• Confusing</td>
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<td></td>
<td></td>
<td>• Good healthcare providers</td>
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<td></td>
<td></td>
<td>• Formal monitoring failing</td>
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<td></td>
<td>Overburden</td>
<td>• Long wait times</td>
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<td></td>
<td></td>
<td>• Earlier than expected discharges</td>
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<td></td>
<td></td>
<td>• Insufficient care</td>
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<td></td>
<td></td>
<td>• Not enough time to form relationships</td>
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<tr>
<td></td>
<td>Surprise with positive experiences</td>
<td>• Excellent care from healthcare professionals</td>
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<tr>
<td></td>
<td></td>
<td>• Individual vs. system level</td>
</tr>
<tr>
<td>Caregiver Activities</td>
<td>Monitoring</td>
<td>• Treatment</td>
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<tr>
<td></td>
<td></td>
<td>• Healthcare providers</td>
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<tr>
<td></td>
<td>Assistance with ADLs</td>
<td>• Bathing</td>
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<td></td>
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<td>• Using the toilet</td>
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<td></td>
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<td>• Movement throughout the home</td>
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<td></td>
<td>• Dressing</td>
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<td></td>
<td></td>
<td>• Feeding</td>
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<td></td>
<td>Assistance with IADLs</td>
<td>• Cooking</td>
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<td>• Transportation</td>
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<td>• Shopping</td>
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<td>• Paying bills</td>
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<td>• Medication administration</td>
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<td>• Housework</td>
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<td>• Laundry</td>
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<td></td>
<td>System Navigation</td>
<td>• Challenges due to lack of information</td>
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<tr>
<td></td>
<td>Emotional support</td>
<td>• In hospital</td>
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<td></td>
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<td>• In home</td>
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<td></td>
<td></td>
<td>• Insufficiently addressed by formal care providers</td>
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<tr>
<td>Advocating</td>
<td>Self-advocating</td>
<td>• Discomfort with being assertive</td>
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<tr>
<td></td>
<td></td>
<td>• Learned skill</td>
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<td></td>
<td>Reasons for advocating</td>
<td>• Parent is unable or uninterested in advocating on their own behalf</td>
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<tr>
<td></td>
<td></td>
<td>• Based on perceptions of limited resources in the healthcare system</td>
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<tr>
<td></td>
<td></td>
<td>• Based on negative experiences</td>
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<tr>
<td></td>
<td>Challenges</td>
<td>• Poor information provision</td>
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<td></td>
<td></td>
<td>• Difficult to find service providers</td>
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<tr>
<td></td>
<td></td>
<td>• Persistence</td>
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<tr>
<td>Theme</td>
<td>Sub-theme</td>
<td>Codes</td>
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<td>---------------------</td>
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<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>Preparation</td>
<td></td>
<td>• Unprepared &lt;br&gt; • Uncomfortable &lt;br&gt; • Did not know they would have to advocate</td>
</tr>
<tr>
<td>Providing information</td>
<td></td>
<td>• Medical history &lt;br&gt; • Mannerisms &lt;br&gt; • What parent was like before</td>
</tr>
<tr>
<td>Collecting information</td>
<td></td>
<td>• Asking questions &lt;br&gt; • Determining who to talk to &lt;br&gt; • Being persistent</td>
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Chapter 5: Caregiver Descriptions of the Ontario Healthcare System

The topic of healthcare features prominently in Canadian political debates and media coverage. For example, during the last Ontario provincial election in 2014, all major political parties included healthcare reform as a component of their party’s platform (CBC, 2014). The Canadian public is exposed to frequent media reports characterizing the Canadian healthcare system as a system in “crisis”, with lengthy wait times, doctor and nursing shortages, and vulnerability associated with an aging population that is predicted to overwhelm the system (Romanow, 2002). Although opinion polls and organized discussions generally suggest that Canadians are appreciative of the universal healthcare afforded to them, they have concerns that are reflective of media portrayals (Soroka, 2011).

Just as the topic of healthcare is widely discussed in the political realm and in media reports, participants also devoted considerable attention to their perceptions of the healthcare system during their interviews. In this chapter, I examine how the Ontario healthcare system was described by caregivers who had intimate experience with it. Specifically, this chapter focuses on answering the first research question, how do filial caregivers perceive the healthcare system? Caregivers’ accounts suggested that they viewed the healthcare system as deteriorating and overburdened. I consider each of these descriptions in turn, and in doing so I contextualize their experiences within broader institutional structures that have implications for the type of care they are able to provide to their parents. Within this context, caregivers identify problems such as insufficient monitoring of their parent’s care and limited healthcare resources that place patients at risk.
“Falling through the cracks”: Deterioration of the Ontario Healthcare System

Participants described the healthcare system as “falling apart” or “going downhill”, and expressed concerns that their parents would “fall through the cracks” of its damaged foundation. They discussed instances where they felt aspects of their parent’s care had been overlooked by healthcare providers, thereby suggesting that appropriate formal monitoring systems were not functioning at an appropriate standard. For example, James (male, 58), described an infection his father developed while in his retirement home after he was discharged from the hospital following shoulder surgery. James noticed that his father’s shoulder dressing was not being changed regularly, and attributed the development of an infection to this aspect of his care being overlooked by formal care providers:

He also had a little bit of a shoulder surgery and the dressing hadn’t been changed, that came from the surgery. We wondered was there anything being done on a daily basis? So something fell through the cracks… if we weren’t checking on him we would have never known about his shoulder dressing not being changed, things like that.

Caregivers’ accounts often reflected the ways in which the healthcare system supported or failed their families. When participants shared accounts of negative experiences that placed their parents at risk, all participants viewed them as largely preventable had appropriate monitoring occurred. In response to asking what led to his father’s hospitalization, Robert (male, 36) responded:

So he [participant’s father] was diagnosed with Type II diabetes when he was around 40. So he was taking, for a long period of time he was taking this pill called *Metformin*. So I guess over time, they weren’t checking his kidney function
regularly and I guess Metformin from what I understand affects your renal function. I don’t know if it was overlooked or neglected or whatever but you know but he wasn’t, those regular check-ups weren’t happening.

Robert’s father developed kidney failure, which Robert blamed on insufficient monitoring of his father’s kidney function by healthcare providers. Caregivers like Robert viewed healthcare providers as responsible for monitoring their parent’s health. However, participants’ accounts suggested that the behaviours of healthcare providers did not always align with their expectations. From the perspectives of participants, healthcare providers did not suitably monitor their parent’s care, and when this happened, their parent experienced damaging consequences such as a deterioration of their health, hospitalization, or in extreme circumstances, death. Recounting a story from her past, Shirley (female, 59) explained that her mother developed a fatal infection while in the hospital and suggested that it could have been treated had hospital staff proactively tested her for a particular strain of bacteria known to cause life threatening infections in older adults:

My mom in [year] died after having a heart surgery at [hospital name] and she was there for 9 days, we brought her home, two days before that there was an outbreak of C. Difficile in the hospital. They denied it. My mom got it. My mom told me, before she was released, and they never checked her, she said you know I think I got that infection, and I said well how do you know, because that was a floor above, she says because I have such bad diarrhea that I’ve never had like this, and she said I’ve never had cramps like this. But you know what, we didn’t click in.
When discussing the deterioration of the healthcare system, some caregivers also remarked that it was confusing and fragmented. Caregivers largely described the fragmented and confusing nature with reference to home care specifically, and explained that they often had contact with a multitude of service providers after their parents were discharged from the hospital. For this reason they reported difficulties navigating the healthcare system. For example, Andrew (male, 39) whose mother was diagnosed with cancer explained:

One thing is there are a lot of organizations to deal with. You know you have CCAC and there are [name of homecare organization], nurses, and there is that and there is you know her doctor and the doctor from the hospital and an oncologist from the hospital and also a palliative care doctor who we saw for the first time last week who is actually also really great. But that’s a lot of different people so I’m having trouble keeping track of who is who and who I need to call if something is wrong.

With so many healthcare providers involved in their parent’s care during the transition from hospital to home, some caregivers expressed difficulties knowing who was responsible for particular aspects of their parent’s treatment plan. Consequently they did not know which healthcare providers should be monitoring their parent’s health, or who they should contact if their parent required assistance.

Within the homecare environment caregivers labeled communication between the Community Care Access Centres (CCACs) and their contracted service organizations as deficient, or as Taylor (female, 22) described it, “where the whole system falls down”. Caregivers referred to a discontinuity in service provision owing to rotating shifts or to the high turnover of personal support workers attending to the care of their parent. Judith (female, 67)
described her experience with personal support workers employed by a company that was assigned to her father’s care by the CCAC:

P: It’s been horrible. If you ask me it’s been horrible… My father was with a company upon one of his discharges, he was with a company called [company name 1] when he was having issues with his feet… He developed some good relationships with this agency and then when he went back [to the hospital], he was admitted again and he was discharged and for some reason they [the CCAC] then put him in with [company name 2], this other provider. So it was really frustrating because we had developed those, and personal care is personal, not everyone works with everyone well right so we had things sort of going and they were familiar with my dad, they were familiar with our house, they knew where things were, they knew a lot and so it’s like well now we’re with [company name 2] and there’s these strange people that we don’t know that are rotating shifts and so who are we getting today and this person knows that there’s a bed wound here and this one doesn’t. We have to reorient them [personal support workers] almost daily and then they’ll come and search for us, search for us in the house and that’s our time to have a little bit of respite, to take a break.

A continuity in formal care was important to participants because they felt that to provide satisfactory care, healthcare providers required a detailed understanding of both the patient, and their environment. From caregivers’ accounts it appeared that when a new personal support worker was introduced to the care environment, they had limited knowledge of participants’ parents which compromised their ability to monitor their parent’s health, and to perform the duties they were assigned. As Judith explained, she felt that new personal support workers were
not aware of the specifics of her father’s case, such as the location of a bedsore which required consistent monitoring to prevent infection.

When describing the deterioration of the healthcare system, participants often grounded their criticisms at the system level rather than at the level of individual healthcare providers. In doing so, they suggested that the system was not falling apart because of any shortcomings in the skills and abilities of healthcare professionals, but rather because of constraints placed upon the healthcare system by polices and resource allocation. In the following excerpt, Linda (female, 63) alludes to a critical incident in the hospital that nearly resulted in the death of her mother:

P: It’s something that never should have happened.

I: Yeah, oh dear.

P: And I just think like, I was staying at the hospital overnight and had I not been staying there that night, my mother could have died.

I: Oh my goodness.

P: And they would have just slupped it off as she just died in her sleep right. You know what I mean?...I’m not saying it’s their fault or the nurses’ fault or anything, but there was just you know uh, I don’t know I can’t find the word I’m looking for. But there were just a few things that happened that night that should never have happened. I blame it on the government.

I: So it’s more the way they’ve set things up then?

P: Yeah. Obviously I’m sure you know, it’s just going to hell right now anyway.
Linda was not willing to disclose the specifics of the night she describes because she wanted to file a formal complaint, but in her account, Linda placed blame for this incident on the way the Ontario healthcare system is structured, rather than on any one individual who was attending to her mother’s care in the hospital. She additionally emphasized that there are particular structural constraints that affect the way hospital staff perform their jobs that may place patients at risk.

Often when caregivers perceived the healthcare system to be deteriorating, they subsequently described particular actions that they engaged in to ensure that their parent was not a casualty of such an environment. When caregivers provided examples of instances where they believed formal monitoring systems failed their parents, they suggested that to prevent other negative events from occurring, some informal practice of monitoring their parent’s care was necessary. In some of the interview excerpts presented in this section, caregivers described first hand experiences where they monitored their parent’s care when formal systems failed. For example, James described learning of his father’s shoulder infection because he was “checking on him” and Linda suggested had she not been present at the hospital her mother could have died. I return to this point in chapters 6 and 7 and explore caregiver actions within the healthcare system in detail.

The Ontario Healthcare System as Overburdened

Participants also perceived the Ontario healthcare system to be strained owing to limited resources. Specifically, they presented the Ontario healthcare system as overburdened because of a high volume of patients and staffing shortages. They identified consequences associated with this overburdened environment including long wait times, hospital discharges that came earlier than expected, formal care that they deemed insufficient, and limited time to form relationships
with healthcare professionals. These perceived consequences of an overburdened healthcare system are discussed in the following sections to demonstrate the context in which caregivers were supporting their parents, specifically as it pertained to the limited availability of healthcare resources.

**Long wait times.** After discharge from hospital, participants’ parents were often sent for medical tests. Caregivers often accompanied their parents to appointments and generally the tests were performed soon after arriving for their appointment. However, although tests were performed quickly, caregivers described waiting a considerable amount of time before learning the results. They characterized the waiting period as worrisome and frustrating because they were concerned about the test results and because while waiting, their parents experienced prolonged suffering with few options for treatment. Additionally, some caregivers explained that they had to wait for long periods before physicians developed a treatment plan for their parent. Connie (female, 50) described waiting months for her mother’s treatment plan to be established, during which time her mother’s health declined significantly:

P: Well it was just kind of frustrating um for her but also for us as caregivers because we knew something was going on but the doctor was just kind of like well let’s wait and see um she had had a colonoscopy before and it came up that, so she was diagnosed with thyroid ticulitus at the beginning of last year from her colonoscopy. But they basically said that you know you don’t need medication at this point, just watch your diet there’s really no restrictions you just kind of eat and hopefully don’t get a flare up. And that was it.

I: Mhmm. Okay.
P: And then there was no follow-up. So then going from there, then she got this chest issue going on and then um and it was ongoing and ongoing and ongoing and we had her back and forth to the doctor who was more kind of like let’s wait and see…That was frustrating because we kept taking her back and it kept coming back no nothing’s wrong. I just wish they had been a little bit more pro-active and then I don’t think she would have gotten into her state of crisis where they, the stomach issues got so severe that she couldn’t leave the house and then of course the recovery time’s longer…it took from the early Spring to the late Fall to finally get an action plan going and find the right medical professional to deal with what she needed… I mean it’s so hard with the healthcare system. I know there’s lots of waiting times and shortages of doctors and professionals especially if they have something specific that needs to be done but when you have a loved one who’s suffering it’s scary to have to wait.

Michelle (female, 24) similarly described difficulties waiting for access to medical assessments that would inform the development and implementation of a treatment plan for her father who was diagnosed with cancer:

P: I think the biggest problem is, not so much not knowing, it’s a lot of the waiting and we don’t understand why we’re waiting. And like we have to wait 4 weeks for a CT scan to see if something on his lung is going to grow but why are we waiting 4 weeks, it just doesn’t make sense to us. We’re just kind of sitting here like sitting ducks waiting for 4 weeks. And so this thing could be growing on his lung and we don’t know why we’re waiting.

I: So do you ever ask them, like what’s the hold up?
P: We just get told, we don’t know, we have to wait. Um there’s so many teams that are involved, like right now he’s getting his lungs drained of all the fluids so the thoracic team is involved and he’s admitted into internal medicine in [name of hospital] so that department is involved and then the oncology from [name of cancer centre] so everyone’s kind of like we have to talk to the oncologist first before we can tell you this and everyone kind of has to talk together and it takes forever and it takes forever for everyone to finally get their message straight to us. It takes days.

Caregivers perceived limited resources to be a factor contributing to long wait times, and worried that the availability of limited resources would place their parents at risk for negative health outcomes. In describing the healthcare system as overburdened, caregivers highlighted the intense emotional experience associated with waiting for test results and treatment for their parent. Their concerns emphasized that they felt powerless to help their parent as they did not personally have control over the resources necessary to facilitate their parent’s recovery.

**Early discharges from hospital.** Participants also described experiences in which their parents were discharged from the hospital earlier than they expected. Participants who were caring for a parent with a complex condition often felt that their parents were discharged from the hospital too soon, and speculated that this was likely because the hospital required the bed for a patient in more critical condition. Linda (female, 63, first excerpt) and Gail (female, 45, second excerpt) shared similar accounts of their mothers being discharged from the hospital earlier than they expected:

I: Yeah, okay I guess so sort of related to her being discharged, did you feel that you were prepared for her to come home?
P: Um not really because uh I didn’t know what to expect. I didn’t know how she was going to be so I was just afraid you know?

I: Yeah, yeah.

P: But they need the bed. You know so I mean I guess it was time.

--

I: Would you say that you felt that she was ready to be discharged, like to come home?

P: No. I don’t think she was ready to come home yet.

I: So in terms of, like how well she had been healing and doing, that type of thing?

P: Yeah so they discharged her because she was medically stable um in my opinion, like she didn’t need urgent care, in my opinion though I don’t think she was quite ready yet because up until the day they discharged her she was on um she was still on anti-biotics. Two days prior they had thought that she probably had blood poisoning.

I: Oh dear.

P: Yeah but luckily she didn’t but still there were all of these little things and the fact that she was on antibiotics, she was still being monitored because she may or may not have had a fever um and uh she couldn’t walk so I’m like oh okay. And also she had a pressure sore on her lower back and I thought well what’s going to happen if this sucker bursts. I can’t take care of this.
I: Right, yeah.

P: So I didn’t think I was prepared and I didn’t think she was quite there yet for her to come home. However, they deemed that she was medically stable so okay.

Caregivers’ accounts of discharges for which they were unprepared indicated a problematic situation in which caregivers were required to assume responsibility for the care of their parent, when the care their parent required was beyond the abilities of the caregiver to provide. Often after discharge from the hospital, participants’ parents had not resumed their prior level of functioning and therefore required additional assistance. For example, both Linda and Gail’s mothers were no longer able to walk after they were discharged from hospital and required assistance with tasks such as using the toilet. Yet, as caregivers explained, such assistance was challenging and they worried that their parents would sustain injuries while they tried to provide assistance for which they were untrained. Therefore, in viewing the healthcare system as functioning with limited resources, caregivers identified instances where limited resources compromised not only the ability of caregivers to support their parents, but also compromised the safety of patients when caregivers could not provide the care they required. In such circumstances some caregivers reported that their parents were repeatedly hospitalized over a short period of time when participants could not provide necessary care within the home. Additionally, other caregivers who I contacted to participate in the study declined because during the period between their parent’s discharge and my phone call, their parent had once again been hospitalized.

Some caregivers also described the sudden discharge of their parents from the hospital. Caregivers explained that they often received little advance notice of their parent’s discharge. From the accounts of caregivers it seemed that discharge times did not take into account the
schedules of caregivers who were often responsible for transporting their parent home. The important role of caregivers during discharge therefore appears not to have been recognized in some instances. For example, Shirley (female, 59, first excerpt) and Taylor (female, 22) described being told about their parent’s discharge:

All of a sudden to me, this is the bad thing about the hospital to me, tomorrow your dad is released. Well you know, maybe I have an appointment, or maybe, I felt awkward. And I didn’t have an appointment and I picked him up and poor dad was already in the waiting lounge and that’s where that nurse told me about you.

I: When it was time for her to leave the hospital then, did you feel like you were prepared for her to come home?

P: No, it was kind of, I got there one day, I was ready to do my regular thing, like hang out til I got to talk to the doctor, whatever, and uh someone just came in and was like oh she’s going home today and I was like oh, okay. And they were like are you okay to take her home and I’m like suuuure. It was kind of just, I got there and it was sprung on me like oh I’m going to take her home.

**Insufficient care.** Caregivers made explicit links between the perceived overburdened nature of the healthcare system, and the level of care their parents received. Often caregivers were not satisfied with the formal care provided to their parents. However, they attributed poor quality care not to individual staff members, but rather to the organization of a system that prioritized critical incidences over personal aspects of care such as bathing and feeding. For
example, Shirley (female, 59) described a conversation she had with a nurse about the formal care provided within the hospital:

Now washing I couldn’t do but I had to ask the nurse to give the wash a one night and she said why don’t we wait until the morning and I said no it’s better now I said because it’s quiet. Yeah, but we don’t have enough staff at night time and in the morning it’s better and I said but if, I could do it if you want me to, and I said I want you to do it now. In all fairness to the poor nurses, I did talk to another one when I had a discussion one evening and she complained that they have really cut back on staff and they no longer have nurses’ assistants, remember they had a nurse and then they had the nurses’ assistant? So she said, well imagine what do we do when I can’t, I would like to, but sometimes I don’t have time to give a bath or a shower to a patient and I might do that but them I’m called for a cardiac patient, she said, now what do I do? So she said we’re constantly being caught in this, not quite looking after each patient, do we feed a patient when they can’t feed themselves? Do we just ignore him? Which is what I saw basically, they put the food in front of them, maybe you might ask, do you want me to cut up your food? Yeah okay they cut it up but then they disappear. And then I look and see the patient not eating.

Caregivers spoke about staffing shortages that they believed contributed to insufficient formal care being provided to patients. Caregivers acknowledged that critical care should take precedence over personal care, but that personal aspects of care were still important. Although participants regarded the formal provision of personal care as desirable, some perceived it to be unrealistic within the context of the overburdened system, and sympathized with healthcare
providers, particularly those working in the hospital. Andrew (male, 39) described his understanding of the nature of hospital staff’s work:

It’s not personal care per se, but it’s also not reasonable to expect that because you know these people are pretty much like me when I go to work, they get paid to do their work and they also need to go home and they have terrible schedules as it is… and all the nurses and doctors are working 12 hour shifts and you know my shifts ended, when I was done I was done and I know theirs aren’t like that so I absolutely empathize on that front. I don’t know how or why people do it but I’m glad they do.

**Limited time to establish relationships with healthcare providers.** Many participants desired a personal connection with the people who were providing formal care to their parent. They spoke of wanting to make sure that they were introduced to the attending physician at the hospital, and some made an effort to get to know the nurses by name. However, caregivers sometimes felt that developing a personal connection was not always possible because of the busy schedules of healthcare providers. Matt (male, 31) reflected on the limited opportunities he had to interact with healthcare providers when his father was hospitalized in a busy city hospital:

It’s a weird place to find yourself because there’s this person that you obviously care about a super great deal and it’s also very obvious, by the nature of the job that doctors and nurses do, they don’t have time to pretend that they really care about your family member, they don’t emotionally care about this person in the same way that you do even close, because they don’t know, they’re doing their job which is to save their life and everything like that but they don’t you know, like people in ERs, they don’t have time to be nice really. They’re all tired, everyone’s working long shifts, too many patients and not enough, it’s like the
classic Canadian story, Canadian healthcare and all that so like there’s just so much um, there’s so much stuff to do and so many dire situations that they just don’t have time to make the family members of the patients feel good, you know?... I think I expected them to be definitely more, everyone watches those medical dramas and stuff, like you kind of expect that you’re going to have more one on one time or maybe the doctor’s going to be around more, you can have more conversations with them, or something, yeah I think I initially expected more communication when I was there, definitely.

Matt describes the misalignment between his expectations and his experiences related to communication and development of a personal connection with hospital staff. Responses like Matt’s suggested that the hospital environment was not conducive to the development of a personal connection with hospital staff because they simply did not always have time to devote spending time with patients’ families. Others spoke of their parents receiving limited attention from physicians and nurses while their parent was hospitalized, and described the importance of having regular interaction with hospital staff to discuss their parent’s care. However, they suggested that because the healthcare system was overburdened, this was not always possible.

Some caregivers described pre-established relationships with their parent’s healthcare providers which they felt contributed to higher quality care for their parent. Although these caregivers still described the healthcare system as overburdened, they believed that because they had a personal connection with healthcare providers, they were able to interact in a way that enhanced the care their parent received. As Kelly (female, 47, first excerpt) and Connie (female, 50, second excerpt) explained:
I know her [mother’s doctor] well. You know, we’ve known each other for a while. So it’s easy to talk to her and get help.

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We were lucky because the hospital that we use is a smaller one. So it is a little bit better in that respect for the quality of the staff that are there I would say because it is a smaller town you know there’s going to be probably somebody that you know, so you can use that to get information. I find that very helpful.

With such accounts, caregivers emphasized the importance of relationships with healthcare providers involved in their parent’s care. For caregivers, pre-established relationships meant that more personal attention would be devoted to both patients and caregivers, and caregivers felt more supported in their role because they had greater access to important information about their parent’s care. Conversely, many caregivers who did not have previously established relationships with their parent’s care providers, stated that they did not receive personal attention from healthcare providers.

**Surprise with Positive Experiences**

While participants predominantly described negative experiences with the healthcare system, some did describe their experience related to their parent’s hospital stay as overwhelmingly positive. However, in doing so they indicated surprise suggesting that their experience challenged assumptions they held about the system prior to their parent’s hospital admittance. In the following excerpt, Joyce (female, 56) describes the unexpected high level of quality care her father received at the hospital:
I expected him to be taken care of but I didn’t expect the level of compassion and kindness, because you read such terrible things and because we haven’t had to deal with this other than small stints in the hospital for operations or whatever. No I was, we were blown away by the kindness and care…. But yeah so we were very, very thankful for the care he got and I know a lot of people say oh that’s not the norm… No we were really lucky. Even when he was back in there for those three days, he was on a different floor and they were just so, so nice. So we were very thankful.

Some caregivers also contrasted their parent’s experience with their own experiences with the healthcare system. Previously some caregivers had been hospitalized themselves and had categorically different experiences than their parents. For example, Janice (female, 51), had recently undergone cancer treatment and during that time also suffered a stroke. She spoke about her experience in the hospital which was characterized by instances of misinformation and discontinuity in care, and compared her experience to her father’s care which she felt was extraordinary:

I ran into some problems, every doctor had different information, and I had many different doctors so for me we never got the same answers, what they were doing wasn’t always told...But with my dad none of that happened. I think [hospital name] and the nurses and all of them are one of the best, his care was absolutely phenomenal…I would definitely recommend [hospital name]. The people there are truly amazing, even if there were multiple ones, they truly, genuinely care for you. There has never been a question about any of that like they are amazing people, compassionate people.
When caregivers described unexpected, positive experiences, their accounts suggested that prior to their parent’s hospitalization they expected to witness poor quality care and an environment characterized by limited resources. However, their accounts also suggested that when they had positive experiences, they attributed the excellent quality of care to individual staff members who displayed personal attention to their parent.

**Chapter Summary**

Caregivers provide care within broader care environments, and it is therefore important that their experiences are contextualized appropriately. Caregivers described the Ontario healthcare system as deteriorating and overburdened, with long wait times, early discharges from hospital, insufficient care, and limited opportunities to interact with healthcare professionals. Caregivers suggested that their parent’s health and care was not appropriately monitored and as a result their parent’s well-being was compromised. However, not all experiences were negative. Caregivers described surprise when exceptional care was provided, which suggests that positive experiences challenged their expectations about the care that their parent would receive.
Chapter 6: Caregiving Activities

In this chapter I focus on answering the second research question, *how do filial caregivers support their parent’s well-being during the transition from hospital to home?* I describe the activities that caregivers engaged in to assist their parents, and the way that such assistance functioned to ensure their parent’s well-being during the transition from hospital to home. I argue that the capacity of caregivers to support their parents differed based on the nature of the activities they were expected to perform. Specifically, when caregivers did not have the required knowledge or necessary resources, they experienced difficulty supporting their parents with particular activities, both while their parent was hospitalized and after their parent was discharged. In such circumstances, their parent’s well-being was compromised.

Additionally, I suggest that the ways that filial caregivers supported their parents, and the challenges they encountered doing so reflect findings presented in the broader literature on family caregiving (e.g., spousal caregiving) during the transition from hospital to home (presented in Chapter 3). However, contextual factors within filial caregivers’ lives limited their ability to support their parents. Specifically, because most filial caregivers were employed full-time, their schedules posed particular challenges as they sought to support their parents within a healthcare system that was often not in alignment with their employment schedules. In this chapter, I elaborate on this finding.

Prior to beginning the interviews for this study, I expected, based on my understanding of the existing literature, that caregivers would report supporting their parents with a wide range of activities during the transition from hospital to home. The stories they shared with me confirmed my expectations. However, what I did not expect to find was the extent to which they assisted their parents within the hospital. Much of the literature about the transition from hospital to home
has tended to focus only on the period after hospital discharge, thereby omitting an examination of a key aspect of the transitional period. In my analysis, I demonstrate that even while their parent was hospitalized, caregivers were heavily involved in their care.

**Assisting Parents with Activities of Daily Living**

Activities of Daily Living (ADLs) include basic activities, generally related to self-care, such as bathing, using the toilet, dressing, feeding, and movement throughout the home (Levine et al., 2004), and throughout the transition from hospital to home caregivers assisted their parents with these activities. For some, performing these activities was temporally limited with assistance decreasing as their parents’ condition improved, whereas for others, assisting their parents with these activities was a more permanent fixture in the support they provided.

During the transition from hospital to home, caregivers assisted their parents with these activities both in the hospital and in the home. When their parents were hospitalized, caregivers expected that hospital staff would be responsible for assisting their parents with ADLs, particularly bathing, feeding, and using the toilet. However, their expectations often shifted through monitoring the formal care their parents received. Specifically, caregivers noticed that formal assistance with these activities was sporadic and inadequate, and as a result, some caregivers assumed responsibility for these activities to ensure that their parent received a level of care that caregivers judged to be acceptable. For example, perceiving nurses in the hospital to be too busy to provide care that was outside of a critical nature, Janet (female, 57) described her experience upon first arriving at the hospital after her mother was hospitalized for a fall that resulted in profuse bleeding on her head and face:

So when I got there she was in a neck brace, they had her in a neck brace because they didn’t know if she had done any more damage. But I totally cleaned her up.
She was, her face was covered in blood and her lips were caked and cracked because it was so thick, because she had so much bleeding. So I cleaned her up because I guess the nurses, you know, they’re pretty busy.

However, engaging in these activities was at times challenging for caregivers because they did not have appropriate access to or authority over the necessary resources. For example, Robert (male, 36) shared a story of a negative encounter with hospital staff while he was attempting to provide support to his father in the hospital:

Some doctors and some healthcare workers, just seems like they’re there to for a job and they’re doing the bare minimum all be it thinking okay well the family’s here so let them step in or do whatever but then it’s frustrating because we have limitations. Like I got yelled at for going and getting him a diaper when he was soiled and sitting in his own feces but I can’t go into the stock room because I’m not staff so he’s going to sit there because you’re not going to change him for how long?

Despite the perceived necessity of caregiver involvement in supporting their parents with ADLs in the hospital, caregivers experienced challenges when they did not have the necessary access to resources to assist their parents. For example, in instances where they did not have access to sanitary resources such as diapers, their parent’s well-being could be compromised. Taylor (female, 22) described often waiting long periods for hospital staff to change her grandmother’s diaper which was concerning to Taylor because her grandmother also had a skin infection that she feared would be exacerbated:
The last time we went to the hospital with the skin infection the area it was in, uh we were trying to figure out like because uh it was her vagina and uh we were trying to, because she’s incontinent, but at the hospital they would take forever to come and change her and we were kind of upset because she’s there for a skin infection and we’re waiting so long with you know stuff on it and uh so that was another thing that we were having trouble with.

Like other caregivers, Taylor described worrying about the exacerbation of infection from prolonged exposure to a soiled diaper. Early in her grandmother’s stay at the hospital Taylor described being unable to change her grandmother’s diaper because she did not have access to the supply room. However, as time passed, Taylor began bringing her own diapers to the hospital so that she could change her grandmother when the hospital staff took longer than Taylor deemed to be appropriate.

After their parents were discharged from the hospital, caregivers reported being solely responsible for assisting their parents with ADLs, though some patients also received formal aid from personal support workers. Caregivers reported that assisting their parents with some ADLs caused emotional discomfort which challenged their ability to provide support. For example, Adam’s (male, 24) mother had a broken wrist and required assistance dressing. As her son, he did not feel comfortable with intimate aspects of dressing her as he explained:

Like you know she needed a lot more help than I anticipated she would need, especially stuff I was uncomfortable with, like she couldn’t get her bra off and it’s like oh shit, I don’t think I can do this.
When the Community Care Access Centre arranged formal assistance, personal support workers were scheduled to perform certain activities on a regular basis. However, caregivers described the necessity of performing these tasks themselves when their parents required immediate assistance outside of the personal support worker’s schedule. When they were faced with performing the activities on their own, they experienced difficulties supporting their parent and explained that they required additional training to be successful. For example, Gail (female, 45), whose mother had a broken hip and a dementia diagnosis, described the things she had to learn once she no longer had 24 hour a day support from a personal support worker who was specifically trained to assist her mother with particular activities:

I had to learn how to lift her. That I didn’t know. There was no need for it before. Because initially, during the first 2 weeks there was somebody always there. But afterwards, when they left I’m like oh my god what happens if she needs to go to the bathroom? So I had to learn how to lift her, how to sit her on the commode. I also had to, what else did I have to learn? Oh changing her. Pretty much before she was very sufficient, she would walk to the bathroom and you know lower her underpants and what not. Now it was a matter of putting on her diaper, knowing which way to turn her so that she didn’t pinch you or hit you or she didn’t get agitated.

When their parent had limited mobility, caregivers assisted them with bathing, using the toilet, and movement throughout the home. Such assistance often involved physically lifting their parent. Gail’s description of how she had to learn how to lift her mother illustrates that these are not straightforward tasks, and that they require additional training. Michelle (female, 24)
described that it was only the intensive professional training she received that allowed her to perform such tasks:

Like when he falls, I’ve had a lot of training... so I know how to safely transport people and move people and help them get up and I know all about that. I’ve had a lot of training about that. I have a, my god, it’s like an 800 page text book just telling me how to properly move people who are disabled so I’m comfortable with that. So if he falls, which he has fallen, I’m the one who helps him get up and I’m the one who knows where to go and how to position him and I can support him. I’m, my mom has a bad arm and she can’t lift, she can’t support him at all so I’m really the physical strength.

Within the home environment, caregivers often were not adequately equipped to support their parents because they were not provided with the requisite technical skills and knowledge. Given that they were expected to assume responsibility for supporting their parents with ADLs, but did not have the capacity to do so, their parent’s well-being was potentially compromised.

**Assisting Parents with Instrumental Activities of Daily Living**

Instrumental Activities of Daily Living (IADLs) are activities that are necessary to function in a community setting, such as shopping, doing laundry, cooking, taking medication, transportation, managing money, and performing housework (Levine et al., 2004). For some caregivers, supporting their parents with these activities was nothing new, as they had already been providing assistance in these ways prior to hospitalization. Participants who reported assisting their parent with IADLs generally performed them within the context of the home environment. However, there were instances where their parent’s length of stay in the hospital
necessitated engagement in particular activities to assist their parents with IADLs. For example, Janet (female, 57) described the tasks she performed during her mother’s 10-day hospital stay:

Like in the hospital I did a lot because I did her laundry, I’d take her nightgowns home and wash them and bring them back the next day. I had to buy her some new stuff because it would be easier to get over her head. She had bills that had to be paid so I had to do that. I had to go to her condo, I cleaned out her fridge, so nothing stinky in there. I was picking her mail up, you know all that little stuff.

Participants also described assisting their parents with transportation after discharge from hospital. This assistance was generally provided in conjunction with picking up medications or attending doctors’ appointments. Some of their parents were no longer comfortable driving, while others experienced mobility issues or decreased cognitive capacity that prevented them from driving alone. For some caregivers who lived with, or close to their parents, this was an easy task. However, others described driving up to an hour to pick up their parents and take them to their scheduled appointments, and then an additional hour to return home after the appointment, sometimes in conjunction to taking a full-day off from work.

Grocery shopping was an activity that many caregivers reported already assisting their parents with prior to hospitalization, particularly when their parent did not drive. For many, this simply continued after their parent was discharged from hospital. However, for others, the time devoted to grocery shopping intensified after discharge. Caregivers described examining all of the ingredients listed on a package to determine if they were appropriate for the maintenance of their parent’s health. For Priya (female, 33), this was the most important and time consuming way that she supported her mother who was instructed that she must abide by a low fat diet to prevent the growth of painful cholesterol deposits. English was not her mother’s first language so
she had difficulty understanding the required aspects of her diet and how she might follow it. Priya explained:

> Like I’ll shop, grocery shopping, and understanding the flyers, where the food is cheaper and stuff like that because for them, it’s not that easy so understanding price matching, making sure we have the ingredients which are more consumable.

Meal preparation was described as an activity that was important in supporting their parents’ recovery. For example, Connie (female, 50) spoke about the importance of providing her mother, who suffered from a stomach ailment, with comfort food:

> I made her things that she liked to eat, so even if she ate a couple spoonfuls of custard or some rice pudding or something just to comfort her…she needed someone to say you know, it’s okay that you feel crappy and it’s okay that you don’t feel like doing a whole lot.

Participants also described managing their parent’s medications after discovering that their parents were not taking medication as prescribed. Improper medication management had resulted in the hospitalization of a number of parents and as a result, participants began to organize and monitor their parent’s medication after they were discharged from the hospital. Pill cases that included slots for each day of the week were used as easy ways to organize medication and provided a mechanism to check that their parents had taken their prescribed medication each day. This meant that caregivers did not have to be physically present each time their parent took their medication, which appeared to be particularly important because a number of caregivers did not live with their parent and many worked during the day.
For the most part, caregivers did not report any challenges in assisting their parents with IADLs. Often assisting their parents could be done in conjunction with activities the caregivers were performing for themselves. For example, while grocery shopping they would pick up items for their parents and when preparing meals they would ensure they made extra portions for their parent. Managing medication did require an understanding of the timing around the administration of each medication but caregivers generally felt that the information they received was sufficient. The tasks associated with these activities often did not require resources other than time, and consequently, in this context, caregivers generally did not encounter problems assisting their parents owing to an inability to access resources.

**System Navigation**

After discharge from the hospital, participants’ parents had a number of recommended follow-up appointments with their family physician or other specialists. Participants described not only driving their parents to these appointments, but also scheduling them which was sometimes challenging. The majority of caregivers reported being employed full-time, which had particular implications for their ability to support their parents. For caregivers who worked during the day, scheduling appointments became an onerous task given that many clinics and medical offices were only open during regular business hours. For example, Andrew (male, 39), who worked in a busy office explained that:

It’s difficult to even take a few minutes to make a phone call because I know I’ll be interrupted so that’s a bit frustrating to me. I know it isn’t, it is a personal matter and so technically work doesn’t frigging care but as I said in general my company does basically, they did say whatever you need, do that. Well part of
what I need is to make phone calls and arrange things so that’s been more difficult
than I’d hoped.

While some physicians’ offices followed up with the patient directly to schedule
appointments, this did not mean that caregivers were not involved in some way in scheduling
appointments for their parents. Some patients did not speak English well enough to schedule
their own appointments, while others were dependent upon their son or daughter to drive them to
the appointment. When parents required transportation from their son or daughter, participants
described calling the offices directly to ensure that they could book an appointment that fit
within their own schedule.

Caregivers described the demanding nature of understanding the healthcare system and
this limited their capacity to support their parent. CCAC Care Coordinators often act as
important resources who help caregivers navigate the system, but some caregivers were not
connected with the CCAC and thus did not have access to knowledge based resources that the
CCAC provides. Some caregivers, like Connie (female, 50), were able to overcome this barrier
by securing knowledge based resources within her own professional network:

Yeah I have a good support system. Professionally too. Because of my profession
[working in an ophthalmologist’s office]. I’m very fortunate. I link arms with a lot
of individuals who could give me some insight on different next steps. So if for
some reason if she couldn’t continue to live on her own, what would my next step
be.

Other caregivers who did not have access to similar knowledge based resources
continued to struggle to understand the healthcare system. Part of the CCAC’s mandate is to
respond to requests for information from all community members. However, some caregivers I interviewed were not aware of the CCAC demonstrating that not all caregivers were in a place to secure resources assisting with system navigation.

Once discharged from the hospital, some patients return home while waiting for admittance to a long-term care facility. As a result, some participants were also directly involved in navigating a branch of the larger healthcare system: the long-term care system. For some older adults who require 24 hour a day care and support after hospitalization, admittance to a long-term care home becomes an option to ensure their safety and well-being. Ontario healthcare system standards dictate that within 45 days of hospital discharge, patients eligible for long-term care will secure a bed in a long-term care home. However, this is not an automatic transition. Patients and/or their family members are required to submit a list of long-term care facilities, with a ranking of their top choices. Participants indicated that this generally took place while their parent was still in the hospital which meant that caregivers, who wanted to see the facilities in person, spent time “shopping” for long-term care homes that they felt would be appropriate for their parent. They often described this as a time consuming activity, where they toured multiple facilities, keeping stock of whether they would be appropriate places for their parents to live based on environmental factors that they perceived would contribute to the best quality of care and emotional well-being of their parent. For example, Taylor (female, 22) wanted a small, quiet facility, but also activities that would keep her grandmother socially engaged, while Joyce (female, 56) questioned staff about how long they had worked at the facilities, as she believed high turnover was an indication of poor quality care.
Emotional Support

Participants were heavily invested in ensuring that their parents were emotionally supported during the care transition. Given that emotional support is often provided in many personal relationships absent of any illness or injury, it may not appear to be a specific caregiving activity. However, among the participants who spoke about this, emotional support for their parents was an intentional activity. They described the level of emotional support as more intensive during their parent’s hospital stay, and the period immediately following discharge. All participants specified that they visited their parent in the hospital almost every day, with some taking time off work, or rearranging their schedules to ensure that they could be there. Although visiting served multiple purposes, such as providing caregivers with the ability to monitor their parent’s care, another central purpose was to ensure that their parents had company and emotional support, which, from their perspective, was ultimately important to the healing process. When parents were in the hospital for long periods of time, participants brought pictures of family members to “brighten up the place” and keep their parent’s morale up. For some caregivers, like Matt (male, 31), providing emotional support was the most important thing they could do as a son or daughter while their parent was hospitalized:

At that point he was really down about the fact that he had been in the hospital for so long and we continued to see him every day and I really felt like he would have just given up if he hadn’t had people come to see him… He’s so alone, feels like you’re never going to get out, it feels like the end of the world, just so disparaging. To have some family members or somebody come in and keep you connected to reality, connected to the fact that there is a world going on outside, you know, it’s not the end of the world. It’s just so damn important.
Throughout the transition from hospital to home, caregivers described monitoring their parent’s emotional well-being, and sometimes observed a deterioration that they did not feel was adequately addressed by formal healthcare providers. For example, Connie (female, 51) explained:

My biggest concern was that the fact that not only was there a physical but there was the mental. There were definite signs of depression and withdrawal and that type of thing and none of that seemed to be addressed. It was just like well if we can fix this, everything will be feeling better and that sort of thing. But when you get the point where you’re just feeling crummy all the time and you kind of bottom out, it’s very difficult to think, okay yeah I’m going to start to feel better. So I think that was the biggest struggle for me. I could do so much but I couldn’t be with her all the time and there didn’t seem to be anybody there, or any kind of plan to help her with the emotional part of the changes. Because it is, like I was saying like it’s huge when you’re active and you’re out and about and then all of a sudden you feel horrible, you can’t leave your house, your leg hurts to walk, there’s no reason why, and not having, still to this day, and still with her leg swelling, they don’t know why.

Caregivers like Connie reported that the professionals involved in their parent’s care were focused on the physical aspects of their parent’s condition, and from the perspective of the caregivers, these same professionals neglected the emotional aspects initiated by illness and injury, which caregivers felt was detrimental to their parent’s recovery. When caregivers observed a deficiency in emotional support for their parents, they intentionally worked to address it and improve their parent’s emotional well-being by comforting them. Caregivers did not
recount any challenges associated with providing emotional support to their parents indicating that this may be one area of care where caregivers do not require additional resources to adequately assist their parents.

**Assisting Hospital Staff**

While their parents were hospitalized, caregivers reported that hospital staff did not always recognize the knowledge they accumulated about their parents over time. This was frustrating for some caregivers who felt that the knowledge they possessed would be useful to healthcare professionals. However, when hospital staff experienced particular challenges related to ensuring a patient’s recovery, they relied upon caregivers to engage in activities to support their parent’s recovery. Nurses generally enlisted caregivers when their parents were not following their prescribed care plans or when their parents were experiencing conditions that were challenging to deal with. For example, Matt (male, 31) described the actions that some nurses took to facilitate the achievement of particular goals related to his father’s care plan:

> I sort of developed somewhat of a relationship with nurses at that place because he was in there for two months but it was kind of the nurses recruiting me to get him to do the things he needed to do. It would be like the nurses would be like you have to eat more, you know stuff like that so they would ask me to help with the emotional side because they understood the emotional side was definitely important so they were trying to get us to help with the goals…He found it easier to do things when mom and I were staring at him in the face rather than just having nurses coming in to do it, you know he’d tell the nurse he’d do it later and

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8 I return to this point in the following chapter, providing detail about the way in which caregivers worked to provide information to healthcare professionals.
they wouldn’t force him, and he’d tell us he’d do it later, and we’d be like no you’re doing it now god dammit.

Shirley (female, 59) similarly described being enlisted by a nurse one night to calm her father when he was hallucinating:

I got a call at 4 a.m. from the nurse…saying my dad was having a bad hallucination, could I please talk to him because he was quite aggressive and he wanted to escape from the hospital…So I told her why don’t you take him for a walk because during the day time the therapist came and took my dad for a walk and I was there and I noticed that his mind came back as he was walking…and I tried telling my dad, you know you can’t, he wanted me to call the police on the nurses because he didn’t recognize that they were nurses and they were keeping him against his will and I said no I’m not going to do that, he said why not and I said because those people are nurses and you are in a hospital, you are very sick, you’re suffering, hallucinations, and believe me, and just trust me, even if you don’t believe, go back to bed, go to sleep, I’ll be there in the morning…So whatever. I wasn’t quite successful but maybe I managed a bit to calm him down, then the nurse said okay we’ll take over.

Caregivers’ accounts showed that when healthcare providers encountered particular challenges treating a patient where the help of family members might be beneficial, they drew upon caregivers to support the patient’s recovery. Caregivers reported being willing to assist hospital staff and were often successful in completing the tasks they were asked to perform. Despite the recognition of the caregivers’ abilities to assist their parents, this arrangement located caregivers as resources, rather than active members of their parent’s care.
Chapter Summary

This chapter examined the activities that filial caregivers perform to support their parent’s well-being and demonstrated the challenges they face when they do not have adequate access to resources, knowledge, and training. Within the hospital, caregivers monitored their parent’s care, and when they perceived the level of care to be inadequate they assumed responsibility for particular aspects of their parent’s care. However, when they did not have access to appropriate resources, their capacity to provide care was limited, and their parent’s well-being was compromised. Similarly, within the home environment, caregivers experienced challenges when they did not have the appropriate knowledge about the healthcare system, and when they did not have the skills to physically support their parent.

The majority of caregivers were employed, and this had particular implications for their ability to support their parent. Specifically, because particular activities they were expected to perform required their attention during their work day, the analysis suggests that the healthcare system may not be supportive of the context of filial caregivers’ lives.

Caregivers reported providing intensive emotional support to their parents while they were hospitalized, and during the period following discharge. They generally did not recount any problems associated with providing such support suggesting that they possessed the skills required to support their parent in this way. They described such support as consequential to their parent’s recovery and stressed that their parent’s psychological well-being was often overlooked by healthcare professionals.

Caregivers were also called upon as resources by healthcare providers to assist in their parent’s treatment. While this suggests that there were times that healthcare providers recognized
the knowledge possessed by caregivers, largely this knowledge went unrecognized. I return to this point in the following chapter.
Chapter 7: Caregivers as Advocates

Early in the interview phase of this study I became interested in the idea of patient advocacy. Prior to conducting the interviews, I had read studies about caregivers that referred to patient advocacy, but the concept was described only tangentially. However, during my first four interviews, when asked what they would recommend to other caregivers, all participants stated that advocating was important. From that point forward I made a point of asking about advocacy if participants did not orient to the subject on their own. However, instances of my direction toward the subject were few and participants often discussed supporting their parent through advocating without any prompting.

Caregivers discussed advocating as critical to ensuring that their parent was receiving the best possible care. Advocating was cited as an ongoing activity that was performed throughout the care transition, both in hospital, and once their parent was discharged. Care Coordinators also identified the ability to advocate as an essential skill within a caregiver’s repertoire. For example, Cathy, a community Care Coordinator, explained:

The need to advocate constantly for their loved one is really important. Advocacy, that’s a huge piece in that role and they learn quickly that they have to advocate and be the squeaky wheel and you may not be the most favoured person but they’re doing what they need to do for their mom, for their dad, for their quality of life.

This chapter focuses on answering the third research question, when filial caregivers experience challenges caring for a parent, how do they obtain resources necessary to support their parent’s well-being? I argue that filial caregivers predominantly ensured their parent’s well-being during the transition from hospital to home through advocating. In Chapter 6, I
examined other activities that caregivers performed to ensure their parent’s well-being. As discussed, caregivers often encountered obstacles when performing these activities because they did not have the necessary resources or authority that would allow them to adequately support their parents. In contrast, when caregivers advocated for their parents, they were successful in ensuring their parent’s well-being largely because through advocating, participants gained access to resources to support their parent’s care. Despite the prevalence of advocating in the caregiving role, my analysis demonstrates that caregivers are not always initially aware that advocating may be an important part of caring for their parent. Additionally, my analysis suggests that caregivers may encounter difficulties in attempting to advocate.

**Reasons for Advocating on Behalf of a Parent**

As discussed in Chapter 6, caregivers experienced challenges caring for their parent when they did not possess the required knowledge, skills and authority, or have access to the necessary resources to ensure their parent’s well-being. In this chapter I show that filial caregivers did not passively accept this arrangement and instead advocated for resources to improve their parent’s care. Ensuring their parent’s safety and well-being was the ultimate goal held by caregivers during the transition from hospital to home, and advocating functioned to obtain that goal.

Participants engaged in advocacy for three major reasons: 1) in response to negative experiences, 2) when they believed that resources were limited in the healthcare system, and that their parent was not receiving the necessary resources and 3) when they felt that their parent was not capable of advocating for themselves. In this section I explore these reasons for advocating and how they are related to obtaining healthcare resources for caregivers’ parents.
Advocating in response to negative experiences. Participants described negative experiences that threatened their parent’s well-being throughout the transition from hospital to home. Some of their parents developed infections while in the hospital and participants felt that, at times, their parent was ignored by hospital staff. Additionally, both in the hospital and at home participants felt that adequate care was not always provided by professionals. These negative experiences were attributed to institutional protocols and procedures, as well the work ethic of individual healthcare providers. Caregivers reacted to these experiences by engaging with healthcare providers to advocate for better treatment for their parent. This meant that phone calls were made to those “in charge”, meetings were scheduled to discuss their parent’s care, and caregivers let staff know that they were “watching” and “monitoring” their parent’s care.

As described in the previous chapter, one outcome of monitoring their parent’s care was caregivers responding by directly providing care themselves when deficiencies in care were perceived. However, when caregivers realized that they did not have the authority or access to appropriate resources to be able to assist their parents, they advocated to secure the attention of those healthcare providers who were positioned to implement change, and to secure necessary resources. For example, Shirley (female, 59) described advocating for better access to physicians within the hospital:

And I thought oh my god my dad is crazy. Even if he wasn’t before, uh maybe this will last so I started telling all the resident doctors, a couple of them, um the nurses, I started on a campaign. I said look, I brought my dad in for a bladder infection and I understand there’s delirium potential from it, but you guys are making him crazy… I told the nurses, with the [medication name], you realize the side effects are really bad, this can’t be good with his hallucinations. … So because of this the floor doctor said he will pass us along to
the geriatric doctor and I said okay that’s fine, that’s good and the geriatric doctor gave me a call and he was very nice, very understanding, he said I just finished talking to your dad and he said really there’s nothing wrong with him… He’s not like, he doesn’t have dementia, he doesn’t have this and that, and I told him about the Lorazepam, he said yes that’s probably a good possibility he said, so he said okay here’s what we’re going to do. We’re going put him back on [medication name], we’re going to put him back but on 1 mg instead of his 2, and then we’re going to keep him on it for one week and then we’re going to cut it back by one quarter, so after one week it’s .75, then .50, .25. And that is the normal course of events how you should take somebody off, slowly, very gently, slowly, so there’s not these kind of side effects.

Shirley’s father was hospitalized for a bladder infection that presented with symptoms such as delirium and confusion. At the time he was also reliant upon an anxiolytic medication as a sleep aid; Shirley discovered when she was questioning the doctor that he had been taken off the medication as part of a protocol to determine the source of the delirium. Once hospitalized her father’s mental state rapidly deteriorated and he began to experience intense hallucinations. Based on her own independent research she learned that a side effect of “going cold turkey” from the medication was hallucinations from medication withdrawal. She therefore attributed her father’s condition to the actions of the hospital staff which were largely related to particular protocols that were put in place to determine the source of his delirium, and consequently advocated on his behalf by demanding an alternative source of treatment. As with other caregivers, Shirley’s efforts were successful; the result of her efforts was a meeting with a geriatrician who agreed that her father’s hallucinations were likely brought on by sudden withdrawal from his medication. His solution was reinstituting her father’s previous dosage and
gradually reducing it so that he would experience limited side effects. Similar to Shirley, when other caregivers suspected that medical errors had been made, they assumed responsibility to both bring the perceived errors to the attention of healthcare professionals, and to demand that the errors were remedied, sometimes by challenging institutional policies.

These types of adverse occurrences limited the capacity of caregivers to ensure their parent’s well-being. Caregivers themselves did not have the ability to remedy negative situations directly because they did not have access to appropriate resources, nor did they have the authority to enact change. For example, Shirley did not have the ability to alter her father’s treatment plan while he was in the hospital. Consequently, she required another professional opinion that was not immediately forthcoming without her intervention. Examples like this demonstrate the ways in which caregivers challenged institutional arrangements and ultimately secured resources (e.g., the attention of physicians) that benefitted their parents. This was the most significant way through which they were able to ensure their parent’s well-being while they were in the hospital.

After hospital discharge, caregivers also described advocating in response to negative experiences with personal support workers in the home, which they identified by monitoring the services personal support workers provided. Within the context of homecare, personal support workers can be a valuable resource because they provide formal care to patients while at the same time providing respite to family caregivers. However, participants did not always see the value in the personal support workers’ contributions. The abilities and work ethic of personal support workers was a particularly polarizing topic among participants. While some caregivers described the personal support workers as “wonderful”, and even developed personal
relationships with them, other caregivers expressed extreme dissatisfaction and frustrations with the actions (or inaction) of personal support workers assigned to their parent’s care.

Caregivers spoke of personal support workers spending time on their phones rather than providing support to their parents, thus not meeting the expectations of caregivers who felt that they should be doing more to support their parent’s well-being. Additionally, caregivers reported instances of personal support workers arriving late and leaving early, sometimes leaving their parent alone in the house. Such situations threatened their parent’s safety, particularly when their parent was classified as at high risk for falls. Care Coordinators provided information that situated caregivers’ experiences within an institutional environment where such instances regularly occurred, and could lead to caregivers advocating for improvements to service. Cathy, a community Care Coordinator, explained:

There’s a lot of people that have gone through the system for years that don’t want to deal with CCAC because we can’t always offer the consistency in staff so you may have you know 5 or 6 different PSWs [personal support workers] coming in and out over a three or four day period …the foundation of all of our care plans are PSWs and you’ve got PSWs that continuously are being paid for an hour but only show up for 20 minute visits or aren’t completing what we’ve laid out in the care plan or don’t even show without notification and somebody is left, it’s almost, somebody is left in soaking wet incontinence products because the a.m. PSW never showed up sort of thing.

When problems with the service provided were identified, caregivers advocated for better support in one of two ways. First, caregivers described speaking directly to the personal support workers to communicate that there were problems and instructed them on ways that they could
improve to meet the caregiver’s standards. Caregivers described this as “managing” the personal support workers but explained that it was sometimes difficult because employees differed from day-to-day, and they often found themselves training new personal support workers about unique aspects of their parent’s care and environment on a daily basis. Secondly, caregivers called the personal support workers’ supervisors to report behaviours they felt were unacceptable and to discuss plans to remedy the situation. For instance, Taylor (female, 22) described her experience identifying personal support worker behaviours she felt were threatening her grandmother’s safety and well-being, and subsequently advocated for better care by talking to their supervisor:

P: At first, at the beginning and kind of in the middle it was more difficult and I had lots of problems with PSWs and I had lots of meetings with the supervisor and stuff because I expected a lot and not that it was a lot but I expected them to do it properly and right. As where I think a lot of old people, if they’re living on their own, I have a feeling that a lot of the PSWs use it to their advantage and kind of slack as I’d say…Some of them would leave early or they’d just play on their phone which I don’t like that either, I mean you’re here for a job, you’re supposed to do it. Especially with respite, that was one of the issues. People leaving before I got back.

I: So your grandma was alone then?

P: Yep. And sometimes I wouldn’t know how long that she would be left alone and it’s an issue because she’s high risk for falls…Basically you have to stay very vigilant because if you don’t then they’re just going to do what they want to do.

(…)
I: So when you would talk to the supervisor, how did that work, did you just have to call?

P: It was a lot of phone tag. For the first while I really didn’t like calling um but then after you do this for so long you kind of just, it’s your thing kind of thing, oh what you can do, and you actually feel like you get some power from it because I mean it is your family member and it’s alright to demand that your family member be taken care of right?

(…)

I: And when you would actually get to talk to the supervisor, how did those conversations go?

P: Most of them went okay. Some of them we’d disagree. I mean that’s, it’s normal for two people to disagree. Um basically what they considered um appropriate to give and not to give was different than what I would think. Um of course by closer to the last 6 months, basically if I needed anything they’d just get it done for me. So if I needed more time, they’d give me more time. If I needed them to take over doing a different job, they’d do it. But at first it wasn’t like that of course… So um I must be a very difficult client for them because I’d call the supervisor quite often and I’d have quite a few PSWs come and go in my home because I wouldn’t accept some of their care.

Through advocating for better care, caregivers were able to secure access to healthcare professionals whose intervention they deemed appropriate to maintain and improve their parent’s health, both in the hospital and at home. However, caregivers were able to secure access to
healthcare professionals more quickly within the hospital environment compared to the home care environment. Within the hospital, nurses and doctors were more physically accessible. Caregivers described searching for nurses and doctors within the halls of the hospital and when they found them, they were able to call for their attention immediately. However, within the home care environment, those in control of healthcare resources were not physically accessible to caregivers. Darlene, a CCAC Care Coordinator identified this as a challenging situation:

I: So there any other ways that that specific transition from hospital to home is really challenging for patients and their caregivers?

P: One of the things that makes it really challenging too is that they’re worried about, if they’re stable enough to be discharged and then once they’re discharged the stark reality, in the hospital there’s three square meals a day and there’s someone always coming in to check on them, so there’s that reality of I’m not having people right there present in case something happens, there’s sometimes feelings of abandonment, isolation, they were getting all this care and they’re not getting it anymore when they’re back home. So there’s a fear of the patient sliding back to a crisis.

While speaking with personal support workers directly did result in some changes that benefitted their parent, substantive change was often only possible when caregivers spoke to those in management positions. Consequently, this meant that caregivers did not always have the authority to implement changes themselves. Therefore, they assertively and repeatedly communicated their concerns to individuals in positions of authority who could implement the desired changes. For example, Robert explained:
P: Unless you call the manager and reach out they won’t step in or they won’t see how things are going or they won’t show up.

I: So have you actually spoken to the manager then before?

P: For a couple of them yeah. It got out of hand with one and we stepped in and we said we don’t want this worker here anymore.

However, managers responsible for personal support workers did not regularly make home visits so caregivers found themselves “playing phone tag” in an attempt to rectify the situation that they felt was sub-standard. Although caregivers were often successful in securing homecare resources that they felt were acceptable, this took time. Personal support workers were there not only to provide care to patients, but also to provide respite to caregivers. Consequently, when personal support workers did not meet appropriate standards or left patients alone, the safety of patients was compromised and caregivers did not receive respite which was detrimental to their own health and well-being. Indeed, Katy, a CCAC Care Coordinator also mentioned the importance of caregiver respite within the context of increasing caregiver responsibility:

Respite care to me as a social worker is so important and caregiver stress and burn out can really impact and affect someone’s quality of life not only the caregiver but the client as well so we need if we want to have people longer and be discharged from the hospital sooner rather than later we need to ensure the caregiver is taken care because they are the ones that are taking the place of what professionals would do.
Advocating based on beliefs about the availability of resources during the transition from hospital to home. When participants advocated on behalf of their parents, this was not always as a result of personally observing negative situations. Participants also described a perception that there are limited resources within the Ontario healthcare system, and consequently felt that it was necessary to advocate to ensure that their parent was a recipient of those resources. For example, when asked about the importance of advocating for a patient, Taylor (female, 22) responded:

Oh it’s really, really important that you do that [advocate] or else nothing’s going to change…if you don’t advocate or stay informed then they’re going to, they’re not going to care. Sadly to say. Whether or not they actually care or not is not the point, whether the care gets taken care of is more the question. If they don’t know when you’re coming [to the hospital, to a long term care facility, or home] then they have to make sure they’re always taking care of the person right? Because they know if they’re not taking care of that person and say I showed up, someone would get an earful.

Based on personal experiences with healthcare providers in the hospital, in her own home, and in a long term care facility, Taylor, like other caregivers, felt that healthcare professionals (including personal support workers and hospital staff) are tasked with a great deal of work and as a result, the care they provide may not be as responsive to individual patient needs as caregivers would like. While it should not be implied by this analysis that healthcare professionals were categorically inattentive to individual’s needs, from caregivers’ perspectives, healthcare professionals have a duty to all patients which may limit the attention they can provide to any one patient. In contrast, caregivers were solely focused on their parent which
meant that they were highly attentive to their parent’s individual needs. Advocacy was seen as a way for caregivers to focus the attention of healthcare providers on their parent, thereby promoting their health as a top priority within an environment with limited resources.

From my own experiences visiting the hospital, I too observed the limited availability of resources. All of the beds appeared to be occupied by patients and there was always a flurry of activity. I also noticed nurses completing a great deal of paperwork when they were not dealing directly with patients. During one visit I could hear an older patient repeatedly calling out that he was cold, without receiving any attention from the hospital staff. At first I could not understand why his cries would go unanswered until I realized that all of the nurses in sight were already occupied with other patients or paperwork. His needs were addressed only when someone, who I believe was a family member, arrived and went to ask someone for an additional blanket. Although the receipt of an extra blanket may seem trivial within the broader context of critical care, this example demonstrates that caregivers had an individual and sole focus on their own relative that was not necessarily shared by healthcare professionals. Therefore, when their parent had a need that appeared to be overlooked by staff, caregivers worked to focus the attention of healthcare providers on the needs of their parents.

Similarly, because healthcare providers were so busy, caregivers felt that their parents could be forgotten if they did not intervene on their behalf within the hospital. For example, Matt (male, 31) explained:

P: Like their job is, yeah, the job of the doctors and nurses is to help to heal the patient and their job is not at all to make the family members feel like they’re well informed or feel comfortable, they’d probably rather that you weren’t even there so they didn’t have to talk, so you didn’t waste their time you know? Nobody was
mean or anything, I got a sense that they were all pretty nice people, but ain’t nobody got time for that (laughing).

I: Yeah I think someone else that I spoke to mentioned that as well and it was tough for them because like you were saying, it is someone you love so when they don’t have that like emotional connection or that personal connection like it was really hard for them.

P: It’s totally not a customer service oriented experience…they’re doing what they need to keep the person healthy or whatever and it may not be in a timely manner that you’d like it to be in you know what I mean, or it may not be in a caring fashion that you’d like it to be in or in a sensitive fashion or anything, like it’s getting done but it’s not pretty, so I think where that feeling of having to advocate or defend or make sure they’re taking good care of him, where those feelings come from is just the fact that you’re not being coddled like at all, like you’re just sitting in a hospital. And they give you the bare minimum amount of information so yeah you feel like if you don’t ask maybe no one, it’s just forgotten about. Maybe no one will come with his pills, like who knows.

Matt’s discussion draws upon a characterization of the healthcare system as overburdened, with staff able to provide only the minimal amount of care to patients. However, for caregivers who were emotionally invested in their parent’s well-being, such a perception often led to advocating for more resources in the form of attention from doctors and nurses. Given that resources (i.e., time) were perceived to be limited, caregivers advocated to ensure that their parents received appropriate attention from doctors and nurses that would ultimately ensure their safety.
Based on perceiving the healthcare system to be overburdened, caregivers felt that they had to monitor their parent’s care. “Checking-in” on their parents was central to caregivers’ accounts which suggested that supervision was necessary to ensure that their parents received an acceptable level of care. For example, Carol (female, 63) explained that without someone to spur action on the part of hospital staff, her father would receive limited attention, and therefore an inadequate level of care:

P: I phone them, the hospital every day to see how he is. And just to make sure they know.

I: That they know?

P: Someone’s interested in his care. If you just lie there and nobody cares then I don’t think you get as much attention.

As described in Chapter 5, caregivers also perceived the healthcare system to be deteriorating. This characterization had implications for the ways caregivers responded once their parent was hospitalized. Specifically, because they characterized the system as deteriorating, caregivers explained that advocacy was important to ensure that their parent’s care was not a casualty of such an environment. When asked what he would recommend to other caregivers, James, (male, 58) whose father developed an untreated infection while in his retirement home, responded:

Be an advocate. That’s probably the biggest thing right there. Because without it, things fall through the cracks and uh if you’re not there you don’t know what’s going on. And I know sometimes it’s difficult if you’re out of town but there are certain circumstances where that doesn’t happen, but if you’re not there
communicating with the doctors and or nurses um you know there are times where things just happen.

Advocating because their parent is not capable of advocating on their own behalf. In part, caregivers assumed the role of patient advocate because their parent was not capable of advocating on their own behalf. This reason for advocacy was most prevalent within the context of the hospital. Some parents were experiencing late stage dementia such that their ability to communicate verbally was limited, and some were unable to communicate in English which prevented them from engaging in direct communication with healthcare professionals. Some experienced temporary cognitive deficits that made clear communication difficult, whereas others were described as “taking a back seat” to their own care and preferred that their caregivers handle any interactions with medical professionals. Caregivers also spoke of time spent trying to track down physicians within the hospital to confront them about particular issues, which was something their parents, confined to a bed, could not do.

Owing to the condition of their parent’s health, participants described their parent as largely dependent upon them. When caregivers described their parent as dependent, their parent’s needs were equated with the needs of children, and caregivers suggested a role reversal, unique to the context of filial caregiving where they assumed the role of protector and advocate to ensure that their parent’s needs were met. For example, Janice (female, 51) described her approach to taking care of her father:

I feel that physically looking after my dad is like a child, he’s my child, more and more so it’s a little bit strange that I have to help him sometimes get dressed, put his socks on, his shoelaces, I defend him as if he’s my child, in front of somebody else, if somebody’s not treating him right I actually defend him as if he’s my
child, I will go to bat for him, very strongly, just like when you have a child and someone’s hurting your child.

When caregivers understood that their parent was unable to communicate for themselves, caregivers continuously monitored their parent’s health and care and advocated for access to more resources when necessary. For example, Michelle (female, 24) described monitoring her father’s treatment and voicing concerns because he was unable to do so himself:

We were making sure he was getting the right amounts of medication and when he was nauseous making sure that they were giving him Gravol and oh what other types of things. Making sure he was seeing a physiotherapist and getting up and walking during the day oh everything, like every little thought we voiced to them, just about the swelling, what were they doing about all the swelling, about the water retention, how much was he eating, everything… he was really out of it. He’s really drugged up. He doesn’t know a whole lot. He’s just going with what people tell him.

For some caregivers, advocating was a collaboration where patients identified their own needs and caregivers ensured that their parent’s concerns were addressed. Shirley (female, 59) described the course of action she and her father took when he believed he had developed an infection while in the hospital:

He said you know, no nurse has been here to check on my catheter, to clean me properly, to clean out the catheter itself and I think I have a fungal infection. My dad said I need some Polysporin, Cortisone, some cream, and ointment. Maybe an anti-fungal ointment, but there’s definitely something there because I haven’t
really been cleaned enough, the catheter hasn’t been looked after, and you know he too realized at that point too that he’s been neglected, technically. And then, nothing, nothing, nothing. I arrived at 3:30 or 4 o’clock, took me half an hour to get the nurse but I think they knew because I’m the daughter I wanted to see the doctor, I was pretty angry at that point and the nurse said well the doctor something, yes will be, but I can go too, and I said okay well you come and I want to see the doctor because I was going to have a few words with him too because I was angry with him. I think the doctor looked at him and said yes you’ve got a little infection, blah, blah, blah, and whatever and I talked to him and I said look, I’m not happy. I’m not happy with what’s happening here. My dad’s been neglected and I said it would be nice you know, no doctor’s coming in here to say hello and talk to my dad.

Participants’ accounts suggested that without an advocate, older patients may not have equitable access to healthcare resources. From their own experiences advocating on behalf of their parents, caregivers themselves identified this current arrangement as problematic. James (male, 58) expressed concerns about older patients who do not have family members involved in their care:

I think the problem is you’re going to deal with more [situations] where there’s seniors who don’t have advocates who you won’t know what’s going on with them because they won’t have anybody to speak on their behalf…We had a lot of times where the nurses would say you know you guys are great, you’re really supporting your parents, or your dad. We got a lot of compliments from nurses
and caregivers too. So I think they’re more surprised when people bring their elderly parents in than when they don’t.

In summary, from the descriptions of their parents’ health conditions it was evident that some would have been unable to identify their own needs and that most would have been unable to advocate on their own behalf to ensure that their needs were met. However, caregivers, with a sole focus on their own parents, were able to identify their parents’ needs and pursue a path of advocacy to obtain resources to ensure their parent’s health and well-being.

While the role of patient advocate was described by caregivers as paramount to ensuring their parent’s safety and well-being, within the hospital context, the role of family caregivers as patient advocates may not be well recognized. Instead, self-advocacy on the part of patients is promoted as illustrated by an excerpt from Grand River Hospital’s *Patient Information and Service Directory*:

> Grand River Hospital is committed to providing safe and quality healthcare but we need your help! You are the most important advocate for your health and being actively involved in your treatment will help ensure the best care possible. Remember these three tips: 1) Be involved in your care. Please ask a member of your healthcare team if you have questions. 2) Please share important health information with your care team (e.g., health history, medication, allergies, etc.). 3) Please make sure you know what to do when you leave the hospital.

As Rothman (2001) explains, this arrangement appears to have roots within patient rights movements of the 1960s and 1970s. These movements were characterized by the promotion of patient autonomy over physician paternalism. Specifically, the emphasis on individual
involvement in treatment highlights a respect for greater patient participation in doctor-patient relationships. Some patients may be adept and motivated to advocate on their own behalf. However, the accounts of participants suggest that many older adults are not capable or willing to follow the advice promoted in the *Service Directory*. Instead, caregivers may be their parent’s best advocate, and as demonstrated, work to fulfill these tasks that are aligned with patient safety and quality healthcare. Nevertheless, the advocacy care work of caregivers may not be well recognized when emphasis is placed solely on individual patient involvement in care.

**Reasons for Self-Advocacy**

Caregivers not only advocated on behalf of their parents, but also self-advocated to secure respite services that would ultimately ensure that they could care for their parent. Caregivers identified respite as one of their key needs during the transition from hospital to home. They worried that without it, they would “burn out” or be unable to attend to other activities such as grocery shopping and attending appointments of their own. CCAC Care Coordinators, like Darlene, were able to provide a comprehensive description of the needs that caregivers expressed to them and respite was mentioned as a key concern:

I: So I guess, what types of needs are they [caregivers] expressing?

P: Um respite a lot of the time, so a lot of them looking for respite hours, the maximum anyone can receive with CCAC in the community is 3 hours a day and so that um can be eaten up very quickly people, you could get 90 hours a month and you can play with those hours, you can have them in blocks of time and then just have weekends off or hire privately, that kind of thing. It’s based on eligibility. Um so a lot of the time it’s respite. You know the caregiver has an appointment, or the caregiver has a meeting or is travelling out of town on
business or whatever and needs extra services in for the client or there’s been a change in status where they’re very overwhelmed and they can no longer manage or cope with what’s going on.

Once their parent was discharged from the hospital, caregivers became largely responsible for their parents’ care, even more so than when their parent was hospitalized. However, their parents also received support from formal services such as personal support workers, which as previously mentioned, functioned dually to provide caregivers with respite and to provide their parents with assistance. Despite formal service implementation, caregivers did not always feel that they were adequately supported and at times advocated on their own behalf to obtain more access to respite services. Some caregivers were experiencing ill health themselves and had little support from their own family and friends. Therefore, when formal support was not available they had little time to focus on themselves, owing to large portions of their time being devoted to caring for their parents. Deficiencies in formal support were thus detrimental to caregiver’s health, particularly those who could not rely upon informal support from family and friends. For example, Linda (female, 63), who was diagnosed with depression, described how it was demanding to care for her mother when she needed time to care for herself:

You know some days are better than others. Some days are hard and I just don’t get time for myself you know. I just need to go have a good cry somewhere. I can’t.

When caregivers perceived their circumstances to be unmanageable, caregivers engaged in self-advocacy to obtain more resources to improve their access to respite, ultimately allowing them to continue to care for their parent without burning out. Gail (female, 45), who was
employed fulltime, viewed the number of hours her mother was assigned a formal caregiver to be insufficient within the context of her schedule:

Initially, they [the CCAC] were um going to give me um 56 hours of help [per week] and I’m like I can’t take her home with that. I refused to take her home with that. And then they offered me this program called [program name]. Which they were going to give me 2 weeks of 24 hour care, followed by the 56 hours and I was very hesitant about taking that because well the two weeks, the [program name] which was 24 hour care, that was fabulous. I was good with that but I was very concerned about the 56 hours because technically 50 hours is what pretty much covers the time that I’m at work right? So it’s 8 hours plus 1 hour to commute and back right? So that’s 10 hours. So that leaves 6 hours for the weekend and I’m like how am I supposed to take, anyways after a few conversations with the hospital, I talked to administrators and stuff. After that big meeting, big conversation that I had with the hospital’s administrators instead of getting 56 hours, they gave me 70 hours.

With caregivers becoming increasingly responsible for the care of their relatives within the home environment, they too require support to maintain their own health and well-being. Caregivers described becoming socially isolated because they gave up activities such as yoga and spending time with friends to be able to care for their parents. However, they contested this arrangement by advocating for more resources that would not only provide support to their parents, but also allow them time to spend on activities that would benefit their own well-being. Advocating was seen as the sole means through which they could secure additional resources, and without engaging in such efforts they would be left to function within current arrangements
that compromised their own health and their capacity to care for their parents. Ultimately, no one else would advocate for caregivers which meant that their ability to advocate for themselves was exceptionally important. Katy, a Community Care Coordinator, summarized her analysis of the characteristics of filial caregivers by saying:

I think this generation of caregivers, they’re pretty savvy about that balance of what I can do and what I specifically can’t do and I think they’re pretty open to asking for help. I think they’re vocal about you know they paid their taxes, they deserve these services. So I would say the majority of caregivers are very upfront, you know I can’t do this by myself, what kind of supports do you have, they want to know what information’s out there so they can make an informed decision. I see much more of that than maybe the generation before where they felt I made a promise therefore I have to do it and they’ll almost kill themselves providing care without asking for help. So my experience, with the people I’ve seen, their families are very much they need more help and we can’t do this ourselves. Very much trying to be aware of what the system has to offer and provide.

Preparing to Advocate

Advocating necessarily involved communication between caregivers and healthcare providers. However, before communication took place, caregivers prepared to advocate in a number of ways. Preparing to advocate involved both the collection and provision of information. Caregivers’ accounts demonstrated that being informed about their parent’s health and care was a necessary antecedent to advocacy, and to prepare to advocate they collected information about their parent’s treatment plan, alternative courses of treatment, medications, diagnosis, and the local healthcare system. Caregivers also provided unsolicited information
about their parent to healthcare providers, and this served as a foundation upon which they could advocate on behalf of their parent. Through these activities, caregivers demonstrated knowledge about their parent that aided in the receipt of resources that supported their parent’s well-being. Despite describing their efforts as largely successful, caregivers still encountered challenges in preparing to advocate and these challenges are described in detail in the sections below.

**Developing advocacy as a skill.** Prior to discussing the ways caregivers prepared to successfully advocate, it is important to note that participants talked about advocating as a skill that was learned, rather than a skill that they already possessed when they entered their role as caregivers. When asked to reflect on what they learned during their parent’s transition from hospital to home, caregivers most often cited understanding that they needed to advocate for their parent. Gail (female, 45) described her experience of becoming an advocate for her mother who was diagnosed with dementia:

P: I think my greatest strength is I’ve become very strong in advocating for her needs and she has to rely on me to do it for her so I certainly put my foot down.

I: And would you say that was something that was always inside of you, like you had that strength already?

P: No, no I think I had to hear it from a few people. Like when I was talking to the CCAC person, because I remember I called her and I said to her they want to discharge her from the hospital and I don’t think she’s ready. And she said, you’re her daughter, you have to advocate for her. So I heard it from her, I heard it from co-workers, I heard it from friends. So eventually, after being told, I was like there’s nobody else, I’ve gotta do it.
Prior to their parent’s hospitalization, many caregivers had little contact with the healthcare system. However, when their parent was hospitalized they became immersed within institutional environments (i.e., the hospital, long-term care homes, homecare) that are governed by particular policies and that operate with limited resources. As a result, caregivers learned that it was necessary to advocate for their parents to ensure that their parent was not overlooked within the institutional environment.

However, despite viewing it as a necessity at the time of the interview, caregivers did not always feel prepared or comfortable advocating when they reflected on their experiences. Taylor (female), at age 22, was the youngest participant and found that because of her age, she felt that she was often not taken seriously by those providing formal care to her grandmother. This assessment caused her to feel uncomfortable when first trying to resolve issues with her grandmother’s personal care:

At first I was very intimidated by talking to um them because one of the issues I had with the PSWs is I’m so young, and they treat me like I was young and that I didn’t know what I was doing which wasn’t the truth and by the end of it it’s like I’ve been doing this longer than you guys have been looking after her so I know what’s right type of thing.

Participants’ accounts demonstrated that advocating was not something that participants initially expected to have to do while caring for their parent. Rather they assumed that satisfactory care would be provided without the need to press for it. When they perceived that such a level of care was not forthcoming, and it became apparent that no one else would advocate for their parent, caregivers assumed a patient advocate role.
**Collecting information.** When their parents were hospitalized, caregivers described frustrations associated with the restricted provision of information about their parent’s health and care, and expressed having a limited understanding of how the healthcare system functioned. However, caregivers did not passively accept this arrangement and instead worked to secure knowledge based resources. This process of collecting information served two essential purposes: 1) easing uncertainty and 2) preparing caregivers to support their parent. Although this section is largely dedicated to explaining the actions implemented by caregivers to be successful advocates, I believe that it is also important to acknowledge the emotional experience that caregivers associated with uncertainty. Caregivers explained that understanding their parent’s diagnosis and aspects of their care served to ease some of the uncertainty associated with their parent’s hospitalization. Caregivers consistently described asking how their parents were doing when visiting the hospital, and when hospital staff could not give them an answer, caregivers discussed feeling frustrated and worried. Caregivers did not want hospital staff to “beat around the bush” but rather to provide direct responses to their questions, or, if a staff member did not have the information, to direct the caregiver to someone who did. Although caregivers understood that sometimes answers could not be obtained as quickly as they would like, the waiting they were required to do was difficult. As Michelle (female, 24) explained:

> It’s just extremely frustrating all the waiting like they should just have a time where they all meet, decide something and it’s done on the spot and I get that the healthcare system doesn’t work like that. But it’s not their family. It’s their patient. And to us it’s our family and there’s a totally different thing and I wish that somewhere down the line there would be more of a correlation between the two.
Collecting information also served the purpose of preparing caregivers to advocate for their parents and Cathy, a Care Coordinator explained that this often helped them to successfully advocate:

They know what’s out there, so they’ve done their research. Those one are very successful for sure and they’re a pleasure to work with you know because there are others that just have no clue and will just say fix it right, it’s like okay [laughter] what can we fix?

Many caregivers reported collecting information about their parent’s health and treatment, and about the healthcare system more generally. Through collecting information caregivers obtained access to knowledge based resources that would help them to act to support their parent. Particularly in the homecare environment, caregivers had to determine who the most appropriate person or organization would be to contact to communicate their concerns. The homecare environment included a multiplicity of healthcare providers, and many caregivers reported confusion about which organization was responsible for particular aspects of their parent’s care. Caregivers therefore conducted research on the healthcare system (e.g., online, through communication with healthcare professionals) which prepared them to communicate with the most appropriate person or organization. For example, James (male, 58) described the process that he and his siblings followed to determine who was responsible for his father’s medical care in the retirement home where he resided. When James’ father developed a shoulder infection after his wound was not properly cared for by formal care providers, James and his family arranged meetings with multiple service agencies to determine who was supposed to be responsible for wound care, and to make sure his father was properly cared for in the future:
P: We assumed a lot and like everybody else, the assumptions didn’t turn to be true.

I: Yeah, and so when you were trying to learn about everything, like how did that learning take place?

P: Well we spent more time meeting with CCAC. You know again, trying to understand how things work and one of the last meetings we had was sort of productive because most people make assumptions of what does happen, but we found out what we assumed was not going to happen so we needed someone to talk to and that was huge. That was mainly through the retirement home and CCAC. Sorry that was more the retirement home, then we went back to the CCAC to make sure that what we got told in the retirement home was correct.

As described in the introductory chapters of this dissertation, at the time the interviews took place, the homecare environment in Ontario was governed by the CCAC who contracted various services out to private agencies. Some caregivers, like James, described confusion with this arrangement and as a result had difficulty determining who they should speak to when they found that their parent’s treatment was inadequate. Therefore, collecting information about who was responsible for particular services prepared caregivers to support their parent because in doing so they identified the organization (or specific individual) to contact that would have the authority to implement change. Although all caregivers who engaged in this process ultimately collected the information they required, they described it as a time consuming process in their already busy lives, particularly when they were employed full-time.
Caregivers also described the importance of engaging directly with healthcare providers to obtain information. Caregivers felt that because of their parents’ ill health or age, they would have difficulty reproducing the information that doctors provided. For example, when asked what was involved in getting ready to advocate, Janice (female, 51) said:

Um make sure you understand what’s happening and if you don’t, get somebody else too, like two people, you should definitely, not be by yourself. Like for instance my father, um for his age he definitely needs another person there to hear what the doctors are saying, that person should not be on their own hearing what the doctor’s say because it’s you and you’re not listening. Like honestly, he didn’t listen so you need another person there to hear what the doctors are saying.

Many caregivers reported making an effort to be present when physicians interacted with their parents because they viewed physicians or other healthcare professionals as the most reliable source of medical information. They provided examples of times in the past where they were not present for physician appointments, and subsequently encountered difficulty obtaining information from their parent, who was unable to recall or explain all of the details their physician had provided. All caregivers mentioned that the information provided by physicians was valuable because they relied upon this information provided to care for and support their parent.

Although many caregivers made an effort to be present when physicians and other healthcare providers interacted with their parents, passively listening to what the healthcare providers were saying was sometimes not a sufficient way of collecting necessary information. When they had the opportunity to communicate directly with the healthcare professionals involved in their parent’s care, often caregivers stated that they asked many questions. Asking
questions of healthcare professionals was raised as an important way to prepare to advocate, and participants recommended that other caregivers should always ask healthcare providers questions. When asked what was involved in advocating for her father, Joyce (female, 56) explained that asking questions of healthcare providers was a key piece. She explained that during a discharge meeting held at the hospital she was told that her father would receive 5 hours of formal assistance per day which at the time she believed would be acceptable. However, upon discharge she realized that her father required a greater number of hours of assistance:

Um to ask as many questions as you can and to really keep that line of communication with obviously your case worker, your most important person and to make sure that the parent is happy, as best as they can be. Comfortable I guess the word is. That they’re comfortable being taken care of. But ask questions. Ask questions. Because you have to get things clarified. Really ask the questions to understand it…you have to absorb how life is going to be back wherever they live with the care and equipment… We didn’t know. And I think we wouldn’t have had that number of days of confusion, because my mother was very stressed about that, those few days where he didn’t have enough hours because he [father] was in bed for a long period of time because people weren’t coming to get him up, do you know what I mean?

Some caregivers like Joyce explained that asking questions was necessarily involved in collecting information, and provided an opportunity to ensure that the information provided by healthcare professionals was clarified and understood. Having a clear understanding of the information provided, particularly in the hospital, was seen as important by many caregivers because after discharge, caregivers would generally be involved in a more intensive level of care
for their parent. It was therefore essential that they understood the information they were given so that they could determine if what they were being asked to do aligned with their own expectations and perceived capabilities. In instances in which a misalignment was perceived, a number of caregivers then requested greater formal support, often in the form of more CCAC instituted support hours.

Some caregivers’ accounts also suggested that information specifically about their parent’s care may not always be proactively provided to caregivers by healthcare professionals. Therefore, it was important that they sought information themselves. Judith (female, 67) recounted the death of her father-in-law while he was in the hospital to explain why she felt asking questions was imperative:

I: What recommendations would you have for someone else caring for a parent who has been in the hospital?
P: I would have, make sure family members are there every day and ask questions. Ask questions of the nurse or doctor. And stay informed.
I: And if they said oh why do I need to be informed what would you tell them?
P: I’d tell them that I’ve heard of people that went in the hospital and didn’t come out. And then they’ll say what happened? Well I guess he got septic or something. There are so many people, older people who just go there and even my father in law. He told us they’re killing me in here, get me out. And they did kill him. And we weren’t in the city where he was so we didn’t see him every day, so I just say go every day.

When information was not directly forthcoming from healthcare professionals, asking questions became an important avenue through which to secure knowledge based resources. By
becoming informed, caregivers established criteria on which they could judge the adequacy of their parents’ care, and work to reduce the likelihood of adverse patient outcomes. For example, when their parents were not recovering, caregivers conducted research to determine whether the doctors’ assessments and prescribed treatment plans (which they had asked questions about) were appropriate, or if alternative courses of action could be taken. They also described collecting information from healthcare providers about when antibiotics might be necessary and when intervention is required for bedsores. Armed with this information, caregivers approached healthcare providers and advocated for intervention when their evaluations indicated that their parent’s current care was inadequate.

While it was evident from caregiver’s accounts that many healthcare providers did share information, and some encouraged caregivers to ask questions, more often caregivers emphasized that persistence was key to obtaining answers to their questions. Connie (female, 50) described waiting months for her mother’s treatment plan to be developed and implemented. Despite regularly asking her mother’s physician about what could be done, she was often met with vague, unsatisfactory responses:

I’ve learned that you have to advocate for yourself or for your parent or your loved one whoever it is that you’re supporting because, especially when they’re in a place that you know they’re not feeling well or in pain they don’t necessarily have the words or the, even the willpower but the energy to just, kind of, you have to sometimes be like a bulldog and keep going after and keep asking the same question over and over and over again until you finally get heard.

Although information was perceived to be important, some caregivers also expressed difficulties retaining all of the information themselves, and suggested that even caregivers should
be accompanied by another person, such as a family member (other than the patient) who could also listen to the information provided. Still others suggested that because the information provided was sometimes overwhelming, taking notes during conversations with healthcare providers was useful. A number of caregivers described taking copious notes about their parents’ care and during our interviews they often referred to them. Their notes functioned as reminders of the information that healthcare professionals had provided, and were viewed as an important source of information that might be required in the future. Carol (female, 63) described the perceived necessity of attending her mother’s physician appointments, and explained that she keeps an updated file on her computer that documents her mother’s medical history and information provided by the physician:

I: And so you go to her doctor’s appointments with her then?

P: Oh yeah because I have to hear what’s going on because she’ll have forgotten by the time she gets out.

(…)

I: And so when you’re there do you ask him questions?

P: I do yeah and I sort of keep a running thing on my computer at home as to what happened when, you know? So that the doctor said this, the doctor said that because I can’t remember it all either, I’m getting senile too.

I: And like in terms of keeping that document on your computer, why do you feel that’s important?
P: Because then they’ll ask you the next time you’re in the hospital how long has she been on this medication or when did this happen and you think oh jeez, I don’t know.

Such accounts suggested that caregivers could be called upon by healthcare professionals to provide information, and subsequently caregivers appeared to be an important resource for healthcare professionals. The previously presented excerpt from Grand River Hospital’s Patient Information and Service Directory stresses the importance of patients sharing information about their health history and medication with their healthcare team to be the best advocates for their own health. However, this analysis suggests that caregivers too may possess this important type of information, which requires collection and collation.

A number of caregivers also described difficulty understanding the information they were given by healthcare professionals and noted that they would sometimes turn to members of their own social networks to gain clarity. Andrew (male, 39) described obtaining medical information from his mother-in-law to make decisions about what he should do next to support his mother:

I: Um and in terms of like medical advice or even like advice in terms of providing care, do you get anything like that from them [social network]?

P: Yes, my mother-in-law was actually a nurse until very recently so yeah I get a lot of medical and other advice there.

I: So could you give me a few examples?

P: Um well understanding the drugs she is taking, what maybe I missed from the staff from the hospital, or she will know why she’s taking something and uh and
sometimes what course of action to take, whether it should be other options or you know what the likely outcome is of certain treatments or yeah.

I: Yeah.

P: Yeah it’s tough to explain, but yeah basically anything I don’t get information elsewhere I will get from her. I also know people aren’t perfect, but in general it gives you a very good direction anyway to start in.

I: Yeah.

P: And not just sitting there having analysis paralysis, you actually continue forward because you have a bit of an inkling of where you should look and what you should do.

In summary, some caregivers explained that information may not always be provided proactively by healthcare professionals, so it was therefore necessary to seek this information themselves. However, such efforts were not always met with the results that caregivers desired (i.e., the provision of information). Accounts such as these suggest that there were times, during their parent’s transition from hospital to home, where caregivers felt ignored by healthcare providers, and overlooked as valuable members of their parent’s care team. Furthermore, these accounts suggest that the onus is often on caregivers to collect information, which may present challenges when caregivers are not aware of the questions they need to ask to obtain information that will be most helpful to them in their role of supporting a relative.

Collecting information was a necessary antecedent to successful advocacy. Through independent research, asking questions, and keeping notes, caregivers developed a picture of their parent’s current care and medical history. This picture fostered knowledge of their parent
that they promoted when they advocated on behalf of their parents. By developing such knowledge about their parent and their parent’s condition, they were able to monitor their parent’s care and compare it with information they collected, thereby making evaluative judgments that they communicated to healthcare professionals. However, collecting information was not always a straight forward process. Caregivers shared a number of challenges they faced when collecting information about their parent, such as an extensive time commitment, and the presentation of confusing and overwhelming information.

**Providing unsolicited information to healthcare professionals.** During the transition from hospital to home, caregivers also provided information about their parent to healthcare professionals. Caregivers provided information that was solicited (based on direct requests from healthcare providers), and information that was unsolicited. Many caregivers suggested that both forms of information provision were essential to ensuring that their parent received quality health care.

While their parent was hospitalized, hospital staff called upon caregivers as resources to provide information about their parent when their parent was not able to do so themselves. For example, caregivers described providing a list of their parent’s medications to hospital staff upon admission or describing their parent’s medical history and current symptoms. Within the homecare environment Darlene, a CCAC Care Coordinator, indicated that when assessments are made to determine service provision, caregivers may sometimes participate in assessments when older adults are unable to do so themselves, but also suggested that at times it could be challenging to connect with caregivers who were employed because CCAC hours did not align with caregiver schedules:
Um but in most of those cases if they [caregivers] are still working full time they have to arrange for time off in order to be there [at the assessment meeting] which is a big deal and so because our working hours are 8:30 to 4:30 so sometimes we can kind of be a bit fluid with that but for instance if somebody wants a visit on a weekend or somebody wants a visit at 8 in the evening, you know, no we can’t do that so it does mean that they are off for that, sometimes it may mean that they can’t be there so I’m connecting with them by telephone to update them or to gather information from them because particularly if they have a parent with some dementia or cognitive impairment there’s a lot that could be missed in my assessment just with that patient right because they, there’s a lot that they’ve left out because they don’t realize or yeah they just haven’t seen it and their family sees it but they don’t. Um so that’s definitely that issue.

In these instances, the information caregivers provided was directly solicited by healthcare providers. While the information they provided was likely beneficial to their parent’s care, caregivers felt that the questions healthcare providers asked, did not always lead to a complete picture of their parent’s unique circumstances.

Therefore, caregivers also provided unsolicited information to healthcare professionals. Often caregivers described possessing information about their parent and his or her health that was accumulated over years of caregiving and through a close relationship with their parent. Caregivers suggested that healthcare providers were not aware of this information, yet they also felt that such information would contribute to better care for their parent. Through providing information that was not directly solicited by healthcare providers caregivers worked to ensure that their parent received appropriate care.
Through the process of providing information, caregivers made healthcare professionals aware of their parent’s unique circumstances and ensured that this information was taken into account when treatment plans were developed and implemented. For example, Robert (male, 36) described ensuring that hospital staff involved in creating a discharge plan took into account his father’s capacity for mobility which had been overlooked in the past:

Well they’re, we make them aware. They’re all cognizant of the fact that mobility is hard with my dad because of the bilateral amputations now, right? So we sort of again, if we’re not there it would just get overlooked, but we explain that we can’t get him to the family doctor, because he has to follow-up with the family doctor a couple times a week.

When their parents experienced multiple hospitalizations or had contact with multiple medical professionals, caregivers characterized themselves as the only common thread in their parent’s care. As a result, they found themselves repeating the same information about their parent’s medical history. This was a frustrating experience but they found that it was necessary to ensure that their parent received a standard of care that they judged to be acceptable. Caregivers also contrasted themselves to healthcare providers by professing an intimate knowledge of their parents’ condition that was inaccessible to professionals who had infrequent contact with their parents. Such knowledge was developed over time and as a result of the relationship they had with their parent. For example, Taylor (female, 22) discussed the knowledge she possessed about her grandmother that she felt healthcare providers might not have:

I: And to compare yourself to let’s say a nurse for example, like do you feel that you really know your grandma a lot better and her needs and that type of thing?
I: Yeah, would you be able to describe that a little more?

P: Let’s see how can I describe it? Um well for pain and stuff um her medication said ‘as needed’ on the bottle but we weren’t doing it as needed because we did it as a preventative measure and we knew if she didn’t do that then she wouldn’t be able to walk and stuff and so when she was in the hospital or the nursing home and they’re not giving it to her, just basically, because she can’t really tell you if she’s in pain um the way she moves her body I know that she needs pain medication or that she’s uncomfortable.

Taylor’s grandmother had dementia and was unable to verbally communicate when she was in pain. She was prescribed a pain medication that Taylor explained the hospital and nursing home staff would not give to her because they did not understand particular cues that indicated she was in pain. However, because Taylor had spent a great deal of time with her grandmother, she was sensitive to these cues. Therefore, while her grandmother was in the hospital or the nursing home and Taylor observed these non-verbal cues, she provided information and advocated on her grandmother’s behalf to have her pain medication dispensed.

Caregivers also monitored their parent’s care environment and advocated for improvements when they perceived the environment to be detrimental to their parent’s health. Caregivers presented knowledge about the interaction of their parent with the care environment that healthcare professionals may not have been aware of, or had perhaps overlooked. Through providing such information, caregivers made staff aware of their parent’s unique circumstances. For example, Matt (male, 31) whose father had been repeatedly hospitalized over a period of six
months, described drawing the attention of a hospital administrator to his father’s weakened immune system after he was placed in a hospital room where Matt believed his father would be more likely to develop yet another infection:

You know, a hospital administrator was helpful when we had a couple issues and he was, he stepped in and they, because my dad has those anti-rejection medications. There were some cases where they had put him in a ward with really sick patients so one of them had [name of contagious illness] and because my dad is susceptible to getting sick because his immune is suppressed from the drugs. And it’s not ideal, it’s not putting my dad in a good situation so we asked why he was put in this room and we were challenged, well do you have private insurance? Well there’s something call reverse precaution where we don’t want, the point of getting him to the hospital is to get him well enough to come home, not to get him more sick so that’s, I felt that was I don’t know if you want to say um maybe borderline discriminatory against, because of the fact that he’s sick, now you’re asking if I have to pay for a private room, well that’s not fair to him right? But he stepped in and they made it sort of right. They put him in a semi, like a two person room so with a, with two curtains so he’s less susceptible to getting more ill right.

Caregivers possessed knowledge about their parent that they accumulated through their relationship with their parent, and also specifically through the act of caregiving. Although caregivers suggested that this information was ultimately important to their parent’s well-being, it appears that the necessary conversational space to convey this information to health professionals is rarely available in institutional settings. Instead, caregivers must actively work to
be heard. For example, as Matt continued to explain, his approach to advocating for his father could be perceived as bothersome by healthcare professionals:

Like take more care of him [father], or like are you sure the machine is working right or are you sure, you know his blood sugar’s okay, his number seems low. And they’re [healthcare professionals] probably thinking everything’s fine, shut up and leave.

Attempting to advocate on behalf of a parent can cause tension between caregivers and healthcare providers. For example, as mentioned previously, Taylor (female, 22) characterized herself as a “difficult client” and Cathy (Community Care Coordinator) mentioned that caregivers who advocate may not be “the most favoured person”. These accounts suggest that advocating can pose problems for caregivers because the process of advocating may disrupt institutional arrangements. However, given the perceived necessity of advocating within the healthcare system, greater recognition of caregivers as patient advocates is essential.

**Participation in the Study as Advocacy**

Some caregivers may collectively act to bring about change at the policy level, which Levitsky (2014) describes as the politicization of caregivers. Although participants in the current study largely did not describe collective action, there were some instances in which caregivers described actions that were indicative of politicization. For example as described in Chapter 5, after an incident in the hospital that she believed nearly resulted in her mother’s death, Linda (female, 63) described keeping documentation of the incident and intending to take it to Premiere Kathleen Wynne to ensure that changes were made to the way that the hospital responds to particular occurrences.
There was one problem that I’ll go right to Wynne with if I have to. It’s something that never should have happened. So I just, I haven’t had time, I have a lot of stuff documented and written down but I have to get out one day, like I said the mornings are not the best time for me, but I need to get out and get that handled soon.

Furthermore, caregivers performed a subtler form of social action by participating in the study interview. From my own experiences interviewing caregivers, I believe that they viewed me as a conduit to the healthcare system; as someone who had a direct line of open communication with parties who could effect change at the system level. Through participation in the interview they understood that their experiences would be communicated to hospital administrators and governmental representatives. For example, James (male, 58) shared with me that he hoped “that this gets something done to rectify the situation”. While it is true that the findings from this study will be reported to Grand River Hospital and the Waterloo-Wellington CCAC, I could not confirm that my study would reach politicians or policy makers, or result in any direct changes to the way that things were done. Nonetheless, such impressions resulted in the participation of a number of caregivers. Indeed, for some caregivers, the sole reason they agreed to participate in the study was to “help the next person or the system” (Robert, male, 36). Therefore, participation in the interview was a way to potentially affect system level changes.

As discussed in Chapter 5, caregivers viewed the healthcare system as “falling apart”, and as a result of participating in this study they hoped that by providing me with information about their own experiences, I could somehow contribute to addressing this situation or make experiences better for patients and their families in general. When they made these statements to me I often felt uncomfortable and tried my best to explain that I could not guarantee any
changes, but was honest about what I intended to do with the findings which were: 1) write my PhD dissertation, 2) communicate a summary of the findings to Grand River Hospital and Waterloo-Wellington CCAC, and 3) attempt to publish the study in an academic journal.

This sub-sample of caregivers wanted an avenue to be heard and from our conversations it appeared that participation in this interview was the only way they felt their concerns could be communicated. Although Patient Relation Units have been established in hospitals across Ontario and a Patient Ombudsman office has been established to respond to complaints about hospitals, long-terms care homes, and CCACs, it appears, based on the conversations with participants, that caregivers desire a more visible platform through which to express their concerns.

**Chapter Summary**

All caregivers who participated in this study described advocating on behalf of their parent, and some also described engaging in self-advocacy to secure respite services. Caregivers advocated for a number of reasons and stressed the necessity of advocating on behalf of their parent to ensure good quality health care. Despite the ubiquitous nature of advocacy, caregivers were often unaware in advance that advocacy would be an important aspect of caring for their parent, and many experienced challenges preparing to advocate. Such findings suggest the need for greater recognition of their role within the healthcare system.
Chapter 8: Reflexivity in Health Services Research

While reading literature about the healthcare system, I came across an article entitled “Portraying Reflexivity in Health Services Research” by Rae and Green (2016). In this paper, a matrix is proposed that guides a way of thinking about reflexivity. Questions proposed within the matrix often gave me pause to reflect on my experiences conducting this research and how I was reflexive during the process. Rae and Green propose a number of questions categorized under “Pre-Research”, “Data Collection” and “Data Analysis” stages of research. In the following sections I reflect on my responses to some of the questions that they pose that help to illustrate my relationship to the research and my role as an “instrument” in the process (Rae & Green, p. 1543).

Pre-Research

Within the context of “Pre-Research” Rae and Green (2016) pose the following question: How do researchers’ broader motivations affect the reason to conduct research in the first place and the choice of topic and research question? They note that although in many instances researchers may be engaging in the research to further their careers, the central motivation should be to contribute to the relevant literatures and add novel contributions to the field.

One factor that motivated me to conduct my study, as I am sure is the case with most students, was indeed the hopes that I would obtain a PhD. However, I was also struck by the relatively sparse academic literature on caregivers during a critical transitional period (i.e., from hospital to home). I hoped not only to contribute to this literature, but more importantly to contribute to the practical knowledge base within a real world setting. When I wrote my proposal I had no idea that my study aligned so well with the goals of particular segments of the healthcare field (i.e., the WWCCAC, Grand River Hospital; see Chapter 4: Methods). My
educational background implored me to design a study that could be practical in nature, but at the time I was not aware of the interest it would generate. During my time as a Master’s student I often questioned whether anyone besides me was interested in my research and I sometimes struggled to believe that there was. However, during the early stages of planning for my PhD dissertation, I learned that there are people within the healthcare field locally who were eager to hear about the experiences of caregivers, and that such research aligned with their organization’s goals. Understanding that I had a receptive audience waiting for the results of my study made me aware that finishing a dissertation alone simply would not be sufficient. I decided that I would also create summary reports appropriate for distribution among Waterloo-Wellington CCAC employees and Grand River hospital employees.

Scholars also argue that researchers should initiate the process of reflexivity when they choose their topic of research (Band-Winterstein, Doron & Naim, 2014). While I must admit that I have limited recollection of the processes that I engaged in during the proposal writing stages of my dissertation, I offer some insights that describe in part my motivations for completing the study. I entered graduate school with an interest in aging and that has not changed. However, while reading the literature I became aware of the role that caregivers often play when older adults experience physical and cognitive limitations. This literature sparked an interest and my focus shifted slightly to the related topic of caregiving during older age. As a child I witnessed my mother and her sisters care for my grandmother who had Alzheimer’s disease. I was too young to remember much but I do remember their dedication and struggles. I remember the difficult moments we experienced as a family, and I remember the immense sadness I felt at losing my grandmother before she was physically gone.
I knew reading the literature that I wanted to focus on family caregivers, specifically those providing care to a parent. From the literature I knew that, to a degree, care provided to older adults with dementia differed from care provided to older adults without such a diagnosis. This finding was a solace to me because at the time I was writing my proposal I felt that it would be too painful for me to interact with caregivers providing care to a parent with dementia but I was unsure of how to exclude them from the study eligibility criteria without saying it was for a personal reason. Therefore, I made a theoretically informed decision based on the literature to focus only on the experiences of caregivers providing care for a parent who did not have a diagnosis of dementia.

This soon changed. While setting up interviews I have to admit that I forgot to ask participants if their parent had a diagnosis of dementia. I assumed that the screening processes in place at the hospital would have excluded such individuals. During my fourth interview I learned that the participant was providing care to his father who was diagnosed with dementia. I recall that at the time I felt some internal discomfort when he revealed this information, but did not express any concerns and instead continued the interview. I was struck by the similarities between his experiences and the experiences of the caregivers who were not providing care to a parent in the context of dementia. From that moment forward I removed the exclusionary criteria relating to individuals caring for a parent with dementia from the study.

Rae and Green (2016) also implore researchers to answer the question: What is the relationship between the researcher and the healthcare field? Before beginning my dissertation research I had limited experience with the healthcare field. I had been a healthcare user and witnessed those in my social network use healthcare services. I have relatives who work as registered nurses, but conversations about their work life are often brief. To summarize my
experience, I was no expert. The limits of my knowledge at the beginning of my research are clear to me now. Throughout the research process, I have gained extensive knowledge not only about how the healthcare system functions, but also of the advantages and disadvantages of not being a healthcare professional while conducting a research study on a topic that is immersed within institutional settings. To illustrate the disadvantages, I offer the following summary of my experiences setting up the logistics of the study.

To begin data collection I required participants. From previous consulting work I had connections with the Waterloo-Wellington Community Care Access Centre (WWCCAC), specifically with the executive director. I believed at the time that the WWCCAC would be a valuable resource for recruiting caregivers to participate in my study as staff members (specifically Care Coordinators) have frequent contact with family caregivers and could therefore be in an excellent position to help with participant recruitment. The executive director supported my study almost immediately because it aligned with the CCAC’s goals, and I soon had approval from the WWCCAC board to include the WWCCAC as a partner in my study.

I was then connected with the Planning Manager of the WWCCAC. We discussed my study protocol and the ways in which the WWCCAC could support my study. I had proposed that I would interview caregivers within two weeks of their parent’s discharge from hospital. This was problematic in terms of recruitment because the Planning Manager informed me that WWCCAC staff often do not have contact with caregivers until a longer period of time has passed. Based on the literature, I believed that the time parameters I set were an essential aspect of the study so the Planning Manager suggested that I also partner with a local hospital because they were more likely to have contact with caregivers during the discharge process which would allow me to contact them sooner.
With valuable input from the Planning Manager I decided that Grand River Hospital (GRH) would be the best hospital to approach because they have the highest number of admissions of older adults in the region owing to their specialized geriatric units. I contacted the research office at GRH and received extensive assistance from a staff member who informed me that to conduct research in association with the hospital I would require the support of a local investigator who worked within the hospital. She connected me with the Director of the Medicine Unit. I contacted him and invited him to be part of the research team. Almost immediately he supported my study because understanding the experiences of caregivers during the transition from hospital to home aligned with informational needs at GRH. Specifically, hospital re-admission rates among older adults were perceived to be too high by GRH representatives. Therefore, the Director of [unit name] had an interest in understanding aspects of the post-hospital discharge experience to determine if there was anything they could do to better support patients and caregivers.

I came to realize that my clinical inexperience influenced my study design. My relative inexperience with the healthcare field initially led me to value academic literature over that of real world experiences. As a member of the research team, the Director of [unit name] provided me with some valuable feedback on my study design, and helped me to understand that some of my study protocols were not reflective of the practical problems that the hospital was facing. My original study protocol called for interviews to be completed with caregivers at two weeks post-hospital discharge and again at two months post-hospital discharge. This time frame was chosen based on the academic literature. However, there was clear misalignment between this literature and the practical challenges encountered by a hospital. The Director of [unit name] stated that most hospital re-admissions occur within one week and 30 days after discharge. Therefore, these
are the most important time periods during which to determine what might be happening in the home environment that potentially contributes to hospital re-admission. Consequently, the time periods were adjusted in my study protocol to reflect the Director’s advice.

I was aware of my clinical inexperience again when attending a meeting to obtain administrative approval for my study at GRH. This meeting was held to ensure that my study would not impose any undue costs on the hospital. Although it was clear that it would not, during my presentation describing the study, one board member suggested that caregivers would likely not be able to tell me the definitive diagnosis of their parent which was important to capture. They therefore suggested that I collect data from patient discharge records as well. This led to a lengthy procedure of determining how such information might be obtained and extensive consultation with GRH’s privacy office.

Ultimately the changes that I made to the study protocol (i.e., the change in time periods and collecting patient information) became irrelevant. When caregivers were recruited by hospital staff I often did not receive their contact information until roughly three weeks had passed making it impossible to interview them at one week post-discharge. Additionally, the hospital had scarce resources and the priority of staff members involved in recruiting participants had to be patient care. Therefore, they had limited time to recruit participants and were unable to engage in a lengthy process to obtain patient consent to release hospital discharge records to me. I understood this but it meant that recruitment was slow and as a result, the decision was made to begin recruitment within the community as well. This meant that I would not have access to patient information, because I did not have any connection to the hospital where participants’ parents received care. At the time I perceived the failure of the study protocols to be a huge setback. However, with time and reflection I no longer perceive any of it to be detrimental to my
study. The caregivers I spoke to reflected on their experiences and provided me with extensive information regardless of when I spoke to them, and although I did not have an objective account of their parents’ diagnoses (i.e., patient discharge records), caregivers were often able to tell me the reason their parent was hospitalized, as well as any other medical diagnoses that were reflected in the care they provided to them. Overall, the experience was a lesson in study feasibility and I learned that being adaptive was an absolute necessity in healthcare research.

At the time all of this was taking place I felt defeated and wished that I had known all of this prior to beginning my study. I felt that perhaps my inexperience with the healthcare system, and my place outside of a healthcare setting (i.e., I was not a medical student or administrator) limited my ability to efficiently implement study protocols. I felt that had I had some previous affiliation with a hospital, things would have gone much more smoothly (although I do acknowledge that challenges may also be experienced by researchers with a medical background who do not have experience with specific hospital units). However, once I actually began conducting interviews I felt that my inexperience with the healthcare system was also a slight advantage. I describe this in more detail in the following section.

**Data Collection**

Rae and Green (2016) also identify data collection as a key period on which to reflect. Specifically, they suggest that researchers answer the following questions to assess the differences between themselves and their participants, explore power differentials in their relationships, and examine how they approach the interview process: *What are the shared and divergent understandings between the researcher and participants with regard to research generally and to the health-related topic? Are there any power differentials between the*
researcher and participant, based on positions held (present or past), health discipline, or education? Are questions (or prompts) inadvertently shaped by popular scholarly opinion?

Reflecting on my experiences during data collection, I can say that I often emphasized the differences between me and the individuals whom I interviewed, and I actively worked to minimize the power differentials that are often perceived to exist between researcher and participant. When I first began interviews with Care Coordinators I explained that I had little experience with the healthcare system and was looking for information to help me understand how particular branches of the system worked in practice. Throughout the interviews I often found myself reminding the Care Coordinators of my inexperience by making the following types of comments:

“So I’m sort of like learning how the system works”.

“Okay and just because I haven’t been part of an assessment or anything, I’m just curious, exactly what does that entail? Is there a checklist you’re going through and what types of things are you asking about? How does that work?”

“Yeah that’s good for me to know because I have no idea so this is a learning experience for me”.

“The actual research topic is pretty new to me so I’m just reading everything. I read policy documents and all of that. There’s a lot to learn”.

By emphasizing my inexperience, I found that I was placing Care Coordinators in a position of authority; they had knowledge that I did not and I was looking to them to educate me. While I cannot provide the perspectives that Care Coordinators had of our conversations, I feel that by portraying myself as a naïve participant in our dialogical encounter, they were open to
educating me about topics related to transitional care, and to voicing their concerns about the healthcare system which often led to fruitful discussions.

My approach was slightly different with the caregivers that I spoke to, but I still found myself placing them in a position of authority while in pursuit of understanding their experiences. This was particularly evident when participants used medical terminology and I questioned them about it. The following interaction took place after Robert had been discussing his father’s ‘hemoglobin’ and ‘white blood cell count’. These were words that I had a vague understanding of, but not enough that I would be able to apply them in conversation about a relative’s care:

P: Because with the renal function it drops so hemoglobin in the agent that carries oxygen to your cells, to your organs right? It’s vital for life and if that’s low or below a certain threshold we request a blood transfusion to get that higher right? So um what is. The doctors know in the 70s they need to do it. It’s critical to life. Then what is his creatin level? What is his urea level? Those are markers for how his kidneys are functioning. If they’re elevated then they need to get his nephrologist involved right, they need to page him

(…)

I: Yeah, yeah. And I just wanted to ask you because you seem to be very in-tuned in terms of medical aspects so you were mentioning the blood tests.

P: Yeah.

I: I was just wondering where you learned all of that because I certainly don’t know any of that.
P: Well my mother’s a registered nurse. She’s retired so she has a thorough medical background. But with us maybe it’s the good genes quote unquote hahaha that’s a joke but um maybe baptism by fire a little bit just knowing, you know you can be present and show up and say how you doing dad or what are the doctors saying or you can, you have a mind of your own you know. You can be involved and understand what’s happening.

In these types of interactions my motivation for asking questions about the source of their knowledge for medical terminology was to understand if it was learned during the transition of their parent from hospital to home. However, by phrasing my question with an emphasis on my ignorance of the subject, I felt that the power dynamics of the researcher/participant relationship that is traditionally described in the literature shifted. There were many instances where participants educated me about particular topics, and in doing so provided me with some insight into their knowledge sources which became important for my understanding of their approaches to advocating on behalf of their parent.

During the interviews I also found that perhaps the power dynamics were shifted because of my age. I have often been told that I look much younger than I am, and this has sometimes led to people not taking me seriously or applying negative age-related stereotypes to me. Most of the participants in this study were older than me and they sometimes compared our ages and age related experiences in life. For example, some would tell me to get ready for being older because it is not always fun. Some participants appeared to expect that I would not have a strong understanding of the healthcare system (and admittedly there is much more I could learn) but I was not offended when they seemed to make this assumption. They often provided me with
extensive information about what they had learned during their tenure as a caregiver which allowed us to explore why and how they learned this information.

Some participants would also tell me that they hoped they had specifically helped me by participating in the interview because they were aware that one component of a successful interview study is that it includes a sufficient number of participants. Within a power hierarchy they were therefore in some ways higher than myself because I was entirely dependent upon them for their participation. Nevertheless, I am aware that power dynamics between researcher and participant were still at play in this study. At the end of the interviews, I also found that some participants explicitly placed me in a position of authority as a liaison between them and the healthcare system. As described in Chapter 7, some participants expressed hopes that I would be able to make a difference through my research. They were aware that I had connections to the hospital where many of their parents had received care and my educational pursuits motivated me to share my findings with the broader academic community. The comments they made about my ability to implement changes often made me uncomfortable and caused me to question how I would ethically handle their perceptions of me. I chose to be honest with them and tell them that I was not sure if I could actually make some kind of change, but that I would share the stories of the caregivers I interviewed with individuals from the WWCCAC and GRH.

Despite some caregivers viewing me as in some way associated with institutions within the healthcare system, I did emphasize during my introduction that I had no medical training or formal affiliation with any part of the healthcare system. I also explained that my mother and aunts had provided care to my grandmother when I was younger. In doing so, my central concern was managing how participants may have viewed me during the interview. I wanted to distance myself from the medical field and suggest that perhaps I had some shared understanding of their
experience (though as I will describe below, this understanding was extremely limited). I did not want to give the impression that I was a healthcare professional because I felt that it would limit what participants were willing to share with me. I believed that should caregivers have complaints about their parent’s care, that they would be unwilling to criticize aspects of the healthcare system if they felt that I was associated with it.

Participants appeared to be open to sharing their experiences with me, both the good and the bad. Some of their experiences were emotionally challenging to deal with and positivist frameworks suggest that the researcher should remain neutral during the interview process. However, Herron and Skinner (2013) discuss the challenges of negotiating emotions within research and argue that to passively listen to a research participant share emotional narratives is insensitive to their experiences and may serve to marginalize participants. Therefore, they argue in favour of expressing emotional responses so that researchers are sensitive to both the context and the participant’s position. I admit that I was not familiar with Herron and Skinner’s work prior to writing this chapter of my thesis. However, in reading their paper on reflexivity in health research I began to interrogate the role my own emotions may have played in shaping the interviews.

I consider myself a highly empathetic person, and during the interviews I continuously found myself silently empathizing with participants, and also verbally acknowledging their struggles. If they encountered challenges when dealing with institutions involved in their parent’s care, I often told them that their experience sounded frustrating (to which they agreed), or would say things like “oh that’s awful” when they would share a troubling story. I also found myself verbally agreeing with them when they would suggest that particular aspects of the
healthcare system were challenging. In doing so I felt that I built rapport, but also inadvertently took sides in their struggles with the healthcare system.

This inadvertent taking of sides caused me to question how the research and policy literature on caregiving influenced my approach to the study. In particular, to what extent did I invite particular responses? I feel that I entered the interviews specifically looking to find problems with the healthcare system. The original title of my thesis title was “the needs and skills of filial caregivers of older adults during the transition from hospital to home” and my interview protocol included questions that were indicative of searching for problems (i.e., “what concerns did you have at the time?”, “was there anything recommended that you felt was out of context for the way you lived your life?”, “what challenges have you experienced?”). During the interviews I also drew upon my previous knowledge of potential challenges that caregivers experience when asking follow-up questions. For example, sometimes caregivers would mention personal support workers, though not say much about them. From my previous review of the literature and my interviews with Care Coordinators I knew that many caregivers experienced challenges with personal support workers. Therefore, I followed-up with questions about their experiences with personal support workers, expecting caregivers to describe negative experiences (which they often did). Much of the literature suggests that caregivers encounter challenges when caring for a parent, and concerns within the policy literature highlight the need to support caregivers who support older adults. I believe that this literature was highly influential in the way I developed my study and, as I will discuss in the next section, to my interpretation of the findings.
Data Analysis

Rae and Green (2016) pose the following questions related to reflexivity in health services research: *How does the researcher’s experience with the field shape analysis? Are some data dismissed as being commonplace, whereas they might warrant deeper interrogation?*

Related to these questions, Mauthner and Doucet (2003) emphasize that in being reflexive, we must move beyond simply identifying our social location (i.e., gender, ethnicity, sexuality) and how that may have influenced the data collection process, to identifying what in particular is guiding our knowledge production during data analysis. Specifically, they note that we must take into account how our own biographies may influence the interpretation of data. As I have mentioned, I witnessed my mother and aunts caring for my grandmother. Therefore, when beginning this study, I believed that perhaps I had some understanding of what it meant to be a caregiver. Hearing caregivers’ stories challenged this assumption. I came to realize that I had no experience of actually caring for an older relative. Additionally, I was an “outsider” to the healthcare field, and I became concerned with how my position would limit my interpretation of caregivers’ experiences.

Yet there were moments when reading through my interview transcripts and notes that I identified with the caregivers and in a way, this helped me to make sense of their experiences. Caregiver advocacy is a central component of this dissertation, and advocating on behalf of a family member, and on behalf of myself, was something that I have experienced (though not as it relates to healthcare). Additionally, when hearing about some of the more troubling experiences that caregivers had, I felt the innate need to intervene. Linda, one of the caregivers in this study, explained that she wanted to report a troubling incident that occurred at the hospital. My immediate response was to remind her of the resources that I had provided at the beginning of
the interview that would assist her in doing so. Although she seemed to have her own plan in place for how she would approach resolving her issues, I found when reflecting on this experience that I have a strong desire to help people and by writing this dissertation I have become an advocate for caregivers as a group.

In answering Rae and Green’s question about dismissing data as commonplace, I feel that as their stories related to the healthcare system I did not do this. Everything was new to me and it often warranted additional research to find out how the healthcare system functioned. There were times that I drew upon the expertise of the nurses in my family to explain how particular aspects of the healthcare system functioned, and I often found myself reading CCAC documents and books on social policy that would help me to appropriately situate my findings within the broader context.

Doucet (2008) and other social scientists also suggest that researchers should imagine that they are sitting next to respondents as they read the analysis and what is written about them. During analysis, I was concerned with how I would write about participants, particularly the caregivers, and tried to imagine their reaction to reading the analysis. Drawing upon Doucet’s approach to being reflexive during the process of analysis, I made notes on printed copies of the transcripts about my reactions to the participant’s words to “examine how and where some of [my] own assumptions and views—whether personal, political or theoretical—might influence [my] interpretation of the respondent’s words, or how [I] later write about the person” (p. 78). This allowed me to see how my own feelings and thoughts might influence my analysis.

While collecting data, I was concurrently writing the second chapter of my thesis that conceptualizes notions of responsibility for the care of older adults based on relevant literature. While doing so I ultimately concluded that families are taking on increasing responsibility for the
care of older relatives, and may not receive support in doing so, despite encountering many challenges. In writing my analysis I drew upon this conclusion and specifically emphasized that caregivers do not always have appropriate knowledge, resources, or authority to support their relatives. Guidance from my advisory committee implored me to consider what society expects from medicine today, and how my own perspectives may have shaped the findings.

I have specific political leanings that value addressing social problems and supporting citizens who are struggling. Like the caregivers who participated in this study, I too am embedded within particular cultural and institutional structures that have influenced my perspectives on the healthcare system. I have nurses who are relatives who often mention that they are overworked, I see Facebook friends post complaints about the healthcare system, I read newspaper articles about the healthcare system, I’ve experienced long-wait times to see medical specialists which affected my physical and mental well-being, and I have watched as my husband’s grandfather was repeatedly hospitalized for what we as his family perceived to be medical errors. Yet I am also incredibly grateful for the healthcare system in Ontario and the countless times that it has helped me and my family members. Nevertheless, I believe that it requires improvements and I believe that this is a common perception. While writing my dissertation I was interviewed by a University of Guelph magazine about my research and the journalist interviewing asked specific questions about what challenges caregivers experience, and what I believe can be done to improve their experiences, suggesting that she too was approaching the interview from a particular viewpoint.

Situating his discussion of expectations of the healthcare system within a medical ethics framework, Hafferty (2007) suggests that society expects that “doctors be available whenever needed and give priority to the interests of patients in front of them at all times” (p. 305). Yet, he
continues, the nature of the relationship between patients and physicians has changed over a generation. Indeed, one participant in this study mentioned that her father was a physician up until the 1990s and felt that during his time as a family physician he was much more available to his patients, often making house calls, compared to physicians today.

A number of caregivers also described empathizing with the healthcare professionals involved in their parent’s care, and expressed concerns that healthcare professionals’ well-being could be affected by the apparent overburdened nature of the Ontario healthcare system. I too empathize with healthcare professionals, and it was apparent to me that it was generally not individual healthcare professionals who were to blame for caregivers’ negative experiences with the healthcare system. Therefore, when interpreting caregivers’ accounts, I placed an emphasis on how the structure of the healthcare system might contribute to negative experiences. I elaborate on this discussion in the following chapter.
Chapter 9: Discussion

This study examined the experiences of filial caregivers in Southern Ontario during the period in which their parent transitioned from hospital to home. The analysis focused on how filial caregivers perceived the healthcare system, the ways in which they worked to support their parent’s well-being during the transition from hospital to home, and the challenges they encountered in doing so. The findings suggest that caregivers provide extensive support to their parents during the transition from hospital to home, yet they are not adequately supported in doing so. This is problematic because informal caregivers are increasingly being placed in a position in which they are obligated to assume greater responsibility for the care of their parents, but without access to appropriate knowledge and resources, patient well-being and caregiver well-being may be compromised. There is therefore a substantial need for greater emphasis on recognizing the role of informal caregivers in the healthcare system and on supporting them and their parents during the transition from hospital to home.

Recognizing the Knowledge Caregivers Possess about their Relative

Within some of the policy and academic literature, family caregivers are described as “partners in care” (Keating, Fast, Dosman & Eales, 2001). As partners in care, family caregivers are viewed as instrumental members of the healthcare team, comprised also of professional members (e.g., physicians, nurses, occupational therapists, personal support workers, etc.). Such a conceptualization underlies the movement toward person centred-care, which has been at the forefront of recent health care reform (Ministry of Health and Long-term Care, 2015; Registered Nurses’ Association of Ontario, 2015; Waterloo-Wellington LHIN, 2014).

Person-centred care is a holistic approach to the delivery of care and treatment in which there is a focus on the whole person, rather than the treatment of their disease alone (Van Royen
et al., 2010). Within this model, the goal of care is to be organized directly around the person in a way that respects their needs, preferences, values, beliefs, and the circumstances of their life and health (RNAO, 2015), and reflects diversity in patient experiences (MacKean, Thurston & Scott, 2005). Person-centred care acknowledges that the family is often a central component of the person’s life, so families (as the person defines them) are recognized as having key roles and as being decision makers within a patient’s care (Hughes, Bamford & May, 2008). Person centered-care redefines the relationship of the person with the healthcare system by promoting collaboration and partnership over paternalism, and thus conceptualizes patients and their family members as partners in care.

The socio-cultural trend away from paternalism in medical encounters has shifted an emphasis away from physician centric notions in providing care. In promoting this shift, one author has recommended that health care professionals should behave “with patients and families not as hosts in the care system, but as guests in their lives” (Berwick, 2009, p. 559). This shift has resulted in the emergence of not only the concept of person-centred care, but also other concepts such as patient-centred care and family-centred care. While these concepts differ in their precise definitions, all are characterized by similar content descriptions that 1) emphasize partnership between patients, caregivers, and healthcare providers, and 2) advocate for a greater recognition of an individual’s unique circumstances (Hughes, Bamford & May, 2008). Therefore, while a number of terms may be used within the medical field and within the academic literature, the terms generally endorse the same ideals.

The Institute for Patient and Family-Centred Care (n.d.), a not-for-profit organization that promotes the understanding and practice of patient-centred care, and whose definition of patient and family-centred care is widely cited within the policy literature, states that,
Patient and family-centred care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families…This perspective is based on the recognition that patients and families are essential allies for quality and safety—not only in direct care interactions, but also in quality improvement, safety initiatives and education of health professionals.

While partnership between healthcare professionals, patients and families appears to be a central tenet of person-centred care, the specific nature of this partnership is not well-defined (Constand, MacDermaid, Dal Bello-Haas & Law, 2014; Wolf, Moore, Lydahl, Naldemirci, Elam & Britten, 2017). Some authors have concluded that to conceptualize the relationship between formal healthcare providers and informal caregivers as a partnership is misleading because in true partnerships, the allocation of power, responsibilities and activities is equal (Ward-Griffin & McKeever, 2000). Within the context of caring for older relatives, it is often informal caregivers who provide the bulk of the care, from a subordinate position relative to formal care providers (e.g., physicians). Other authors, writing about patient and healthcare provider partnerships specifically, have suggested that institutional rules often limit the degree of influence patients can have over their own care (Norlyk & Harder, 2009). Therefore, while partnership models promote equality in relationships between healthcare providers, patients, and their families (Thoranrinsdottir & Kristjasson, 2014), questions arise about the possibility of positioning patients and their families as equal partners in care.

Caregivers participating in the current study described extensive involvement in their parent’s care, but had little opportunity for collaboration with healthcare providers. Many caregivers described having limited time to interact with healthcare professionals, and often were
unaware of who was responsible for particular aspects of their parent’s treatment. Additionally they described hospital discharges for which they were unprepared and in some cases they were given little advanced notice of their parent’s discharge from the hospital despite their necessary involvement. Furthermore, they described the development of discharge plans that included little proactive consultation with them about their own unique circumstances. They also noted that they often felt like they did not receive enough information about their parent’s health and treatment, and were not proactively consulted about their knowledge of their parent’s health. Such findings suggest that caregivers were not treated as equal partners in their relative’s care. However, the findings also suggest that it may not be realistic to position family caregivers as equal partners in care. Consistent with this notion of inherent inequality, caregivers often encountered challenges providing care to their relative owing to institutional policies and their own limited authority within institutional settings.

Such findings suggest that before promoting partnership models, a more nuanced understanding of caregivers’ roles and their relationships with healthcare providers, and with the healthcare system more generally, is necessary. This is particularly important given that person-centred care has had a strong influence on the development of policy in Ontario. For example, a central goal of Local Health Integrated Networks in Ontario is to create a healthcare system that is person-centred (Ministry of Health and Long-term Care, 2015; Waterloo-Wellington LHIN, 2014).

The current analysis suggests that one way in which caregivers would like to collaborate in partnership with healthcare professionals is by providing them with information about their relative, promoting a greater recognition of their unique circumstances. Much of the literature on the provision of information during the transition from hospital to home has focused on
deficiencies in the unidirectional flow of information from healthcare providers to family
caregivers (Bull, 1992; Bull & Jervis, 1997; Docherty et al., 2008; Driscoll, 2000; Dunbrack,
2005; Elliott, Forbes, Chesworth, Ceci, & Stolee, 2014; Graham, Ivey & Neuhauser, 2009;
Robinson, Pesut, & Bottorff, 2012; Shyu, 2000). As such, limited focus has been on the
information that caregivers provide to healthcare professionals. The analysis presented in
Chapter 7 suggests that caregivers possess important information about their relative that is not
always proactively integrated into the care and treatment of their parent. This is not to suggest
that caregivers were never consulted by healthcare providers during the transition from hospital
to home. Caregivers did describe instances where healthcare providers requested information
from caregivers about their parent’s medical history, and enlisted their assistance in the
rehabilitation process. In these circumstances, caregivers were drawn upon as informants and
assistants, ultimately being used as resources by healthcare professionals. Their knowledge about
their parent was therefore only recognized as healthcare professionals sought information they
deemed relevant for treating the patient (Ronch, 2004). Healthcare professionals may therefore
be missing important information about the patient that could be relevant for treatment.

The analysis also suggests, however, that caregivers actively worked to provide
information to healthcare providers to improve the quality of care that their parent received.
Caregivers had a sole focus on their parent’s health and care throughout the transition from
hospital to home, which as other authors have stated, is often not the case for healthcare
professionals who must provide assistance and treatment to many patients (Allen, 2000). Many
caregivers also described what has been termed “contextual sensitivity” (Vaartio, Leino-Kilpi,
Salantera & Suominen, 2006, p. 288), in that they possessed knowledge about their parent’s
unique situation that was sometimes overlooked by healthcare professionals. Due to perceptions
that the healthcare system was deteriorating and overburdened, and based on direct experiences of their parent “falling through the cracks”, caregivers felt it necessary to monitor their parent’s care and share information with healthcare professionals when they believed that their parent’s well-being was threatened.

Caregivers also actively worked to provide information that was different in nature from the information that was solicited by healthcare professionals, or information that they collected based on monitoring their parent’s care. Such information appeared to be accessible to caregivers because of their long-standing relationship with their parent, and intimate involvement in their care over time. This type of knowledge has been described in the literature as local knowledge (Harvath et al., 1994), and represents unique knowledge that caregivers possess about the care recipient. The information provided by caregivers may be just as important as information located within patient medical records (Mitnick, Leffler & Hood, 2010), and family caregivers may be in a position to better understand their relative’s needs due to their pre-existing relationship with their relative/patient (Hirsch, Forlizzi, Hyder, Goetz, Stroback & Jurtz, 2000; Wiles, 2003). The analysis supports this, with caregivers’ accounts suggesting that the local knowledge that they shared with healthcare providers contributed to improved care for their parent.

Although recognizing individual’s unique circumstances is promoted in the philosophy of person-centred care, healthcare professionals may not attribute as much value to the local knowledge held by family caregivers (Ward-Griffin, 2001). Rather, more general knowledge about illness and treatment, derived from education and experience may be emphasized (Allen, 2000). It is unclear why this is the case, though Edvardsson, Fetherstonhaugh and Nay (2010) explain that little empirical research has examined how person-centred care is understood by
various stakeholders, including healthcare professionals. Therefore, different stakeholders may give greater weight to different components of person-centred care. Consequently, tension and conflict can therefore arise between caregivers and healthcare professionals when both claim expertise over the needs of a patient (Levine & Zuckerman, 2000; Ronch, 2004).

While caregivers shared few instances of direct, hostile conflict with healthcare professionals, the analysis suggests that caregivers’ knowledge was excluded from formal information sharing practices. Caregivers described having to take the initiative to provide healthcare professionals with such information, sometimes having to set meetings with administrators before their concerns were heard. Further, some caregivers also worried that they would be negatively received by healthcare providers when they raised concerns about their parent’s care.

The findings suggest that greater emphasis needs to be placed on providing the opportunity for caregivers to share information about their relative in a formalized way. This is not to suggest that the local knowledge of caregivers should be given greater epistemic value over the more general knowledge and expertise of formal care providers. Rather, what is needed is an incorporation of both knowledge sources to provide optimal patient care (Harvath et al., 1994; Prior, 2003). Such an arrangement would promote greater collaboration among caregivers and healthcare providers, in a way that respects the contributions of both parties (Ciuffo, Hader & Holly, 2011).

**Supporting Family Caregivers**

As previously discussed, both person-centred care and family-centred care are characterized by common attributes. However, there is a particular difference that is relevant to the context of care in older age. When the inclusion of family is promoted in person-centred care,
it is often inclusion in the form of ensuring that they are recognized as members of the care team (Hughes, Bamford & May, 2008). The philosophy of family-centred care, as described within pediatric settings, also recognizes the family as playing a key role in their child’s care, but further emphasizes that caregivers too have needs that require attention (MacKean, Thurston & Scott, 2005; Shields, Pratt & Hunter, 2006). The findings from Chapters 6 and 7 suggest that this latter component may be a particular aspect of family-centred care that could be more widely emphasized when working with caregivers of older adults.

The analysis presented in Chapter 6 and Chapter 7 suggests that caregivers were intensely involved in supporting their relative both in the hospital and in the home. Participants described being largely responsible for assisting their parent with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), but they often encountered challenges that threatened both their parent’s well-being and their own well-being. These findings suggest that caregivers are placed in a position where they are expected to perform particular activities to support their parent’s well-being, but do not have the necessary support to do so.

Involvement in direct care work. Caregivers who participated in this study described extensive involvement in the care of their parent, through assisting them with ADLs and IADLs. Such assistance was not limited to the homecare environment, with many caregivers describing the provision of assistance during the period that their parent was hospitalized as well. Within the transitional care literature, the activities that family caregivers engage in within the hospital are often not extensively examined, with a large focus often being on the period initiated with discharge from hospital. However, given that transitions, as characterized by Schumacher, Jones and Meleis’ (1999) theory of transitions, begin with an event that brings about upheaval, the
period of hospitalization is important to investigate and thus this study provides a deeper understanding of filial caregiver experiences during the transition from hospital to home.

While caregivers often expected that healthcare professionals would largely be responsible for assisting their parent with ADLs, through monitoring their parent’s care, participants judged assistance to be inadequate and subsequently their expectations about who would provide care were shifted. In a seminal report on the future of the Canadian healthcare system, Romanov (2002) explains that as healthcare provider workload increases, responsiveness to patients and their families decreases. The work loads of hospital nurses, for example, have increased because nurses have been required to assume duties of administrative and support staff following cut-backs in these positions. This has meant that nurses have less time available to provide direct personal care to patients.

Yet as caregivers explained, this type of care is still important. Caregivers described instances where their parent developed infections because personal care, such as bathing, was not provided in a timely manner. They therefore were often obligated to assume responsibility for these activities themselves, but frequently met challenges in supporting their parent because they often did not have the necessary authority, skills, or resources that such assistance required.

These findings suggest that greater emphasis needs to be placed on understanding what caregivers can reasonably be expected to do. Within the nursing literature, Ward-Griffin and McKeever (2000) have stated that expecting family caregivers to provide care to their relatives without the necessary resources and authority is unacceptable and raises ethical concerns. They caution that failure to provide caregivers with the resources necessary for the tasks that they are expected to provide risks both patient and caregiver health, and subsequently can result in greater healthcare costs.
Conducting caregiver assessments may be an important first step in supporting caregivers. Caregiver assessments are tools and procedures used to understand caregiver needs, and sometimes their risk for adverse outcomes (The Change Foundation, 2016b). Through such assessments healthcare professionals could determine the tasks that caregivers are capable and comfortable performing, and whether the resources that are required are readily available and accessible (Given, Sherwood, Given & Webb, 2008). Such assessments are not used for the purposes of identifying deficits among caregivers, but rather to determine what kind and level of support would be beneficial.

Findings from an Ontario based study involving an in-depth examination of the needs of family caregivers of older hip fracture patients support this recommendation. Caregivers participating in this study expressed that they wanted healthcare providers to recognize that each family had a unique situation, focusing on assessing their strengths and weaknesses (e.g., understanding of medical language, medical skill sets, health system understanding, comfort levels, and family dynamics) (Giosa et al., 2014). Such assessment would allow for the identification of caregiver capacity to provide care.

Numerous caregiver assessment tools exist, but as the Change Foundation (2016b) has stated, these tools are rarely used in practice because little time is devoted to caregiver assessment, and healthcare providers often feel unprepared to conduct them. Yet because caregivers are instrumentally involved in the care of their older relatives, and because caregivers are struggling to support their parents, greater recognition of their unique circumstances needs to be emphasized across care environments. As discussed, the analysis suggested that caregivers did not always have the authority or resources to support their relative. Therefore, assessment tools must be developed in a way that recognize the organizational context, and emphasize that there
may be some tasks that caregivers cannot reasonably be expected to perform due to their subordinate position in the healthcare system.

Caregiver assessment can only ever be a first step in supporting caregivers. Strategies must also be developed to assist caregivers when assessments indicate that they do not have the capacity to provide care, or are at risk for detrimental outcomes. This may pose some challenges for the current healthcare system. Should an assessment indicate, for example, that a caregiver requires greater respite, but they are already provided with the service maximum, questions may arise about what can reasonably be done to support the caregiver. Although a simple answer does not exist, working to address system level issues that limit the usefulness of respite services could be an important avenue of change. I return to this point in the following section.

Providing respite to family caregivers. Within the caregiving literature, family caregivers are often described as advocates for their older relatives. While findings from the current study similarly suggests that caregivers advocated on behalf of their parents, caregivers who participated also described advocating for themselves in an attempt to secure respite services that would allow them to maintain their own well-being. Some caregivers engaged in self-advocacy which involved educating others, such as CCAC Care Coordinators and PSW managers, about their needs and persuading them to grant access to respite services. Caregivers’ accounts suggested that their needs were not fully considered in the allocation of formal services so there was therefore an onus on caregivers to communicate their needs to those in positions of authority.

Self-advocacy has not been previously identified as a caregiver activity in the literature on family caregiver experiences during the transition from hospital to home in Ontario. For example, while Byrne and colleagues (2011) suggest that spousal caregivers in Ontario advocate
for their spouses to ensure their well-being, advocating for resources to support their own needs was not discussed. Future research should examine experiences of self-advocacy among all family caregivers to provide a deeper understanding of the activities engaged in by family caregivers during the transition from hospital to home.

The apparent necessity of self-advocacy suggests that filial caregivers are often not supported in their role. Just as the current findings suggest, the theory of transitions (Schumacher et al., 1999), also emphasizes the importance of recognizing the needs of family caregivers given that a transition in the life of an older adult (e.g., the transition from hospital to home) often precipitates a simultaneous transition in the lives of their families. Subsequently it is important that filial caregivers’ own needs are recognized and that they are supported during the transition from hospital to home.

Researchers have long maintained that caregivers of older adults experience poorer physical and psychological health compared to non-caregivers (Pinquart & Sorensen, 2003, Wiles, 2003). Three participants in the current study classified their own health as “fair” and an additional participant classified her health as “poor”. Yet, despite their own ill health, they continued to provide extensive support to their parent. These caregivers described difficulty finding time to attend to their own needs, and care plans did not appear to take into account their own ill health. Others who described their health as “very good” expressed concerns about becoming socially isolated or burning out should the demands of caring for their parent become too great. Some participants were also much younger than has typically been described in the literature. Three participants were in their early to mid 20s and enrolled in school at the same time they were providing care to their parent (or in the case of one participant, a grandparent). Two of these participants were balancing school and caring for their parent along with part-time
work, and expressed worries that they would not be able to manage should their parent continue to require extensive support.

Structural arrangements within the Ontario healthcare system may be implicated in the lack of support that caregivers received. Scholars have argued that the experiences of caregivers can only be understood by situating their accounts within the broader institutional environments and systems that govern access to resources (Allen, 2000; Wiles, 2003). Findings from a British Columbia based study suggest that within the homecare environment, formal (i.e., personal support workers) and informal (i.e., family caregivers) systems are interconnected (Sims-Gould and Martin-Matthews, 2010). The current analysis supports this assertion. Even when services were in place to provide caregivers with respite, caregivers’ accounts suggested that respite hours were often interrupted by the schedules and behaviours of personal support workers. Caregivers within this study spoke of high turnover among personal support workers and inconsistency in workers from day to day. As a result, caregivers’ respite time was often interrupted by the necessity of orienting new personal support workers to the home environment, and making them aware of their parent’s needs and preferences. These findings support those of other studies which identified a key role of family caregivers as care managers (Rosenthal, Martin-Matthews & Keefe, 2007; Sims-Gould & Martin-Matthews, 2010a) and suggest that family caregivers are detrimentally affected by worker turnover, inconsistencies in workers from day to day, and worker scheduling (Martin-Matthews & Sims-Gould, 2008; Sims-Gould & Martin-Matthews, 2010a).

Personal support workers are employed under precarious working conditions, with many working on a part-time or contractual basis, receiving low wages (Kelly & Bourgeault, 2015; Lum, Sladek & Ying, 2010), and there is high worker turnover within the personal support
worker profession (Wiles, 2003). This employment landscape may in part contribute to the problems identified by caregivers participating in the current study. While it may not be possible to restructure all these features of the home care environment due to current fiscal and other constraints, clients and families may experience decreased stress associated with inconsistent home care schedules if they are consistently kept informed about changes to scheduling (Byrne, Sims-Gould, Frazee & Martin-Matthews, 2011). Such an arrangement would help to manage the expectations of family caregivers, and value them as members of their parent’s care team. However, it is also important to address system level issues related to the precarious nature of personal support worker’s employment landscape. Conversations at the level of provincial government are currently taking place that may inform strategies for improving the nature of personal support worker’s employment conditions (Kelly & Bourgeault, 2015).

Organizations such as CARP (formerly known as the Canadian Association for Retired Persons) consistently engage in a politicized form of advocacy (i.e., campaigns) on behalf of caregivers of older adults, asserting that caregivers require more support in the form of respite. The current analysis supports the need for continued organized efforts. While participants engaged in self-advocacy to secure additional respite services, and their efforts were often successful, a wider system level focus on the needs of caregivers is necessary. This is particularly important if the healthcare system is built upon a reliance on family caregivers to support their older relatives. Therefore, in promoting greater support for family caregivers, examinations of the context of formal caregiving is also necessary.

**Implications for policy.** The analysis presented in Chapter 6 and Chapter 7 suggested that filial caregivers were extensively involved in supporting their parents both in the hospital and in the home. Sims-Gould and Martin-Matthews (2010b) argue that findings such as these are
important from a policy perspective because they emphasize the critical role that family members play within the healthcare system. Consequently they argue that, “policy designed to support family caregivers is intimately tied to home care policy. Comprehensive caregivers support policy must be inclusive of home care policy and vice versa” (p. 422). The Canadian Medical Association (2016) views caregivers as instrumental within the healthcare system and similarly states that the health of caregivers must be considered when designing any policies related to the care of older adults. Therefore, although policies such as Aging in Place offer many advantages, implications for caregivers must be fully considered (Williams et al., 2009). Aging in Place is often associated with promoting independence among older adults by helping them to remain in their homes or communities; yet, this independence may only be possible through the assistance of family members (Minkler, 1996; Wiles, Leibing, Guberman, Reeve, & Allen, 2011).

Research also suggests that there is variability in the way that homecare services are assigned in Ontario based on the discretion of case managers, which suggests that in practice, homecare policy may actually be created “from the ground up” (Peckman, Williams & Neysmith, 2014, p. 133). Peckman, Williams and Neysmith conducted a balance of care simulation in which vignettes were presented to 16 case managers employed by the CCAC. The vignettes varied based on the needs of the care recipient and the presence of an informal caregiver. Case managers were asked to assign services based on the content of the vignettes. Results of the simulation demonstrated that when an informal caregiver was present, case managers were likely to assign fewer hours of service, suggesting that caregivers were expected to make a contribution to care. The authors conclude that such an arrangement, where case managers use discretion about service provision, may provide advantages such as creating space
for more individualized care plans, but they also caution that it limits accountability and the extent to which decisions can be contested by patients and their families. The analysis presented in the current dissertation suggests that caregivers were largely successful in contesting decisions, but this meant the onus was largely on caregivers to secure services, and as noted in the analysis, advocating was not always something that caregivers realized they would have to do. Therefore, in finding ways to support caregivers it may be necessary to view caregivers as individuals who may require support as well.

**The Importance of Advocating**

Descriptions of situations in which caregivers advocated on behalf of their parents were prevalent in caregivers’ accounts. Caregivers described advocating for their parents both while their parent was hospitalized, and in the homecare environment. Scholars have argued that advocacy is a necessity within the current healthcare system (Haw, 2007; Levine et al., 2004), and my analysis supports such an assertion. Caregivers described advocating for a number of reasons which have not previously been identified in the literature. This study therefore contributes to the scholarship on patient advocacy in new ways.

**Preventing adverse health outcomes.** One of the main reasons that caregivers described advocating for their parent was because they perceived the healthcare system to be functioning with limited resources, and as a result their parent would not receive appropriate care. Specifically, they described worrying that their parent would be forgotten or that important aspects of their care would be overlooked, and therefore advocated in a proactive manner to ensure that their parent received the attention of healthcare providers. They also described instances in which their parent’s care had been overlooked or preventable adverse health events had occurred, which suggests that their concerns were often warranted. Independent research
has also found that when healthcare resources are limited, patient care can be compromised. A meta-analysis of studies documenting the relationship between the staffing level of registered nurses in hospitals and patient outcomes demonstrated that when there was a greater number of nursing staff, the risk of in-hospital patient mortality was decreased. Additionally, when hospitals had lower nurse-to-patient ratios, there was lower risk of adverse patient events such as hospital acquired infections (Kane, Shamliyan, Mueller, Duval & Wilt, 2007).

Returning to the notion of person (or patient or family)-centred care, the Institute for Patient and Family-Centred Care notes that one of the core concepts of patient and family-centred care is participation. This means that “patients and families are encouraged and supported in participating in care and decision-making at the level they choose” (emphasis added). While the current analysis suggests that caregivers wanted their input to be recognized and valued, and that they were involved in participating in their parent’s care to a considerable extent, it must be acknowledged that not all caregivers will desire extensive involvement in the care of their relative, and that some caregivers may experience difficulties doing so. Writing within the context of parents caring for children with developmental disabilities, MacKean, Thurston and Scott (2005) emphasized collaboration between healthcare providers and family members as a key principle in person-centred care. Through interviewing parents about their involvement in their child’s care the authors found that collaboration was not realized in practice and instead there was a “devolution of responsibility” (p. 81) from healthcare professionals to family members for the care and safety of their child. Rather than being consulted about the desired level of involvement in their child’s care, they instead felt that they had no choice but to take on responsibility to advocate for their child.
Returning to a discussion of partnership in person-centred care, in positioning patients and caregivers as partners in care, caregivers are implicitly required to assume the role of patient advocate (Bleakley, 2014). With the promotion of person-centred care within healthcare systems, patients and caregivers are expected to voice their concerns and preferences surrounding patient safety and healthcare quality, even when they may not be capable or interested in doing so (Gilleard & Higgs, 1998). As part of a partnership model, to a degree, families are relied upon to protect patients through monitoring safety and well-being (Rathert, Brandt & Williams, 2011), and caregivers may therefore feel a responsibility for monitoring their relative’s care (Hurst, 2001). The World Health Organization (2013) questions whether placing responsibility for safety on individuals when they are vulnerable is ethical. Additionally, some authors have argued that when caregivers monitor their relative’s care due to low expectations that appropriate care will be provided by healthcare providers because of limited resources, caregivers have little choice about the level of their involvement in their relative’s care (Boise & White, 2004; Shields, 2009; Thorarinsdottir & Kristjansson, 2014).

Caregivers in the current study described visiting their parent in the hospital each day, and spending time with them after they were discharged. Although this served as an opportunity to provide intentional emotional support, caregivers also described this as a way to monitor their parent’s care. They discussed the necessity of being vigilant and watchful, and noted that they often made evaluative judgments about the care their parent was receiving. When they observed inadequate care they advocated for improvements, and sometimes worked in a preventive capacity to make sure problems did not occur. Participants did not mention a disinclination for these practices; however, they did encounter barriers that limited their capacity to monitor and evaluate their parent’s care. I return to this point again below.
**Equitable access to health care.** Advocating because their parent was unable to participate in their own healthcare was also prominently described by participants. The implications of such an arrangement are important to consider because these findings suggest that older patients, or patients without someone to advocate on their behalf may not have equitable access to healthcare.

The Ontario Ministry of Health and Long-Term Care (2015) has identified health equity as a key provincial priority, and equity is often cited as a key characteristic of high quality health care systems (Health Quality Ontario, 2015a). Health Quality Ontario (n.d.), states that “health equity allows people to reach their full health potential and receive high-quality care that is fair and appropriate to them and their needs, no matter where they live, what they have or who they are” (p. 7). This definition recognizes that some people may need more resources or services to be healthy, and subsequently means that people are able to receive care that is fair and appropriate to them.

Related to health equity, health care equity refers to the health care system’s ability to provide appropriate and timely care (Health Quality Ontario, n.d.). The prevalence of advocating within caregiver’s accounts suggests that the principle of health care equity is not being realized in practice. Judging from caregiver’s accounts, appropriate and timely care was only obtained when caregivers interceded to advocate for their parent’s needs. Inequitable access to healthcare can be a consequence of situations where some patients have an individual to advocate on their behalf for services that another patient may subsequently not receive (O’Reilly, Tierney, Remfry & Petch, 2015).

In both Canada and the United States, a number of private companies have emerged that provide professional patient advocate services (Integrity Healthcare Consultants, 2015).
Professional patient advocates are generally individuals who have previously been employed in the healthcare field, and who work for individuals and their families, providing a consistent presence as they move through the healthcare system. While the services offered may vary depending on the company, they generally include conducting research, coordinating services, attending meetings with healthcare providers, and reviewing medical files (Katsarov, 2017). They are distinguishable from hospital patient advocates in that they are employed by the patient and their family, rather than by a hospital, and will provide services regardless of where care is offered (Integrity Healthcare Consultants, 2015).

Although the role of private patient advocate has received little attention within the academic literature, a number of physicians and educators have expressed concerns about the further healthcare inequities that the presence of private patient advocates could create (Integrity Healthcare Consultants, 2015; McKinney, 2011). Fees associated with the services offered by private patient advocates may restrict access to only those who are able to afford such services (O’Reilly, Tierney, Remfry & Petch, 2015). Further, concerns around the emergence of patient advocacy companies have been expressed grounded within the argument that the very existence of such companies suggest that the Canadian healthcare system is in effect “broken” (Integrity Healthcare Consultants, 2015, no page number). Specifically, when advocating for patients becomes a necessity, it implies that the healthcare system is too complex for patients and their families to navigate on their own.

These recent trends, coupled with the findings from the present study suggest that any proposals to address healthcare equity in Ontario need to acknowledge the conditions that lead to the need for patient advocacy in the first place. Although such conditions are likely associated with limited resources, it could also be that the promotion of person-centred care requires
caregivers to assume the role of patient advocate (Bleakley, 2014). Some researchers have suggested that policy makers view partnership models as desirable because they promote cost containment by placing greater responsibility on informal caregivers to be involved in their relative’s care (Keating, Fast, Dosman & Eales, 2001). Therefore, the implications of the promotion of partnership models warrant further consideration.

Although further research on the relationship between patient advocacy and person-centred care is necessary, promoting change within the healthcare system will take organized efforts, and caregivers interested in advancing change may be well positioned to engage in such efforts. Levitsky (2014) describes the politicization of caregivers whereby they “(1) come to view longstanding ‘private’ needs or interests as matters of legitimate public deliberation and decision making, (2) imagine solutions to their unmet needs or interests, and (3) make claims to an official agency or other perceived responsible party for action”. Some caregivers, frustrated by their experiences with the healthcare system, thus engage in highly visible forms of social and political action through the formation of advocacy groups and making demands of those in positions of authority. As described in Chapter 7, a number of caregivers mentioned that their main motivation for participating in the study was so that their concerns would be heard by those in positions of authority in the healthcare system. While this may not meet the criteria for politicization, it emphasizes that when seeking to address system level issues, caregivers are a key group of stakeholders that should be consulted.

**Barriers to advocacy.** The analysis suggests that there were a number of barriers that caregivers encountered or identified when advocating on behalf of their parents. These barriers included access to information about the patient, discomfort challenging healthcare professionals, and linguistic barriers. These barriers often limited the ways that caregivers could
participate in their parent’s care. As discussed in the previous section, it is important to identify and address system level issues that lead to the necessity of advocating; yet, it is also important to recognize that even within a perfect healthcare system, there could still be human errors that would require the involvement of caregivers and patients to identify and remedy. Therefore, because the healthcare system may always require the participation of patients and caregivers, and because patients and caregivers may desire some form of participation, it is important that barriers that prevent their involvement are removed, or at least addressed. In the following sections I discuss each of the identified barriers, and propose preliminary solutions to address them.

In offering solutions to remove the barriers to advocating within the healthcare system, I am not suggesting there should be a downgrading of responsibility to caregivers for the safety of their relative. Rather, I am suggesting that continuous work needs to take place to address system level issues that lead to the necessity of advocacy, while also creating clear pathways for caregivers to participate in the care of their relative when they want to, and when situations arise that warrant caregiver intervention.

Access to information. The analysis presented in Chapter 7 suggested that possessing information about their parent’s care was an important antecedent to successful advocacy. Other scholars have argued that good advocates must be both informed and intimately involved in the situation that they represent (Blancato, 2004), and becoming educated helps caregivers to influence the healthcare system (Wuest, 2000). Yet, the analysis suggests that caregivers were not always provided with important information that would assist them in advocating for their parent. Caregivers often noted that there were deficiencies in the provision of information about their parent’s health and treatment. They described requiring this information so that they could
evaluate their parent’s needs and necessity of medical intervention. Identifying patient needs has been described as a first step in patient advocacy (Huber, Nelson, Netting & Borders, 2008) but when caregivers were hindered by a lack of information, they actively worked to overcome these deficiencies by persistently asking questions of healthcare providers.

Therefore, it appeared that the onus was generally on caregivers to collect information, as it was often not provided proactively by healthcare professionals. Studies in both the United States and Ontario have identified a similar arrangement, whereby caregivers have described the necessity of taking initiative to communicate with healthcare professionals (Bull & Jervis, 1997; Foust, Vukovic & Henriquez, 2012; Glenny et al., 2013; Graham et al., 2009). Glenny and colleagues (2013) caution that there are problems associated with placing the onus on caregivers to seek information from healthcare professionals. Apart from the frustration expressed by caregivers with such an approach, the informational needs of some caregivers may change over time (Cameron, Naglie, Silver & Gignac, 2013), they may not be aware of the information they require throughout a care transition, and may only realize that they are missing crucial information as time progresses (Byrne et al., 2011; Ghazzawi, Kuziemsly & O’Sullivan, 2016). Further, the current analysis suggests that caregivers often had insufficient time to spend with healthcare professionals, and sometimes had difficulty contacting healthcare professionals, particularly when they were employed full-time, which could further diminish their ability to obtain information.

Particularly within the homecare environment, a number of caregivers noted that they also had difficulty determining who was responsible for their parent’s formal care, and the analysis suggests that this compromised their ability to advocate. From the perspective of family caregivers, the Ontario healthcare system has been described as confusing (Wiles, 2003), and
many caregivers participating in the current study similarly described difficulties understanding the organization of the healthcare system. Other authors have noted that advocating involves working to influence those in positions of authority. Those with authority are individuals “who can make choices about who gets care, who qualifies for services, and how services are delivered” (Huber, Nelson, Netting & Borders, 2008, p. 5). Advocating necessarily involved a target, but it often took a considerable time commitment for caregivers to be able to identify those in positions of authority who could rectify situations that caregivers felt were detrimentally affecting their parent’s wellbeing.

Researchers have suggested that involving family caregivers in healthcare team meetings is a promising practice to facilitate information sharing between healthcare providers and caregivers (Glenn et al., 2013). Not only would such meetings enable access to information, they would also provide direct access to healthcare providers, thus helping caregivers to identify those in positions of authority. Such meetings would need to take into account the schedules of filial caregivers, particularly to ensure that participation in these meetings would not require additional time off from work. Additionally, it must also be acknowledged that some caregivers may not want to participate in such meetings, so their decision to decline participation should also be respected.

Although this section has concentrated on the importance of providing caregivers with information, and as described in Chapter 7 many participants explained how collecting information was instrumental to their ability to support their parent, another perspective is important to recognize. Specifically, there can be challenges associated with retaining and understanding the information that is provided, and collecting information may not always be beneficial.
Some of the participants in the present study described having difficulty remembering the information that was provided to them by healthcare professionals. Similarly, findings from studies in the United States and Ontario suggest that when information is provided, caregivers may have difficulty remembering it, and may also misinterpret the information (Foust, Vukovic & Henriquez, 2012; Giosa et al., 2014). Furthermore, some caregivers also described conducting their own independent research. Participants generally viewed this activity as a useful way of collecting information, but there can be detrimental consequences associated with seeking health information. For example, among individuals with high health anxiety, searching for health information on the internet can be a distressing experience associated with increased anxiety (Muse, McManus, Leung, Meghreblian, & Williams, 2012). Although similar research has not been conducted with caregivers of older adults, it is reasonable to expect that searching for information could also be associated with distress among caregivers with high health anxiety.

Discomfort challenging healthcare professionals. My analysis suggests that the main goal of advocating was to influence change that would ensure the safety and well-being of participants’ parents. Caregivers often did not have the authority, abilities or resources to produce direct change themselves, so they brought their concerns to the attention of individuals who had the power to change the situation. Advocating therefore involved the assertive communication of concerns to healthcare professionals.

However, the analysis presented in Chapter 7 suggests that some caregivers expressed discomfort engaging in such communication with those in positions of authority. Scholars have maintained that families are often located within subordinate positions relative healthcare professionals (Haw, 2007; Hewitt, 2001; Huber, Nelson, Netting & Borders, 2008; Wuest & Stern, 1990). Indeed, issues of power and inequality between patients and healthcare providers
are central to examinations of advocacy (Hewitt, 2001), and it is necessary to understand whether patients and their caregivers are positioned to successfully challenge medical authority.

Research suggests that the ability to be assertive with healthcare professionals likely develops over time, and after needs are repeatedly unmet (Wuest & Stern, 1990; Wuest, 2000). The inability to behave assertively with healthcare may therefore be a barrier to caregivers who are new to their role or who have had limited interaction with healthcare professionals. While some caregivers assertively ask questions of their relative’s formal care providers, others may be more hesitant, particularly when they perceive care providers to be too busy or when their interactions have been unsatisfactory in the past (Dunbrack, 2005).

Further, some researchers have examined the reasons why some patients may be hesitant to question their physicians, even when institutional policies allow and even encourage patients to participate in this way (e.g., the promotion of person-centred care). Findings from focus groups with a highly educated and affluent group of patients suggest that for some patients, behaving assertively within clinical encounters could run the risk of being labelled difficult, and could thus negatively affect the physician-patient relationship (Frosch, May, Rendle, Tietbohl & Elwyn, 2012). Patients participating in the focus groups worried that should they be labelled as difficult, their quality of care would decline. Presumably, such findings could also apply to caregivers, with concerns around the quality of care that would be offered to their relative. Frosch and colleagues conclude that there are widely held societal views about patient participation in care that may disincline patients to challenge medical authority. Additionally, they suggest that many physicians believe that they are behaving in ways that promote patient involvement, yet as the findings indicate, patients do not share this perception.
Therefore, it is important that future research examines where there may be misalignment in the perceptions of patients, caregivers, and healthcare professionals regarding patient or caregiver participation in healthcare. While some researchers suggest that nurses, for example, may knowingly act as gatekeepers, preventing access to physicians (May, Ellis-Hill & Payne, 2001), it could also be that those in positions of power are not aware that their actions, or the organizational culture norms which govern their actions (e.g., regarding language, group boundaries, power dimensions, relationships) are preventing patients and families from engaging with healthcare providers (Huber, Nelson, Netting & Borders, 2008). Research could make explicit the ways that organizational culture norms may prevent caregivers from engaging with healthcare providers. Findings could then be incorporated into medical training so that these norms are made explicit and healthcare providers could work to challenge these norms in their everyday practice (Frosch et al., 2012).

**Linguistic barriers.** A number of participants expressed concerns about caregivers who may not have the same resources or abilities that they did that allowed them to successfully advocate. All caregivers who I interviewed were fluent in English, and all described successfully securing the desired resources to meet their parent’s needs. Despite expressing initial discomfort challenging institutional arrangements through advocating, being able to communicate in English was an important advantage for these caregivers.

If advocacy is a necessary antecedent to securing additional resources and ensuring patient safety, then those caregivers who do not speak English may not be able to understand the information or communicate their concerns to healthcare professionals, subsequently diminishing their ability to advocate for a parent. Indeed, during the transition from hospital to home caregivers who do not speak English have been described as facing particular challenges...
accessing appropriate information and services (Graham et al., 2009). Ways to overcome linguistic barriers in the provision of information could include the development of strong partnerships between ethnically and linguistically diverse community-based organizations and health care organizations. The development of partnerships could provide readily accessible translation services and could assist in the development of written health care information available in a variety of languages.

However, such a solution will take dedicated staff efforts and substantial resources. The development of partnerships requires “frequent meetings; clear roles and responsibilities; human resources, time, locations, costs and available technology; and agreement on project management tools and strategies” (Saint Elizabeth, 2013, p. 21). Furthermore, successful partnerships require a shared purpose, focused on achieving collective outcomes, and require strong staff buy-in (Compassion Capital Fund, 2010). Therefore, substantial groundwork is necessary to implement such a solution.

**Strengths and Limitations**

A strength of the current study was the qualitative approach that allowed for a detailed examination of caregivers’ experiences during the transition from hospital to home. Policy makers and organizations involved in the formal care of older adults have called for the input of family caregivers who have been traditionally underrepresented in conversations about long-term care (Expert Group on Home and Community Care, 2015; Health Quality Ontario, 2015b). Therefore, this study contributes to the conversation and provides findings that could be valuable as policy makers and government seek to change structural components of the healthcare system that will improve patient outcomes and support family caregivers.
The sample for this study was composed strictly of filial caregivers, who are the largest group of caregivers of older adults in Canada, and as research suggests, may experience caregiving differently than other groups of caregivers, such as those caring for spouses (Byrne et al., 2011). Therefore, a focus on their experiences contributes to the literature on caregiving by allowing for identification of issues that may be specific to this group of caregivers.

Specifically, participants described a role reversal which is unique to the filial caregiver experience (Bastawrous, Gignac, Kapral & Cameron, 2015). Filial caregivers suggested that while their parents had supported them throughout their own lives, during the transition from hospital to home, they assumed this role to support their parents particularly through the act of advocating. Additionally, as mentioned, filial caregivers described engaging in self-advocacy to bring their own needs to the attention of those with the authority to provide respite services. Finally, caregivers also described contextual factors within their own lives limited their ability to support their parents. Specifically, they noted that they experienced challenges navigating the complexity of the Ontario healthcare system because particular aspects required that they take time off from work, or because the service hours of healthcare facilities did not align with their own scheduling needs. Consequently, their own unique needs and contexts should be taken into account when treatment plans are developed.

Further, though the sample was relatively small, it was also diverse. Participants reported that their parents were hospitalized for a number of differing reasons, and the complexity of the care they required varied. Additionally, there was diversity in the educational background, employment status, income level, health, and age of participants. While the sample was mainly composed of women, this further illustrates the gendered nature of informal caregiving as the literature suggests that it is often daughters who provide care to their parents (Brody, 2004).
Across this diverse sample, all caregivers expressed challenges caring for their parent and all mentioned instances where they advocated for their parent.

This study also has some limitations that require consideration. Care recipients were not interviewed over the course of this study. Their perspectives would have likely yielded useful insights about the transition from hospital to home, and the ways that patients and caregivers may work together. Research suggests that during the transition from hospital to home, patients and their filial caregivers may collaborate to overcome deficiencies in care from healthcare providers (Bull & Jervis, 1997). Future research could specifically examine the ways in which care recipients are implicated in the process of advocacy given that the current analysis suggested that it may sometimes be a collaborative effort between patient and caregiver.

Another limitation is that while the study included the perspectives of a small number of CCAC Care Coordinators about the topics raised by caregivers, other formal care provider groups such as physicians, nurses, and personal support workers were not represented in the data set. Therefore, their perspectives about interactions with caregivers during the transition from hospital to home were excluded. Future research that examines their perspectives about interactions with caregivers could be a useful avenue to pursue, given that they were closely implicated in caregivers’ accounts.

Additionally, while caregivers’ accounts suggested that there were structural conditions that compromised their ability to support their parents, a direct examination of institutional arrangements was not conducted. Therefore, future research should examine the ways in which institutional arrangements may detrimentally affect caregivers and patients. It is likely that those individuals who have power to produce change may not be aware of the ways that organizational norms and procedures that govern their actions may detrimentally affect patients and their
caregivers (Huber, Nelson, Netting & Borders, 2008). As such, institutional ethnographies offer a useful way of examining institutional practices. Institutional ethnographies involve in-depth examination of institutional practices as they are carried out by workers and seek to identify standardized organizational practices that may compromise client and patient safety (Liberati, Gorli, Moja, Galuppo, Ripamonti & Scaratti, 2015). When utilizing institutional ethnography methodology researchers engage in field work within the chosen institution, observe workers as they engage with clients (or patients) as they perform their daily tasks, interview clients and workers, and record interactions between workers and between workers and clients (Rankin, 2014).

One institutional ethnography conducted in Canada has already generated important insights into the ways that institutional practices that govern the work of nurses can compromise patient well-being. Rankin (2014) observed Peggy and her daughter Laura (caregiver) over Peggy’s month long hospitalization in an Alberta hospital following a radical neck dissection associated with oral cancer, and documented structural conditions that threatened Peggy’s well-being. For example, as part of their daily routine nurses were required to input data about each patient into a standardized form located within a computer software program. While the intention of this work was to enhance decision making related to patient discharge, Rankin observed that many of the issues that Peggy was experiencing were not appropriately captured by the standardized form. As a consequence, on paper, Peggy appeared to be approaching a health status that would make her ready for discharge from the hospital, but observations made by her daughter suggested that there were other components of her health that suggested she still required extensive formal care. This caused conflict between the nurses and Laura who disagreed about Peggy’s readiness for discharge. While the nurses’ work was aligned with clearing beds
(as informed by the computer program), it was clear that Peggy’s needs and the needs of her daughter were not being met.

While the study provided an individualized account, the lessons learned from the case study suggest more general issues that were documented through the process of the institutional ethnography. Through following Peggy and Laura, the authors identified issues with organizational routines that could also influence how other patients are cared for, and suggest the need to critically examine the processes that govern the work of healthcare professionals.

**Conclusions**

This dissertation provides insights into the role of filial caregivers during the transition from hospital to home; a period during which patients and their families may be vulnerable. Caregivers reported being intensely involved in their parent’s care both in the hospital, and after discharge, and also reported a number of challenges that they encountered while attempting to support their parent. The findings suggest that greater attention needs to be paid to recognizing the role of caregivers and supporting them in the activities that they perform to maintain the health and well-being of their parent, as well as ensuring that their own well-being is not threatened.

Ultimately, consideration needs to be given to what caregivers can reasonably be expected to do given the structural conditions under which they provide support. Additionally, as the provincial healthcare system moves toward a model of person-centred care, it is important to ensure that collaboration between healthcare providers and caregivers takes place in a way that recognizes the contributions of caregivers, while also ensuring that they are not unduly relied upon to protect patient safety and well-being when they are not equipped to do so.
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Appendix A: Ethics Approval Certificates

TRI-HOSPITAL RESEARCH ETHICS BOARD (THREB)
(A shared service for Cambridge Memorial Hospital, Grand River Hospital and St. Mary's General Hospital)
Grand River Hospital, Rm. K501, Kaufman Building, 835 King Street West, Kitchener, Ontario, N2G 1G3
Tel: (519) 749-4000 ext. 5267 Fax: (519) 749-4274

February 3, 2016

CERTIFICATE OF APPROVAL
THREB #2015-0582

Mr. Nael Abumustafa
C/o Kara Stroud
29 Lowes Road W.
Guelph, ON
N1G 4X2

Dear Mr. Abumustafa,

THREB# 2015-0582: The Needs and Skills of Filial Caregivers during the Transition of Older Adults from Hospital to Home, Version 1, December 7, 2015.

GRH

Study Identification Number: THREB #2015-0582

1. THREB Application for Review received December 09, 2015. Revised version date February 1, 2016.
2. Administrative approval received December 09, 2015 GRH
4. Consent to Participate Form: (Caregivers) Version Date: November 11, 2015. Consent to Participate and Description of the Research, Potential Discomforts or Inconvenience. Study Results, Research Ethics Board Contact, The Needs and Skills of Filial Caregivers during the Transition of Older Adults from Hospital to Home. Signature page. Revised version date February 1, 2016.
8. Survey and Interview Protocols: Care Coordinator Interview Questions

Initial Approval Date: February 3, 2016
Anniversary Date for Renewal: January 06, 2017

Thank you for your application requesting approval of the above research study. Members of the Tri-Hospital Research Ethics Board (THREB) reviewed your
application at the January 06, 2016 meeting and approved the study with some conditions. Those conditions have now been met and you have final THREB approval for the study. The study is to be reviewed in one year, before the next “Anniversary Date.”

Approval is granted to conduct the research project in accordance with the above protocol.

Requirements for ongoing approval include:

a. Annual progress reports for review and continued approval of the study by THREB;
b. Submission of any changes in the protocol, informed consent documents, information sheets, questionnaires, recruitment posters or other study materials;
c. Timely reporting of all local serious adverse events;
d. A final report, upon completion of the study, submitted within three months.

If there is a contract or data sharing agreement, the study may not commence until those documents have been finalized. The study is to be reviewed in one year, before the next “Anniversary Date.”

NOTE: The above Study Identification Number THREB #2015-0582 has been assigned to your project. Please use this number on all future correspondence.

Please call me if you have any questions.
Sincerely,

[Signature]

Michael D. Coughlin, Ph.D.
Chair, Tri-Hospital Research Ethics Board

Cc: Karla Stroud
RESEARCH ETHICS BOARDS
Certification of Ethical Acceptability of Research
Involving Human Participants

APPROVAL PERIOD: April 5, 2016
EXPIRY DATE: April 5, 2017
REB: G
REB NUMBER: 16FE027
TYPE OF REVIEW: Delegated Type 1
PRINCIPAL INVESTIGATOR: O’Doherty, Kieran (chohertk@uoguelph.ca)
DEPARTMENT: Psychology
SPONSOR(S): None
TITLE OF PROJECT: The Needs and Skills of Filial Caregivers during the Transition of Older Adults from Hospital to Home

The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human participants in the above-named research project and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that researchers:
- Adhere to the protocol as last reviewed and approved by the REB.
- Receive approval from the REB for any modifications before they can be implemented.
- Report any change in the source of funding.
- Report unexpected events or incidental findings to the REB as soon as possible with an indication of how these events affect, in the view of the Principal Investigator, the safety of the participants, and the continuation of the protocol.
- Are responsible for ascertaining and complying with all applicable legal and regulatory requirements with respect to consent and the protection of privacy of participants in the jurisdiction of the research project.

The Principal Investigator must:
- Ensure that the ethical guidelines and approvals of facilities or institutions involved in the research are obtained and filed with the REB prior to the initiation of any research protocols.
- Submit a Status Report to the REB upon completion of the project. If the research is a multi-year project, a status report must be submitted annually prior to the expiry date. Failure to submit an annual status report will lead to your study being suspended and potentially terminated.

The approval for this protocol terminates on the EXPIRY DATE, or the term of your appointment or employment at the University of Guelph whichever comes first.

Signature: Date: April 5, 2010

L. Kuczenski
Chair, Research Ethics Board-General
Appendix B: Resource List Provided to Caregivers

Caregiver Resources

The resources identified in the table below are a select list of contacts that could be helpful if you require more information or are experiencing difficulty in your role as a caregiver. Procedures for reporting concerns to the Community Care Access Centre or to Grand River Hospital are presented on the following two pages.

If you or someone else is experiencing a medical emergency please call 911 immediately.

<table>
<thead>
<tr>
<th>Resource</th>
<th>Telephone Number</th>
<th>Availability and Purpose of Services</th>
<th>Geographic Region Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>Here 24/7</td>
<td>1-844-437-3247 or TTY 1-877-688-5501</td>
<td>Call any time to access addictions, mental health and crisis services</td>
<td>Waterloo-Wellington-Dufferin</td>
</tr>
<tr>
<td>Mental Health Helpline Ontario</td>
<td>1-866-531-2600</td>
<td>Call anytime for free mental health services information</td>
<td>Ontario</td>
</tr>
<tr>
<td>Telehealth Ontario</td>
<td>1-866-797-0000</td>
<td>Call anytime for health advice or information. A registered nurse will take your call.</td>
<td>Ontario</td>
</tr>
<tr>
<td>Community Care Access Centre (CCAC)</td>
<td>310-2222 (no area code required)</td>
<td>The CCAC provides support and information related to healthcare. If you are not already linked with your local CCAC you can call this number for more information about the services they offer and to refer your family member</td>
<td>Ontario</td>
</tr>
</tbody>
</table>
Procedure for Reporting Community Care Access Centre Related Concerns

If you or your family member are already associated with your local Community Care Access Centre but have some concerns or would like to file a complaint please follow these steps:

1. Contact your Care Coordinator to discuss your complaint by phone at 519 883 5500. Your Care Coordinator is familiar with your situation and wants to hear what is going well for you and what can be improved. Your Care Coordinator will work with you, your family, or your caregiver to respond to your complaint. Most patient complaints are successfully resolved at this level.

2. If, after speaking with your Care Coordinator, your complaint is not resolved to your satisfaction, you can ask to speak to his or her manager.

3. CCAC Patient Relations Representative can be directly reached by phone at 519 883 5500 ext. 5563 or by email at patient.relations@ww.ccac-ont.ca. He/she will call you within 24 hours. You can ask your care coordinator to have the Patient Relations Representative contact you directly.

4. If, after speaking with a manager, your complaint remains unresolved, you may request a formal review. The manager will inform you how to proceed with a formal CCAC review.

Following the CCAC formal review process, if you remain unsatisfied with the decision, you have the right to appeal that decision to the Health Services Appeal and Review Board (HSARB), if it concerns your eligibility for service, the type or amount of service you receive, or why services were discontinued.

Health Services Appeal and Review Board
151 Bloor Street West, 9th Floor
Toronto, Ontario
M5S 1S4
416 327 8512
Procedure for Reporting Grand River Hospital Related Concerns

If you have a concern about the services received through Grand River Hospital you are encouraged to speak with your family member’s healthcare team directly.

If your concern requires further attention or you feel that it should be addressed by someone not directly providing your care, you’re welcome to contact the clinical manager in the area providing care or the patient relations coordinator. The patient relations coordinator is there to support relationships and communication between patients, their families and the healthcare team considering the unique needs of each patient and family.

The patient relations coordinator can be contacted by telephone at 519-749-4300 ext. 2966

Or by email at feedback@grhosp.ca (to protect your privacy the hospital suggests that you do not submit any personal health information via email)
Appendix C: Caregiver Demographic Questionnaire

1. Gender: _______

2. Which of the following best describes your marital status?
   - Single
   - Married
   - Separated
   - Living in common law
   - Divorced or formerly lived with someone as if married
   - Widowed
   - Other (please specify)

3. What is your current age?_______

4. How far did you go in school?
   - Some high school or less
   - Completed high school
   - Some college/university
   - Completed college/university
   - Post graduate

5. How would you rate your current health? Would you say it’s:
   - Poor
   - Fair
   - Good
   - Very good
   - Excellent

6. What is your current employment status?
   - Part-time
   - Full-time
   - Unemployed and seeking work
   - Retired
   - Casual (on and off)

7. What is your annual family income (the sum of incomes of all members of the family) over the course of one year?
   - Under $5,000
   - $5,000-$15,999
   - $16,000-$25,999
   - $26,000-$45,999
   - $46,000-$60,999
   - $61,000-$75,999
☐ $76,000-$100,999
☐ $101,000-$150,999
☐ $151,000-$200,999
☐ $201,000-$250,999
☐ Over $251,000
Appendix D: Caregiver Interview Guide

The following is a guideline of topics and questions for the semi-structured interviews that will be conducted with caregivers of older adults who are experiencing a care transition from hospital to home. The purpose of this interview guide is not for it to be used in a static way (i.e., questions will not be read out in a linear fashion akin to a survey). Rather, the interviewer will endeavour to conduct the interview as a naturalistic conversation on the topic of interest, covering all questions in a naturalistic way.

**Personal Background**
Tell me a little bit about yourself and your relative?

  What is your relationship to ______ (name of parent)?
  What was the reason for ______’s hospitalization?
  If any, what other medical conditions does ____ have?
    How long have you been a caregiver for ______?
    [If yes] Can you tell be a little bit about this previous experience?
    What are ______’s living arrangements? (e.g., do they live with you? Do they live on their own?)
      Why did you decide on this location for care?
      Do you have any children that you currently care for? If so, how many?
      Do you have any siblings?
    Can you tell me a little bit about the discharge plan you received?

**Hospitalization**
Take me back to the day that your parent was hospitalized.

  What happened?
  What led up to it? Had anything like that happened before?
  How did you respond? How did the rest of your family respond?

What happened at the hospital?
How long were they hospitalized?

**Discharge**
How did you decide who would be caring for your parent?
Tell me about the whole discharge process.

Were you satisfied with it?

In what aspects were you involved?

Who did you talk to?

What information did you receive with respect to your parent’s condition and care? Did you understand it?

What kind of information did you provide?

Is there any additional information you wish you had received or been asked for?

Did the plan take into your own wishes or preferences?

What concerns did you have at the time?

Was there anything recommended that you felt was out of context for the way you live your life?

Did you feel like they were ready to be discharged? Did you feel ready for them to be discharged?

**Needs Associated with the Hospitalization of their Relative**

Tell me about your daily routine since your parent was discharged from the hospital.

How as it changed since before you were a caregiver for your parent? [prompts: leisure time, relationships, employment]

In what ways has your life stayed the same?

Have you had to take any time off work? How easy was that for you to do? If not, do you feel like that would be something that you want to do?

What do you help them with? [health care, shopping, cleaning, cooking, banking]

Did you help your parent in any other ways before they were hospitalized?

Did you talk about their health prior to their hospitalization?

Have you modified the home environment in any way since they were discharged home from the hospital?

What concerns or worries do you have now that they are out of the hospital?

What challenges (needs) have you experienced since ____ was discharged from the hospital?
[prompts: with health care professionals, managing aspects of your own life including work and child care, with the care recipient, finding information, having a need for training, interacting with other family members, deciding how care would be managed]

Right now, what do you think is the most challenging thing about all of this?
Did you have expectations for other people during this time?
What types of decisions do you feel yourself making that you maybe didn’t make before?

**How Caregivers Address these Needs**

Is there anything you have done to overcome some of these challenges? *(make note of the needs they list from the previous section to ask about each individually)*

- What would you say are your current strengths or weaknesses at addressing your relative’s care?
- Why did you pick that strategy rather than another? What influenced that approach?
- If one strategy didn’t work, did you try another?
- Why do you think that strategy didn’t work?
- Do you have any outside help?
- What have you been frustrated about?
- Is there anything that you felt prepared for?

What would you recommend to someone else who has a relative that has just been discharged from the hospital?

Who have been the biggest supports to you during this time?

- What have they done to help you? [formal, informal, instrumental, emotional support]
- Do you talk to your siblings about this at all? Any disagreements?

Have you turned to anyone or anything for information about your relative’s condition or care [relatives, friends, the internet, books]?  
- If you have questions, who do you talk to?
- Has their/the advice been helpful? Do you solicit the information or do they volunteer it?
- How have you used this information?

What kinds of things do you talk about with your parent?
- Do they tell you what they need?
- Do you work through challenges together?
What is your biggest priority at this time? How do you prioritize?

If you have had previous experience with the healthcare system, how did it prepare you to deal with your current situation?
Appendix E: CCAC Care Coordinator Interview Guide

**Introduction**

My name is Karla Stroud and I’m researcher from the University of Guelph. For my PhD dissertation I am looking at the experiences of caregivers who are caring for their parent, when their parent has been discharged from hospital to home. In order to provide some context for those caregiver interviews and to help me to understand transitional care in more detail I would like to ask you some questions about the work you do.

**Background Information**

To start off, I’d like just like to get to know you all a little bit. Please tell me about yourselves as well as your role at the CCAC?

**Working with Clients**

What type of interactions you have with family members? (specifically sons and daughters?)

- Care conference? Meeting at discharge?
- Do you work as part of team in the hospital?

What kind of questions do they ask you?

- Do you see them advocating for themselves and their parents?

Who do you see as your main client? Patient or caregiver? Who do you have the most interaction with?

**The Transition from Hospital to Home**

Please describe the transition from hospital to home for patients.

- In what ways do you participate? Please tell me about the process a patient comes to you in (referral process?). Can you tell be about the health care assessment?
- In what ways do the families participate?
- How is it determined when someone is ready to be discharged?
- How are discharge plans created and what do they include?
- How are the numbers of hours of service calculated?
- How do you work with community care coordinators?
- Have you noticed them advocating for themselves or their parent?

In what ways is the transition from hospital to home challenging for patients and their caregivers?
What do you see as the biggest challenges facing these families? Have they expressed any of this to you?

Are there ways that you work to create solutions with patients and their families?

What does a successful transition look like to you?

What needs do caregivers have? How do they address these needs?

How much responsibility is the family expected to take on in caring for their parent?

How are things different when transitioning from home as opposed to a long-term care facility?

**Looking Toward the Future**

What type of information would be helpful to hear from clients (i.e., patients and family members) for you to better serve them?