

HEALTH & SOCIAL SERVICE USE: CAREGIVERS OF STROKE SURVIVORS

ACCESS AND USE OF FORMAL HEALTH AND SOCIAL SERVICES BY CAREGIVERS
OF STROKE SURVIVORS: AN INTERPRETIVE DESCRIPTION STUDY

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TITLE: The Access and Use of Formal Health and Social Services by Caregivers of Stroke Survivors: An Interpretive Description

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Lay Abstract

Caregivers often experience challenges supporting stroke survivors. Their caregiving role may negatively affect their health and ability to return to their previous lifestyle. Little is known about stroke caregivers' use of funded supportive services. The purpose of the study was to better understand caregivers' experience using health and social services as well as the factors that influenced their access to and use of these supportive services. Findings showed that: (a) few caregivers use services despite expressing a need for these services (e.g. counselling), (b) caregivers struggle to trust the health providers supporting the stroke survivors, (c) caregivers' social lives are often greatly affected by their caregiving role which in turn impacts their need for services, and (d) caregivers pay many financial costs when using supportive services. Overall, better ongoing assessment of stroke caregivers is required including using tailored services to meet their needs and help them in their caregiving role.

Abstract

Background: Evidence has shown that family and friend caregivers of stroke survivors are significantly and negatively impacted by caregiving. The negative effects of caregiving may persist over time suggesting the need for ongoing care and support. However, little is known about caregivers' use of formally funded health and social services or the factors influencing their access to and use of these services.

Purpose: To increase understanding of: (a) the context of providing care for a stroke survivor; (b) the experiences of stroke caregivers in accessing and using formal health and social services; and (c) the factors that influence stroke caregivers' use of formal health and social services, from the perspective of stroke caregivers and healthcare providers.

Methods: A qualitative study was conducted using interpretive description. In-depth interviews were conducted with caregivers of survivors who experienced a stroke between six months to five years ago and healthcare providers who support caregivers and stroke survivors. Constant comparison was used to identify codes and develop key thematic constructs.

Results: Interviews were conducted with 22 stroke caregivers at an average 30 months post-stroke and 18 health providers. Key findings include: (a) few caregivers use services, (b) caregivers face challenges accessing services, (c) services used by stroke survivors benefit caregivers, and (d) factors influencing stroke caregivers' use of services include: adequacy of social support networks, finances and transportation, and trust in leaving the stroke survivor under the care of health providers.

Conclusion: Stroke caregivers experience significant challenges in accessing and using formal health and social services. These challenges could be addressed by increasing availability of subsidized community-based supports such as respite and counselling tailored to meet the

ongoing needs of caregivers. Systemic change is needed by the health system that readily includes and supports caregivers throughout the stroke recovery continuum, particularly in the community setting.

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List of Abbreviations and Symbols

ADL	Activities of daily living
CAS	Complex adaptive systems
CCAC	Community Care Access Centre
ESD	Early supported discharge
HP	Healthcare provider
IADL	Instrumental activities of daily living
ID	Interpretive description
LHIN	Local Health Integration Networks
MCC	Multiple chronic conditions
MCCRN	Multiple chronic conditions research network
OSN	Ontario stroke network
QOL	Quality of life
PSW	Personal support worker
RC – MCC	Role of complexity in care of patients with multiple chronic conditions
RRC	Regional rehabilitation center
SCG	Stroke caregiver
SLP	Speech language pathologist

Declaration of Academic Achievement

This thesis is a report of original research that I conducted under the supervision of Drs. Jenny Ploeg, Maureen Markle-Reid, and Pat Strachan commencing in September 2012. Committee members contributed to the: (a) development of the research proposal including the topic, design, research questions, study sample, location of data collection, and data collection tools, (b) research ethics board submission, (c) data analysis processes, (d) chapter drafts of the dissertation, and (e) final drafts of the complete dissertation. Throughout data collection I was the only interviewer and observer. Melissa Dawson and Montana Fisher-Shotton transcribed audio recordings.

Chapter 1

Introduction

Experiencing a stroke can be a profound and life altering experience, not only for the stroke survivor but also for their family and friend caregivers (hereafter referred to as caregivers). Strokes typically occur suddenly and with little warning, leaving those affected ill prepared to deal with the resultant disability and life changes. As people age, their risk of experiencing a stroke increases, with 70% of all strokes occurring after the age of 65 (Kelly-Hayes, 2010). The effects of stroke are often long-standing, and often occur in the context of other chronic conditions (Krueger et al., 2015). Stroke survivors frequently require longer-term support from caregivers after their stroke when they have returned to living in a community setting (King, Ainsworth, Ronen, & Hartke, 2010; Krueger et al., 2015; Ploeg et al., 2017). Governments and health systems are increasingly focusing on providing services and supports to enable stroke survivors to recover at home in the community (Health Quality Ontario, 2016). The number of long-term care home beds in Ontario grew only by only 2% from 2009/10 to 2013/14, while the older adult population over the age of 75 increased by 11% (Health Quality Ontario, 2016). This suggests that caregivers are increasingly providing more supports to older adults in the community setting. While providing ongoing assistance to a stroke survivor can be rewarding, it can also have a negative impact on the health and well-being of the caregiver (Rigby, Gubitz, & Phillips, 2009). For example, prolonged (> 6 months) caregiving has been shown to have an association with increased depression, anxiety, and even mortality in caregivers (Rigby et al., 2009).

Given the central role that caregivers play in supporting stroke survivors to remain in their homes, it is necessary to find ways to support them in their caregiving capacity. However,

to date little is known about caregivers' experience accessing and using health and social services to help them manage their health and caregiving role. Furthermore, there is a paucity of information related to what factors influence caregivers' use of these services.

In this introductory chapter, I provide a summary of the background and context of stroke and caregiving in order to provide the rationale for this research study. A statement of the research purpose including detailed research questions follows. Next, I present my personal statement including the reflective lens that I bring to this research. The chapter concludes with a brief description of the structure of the dissertation.

Background

It is estimated that each year approximately 62,000 Canadians will experience a stroke (Heart and Stroke Association, 2018). Of these strokes, 5.1% (3,162) will lead to death while 58,838 Canadians are expected to survive their stroke (Public Health Agency of Canada, 2009). In 2018, approximately 405,000 Canadians were living with the effects of stroke, including various disabilities related to mobility, physical independence, and social functioning (Heart and Stroke Association, 2018). Stroke also takes a toll on people in other countries; for example, a study from the UK found that 20% - 30% of stroke survivors showed poor outcomes over the ten-year follow up period, with decreased engagement in activities of daily living (ADLs) and increased disability (Wolfe et al., 2011).

A stroke occurs as a result of a disruption of the blood supply to an area of the brain, with damage reflective of the magnitude of the stroke and the area of the brain affected by the stroke (Heart and Stroke Association, 2018). There are three kinds of stroke: (a) haemorrhagic, characterized by uncontrolled bleeding in the brain; (b) ischemic, characterized by a blockage that prevents blood flow to the brain; and (c) traumatic subarachnoid haemorrhagic (aneurysm

rupture) (Heart & Stroke Association, 2018; Heart and Stroke Association, 2014; Public Health Agency of Canada, 2009). While most strokes occur after the age of 70, strokes are increasingly occurring in adults in their 50s and 60s (Heart and Stroke Association, 2014). Common effects of stroke include aphasia, disordered comprehension or expression of words (affecting approximately a third of adults affected by stroke), physical deficits such as paralysis or reduced mobility that affect ability to complete activities of daily living (ADLs, e.g. personal hygiene, mobility, eating) and instrumental activities of daily living (IADLs, e.g. communication, transportation, managing finances), and cognitive impairment affecting memory or execution of complex tasks (Clarke, Marshall, Black, & Colantonio, 2002; Rombough, Howse, Bagg, & Bartfay, 2007). As people age, their risk of stroke increases; stroke occurrence increases twofold each decade after the age of 45, and more than 70% of strokes occur in people 65 years of age and older (Heart and Stroke Association, 2014; Kelly-Hayes, 2010; Ontario Stroke Network, 2016; Public Health Agency of Canada, 2010).

Rhoda (2013) found that 82% of stroke survivors will have activity limitations and will require help with ADLs often persisting over time despite gradual progress in recovery. Negative health outcomes for stroke survivors can include the development of depression, vascular cognitive impairment, and post-stroke fatigue (Eskes et al., 2015). Long-term studies on stroke survivors and their family caregivers determined that at three years post-stroke, 26% of stroke survivors were disabled (Barthel index < 15), and at seven years post-stroke, 16.5% of stroke survivors (mid-sixties in age at initial stroke) had experienced a recurrent stroke, suggesting that in many cases the caregiving role is likely to persist or even increase with time (Patel et al., 2006; Persson et al., 2015).

Stroke recovery may also be complicated by the presence of other chronic conditions (Ostwald, 2008). Up to 75% of stroke survivors have three or more comorbidities complicating their recovery and resulting in the need for ongoing care (Gruneir et al., 2016). Hypertension is both a risk factor for stroke, and the most commonly occurring comorbidity in people who have survived a stroke (Karatepe, Gunaydin, Kaya, & Turkmen, 2008; Robitaille et al., 2012). Other multiple chronic conditions (MCC) commonly reported in conjunction with stroke include arthritis, asthma, mood disorders and/or anxiety, hyperlipidemia, and diabetes (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005; Roberts, Rao, Bennett, Loukine, & Jayaraman, 2015). The co-occurrence of these conditions with stroke can result in the need for: complex medication regimes, multiple specialist consults and increased challenges with self-care (Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007).

Stroke is the leading cause of disability in Canada with an estimated 75% of adults with stroke having some type of impairment, and up to two-thirds having severe deficits (Canadian Institute for Health Information, 2012). Approximately 30% of Canadian stroke survivors will transition from acute care to inpatient rehabilitation or to complex continuing care prior to returning home or transitioning to long-term care (Canadian Institute for Health Information, 2012). About half of the individuals in Ontario who experience a stroke will be treated in the emergency department, then transferred to acute inpatient hospital care and then discharged back to their homes where they will require further care and rehabilitation (Canadian Institute for Health Information, 2012). Stroke survivors discharged from hospital to the community may receive services such as outpatient rehabilitation, home care services, community-based programs, primary care services or palliative services (Canadian Institute for Health Information, 2012). However, caregivers provide most of the daily care once the stroke survivor returns to

their home, with 61-91% of carers providing support with basic and instrumental activities of daily living at 12 months post-stroke (Tooth, McKenna, Barnett, Prescott, & Murphy, 2005). Furthermore, stroke caregivers provide up to 32 hours of care per week for stroke survivors in the first year following stroke (Tooth et al., 2005).

Due to the sudden onset of stroke and the often-resultant decline in the stroke survivor's health, the caregiver is required to adjust very quickly to a new set of circumstances. This is quite different than caregiving in the context of many other chronic diseases, where onset is more gradual and caregivers have more time to adjust to their role (Bereton & Nolan, 2002; Bernell & Howard, 2016). The sudden onset of stroke, in combination with the potentially long recovery period, can place caregivers at increased risk of experiencing a decline in their own physical and mental health (Camak, 2015; Tooth et al., 2005). These caregiver outcomes may include depression, anxiety and decreased cognitive function and quality of life, as well as physical strain, exhaustion and increased risk of stroke (Andrew, Kilkenny, Naylor, Purvis, & Cadilhac, 2015; Camak, 2015; Han & Haley, 1999; Kniepmann, 2012; Olai, 2015).

The most recent Canadian Stroke Best Practice Recommendations emphasize the variability and continuing nature of stroke recovery as well as the need for a holistic approach to stroke management that includes ongoing provision of services for stroke survivors and caregivers beyond the stroke survivor's discharge from acute services (Cameron et al., 2016).

Acknowledgement of the important role of caregivers is increasing and with this acknowledgement has come the recognition that they must be included in the circle of care for stroke recovery (Hebert et al., 2016).

Becoming a stroke caregiver can be challenging and is often characterized by a lack of preparedness for and understanding of the caregiving role, uncertainty about available services,

relationship upheaval, and social isolation (L. Chen, Xiao, & De Bellis, 2016; Lutz, Young, Cox, Martz, & Creasy, 2011). Once the stroke survivor is discharged home, the caregiver may not retain the information presented to them by healthcare providers because they do not appreciate its relevance or feel anxious about the discharge process (White, Brady, et al., 2014). During the early post-stroke time period, health providers often pay limited attention to caregivers as the stroke survivors' needs take priority leaving the caregivers feeling undervalued and at risk for health issues pertaining to their own physical and emotional health such as depression and caregiver burden (Bakas et al., 2014; Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005). A lack of self-care practices by the caregiver is also common during this timeframe and could potentially constrain them from accessing services to support them in their caregiving role (Bakas et al., 2014). The scientific literature suggests there is a need for readily available and accessible health and social services to support caregivers in the community setting (Camak, 2015; Tooth, McKenna, Barnett, Prescott, & Murphy, 2005).

Once caregivers begin providing support in the home environment, they may face new challenges such as managing cognitive changes in the stroke survivor or developing new ways of communicating with the stroke survivor. The evidence suggests that caregivers of stroke survivors who face ongoing stress have a 23% greater risk of having a stroke compared with those who experience less stress in their caregiving role (Camak, 2015). Throughout the caregiving journey, caregivers' use of services such as counselling and respite may support them to care for their own health.

Formal health and social services have the potential to support stroke caregivers resulting in improved health and quality of life. For example, when caregivers used a formal family support program (starting within six weeks post-stroke) researchers found that caregivers

receiving the program had greater improvements in physical health, mental health and quality of life at six months post-stroke compared with the normal care control group (Mant, Carter, Wade, & Winner, 2000; Simon, Kumar, & Kendrick, 2008). The goal of community-based services, such as personal support workers and specialized caregiver support programs is to assist caregivers and provide them with respite from their caregiving roles (Mant et al., 2000). Other services include social workers to facilitate access to funding for equipment and counselling to help caregivers deal with the often profound life changes that affect the whole family when someone has a stroke (Grant, Hunt, & Steadman, 2014b). Research has shown that caregivers use formal health and social services such as general practitioners, community nurses, counselling and day centres even after a considerable time has passed since the stroke (King & Semik, 2006; Simon et al., 2008). Furthermore, research also showed that those caregivers who were using services, were for the most part satisfied with the services they utilized (King & Semik, 2006). However, not all caregivers make use of these services (Andrew et al., 2015; King & Semik, 2006; Masry, Mullan, & Hackett, 2013). Despite stroke caregivers' need for ongoing support, only 5% to 19% of caregivers use respite care (King & Semik, 2006; Simon et al., 2008). Little is known about caregivers' experience using formal health and social services and the factors that influence access to and use of these services. Obtaining a clear understanding of caregivers' experience accessing and using formal health and social services is needed to better understand the facilitators and barriers to service use. This information can be used to inform the design and delivery of services that better support stroke caregivers in their caregiving role. Given the increasing prevalence of stroke, the importance of effectively supporting stroke caregivers will only increase with time (Heart and Stroke Association, 2018).

In summary, caregivers of stroke survivors often experience high levels of burden related to their caregiving role resulting in negative consequences such as stress, caregiver burden and depression. Some formal health and social services have the potential to address caregiver needs and support them as they care for stroke survivors residing in community settings. However, even though caregivers need services and are aware that some services are available, they are underutilized. Little is known about the experience of stroke caregivers in accessing and using formal health and social services, particularly in the Canadian context, and the factors that influence their use of these services.

Purpose of the Study

The purpose of this study is to explore the experiences of caregivers of community dwelling stroke survivors in accessing and using formal health and social services. Specific research questions include:

- 1) What is the context of providing care to a stroke survivor for stroke caregivers?
- 2) What are the experiences of stroke caregivers in accessing and using formal health and social services?
- 3) What are the factors that influence stroke caregivers' access to and use of formal health and social services?

Personal Statement - Researcher Reflective Lens

The researcher's perspective including their clinical and academic training and experience is an important influence on the generation and conduct of qualitative research (Thorne, Joachim, Paterson, & Canam, 2002). There are a number of factors that have helped to inform the development of this research proposal and the focus of my dissertation research. Prior to beginning my doctoral studies at McMaster University, I worked as a visiting nurse for

the Victorian Order of Nurses. In this capacity I frequently worked with older adults and their family/friend caregivers. In this role, I had the opportunity to see and understand some of the challenges they faced. For example, older adults, often female, were faced with taking on a primary caregiving role and becoming the sole manager of household activities. Adult children were stressed as they sought to support their own young families and provide support to their ailing parents.

Later, while working as a care coordinator at the Hamilton Niagara Haldimand Brant Community Care Access Centre, I had to communicate difficult decisions about service provision to patients and their families. For example, I had to explain to caregivers that personal support worker hours were available in limited amounts and often at prescribed times. I saw how caregivers struggled to balance employment with caregiving and were constantly torn between competing demands. The provision of homecare services was key in enabling some people to remain in their homes. However, in other situations the limitations of the system such as constraints on the amount of formally provided respite or personal support worker hours meant that caregivers were too heavily burdened, and clients were unable to remain safely in their homes. These experiences encouraged me to explore these topics in my dissertation research.

For my Master's thesis, I conducted a historic cohort study of prognosis using a cross-sectional approach to quantify the association between recent family function and child behaviour. This experience enabled me to become acquainted with relevant quantitative data collection tools and techniques. However, the study methodology precluded increasing my understanding about the factors influencing use of health and social services. As I was becoming familiar with the stroke literature, I realized that health and social service use by caregivers of

stroke survivors had received little to no attention. Consistent with my use of Thorne's (2016) approach to interpretive description, which endeavours to find "associations, relationships and patterns within the phenomena that has been described" (p. 56), I bring a constructivist lens to this work. A constructivist perspective suggests that individuals' understanding of the world is influenced by their social interactions and is individual in nature (Thorne, 2016). Therefore, the findings from this research will be situated within the work of other experts in the field and this prior knowledge will provide the scaffold on which to build new knowledge.

Researcher's Assumptions

This research is based on the following five assumptions which are also informed by an interpretive description approach (Thorne, 2016): (a) as a clinician and researcher, my experiences, perspectives and outlook will influence the questions I ask, the interpretation of the data and final situation of the study results, (b) the findings from this study will not be bound by the context in which the research was conducted but will be true to the context in which such experiences occur, (c) the experiences and perspectives of the study participants will influence my understanding of the study findings, (d) I acknowledge that there are multiple realities and that there are social aspects of human experience which will influence the study findings, and (e) the experiences of an individual are shaped by their interactions with the components of the systems surrounding them which are themselves interactional. These five assumptions are fundamental for ensuring that the research is meaningful and relevant, and will ensure that this research provides a contribution to informing the improvement of the health care system in order to benefit stroke survivors and their caregivers.

Structure of the Thesis

The thesis consists of five chapters with chapter one providing an overview of the research and a brief introduction to the study purpose and research questions. Chapter two presents an in-depth review of the literature including identified knowledge gaps. Chapter three consists of the research methods. In chapter four, the results of the data analysis are described and in the final chapter, the implications and conclusions of the research are presented.

Chapter 2

Literature Review

Introduction and Overview of Chapter

This chapter provides a review of the literature and the conceptual framework that guided the study. The background literature provides an overview of the burden of stroke and its impact on caregivers and best practice guidelines and policies. This is followed by a detailed literature review describing the formal health and social services used by stroke caregivers and their experience accessing and using these services including the factors that influence service use/non-use.

Conceptual Framework

In order to provide structure and guidance when conducting research, it is helpful to inform and situate the research process within a conceptual model or framework, and use this as a lens through which to view, guide and situate the research. A conceptual framework can be defined as, “a network of linked concepts that together provide a comprehensive understanding of a phenomenon. Each concept of a conceptual framework plays an ontological or epistemological role in the framework” (Jabareen, 2009, p. 59). Therefore, an appropriate conceptual framework or model must allow for exploration of the research object or be adaptable to meet these needs. The framework used in this study is an adaptation of Grembowski et al.’s (2014) conceptual model of the role of complexity in the care of patients with MCC.

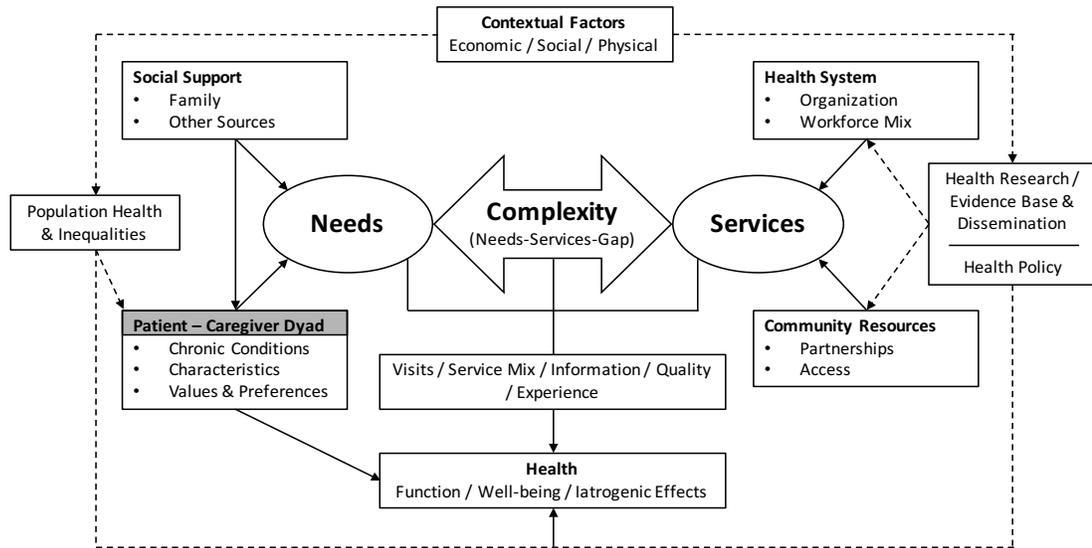


Figure 1. Conceptual framework of the role of complexity in the care of patients with MCC (RC – MCC). Adapted with permission from D. E. Grembowski

This framework was chosen because of its emphasis on a broad range of health, social and contextual factors that influence the person and their caregiver and their interactions with the health system. The framework includes multiple components, for example, financial factors, social support factors and person-related factors that influence the patient and the caregiver and their need to access and use health and social services. The framework also includes health system specific factors such as community resources, health evidence and health policies that also influence the availability and provision of health services to meet patient needs. For the purpose of this research the framework was adapted to include the patient-caregiver dyad because both caregivers and stroke survivors access services to support the stroke recovery journey.

Grembowski et al. (2014) developed a conceptual framework of the role of complexity in the care of patients with MCC (called here: RC – MCC) that framed complexity as the gap between patient needs and the ability of the system to meet those needs. The RC – MCC arose from the recognition of the importance of complexity, “defined as the misalignment between patient needs and the current health services structure” (Tinetti & Basu, 2014, p. S3).

Literature drawing upon the work of Grembowski et al. (2014) highlight: (a) the need to focus on the complex interaction between patient needs, service provision, and potentially complicating factors such as the social and environmental circumstances, (b) the need for team-based approaches, and (c) complexity as a characteristic of health systems (Castner, Wu, Mehrok, Gadre, & Hewner, 2015; Lee et al., 2016; May et al., 2015). Overall, of the seven conceptual frameworks of medical complexity investigated by Zullig et al. (2016) for potential application in this study, the work of Grembowski et al. (2014) provides the most comprehensive framework (RC – MCC) to guide research on caregivers of stroke survivors who are also managing MCC. The framework identifies multiple factors that influence the person, their needs, available services and the potential interactions between these factors making it well suited to guide study development and implementation. Furthermore, the framework required minimal adaptation for use in the research, namely adding the caregiver - stroke survivor dyad in place of the patient.

The health care system is a complex system comprised of several subsystems that may themselves be complex. These subsystems may be identified at the level of individual patients, their families, or involved medical centers (Lipsitz, 2012). While the health care system may be very difficult to understand or may even be intractable, its subsystems while still complex might be more easily understood. Aggregating understanding of several health care subsystems can

then help to improve understanding of the complex health care system as a whole (Kannampallil, Schauer, Cohen, & Patel, 2011). A significant challenge encountered when studying caregivers within a healthcare context is accommodating for the complexity of the interactions between caregiver, patient, their environment, health professionals and the health system. In the case of stroke caregivers, these interactions are potentially further complicated by the stroke survivors' recovery trajectory and other chronic conditions they may be managing (Gallacher et al., 2014).

The MCC research network (MCCRN), funded by the Agency for Healthcare Research and Quality in the USA, published the findings of their collaborative efforts to further knowledge, theory and methodology in the field of MCC research (LeRoy et al., 2014). As part of this collaborative effort, a number of key areas for future MCC research were identified, one of which is the importance of studying individuals in a setting that includes their family and their community (LeRoy et al., 2014). The MCCRN recognized the need to understand complexity in MCC and to understand how a conceptual framework can influence care, research and policy (LeRoy et al., 2014).

Caregivers' experiences providing care to stroke survivors and interacting with health and social services is complex and influenced by many factors both internal to the health system and more broadly within the social-economic system in which they live and function. The RC – MCC framework provides a relational perspective on the patient or caregiver, the health system and the socio-economic factors, which exert influence on the interactions between caregivers and the healthcare system (Grembowski et al., 2014). Therefore, this perspective provided a valuable structure to inform this research. The RC – MCC framework was used to inform the questions used in the in-depth interviews with stroke caregivers and health providers and the interpretation of study findings.

Stroke Survivors and Burden of Stroke

Stroke accounts for approximately 350,000 hospital visits in Canada each year with over 62,000 strokes occurring over the course of a year (Heart and Stroke Association, 2018).

Although the risk of stroke increases with age, four out of five Canadians over the age of 20 already have at least one condition that places them at increased risk of having a stroke, such as obesity or type two diabetes (Public Health Agency of Canada, 2009). Estimates suggest that approximately 1.6 million Canadians either have heart disease or have had a stroke and approximately 405,000 people in Canada are currently living with the ramifications of a stroke (Canadian Institute for Health Information, 2012; Heart and Stroke Association, 2018; Public Health Agency of Canada, 2009). While research suggests that about 14% of stroke survivors fully regain their physical functioning, 25% - 50% may require some support with ADLs and half of stroke survivors may continue to live with partial paralysis (Gordon et al., 2004). The consequences of a stroke can compromise stroke survivors' well-being with effects that may persist for up to ten years, meaning that many stroke survivors are living in the community with ongoing physical and/or cognitive limitations (Wolfe et al., 2011).

Up to 75% of stroke survivors have three or more co-morbid conditions (Gruneir et al., 2016). Six million adults in Canada have hypertension, a major risk factor for stroke and the most frequently reported MCC in stroke survivors (Karatepe et al., 2008; Robitaille et al., 2012). An accepted definition of MCC stipulates the occurrence of two or more chronic conditions that are expected to persist for a year or longer and require ongoing medical intervention or that impact activities of daily living (Parekh, Goodman, Gordon, & Koh, 2011; Vogeli et al., 2007). As people age, combinations of hypertension, arthritis, heart disease, cancer, and diabetes

comprise the top five most frequently occurring MCC in older adults (Canadian Institute for Health Information, 2011).

A cross-sectional study of over a million participants in Scotland explored the incidence of MCC within the context of stroke and found that stroke survivors were almost twice as likely as those without strokes to have one or more additional comorbidities (Gallacher et al., 2014). Further, a retrospective cohort study in Ontario of almost 30,000 participants who had experienced stroke at least six months prior found that almost 75% of study participants had three or more comorbidities (Gruneir et al., 2016). In a previous narrative review, the prevalence of MCC in stroke survivors was found to be upwards of 60% with predominant comorbidities being hypertension, arrhythmia, coronary artery disease and diabetes (Ostwald, Wasserman, & Davis, 2006). The co-occurrence of stroke and comorbidities increases patient-related costs and increases the likelihood that stroke survivors will require greater acute care treatment in an inpatient setting (Gruneir et al., 2016). Furthermore, a review of the most recent Canadian stroke best practice guidelines determined there was no guidance or mention of MCC as it pertains to supporting patients, families or caregivers following stroke (Nelson, Grudniwicz, & Albadry, 2016). This failure to recognize the impact of MCC could potentially shift the burden of care onto caregivers and further complicate the stroke survivors' recovery.

Family and Friend Stroke Caregivers

Caregivers of stroke survivors can be family members (e.g., spouse, parent, child) or friends and acquaintances. These caregivers provide the majority of care to the stroke survivor at home (Heart and Stroke Association, 2017). The literature indicates that the majority of stroke caregivers are either spouses of stroke survivors or their adult children (C. S. Anderson, Linto, & Stewart-Wynne, 1995; Giovannetti et al., 2012; Watanabe et al., 2015). Spouses constitute

upwards of 60% of stroke caregivers while adult children make up to one third of stroke caregivers (C. S. Anderson et al., 1995; Giovannetti et al., 2012; Haley et al., 2009; Watanabe et al., 2015). The age of stroke caregivers varies but on average will range from 50 to 65 years, and 70-85% will be female (Andrew et al., 2015; Ekstam, Johansson, Guidetti, Eriksson, & Ytterberg, 2015; King & Semik, 2006; Watanabe et al., 2015).

Impact of Stroke Caregiving and Unmet Caregiver Needs

There has been extensive literature on the negative impact of stroke caregiving on outcomes such as psychological health (e.g., burden, stress and anxiety), social impacts (e.g., relationships with friends, family members and colleagues), and finances and employment (C. S. Anderson et al., 1995; Andrew et al., 2015; Camak, 2015; Gaugler, 2010; Lutz et al., 2011; Rigby et al., 2009). The following sections discuss the impacts of caregiving as they pertain to: (a) caregiver psychological and physical health outcomes, (b) caregiver adjustment and isolation, (c) finances and employment, and (d) the unmet needs of caregivers.

Family caregivers are often faced with many life changes as a result of their caregiving role and this can place them at risk of being overwhelmed and psychologically stressed (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). While there is considerable literature corroborating the challenges experienced by caregivers during the stroke survivors' transition from hospital to home, recent work by Pucciarelli et al. (2018) found that caregiver anxiety and overall burden increases over the first year suggesting that the impacts of caregiving go beyond this initial transitional period. Furthermore, caregivers often overlook their own health needs in order to provide care to their family member, potentially compounding the effects of caregiving (Bakas et al., 2014).

Research has shown that caregivers of stroke survivors, particularly those who are older adults, have reported feeling tired and chronically stressed, and have fears about the future (Coombs, 2007). Additional impacts of caregiving include negative outcomes such as strain/stress, poor health status and reduced quality of life, which can continue for an indeterminate period of time following the stroke (Gaugler, 2010; Rigby et al., 2009). The effects of providing prolonged caregiving to stroke survivors can also impact non-spousal caregivers, who may have very different needs than spousal caregivers. As such, research has shown that adult child caregivers and other caregivers such as nieces, nephews and friends also report considerable strain from their role (C. S. Anderson et al., 1995).

Regarding spousal relationships post-stroke, research suggests that there are three key trajectories for couples' perspectives of their spousal relationships: (a) those where spouses re-established their emotional, spousal connections with each other, (b) those where spouses reconfigured their spousal connections to include the caregiver and care receiver roles, and (c) those where spouses could not reconnect following the stroke (S. Anderson, Keating, & Wilson, 2017). Another study determined that only half of spousal caregivers were satisfied with their life one year post-stroke (Ostwald, 2008). Other research suggests that the greatest predictor of life satisfaction in spousal stroke caregivers was their ability to cope with the demands of caregiving, not the actual adult with stroke's individual needs for support in ADLs (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005).

The caregiving role can be time consuming, taking time away from leisure, social activities or work (Rigby et al., 2009). Lutz et al. (2011) found that stroke caregivers often feel isolated with little opportunity to benefit from the support of others or attain relief from their caregiving role. Hospital discharge of the stroke survivor marks a key time of adjustment for

stroke caregivers and it is not until then that the full realization of their caregiving role emerges. Impacts of providing care for a stroke survivor at home can include the need for caregivers to adjust to altered behaviours in the stroke survivor, such as night waking. Caregivers also often assume new roles in the household such as paying for bills and doing lawn care (Lutz et al., 2011).

The researchers of two Australian studies explored the unmet needs of stroke caregivers (C. S. Anderson et al., 1995; Andrew et al., 2015). They reported limited availability of respite care for caregivers, with 24% being unable to access care despite their expressed need for support (Andrew et al., 2015). Although many caregivers received help from other family members and community assistance, 88% of caregivers still felt that caregiving led to negative effects on their lives such as anxiety, frustration and fear suggesting that their emotional needs continued to be unmet (C. S. Anderson et al., 1995). Furthermore, more than half of the caregivers felt they could not leave the stroke survivor unattended for fear they could injure themselves (C. S. Anderson et al., 1995).

Research using a cross-sectional survey in Australia investigated the long-term impact of stroke on the social lives of caregivers and stroke survivors (Andrew et al., 2015). The results showed that approximately 45% of caregivers reported moderate to extreme changes to their leisure lives including a decrease or change in the type of activities they could participate in; between 20% and 30% of caregivers reported moderate to extreme changes to their social lives (spousal, family or friend relationships) (Andrew et al., 2015). Younger caregivers describe needing more support than their older counterparts as they face the competing demands of younger and older family members, employment and loss of leisure time potentially resulting in social isolation and compromised well-being (Andrew et al., 2015).

Time spent caregiving may also interfere with employment leaving families in compromised financial positions and the caregiver feeling divided between their caregiving and working roles (Covinsky et al., 2001). Andrew et al. (2015) found that, at a median time two years post-stroke, approximately 40% of caregivers reported moderate to extreme changes to their work lives such as having to make substantial reductions to the number of hours they worked. They also found that 28% of caregivers lost income and 50% incurred personal expenses as a result of assuming a caregiving role (Andrew et al., 2015). Financial issues tend to impact caregivers especially when the stroke survivor is the primary wage earner in the family, but can sometimes occur when the primary caregiver is an adult child (C. S. Anderson et al., 1995).

Health Provider Roles in Stroke Care

Health providers have the potential to play a critical role in assessing stroke caregivers' needs, their requirements for services and helping them access these services. Research has shown that studies evaluating interventions for stroke caregivers explore the effect of the interventions on caregiver preparedness, something that nurses will assess in the course of discharge planning for stroke survivors (Bakas et al., 2014). Integral parts of the caregiver nursing assessment are the presentation of the assessment as an opportunity to discuss caregiver perspective and service needs, follow-up with other health providers on care coordination, and connecting caregivers with other health provider services (Levine, 2011).

However, the demands of caregiving and its associated challenges are rarely fully realized until the stroke survivor returns to the community. Therefore, an ongoing relationship between the healthcare team and the stroke survivor and caregiver is required to monitor the physical and emotional repercussion of caregiving on the caregiver (Grant, Hunt, & Steadman,

2014a). The Canadian Stroke Best Practice Recommendation: Mood, Cognition and Fatigue Following Stroke practice guidelines point to the need for caregiver assessments for psychological and support needs as an integral part of continuing stroke management (Eskes et al., 2015). Stroke caregiver research that seeks to explain or enhance the delivery of services to this population should ideally incorporate the health provider perspective to better understand where gaps between needs and service delivery are occurring.

Access and Use of Formal Health Services by Stroke Caregivers

A comprehensive review of the literature was conducted on access to and use of formal health and social services by caregivers of stroke survivors. The questions that guided this review were: 1) What are the experiences of stroke caregivers in accessing and using formal health and social services? and 2) What factors influence stroke caregivers' access to and use of formal health and social services?

In this context, formal health and social services will be defined as those services that directly support caregivers or indirectly affect the caregiver by providing services to the stroke survivor. Examples of formal health and social services used to support stroke caregivers in their caregiving role included: (a) counselling, (b) caregiver support groups, (c) medical appointments (primary and specialist care), and (d) respite care. Examples of services that are directed to stroke survivors but that could benefit caregivers include: (a) care provided by personal support workers, (b) speech language pathology, (c) physiotherapy/occupational therapy, and (d) adult day programs.

Search strategy.

The following electronic databases were searched: AgeLine, CINAHL, EMBASE, Medline, and PsychInfo. Search terms were adapted as appropriate to each database and

included: caregivers, carer, survivor, patient, stroke, cerebrovascular accident, brain infarction, CVA, cerebrovascular event, health services, community health services, health services for people with disabilities, health services for the aged, social work suburban health services, urban health services, community networks, social, social support, social service, health services research, utilization, and usage. The initial search strategy was run in MEDLINE and modified as necessary for the other databases (Appendix A). Where applicable, medical subject heading (MeSH) nomenclature was used. To ensure that the search was comprehensive, a health sciences librarian was consulted during the development of the search strategy.

The search also included: (a) hand searching of article reference lists, and (b) a Google search. Studies were included that met the following criteria: (a) English language, (b) research studies or systematic reviews published between January 2000 and November 2018, (c) exploration of stroke caregivers' access to and use of formal health or social services in the community, and/or exploration of stroke survivors' access to and use of formal health or social services in the community for the stroke survivor or the caregiver and/or exploration of the factors that influence stroke caregivers' access and use of formal health or social services. Once all electronic databases were searched, duplicates were removed and the remaining articles were reviewed first by title, then by abstract and finally by a full reading of the remaining articles to identify those articles that met the inclusion criteria (Figure 1).

Results.

After removal of duplicates, a total of 382 unique articles remained. Of these unique articles, 287 were removed because they did not focus on stroke caregivers and survivors post-stroke; 71 were removed because they did not look at stroke survivor or caregiver service access or use; 16 were removed because they were not focused on stroke survivor or caregiver service

access or use in a community context. Two articles were added after completing an additional Google search. Ultimately ten articles were found that met the inclusion criteria (Chan et al., 2009; P. Chen, Fyffe, & Hreha, 2017; Ghose, Williams, & Swindle, 2005; Hare, Rogers, Lester, McManus, & Mant, 2006; King & Semik, 2006; Masry et al., 2013; Pindus et al., 2018; Simon et al., 2008; Torbica, Calciolari, & Fattore, 2015; White et al., 2007).

Description of reviewed articles.

The ten articles included three qualitative studies (Hare et al., 2006; Masry et al., 2013; White et al., 2007), two mixed-methods studies (P. Chen et al., 2017; King & Semik, 2006), four quantitative studies (Chan et al., 2009; Ghose et al., 2005; Simon et al., 2008; Torbica et al., 2015), and one systematic review (Pindus et al., 2018). The qualitative study designs included: a cross-sectional phenomenology study (Masry et al., 2013) and a thematic cross-sectional study (White et al., 2007). One qualitative study did not describe its design (Hare et al., 2006). The quantitative study designs included: a retrospective cohort study (Chan et al., 2009), a cohort study with a case-control sub-study (Ghose et al., 2005), an unspecified cohort study (Simon et al., 2008), and an observational, prospective, incidence-based study (Torbica et al., 2015).

Study participants included: (a) only caregivers of stroke survivors (P. Chen et al., 2017; King & Semik, 2006; Simon et al., 2008), (b) caregivers of stroke survivors and stroke survivors, (Hare et al., 2006; Masry et al., 2013; Pindus et al., 2018) and (c) only stroke survivors (Chan et al., 2009; Ghose et al., 2005; Torbica et al., 2015). The studies were conducted in Australia (Masry et al., 2013), Canada (White et al., 2007), Italy (Torbica et al., 2015), the UK (Hare et al., 2006; Simon et al., 2008), the USA (Chan et al., 2009; P. Chen et al., 2017; Ghose et al., 2005; King & Semik, 2006), and one systematic review and meta-ethnography included participants

from Australia, Canada, England, Iran, Northern Ireland, Norway, Scotland, Sweden, UK and the USA (Pindus et al., 2018).

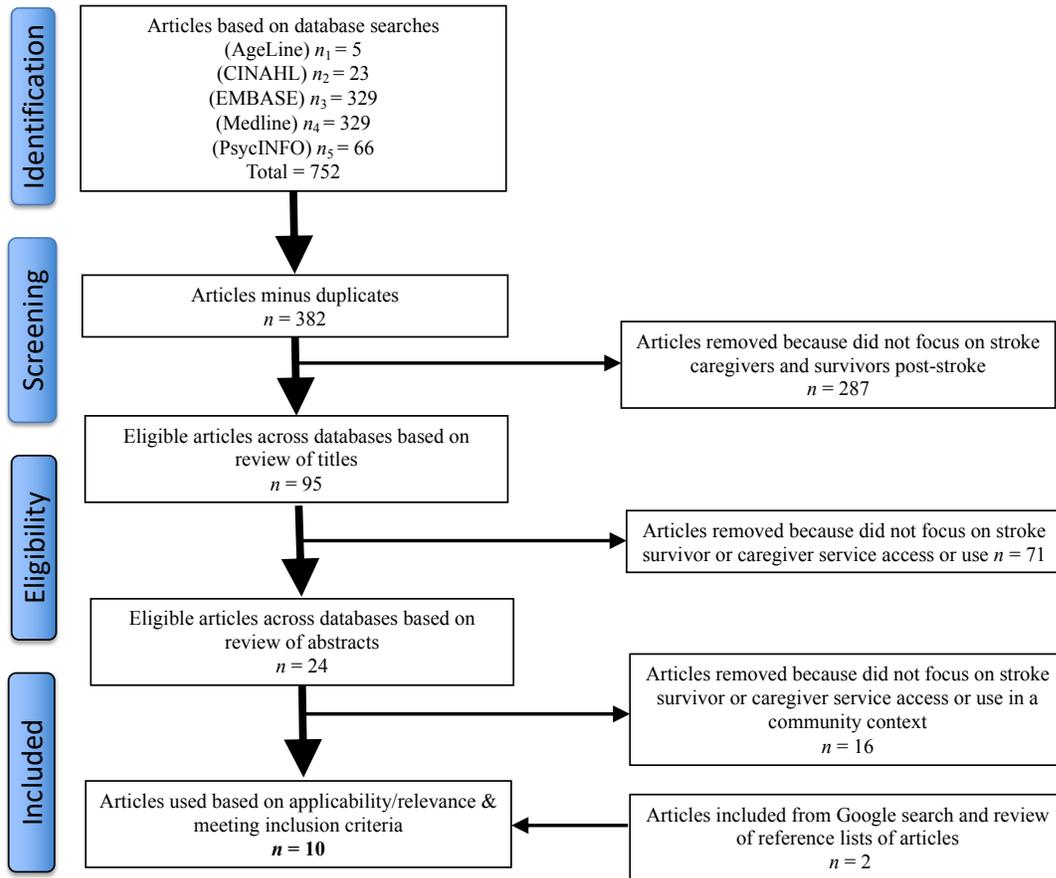


Figure 2. PRISMA flow diagram. Stroke caregiver use of health and social services.

The length of time since the stroke varied from 6 weeks to 22 years across the studies. Details of each study including country, purpose, design, sample, methods, results are presented in Table 1 and an appraisal of the articles is presented in Table 2.

Stroke caregivers' experience accessing and using formal health and social services.

Five of the ten reviewed studies explored caregiver and stroke survivor experience in using formal health and social services (P. Chen et al., 2017; Hare et al., 2006; King & Semik,

2006; Simon et al., 2008; Torbica et al., 2015) (Table 1). Stroke survivor use of formal health and social services was included as it also may have benefited caregivers. Research conducted in the UK determined that 96% of 105 stroke caregiver-survivor dyads were using some type of formal services (e.g., general practitioner, physiotherapist, home carer, counsellor, speech therapist, or night nurse) at 15 months post-stroke, while most made use of several services (average of 4.1 services at 15-months post-stroke) (Table 1) (Simon et al., 2008). Stroke caregivers reported using the following services: general practitioner (77.4%), community nurse (73%), social services (41.9%), day centres (31.1%), hospital outpatient (36.5%), specialist stroke support nurse (20.3%), speech therapist (20.3%), voluntary support groups (17.6%), inpatient care/respite (5.4%), community psychiatric nurse (4.1%), and counsellor (1.4%) (Simon et al., 2008). An Italian study of 532 stroke survivors found that 6 – 12 months post-stroke, stroke survivors had accessed the following services: inpatient rehabilitation (0.9%), outpatient rehabilitation (20.9%), hospitalization (4.6%), imaging (39.3%), visits to general practitioner or specialist (78.9%), drugs (82.5%), and nursing home (1.6%) (Torbica et al., 2015). A study from the USA found that 80% of the 20 participating stroke caregivers wanted more rehabilitation for the stroke survivor (P. Chen et al., 2017). (Table 1)

A study of 93 stroke caregivers in the USA found that they continued to use services such as home health care (51%), spiritual support (49%), talking with peers (37%) and counselling (20%) up to two years post-stroke (King & Semik, 2006). However, very few stroke caregivers used services such as transportation, financial guidance and information on resources and survivor behaviours (King & Semik, 2006). A study in the UK determined that approximately half of the 27 study participants received some type of service (e.g. private home care, social

Table 1

<i>Characteristics of reviewed studies</i>						
Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Chan et al., 2009	Northern California, USA	Examine utilization of outpatient & home care services after stroke	Retrospective cohort study	11,119 patients hospitalized for a stroke between 1996 and 2003 Mean age: 69.7 years, SD 13.0 years, gender: 51.1% female	Patient database, census track data;	<p><i>Factors influencing use</i></p> <p>Factors associated with more outpatient rehabilitation visits:</p> <ul style="list-style-type: none"> Younger age Male gender Non-white race Urban residence Higher income living area Ischemic stroke Longer acute care length of stay <p>Factors associated with more home health care:</p> <ul style="list-style-type: none"> Older age Female gender Non-white race Urban residence Ischemic stroke Longer acute care length of stay
Chen et al., 2017	Unspecified USA	Explore factors associated with burden & stress among informal caregivers of adults with stroke who experience spatial neglect (SN)	Unspecified mixed-methods study	20 caregivers (CG) of adults with stroke an average of 289 days post-stroke Age: Mean 56.9 yrs, SD 12.7 years, gender: 60% female	Semi-structured interviews, self-reported demographics, socioeconomics & health status, functional ability questionnaire; caregivers' perception of survivors need for additional therapy and reason why additional therapy not received	<p><i>Experience in access and use</i></p> <p>Areas that caregivers identify for more service provision: 80% of caregivers identified a need for more rehabilitation, with mobility issues being the most commonly identified area of focus for services.</p> <p><i>Factors influencing use</i></p> <p>The primary reason for not receiving additional therapy was not enough income & insufficient insurance coverage reported by 44.4% and 42.8% of CGs of survivors with and without spatial neglect respectively. Spatial neglect associated with increased informal caregiving time.</p>

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Ghose et al., 2005	USA	Evaluate relationship between post-stroke depression (PSD) & healthcare utilization; evaluate relationship between other mental health diagnoses & medical utilization	Cohort study; case-control sub-study	56,093 stroke survivors discharged between October 1, 1990, and September 30, 1997; 204 stroke survivors (34 with PSD, 170 w/o PSD) 1) National database: n=50,922, mean age 67.4, SD 10.15, gender: 1.8% female 2) Local Veterans Affairs Med. Center (VAMC): n=483, mean age 66.49, SD 9.78, gender: 0.8% female 3) Selected VMAC: n=197, mean age 63.49, SD10.06, gender: 1.0% female	U.S. Dept. of Veterans Affairs administrative databases, 3 years of post-stroke health care utilization data;	<i>Factors influencing use</i> 5% of veterans received PSD diagnosis & 4% received other mental health diagnosis; PSD increases number inpatient hospitalization days & outpatient visits; other mental health diagnosis increased medical utilization; both PSD & other mental health diagnoses independently predicted medical utilization

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Hare et al., 2006	Birmingham, UK	Identify long-term support needs of adults with stroke, and their CGs	Unspecific qualitative study	27 stroke survivors & 6 CGs, 6 weeks to 22 years post-stroke Stroke survivors - gender: 48% female, median age 66-75 years across 3 groups CGs - gender: 100% female	Focus groups, constant comparison analysis	<p><i>Experience in access and use</i></p> <p>Approximately half of participants received some degree of support on a regular basis, e.g. family, private home care, social services & homecare.</p> <p><i>Factors influencing use</i></p> <p>3 major themes emerged: (1) emotional & psychological problems, including anxiety & stigma; (2) lack of information available for adults with stroke & their families; (3) service contacts, including importance of Primary Care as first point of contact for information or problems, social services & home care. Both patients and caregivers wanted more information about topics such as benefits advice & opportunities to network. Almost none knew which agency to approach for assessments or funding. Most were unaware of support groups such as Stroke Association.</p>

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
King & Semik, 2006	Unspecified USA	Identify the most difficult times, unmet needs, & advice of caregivers during the first 2 years of stroke CGs	Cross-sectional mixed-methods study	93 stroke CGs 2 years post-stroke; gender: 64% female, average age of 56.7 years	CG demographics, socioeconomics & health status; stroke survivor cognition, motor & communication function	<p><i>Experience in access and use</i></p> <p>Percentage of participants using resources:</p> <ul style="list-style-type: none"> • Home health care: 51% • Spiritual support: 49% • Talking to peers: 37% • Recreation services (survivor): 28% • Vocational services (survivor): 22% • Counselling: 20% • Support group: 20% • Stress management 20% • Respite: 19% • Helpline: 2% <p>Unmet needs of survivor identified included equipment, therapy, social-recreational, counselling, transportation and finances Unmet needs of CGs included: respite, peer sharing, professional counselling, legal assistance, financial advice, information (e.g., stroke prevention)</p> <p><i>Factors influencing use</i></p> <p>Presence of unmet needs of CGs related to CG age: unmet needs – 52.5 years, no unmet needs – 62.5 years; financial problems related to unmet needs; CG race: white (versus non-white) related to more unmet needs; lack of information related to unmet needs</p>

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Masry et al., 2013	Sydney, Australia	Investigate the psychosocial aspects of the experiences, concerns and needs of stroke CGs	Cross-sectional phenomenology	20 stroke CGs and 20 stroke survivors at least 3 months post-stroke; CGs – gender: 16 female, 4 male, 65% were 61 years or older	CG and stroke survivor demographics; duration of caregiving; type and intensity of caregiver activities	<p><i>Experience in access and use</i></p> <p>Unmet needs of CG: stroke education & knowledge, improved access to & quality of services & informal support, CG needs mostly not met & tied strongly to stroke survivors’ access to services and resources</p> <p><i>Factors influencing use</i></p> <p>CGs experienced changes in personal circumstances in five domains since becoming a caregiver:</p> <ul style="list-style-type: none"> • Relationships and support • Caregiver factors • Stroke survivor factors • External stressors • Positive outcomes

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Pindus et al. 2018	Australia, Canada, England, Iran, Northern Ireland, Norway, Scotland, Sweden, UK, USA	Describe & explain stroke survivors' & informal CGs' experiences of primary care & community healthcare services; offer solutions for how healthcare services could address negative experiences	Systematic review & meta-ethnography	51 qualitative studies of community-dwelling stroke survivors and/or informal CGs' experiences of primary care and/or community healthcare services	Medline, CINAHL, Embase & PsycINFO databases (range 1996-2015); original authors' interpretations of participants' experiences were identified across studies & used to develop a novel integrative account of the data	<i>Factors influencing use</i> Three constructs: (1) marginalization of stroke survivors & CGs by healthcare services, (2) passivity vs. proactivity in relationship between health services & patient/CG dyad, (3) fluidity of stroke related needs for both stroke survivors & CGs; continuity of care, limitations in service access & inadequate information about service access & use drive perception of marginalization & passivity for adults with stroke & CGs; fluidity apparent through changing information needs & psychological adaptation to long-term consequences of stroke
Simon et al., 2008	UK south coast	Explore formal care provision to community-dwelling adults with stroke & their informal CGs	Unspecified cohort study with data collection prior to discharge & 6 weeks & 15 months post-discharge	Prior to discharge: 105 stroke CGs, mean age 67 years, gender: 77 female, 28 male 6 weeks post-discharge: 74 CGs, mean age 66 years, gender: 54 female, 20 male 15 months post-stroke: 53 CGs, mean age 66 years, gender: 39 female, 14 male	3 fully structured interviews; questionnaires for psychological & self-rated physical health, social well-being, handicap of adult with stroke, formal community service	<i>Experience in access and use</i> Most CG-stroke survivor dyads used multiple services (mean 5.4 services) & 74% of CGs were satisfied with formal services; number services used decreased from 6 weeks to 15 months (5.5 vs. 4.1) but not time allocated; service satisfaction at 6 weeks post-stroke was most affected by quality of informal support; service satisfaction at 15 months post-stroke was most affected by quality of dyad relationship. Examples of services used by CGs at 15 months after stroke: general practitioner - 77.4%, community nurse - 73.0%, physiotherapist - 63.5%, occupational therapist - 54.1%, home carers - 47.3%, social services - 41.9%, hospital outpatient - 36.5%, day centre - 31.1%, specialist stroke support nurse - 20.3%, speech therapist - 20.3%, voluntary support groups - 17.6%, inpatient care/respice - 5.4%, cleaner: 5.4%, community psychiatric nurse - 4.1%, counsellor - 1.4%

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Simon et al., 2008 continued ...						<p><i>Factors influencing use</i></p> <p>Factors predicting more services used at 6 weeks:</p> <ul style="list-style-type: none"> • More functional handicap of survivor • CGs with poorer perceived health used more services <p>Factors predicting more time allocated to service use at 6 weeks:</p> <ul style="list-style-type: none"> • More functional handicap of survivor • CGs with fewer informal supporters used more supports • CGs with other care commitments <p>Factors predicting more services used at 15 months:</p> <ul style="list-style-type: none"> • Functional handicap of survivor • Social support quality • Prior caregiving experience <p>Factors predicting satisfaction with services at 15 months:</p> <ul style="list-style-type: none"> • Quality of relationship with stroke survivor • Age of CG <p>Key finding: If CG had fewer informal supports, then they received more services after 1 year</p>

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
Torbica et al., 2015	Northern, central & southern Italy	Investigate impact of informal care on utilization of health services; analyze role of informal care in access to & use of rehabilitation services during stroke recovery	Observational, prospective, incidence-based, multi-centre study with data collection at 3, 6, 12 months post-stroke	532 stroke survivors	Socio-demographic, clinical (co-morbidities, stroke type, stroke severity, physical disability, quality of life) & economic data on stroke survivors & informal CGs; longitudinal log-linear model, double hurdle model	<p><i>Experience in access and use</i></p> <p>Services used 6-12 months after stroke: inpatient rehabilitation - 0.9%, outpatient rehabilitation - 20.9%, hospitalization - 4.6%, imaging - 39.3%, visits to general practitioner or specialist - 78.9%, drugs - 82.5%, and nursing home - 1.6; healthcare costs 6-12 months post-stroke were €5,825/patient (68% of this rehabilitation costs)</p> <p><i>Factors influencing use</i></p> <p>CG presence was associated with 55% increase in healthcare costs but amount of informal care did not affect healthcare costs; CG presence increased probability of access to rehabilitation services, but not amount of services used</p> <p>Factors positively associated with accessing rehabilitation services:</p> <ul style="list-style-type: none"> • Presence of informal CG • Lower CG age • Stroke related neurological deficit at admission • Higher disability level • Living in metropolitan urban centre

Table 1 Continued

Citation	Country or region	Purpose	Design	Sample	Methods	Main results
White et al., 2007	Montreal, Canada	To determine the factors that act as barriers and facilitators to stroke caregiving role	Qualitative thematic, cross-sectional, 1 year or less in caregiving role	14 stroke caregivers, gender: 7 female, 7 male, majority over 50 years of age (true value not stated)	Sample identified based on stroke survivors discharged to community or rehab from acute care teaching hospital, focus groups of 2-4 CGs	<p><i>Factors influencing use</i></p> <p>Barriers</p> <ul style="list-style-type: none"> • Lack of coordination with health team • Intensity of caregiving • Negative effects on lifestyle • Lack of community support for CGs <p>Facilitators</p> <ul style="list-style-type: none"> • Coordination of care • Progress towards a sense of normalcy • Competence in CG role • Social supports • Accessible community services

services, and home care) on a regular basis (6 weeks – 22 years post-stroke) (Hare et al., 2006). (Table 1).

The authors of several studies found that while caregivers rated various services as important, few actually used these services. Services used infrequently despite being rated as important were respite, stress management, and conversing with peers (King & Semik, 2006; Simon et al., 2008) (Table 1). Over half of stroke caregivers participating in a USA study rated counselling, support groups and stress management services as important; however, these services were only used by 20% of caregivers (King & Semik, 2006). Further, 34%-74% of caregivers in that study stated during in-depth interviews that services such as respite, stress management strategies and engaging with peers were important to them although they were not using these services (King & Semik, 2006). The authors of several studies mentioned unmet caregiver service needs that included services providing information relevant to caring for stroke survivors, social-recreational supports and rehabilitation (P. Chen et al., 2017; King & Semik, 2006; Masry et al., 2013). However, an examination of caregivers' experiences in using these formal health and social services in the UK revealed that 74% of caregivers were satisfied with the limited services they did use up to 15 months post-stroke (Simon et al., 2008) (Table 1).

In summary, very few studies have explored the use of formal health and social services by caregivers of stroke survivors. The studies found by this literature review mainly speak to the type and frequency of different services used and less so to caregivers' experience using these services. The limited research available indicates that stroke caregivers continue to access a variety of formal health and social services a considerable time after the stroke occurrence. Services used more frequently by caregivers included: homecare services, peer support and the

services of a general practitioner. Services used less frequently by caregivers included: counselling, inpatient respite and helplines. Caregivers report positive experiences and value in using formal health and social services although there is little research on this. Furthermore, studies also determined that caregivers were failing to use services that they nevertheless deem as important. These findings suggest that there is a gap in our understanding of stroke caregivers' experience accessing and using services within the Canadian context.

Factors influencing stroke caregivers' use of formal health and social services.

All ten of the reviewed studies explored factors that influence use of formal health and social services by caregivers and stroke survivors (Chan et al., 2009; P. Chen et al., 2017; Ghose et al., 2005; Hare et al., 2006; King & Semik, 2006; Masry et al., 2013; Pindus et al., 2018; Simon et al., 2008; Torbica et al., 2015; White et al., 2007). Factors influencing stroke survivor use of formal health and social services were included as they also may have affected caregivers. The ten studies included the following designs: three qualitative studies (Hare et al., 2006; Masry et al., 2013; White et al., 2007), two mixed-methods studies (P. Chen et al., 2017; King & Semik, 2006), four quantitative studies (Chan et al., 2009; Ghose et al., 2005; Simon et al., 2008; Torbica et al., 2015; White et al., 2007), and one systematic review (Pindus et al., 2018) (Table 1).

A number of factors impacted service access and use by caregivers and stroke survivors including demographic factors such as age and gender (Chan et al., 2009; P. Chen et al., 2017; King & Semik, 2006; Simon et al., 2008; Torbica et al., 2015), caregivers' knowledge of services (Hare et al., 2006; King & Semik, 2006; Masry et al., 2013; Pindus et al., 2018; Simon et al., 2008), social-relational factors such as marginalisation of caregivers (Hare et al., 2006; Pindus et al., 2018), service provision and accessibility factors such as type of available services (Masry et

al., 2013; Pindus et al., 2018; White et al., 2007) and stroke survivor-related factors (Chan et al., 2009; Ghose et al., 2005; Simon et al., 2008; Torbica et al., 2015) as described in more detail below (Table 1).

Specific demographic factors that were associated with service use included: age, gender, income, place of residence and race (Chan et al., 2009; P. Chen et al., 2017; King & Semik, 2006; Simon et al., 2008; Torbica et al., 2015) (Table 1). In a USA study, increasing stroke survivor age was associated with higher levels of service use in older female stroke survivors (Chan et al., 2009). However, the same study determined that decreasing stroke survivor age was associated with greater levels of outpatient rehabilitation service use (Chan et al., 2009). This study also reported that male stroke survivors were more likely to use outpatient rehabilitation services and female stroke survivors were more likely to receive homecare services (Chan et al., 2009). In a study from Italy, a finding of note was that increasing age of caregivers was associated with less use of services by stroke survivors (Torbica et al., 2015). In these instances, older caregivers may have their own health constraints, therefore rendering them less able to support the stroke survivor in using services as well as limiting their own service use. This finding may indicate an increased need to support both older caregivers and older stroke survivors (Torbica et al., 2015) (Table 1).

Financial factors including household income, insurance coverage and the costs associated with using services impacted service access and use by stroke survivors and their caregivers. Chan et al. (2009) reported that stroke survivors who had higher median household income made greater use of outpatient rehabilitation in the USA. In addition, the authors of two studies determined that costs associated with service use as well as a lack of insurance coverage

hindered caregiver and stroke survivor access and use of services (P. Chen et al., 2017; King & Semik, 2006) (Table 1).

Torbica et al. (2015) explored the impact of informal care on formal care utilization in Italy and found that total healthcare costs were higher for stroke survivors who had an informal caregiver, irrespective of the hours of support provided, compared to stroke survivors without informal caregiver support. The authors suggest that the high healthcare costs associated with informal caregiving arise because the caregivers may have facilitated the stroke survivors' use of rehabilitation and other services (Torbica et al., 2015) (Table 1).

Researchers identified geographic location as a determining factor for service use, with those who lived in urban settings having greater overall service use (Simon et al., 2008) and greater use of outpatient rehabilitation (Chan et al., 2009; Torbica et al., 2015) (Table 1). These findings suggest that those who are situated in rural settings may experience challenges in accessing and using community-based services intended to support them.

Chan et al. (2009) reported that stroke survivors who were non-white made greater use of outpatient rehabilitation services than stroke survivors who were white in the USA (Chan et al., 2009). The authors hypothesized that access to rehabilitation services by non-white stroke survivors likely was facilitated by increased cultural sensitivity among health service providers who have received unconscious racial bias training (Chan et al., 2009). Paralleling this finding is the observation by the authors of another study from the USA that non-white caregivers showed a lower incidence of unmet caregiver needs than white caregivers (King & Semik, 2006) (Table 1).

Knowledge-related factors influenced service access and use in several ways. For example, when caregivers had limited knowledge of available services this hindered their access

to services (Hare et al., 2006; King & Semik, 2006). The author of a UK study found that even in situations where the survivors' stroke occurred several years earlier, caregivers demonstrated a lack of knowledge of services available to them, suggesting that length of caregiver experience does not necessarily increase knowledge of and access to services (Hare et al., 2006). However, another study conducted by Simon et al. (2008) in the UK found that having caregiving experience and other care commitments led to an increased use of formal services for stroke survivors. Further research is warranted to understand the mechanism by which these factors influence caregiver access and use of services. Information on a broad array of topics, such as stroke management, employment benefits counselling and making community connections was felt to be lacking by both caregivers and stroke survivors and, of particular note, there was an identified lack of awareness of support groups like the Stroke Association by caregivers and stroke survivors alike (Hare et al., 2006) (Table 1).

Caregivers also faced challenges in finding out about caregiver training. For example, caregivers reported that many service providers discussed the importance and requirement for caregiver training, but not necessarily how caregivers were going to acquire this training, which contributed to caregivers' levels of anxiety (Pindus et al., 2018). Moreover, caregivers and stroke survivors alike expressed dissatisfaction about the insufficiency of information available on stroke, particularly regarding post-stroke health and symptom management (Masry et al., 2013; Pindus et al., 2018) (Table 1).

Examining the impact of social-relational factors on service access and use, the marginalisation of stroke caregivers and their fear of stigma around stroke were found to be important (Hare et al., 2006; Pindus et al., 2018). In a UK study, caregivers felt they had to be care experts with little opportunity for respite and in some cases were unwilling to ask for help

for fear of upsetting the stroke survivor (Hare et al., 2006). It is argued that managing the chronicity of stroke at the policy and societal level is necessary to address the long-term exclusion and isolation that is experienced by some stroke survivors and their caregivers (Hare et al., 2006) (Table 1).

Several factors related to the quality and availability of services influenced access and use of services. The literature suggests that caregivers were frustrated by the lack of ongoing care provision or acknowledgement that more care was required once the stroke survivor returned to the community (Pindus et al., 2018). Caregivers also felt that the prevailing attitude from the health system was that they would be the primary caregivers for the stroke survivor with few or no formal services being provided to assist them (Pindus et al., 2018). In addition, the low quality of some available services (Masry et al., 2013) as well as the lack of availability of some services such as respite and accessible community services constrained caregivers' and stroke survivors' access and use of services (Pindus et al., 2018; White et al., 2007) (Table 1).

Higher use of services was associated with higher levels of stroke survivor disability (Simon et al., 2008; Torbica et al., 2015), longer acute care hospitalization of the stroke survivor (Chan et al., 2009), post-stroke depression in the stroke survivor (Ghose et al., 2005), having an ischemic stroke (Chan et al., 2009), and having spatial neglect (Chen et al., 2017). A positive association between the extent of the stroke survivor's disability and caregiver service use has been shown by a study from the UK (Simon et al., 2008) (Table 1).

In summary, the studies included in this review have identified several individual, organizational, and system factors that impact caregiver and stroke survivor service access and use. Some factors act as barriers and others as facilitators to access and service use. Facilitators to service use included: higher income, better social supports, urban residence, longer acute care

hospitalization of the stroke survivor, a diagnosis of post-stroke depression in the stroke survivor, ischemic stroke in the stroke survivor and survivor use of services. Barriers included: costs associated with service access and use, lack of insurance coverage, poor quality of services, limited availability of certain services, and limited knowledge of available services. The findings suggest that services for caregivers and stroke survivors are available but they are not always accessed and used. While several factors have been identified, there is a gap in knowledge about how these factors, at the population, health system, community and individual level, impact caregivers' ability to access and use health and social services, particularly within a Canadian context. A qualitative study design could be used to facilitate a greater understanding of these factors. Furthermore, the findings would be well-placed to inform optimization of current service provision and to develop targeted initiatives directed towards addressing stroke caregiver needs.

Quality assessment of included studies.

The methodological quality of the ten included articles was assessed. The qualitative studies (Hare et al., 2006; Masry et al., 2013; White et al., 2007) were assessed using the appraisal tool for qualitative studies from the Critical Appraisal Skills Programme (2018). The mixed-methods studies (P. Chen et al., 2017; King & Semik, 2006) were assessed using the mixed methods appraisal tool presented by Pluye and Hong (2014). The quantitative cohort studies (Chan et al., 2009; Ghose et al., 2005; Simon et al., 2008; Torbica et al., 2015) were assessed using the appraisal tool for cohort studies from the Critical Appraisal Skills Programme (2018). The systematic review (Pindus et al., 2018) was assessed using the appraisal tool for systematic reviews from the Critical Appraisal Skills Programme (2018). All articles met the majority of the specified quality appraisal criteria (Table 2). Of the ten articles, four fulfilled all

the applicable quality appraisal criteria, and the remaining six articles fulfilled between 60% and 83% of the applicable quality appraisal criteria.

The limitations of the studies included: poor description of the qualitative and quantitative arms of the mixed-methods studies (P. Chen et al., 2017), small sample size (P. Chen et al., 2017), no mention of weighting of the respective study arms (P. Chen et al., 2017; King & Semik, 2006) and the potential for recall bias in the qualitative studies depending on the studies' requested recall timeframe (Hare et al., 2006; Masry et al., 2013; White et al., 2007).

The qualitative studies provided insufficient description of the research design (Hare et al., 2006), an overall lack of detail regarding the guiding questions for the participant interviews and focus groups (Hare et al., 2006; Masry et al., 2013), and no explanation of the theoretical underpinnings of the studies (Hare et al., 2006; Masry et al., 2013; White et al., 2007). Sample sizes varied from 6 to 20 caregivers meaning that a limited amount of data could be extracted to inform the research questions. This suggests that the findings should be further validated by research with larger sample sizes and a broader representation of caregivers. Caregivers sampled in these studies tended to be female and were primarily the spouse of the stroke survivors they supported (Hare et al., 2006; Masry et al., 2013; White et al., 2007) and some had limited experience in their caregiving role (White et al., 2007).

Methodological limitations of the quantitative study designs included the use of weak study designs, e.g., retrospective cohort (Chan et al., 2009; Ghose et al., 2005) or cohort designs (Simon et al., 2008; Torbica et al., 2015) and a case control sub-study (Ghose et al., 2005). Some study samples were limited in that they excluded certain groups (e.g. when race/ethnicity was other than Asian, black, Hispanic, or white) (Chan et al., 2009), only included participants

Table 2

Critical Appraisal of Included Articles Adapted From: Critical Appraisal Skills Programme (2018); Pluye and Hong (2014)

Quantitative Cohort Studies ^a	Representative sample	Patients similar	Outcomes objective	Sufficient follow-up	Withdrawals described	Reliable measures	Appropriate statistics				Overall appraisal
Chan et al. 2009	Y	Y	Y	Y	Y	Y	Y				Include
Ghose et al., 2005	N	Y	Y	Y	N/A	Y	Y				Include
Simon et al., 2008	Y	Y	Y	Y	Y	Y	Y				Include
Torbica et al., 2015	Y	Y	Y	Y	Y	Y	Y				Include
Qualitative Studies ^b	Clear research aim	Methodology appropriate	Design appropriate	Recruitment appropriate	Clear how data collected	Relationship between researcher/participant considered	Ethical issues discussed	Analysis rigorous	Clear statement of findings	Value of research discussed	Overall appraisal
Hare et al., 2006	Y	Y	N	Y	N	N	N	Y	Y	Y	Include
Masry et al., 2013	Y	Y	Y	Y	Y	N	N	Y	Y	Y	Include
White et al., 2007	Y	Y	N	Y	N	N	N	Y	Y	Y	Include

Notes. ^an = 4, ^bn = 3

Table 2 Continued

	Clear research questions	Collected data address question	Relevant Qualitative data source	Relevant qualitative data analysis	Consideration of context	Consideration researchers influence	Relevant sampling strategy	Representative sample	Appropriate measurements	Acceptable response rate	Relevant mixed methods design	Relevant integration qual & quantitative	Consideration limits to integration qualitative & quantitative	Overall appraisal
Mixed Methods Studies ^a														
King & Semik, 2006	Y	Y	Y	Y	Y	N	Y	Cannot tell	Y	Can't tell	Y	Y	N	Include
Chen et al., 2017	Y	Y	Y	Y	Y	N	Cannot tell	Cannot tell	Y	Y	Y	Y	N	Include
Systematic Reviews ^b	Clear research questions	Right type of papers	Important, relevant studies	Authors assessed quality of studies	Reasonable to combine results	Overall results clear	Precision of results	Results applicable to local population	All-important outcomes considered	Benefits worth harms and costs				Overall appraisal
Pindus et al., 2018	Y	Y	Y	Y	Y	Y	N/A	Y	Y	Y				Include
<i>Notes.</i> ^a <i>n</i> = 2, ^b <i>n</i> = 1														

from Veterans Affairs (Ghose et al., 2005), or were of small size (P. Chen et al., 2017; White et al., 2007). Additionally, one study showed only a small amount of the variation in the utilization of services that was accounted for by their regression model, suggesting that healthcare use was moderated by a number of complex factors that were not captured by their database (Ghose et al., 2005).

Further, in one quantitative study the authors suggest that caregivers facilitated the use of services by stroke survivors but collected no data to corroborate this nor did they discuss caregiver specific use of services (Torbica et al., 2015). Finally, two studies had small sample sizes (P. Chen et al., 2017; White et al., 2007) thereby potentially limiting their generalizability, and one study had a low (52/105) retention rate (Simon et al., 2008).

Generalizability of the results reported in the systematic review and meta-ethnography by Pindus et al. (2018) is limited by a lack of available data regarding stroke severity, long-term impairments, socioeconomic variables, and ethnicity. Also, insights about the changing nature of healthcare needs over time were difficult to gain because the reviewed studies followed a qualitative study design with most being cross-sectional (Pindus et al., 2018). Finally, while the authors state that they likely reached data saturation, they do not provide any information about how they confirmed this (Pindus et al., 2018).

Summary of literature review main results.

In summary, few studies have investigated the use of formal health and social services by caregivers of stroke survivors and some of these studies had methodological limitations. The limited research available indicates that stroke caregivers continue to use formal health and social services in the community after the stroke survivor is discharged. Caregivers often used services that included: homecare services, peer support and the services of a general practitioner.

Less frequently they used: counselling, inpatient respite and helplines. Caregivers found the services helpful for them although there is little research on this. Importantly, studies determined that there were some services that caregivers evaluated as important but that they did not use.

Factors associated with service use by caregivers and stroke survivors included being an older female stroke survivor (homecare) or a younger stroke survivor (outpatient rehabilitation), and having a higher household income. Factors that hindered or were associated with less service use by caregivers and stroke survivors were costs of services, lack of insurance (USA context), poor service quality and deficient knowledge of services. Mixed findings were identified with regard to the influence of prior caregiving experience on service use with one study finding that prior caregiving experience was associated with increased use of homecare, but another study suggesting that length of caregiving experience spanning several years did not lead to increased knowledge of services available to caregivers.

Overall, caregivers felt they were expected to be the primary caregiver with limited formal services available to support them in the community. Furthermore, caregivers were reticent to ask for help for fear of upsetting the stroke survivor they were supporting. The results of this review demonstrate that some caregivers use certain types of services long after the stroke survivor experienced their stroke such as homecare services, peer support and the services of a general practitioner. However, other caregivers made no use of services even if they found them important such as counselling, support groups and stress management services. The results of this review suggest that several factors are important in limiting caregivers' use of services while also potentially increasing caregivers' need for services to support them, such as higher age and residing in rural areas. Nevertheless, we have limited understanding of caregivers' experience in accessing and using these services.

Significance of Research

To date there has been little research conducted on stroke caregivers' experiences of accessing and using formal health and social service and the factors associated with their use of services. The proposed study will help address this knowledge gap by using a qualitative approach that will enable in-depth exploration of the potentially influential factors of stroke caregiver health and social service use within a Canadian context. Interviewing both caregivers and health professionals who work with stroke survivors and their caregivers, referred to as the thoughtful clinician perspective by Thorne (2016), will contribute a holistic perspective to the knowledge foundation on this topic. This information can then be used to inform and potentially improve practice and policy to better meet the needs of caregivers and stroke survivors.

Chapter 3

Methodology

Introduction and Overview of Chapter

This chapter provides the rationale for using a qualitative interpretive descriptive (ID) research approach (Thorne, 2016). Details of the specific methodological approach will be explained and a comprehensive description of the study setting, recruitment strategies, processes of data collection and analysis, and interpretation of study findings will follow. The chapter closes with a discussion of the actions taken to ensure study quality and a description of the steps taken to ensure ethical conduct of the research.

Rationale for Qualitative Research Design

A qualitative research approach enables the researcher to attain a rich and extensive understanding of a topic or issue by using techniques such as collecting multiple sources of data, conducting research in a natural setting and using research approaches that are inductive and emergent in nature (Cresswell, 2007). Since researchers are the “key instruments” in qualitative research, they can tailor their interview questions to help elucidate a topic or issue to foster a rich understanding of an individual’s experience and explore clinically-focused issues (Cresswell, 2007). In designing this research study, I sought to achieve a comprehensive understanding of stroke caregivers’ experience accessing and using formal health and social services and the factors influencing their use of these services. As described in the literature review, stroke caregivers have reported multiple factors that influence their access and use of services (Hare et al., 2006; King & Semik, 2006). However, this literature also shows that while caregivers value these services for the supports they are providing, few caregivers make use of them (Grant et al., 2014a; Hare et al., 2006; King & Semik, 2006).

Interpretive Description

The interpretive description approach was developed in the late 1990's in response to the need to adapt earlier methodological approaches to better reflect the context in which they were being applied, for example, when studying health or illness conditions from the perspective of the individual (Thorne, Kirkham, & O'Flynn-Magee, 2004). The purpose of interpretive description is to, “generate knowledge relevant for the clinical context of applied health disciplines” (Hunt, 2009, p. 1284). Earlier qualitative approaches, while methodologically rigorous, were viewed to be rigid in terms of their application, often with the ultimate goal of theory development, thus making them unsuitable for application to complex clinical questions (Thorne, Kirkham, & MacDonald-Emes, 1997).

Thorne and her colleagues developed ID “for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding” (Thorne et al., 2004, p. 3). ID is situated within a post-positivist paradigm, grounded in the tradition of naturalistic inquiry (Lincoln & Guba, 1985) and aligns with a constructivist ontological stance. Studies conducted using this method should adhere to a number of underlying assumptions: (a) research should be conducted in a natural setting with respect given to the rights of all participants, (b) research should value and embrace subjective and experience-based learning acknowledging that there is a “socially constructed element to human experience” that is inseparable from “it's essential nature”, (c) there should be recognition and acknowledgement that individuals create their own reality based on their subjective experiences and these realities can be contradictory, and (d) the researcher and study participant will have an interactive relationship with shared realities that will influence the research results (Thorne, 2016, p. 82). ID studies should “attend carefully to the time and

context within which human expressions are enacted” (Thorne, 2016, p. 82). ID with its ready acceptance of the contextual nature of human behaviour and interpretive elements, is well situated to enable clinician researchers to explore multi-faceted clinical issues with a rigorous, well-established methodological approach that is both informed by and can inform clinical practice (Thorne et al., 1997).

Inherent in ID is the inclusion of the thoughtful clinician perspective, an aspect that entails using interviews with practitioners to supplement the data collected from interviews with primary study participants (Thorne, 2016). Practitioners’ expertise and exposure to many clinical examples positions them to provide a broader perspective about study findings and when triangulated with other participant data may increase generalizability beyond a potentially discrete environment (Thorne, 2016).

The RC – MCC framework, which defines complexity as the mismatch between the needs of the patient and the services provided by the health care system, was an appropriate framework to guide development of this study because of its emphasis on inter-relational components that influence the patient and their interaction with the health system (Grebowski et al., 2014; Zullig et al., 2016). The comprehensive nature of the framework takes into account patient, health system and community wide contextual factors (Grebowski et al., 2014). Within the RC – MCC framework, the person or dyad is directly impacted by social and individual-based factors such as characteristics, values and preferences. Grebowski et al. (2014) also recognized that there are contributing factors that, while external to direct influence on the constructs of need or services, still impact the stroke survivor-caregiver dyad and their ability to use services.

For the purposes of this research, the RC – MCC framework was modified to include the stroke survivor-caregiver dyad thereby allowing for exploration of services used by both stroke caregivers and stroke survivors (Grembowski et al., 2014). I reflected on the application of the study findings to inform the RC – MCC framework and increase our understanding of the factors that influence caregivers' use of services.

Setting

The research took place in southern Ontario within the communities of Brantford, Burlington, Dundas, Hamilton, Grimsby, Guelph, Hagersville, Kitchener, Middlesex County, Paris, Scarborough, St. Catherine's, Stoney Creek, and Wellington County. Ontario is Canada's most populous province with an estimated incidence of 25,000 strokes each year of which 40% will be left with residual impairment (Ontario Stroke Network, 2013; Statistics Canada, 2016). The residents of Ontario receive stroke-related services via 10 regional stroke networks and 11 regional stroke centres (CorHealth Ontario, 2019).

Sampling and Recruitment

Sampling strategies and sampling size.

There is no predetermined upper or lower limit for sample size in an interpretive description study however, sample size should be justified by appropriate rationale that is also compatible with the proposed research questions (Thorne, 2008). Therefore, a search of the literature was conducted to explore sample size variation across a selection of ID studies conducted in nursing and health sciences. The sample sizes across six studies in these disciplines ranged from between eight to 18 participants with an average sample size of 12 (Andreasen, Lund, Aadahl, & Sorensen, 2015; Atkinson & McElroy, 2016; Durlacher, Verchere, & Zwicker, 2015; Kimber, Georgiades, Jack, Couturier, & Wahoush, 2015; Macartney, Stacey, Harrison, &

VanDenKerkhof, 2014; Williams & Haverkamp, 2015). I proposed an overall sample size of 25-35 with between 15 to 20 stroke caregivers and 10 to 15 health providers. The inclusion of health providers was consistent with ID's emphasis on the value of the thoughtful clinician perspective. The addition of health providers as study participants allowed for triangulation of the data and provided an alternate perspective grounded across time and context, thus helping to ensure the analytic rigor of the study findings (Thorne, 2008).

A combination of four purposive sampling strategies were used: criterion sampling, maximum variation sampling, theoretical sampling and snowball sampling (Thorne, 2016). Initially, criterion sampling, the selection of participants based on the fulfilment of specific criteria was used to recruit study participants (Thorne, 2008). Eligible caregivers who met the following inclusion criteria were enrolled in the study: (a) family or friend caregivers over the age of 18 years who had experience providing support to a stroke survivor in the community setting, and (b) English-speaking. The caregiver was defined as a family member (e.g. spouse, child, parent) or friend who had experience providing physical or emotional support to a stroke survivor. Those caregivers who only had experience with providing support to a stroke survivor who was residing in alternative level of care such as inpatient rehabilitation, acute care hospital or long-term care were ineligible to participate in the study. Stroke survivors were required to be over the age of 18 and to have experienced their stroke at least six months and no more than five years ago. Eligible health providers who met the following inclusion criteria were enrolled in the study: (a) provided direct or indirect care to the stroke survivor and/or stroke caregiver and (b) provided or were able to provide information and /or education regarding community-based services for a stroke caregiver.

Maximum variation sampling was used to maximize diversity of participants on characteristics relevant to the research (Patton, 1990). Stroke caregivers were sampled based on diversity in their geographic location, the length of time they had been a caregiver (six months – five years), their gender and employment status, and caregiver and stroke survivor age. The health providers were sampled based on diversity in their professions and geographic location.

Theoretical sampling, the selection of participants to fulfill specific criteria or explore an idea or finding was used later in the data collection process (Bagnasco, Ghirotto, & Sasso, 2014). As data collection proceeded effort was made to include health providers who assisted stroke caregivers and stroke survivors in their homes as well as in outpatient settings. This was done because preliminary findings suggested that health providers who provided care in the home would have different perspectives to offer on the experiences of stroke caregivers in accessing and using formal health and social services.

Finally, snowball sampling, a non-probability sample technique where identified members of a population help identify others within the population, was also used to recruit stroke caregivers and health providers. Health providers and stroke caregivers were asked to reach out to their networks to identify possible study participants, enabling me to broaden my sample. Caregivers identified other caregivers and health providers identified both caregivers and other health providers. I recruited an overall sample of 40 participants with 22 stroke caregivers and 18 health providers.

Recruitment strategies.

Two different recruitment approaches were used, one for stroke caregivers and one for health providers (Figure 3). The initial stroke caregiver recruitment strategy involved distributing study information cards, posters and introducing the study to stroke caregivers at the

partner organizations of the Central South Regional Stroke Network. I attended meetings associated with: (a) Ontario Stroke Recovery Chapters, (b) follow-up clinics for stroke survivors, (c) YMCA Fit for Function programming, (d) adult day programming, (e) Regional Stroke Network meetings, (f) March of Dimes meetings, and (g) aphasia programs in the South Western Ontario region. Recruitment cards and posters were left behind at the meetings and organizational liaisons were asked to distribute them to interested participants who then contacted me if they wished to participate in the study. In addition, potential participants were recruited using study posters and information cards distributed by nurses at the Neurosciences Ambulatory Clinic located at the Hamilton General Hospital, Hamilton Health Sciences. I spoke with stroke caregiver liaisons at ad-hoc meetings and distributed contact cards so that the liaison could provide study information to other stroke caregivers or health providers who were interested in participating in the study. As recruitment proceeded, snowball sampling was also used whereby study participants contacted other potential participants within their network and introduced the study to them, a process that led to the recruitment of additional participants. Additionally, I worked to develop relationships with a broad group of health providers who worked with stroke survivors and their caregivers. This networking made it possible to distribute study information cards to potential stroke caregiver participants who could contact me to express their interest in participating in the study. Those interested participants who contacted me and met the study inclusion criteria were recruited to participate in the study.

A research coordinator at the Central South Regional Stroke Network distributed study information cards and posters, which facilitated recruitment of health providers. I also attended meetings of various groups to recruit health providers including: (a) Ontario Stroke Recovery Chapters, (b) follow-up clinics for stroke survivors, (c) YMCA Fit for Function programming,

(d) adult day programming, (e) Regional Stroke Network meetings, (f) March of Dimes meetings, and (g) aphasia programs in the Southern Ontario region. At these meetings, I described the study to health providers, answered their questions and invited them to participate in the study. As the study proceeded, health providers who participated in the study were able to connect me with other health providers. This process of snowball sampling enabled me to recruit health providers that were not reached using the initial recruitment strategies. My professional networks (e.g. contacts through previous employment with the LHIN and Victorian Order of Nurses) also facilitated additional recruitment of health providers, which added to the diversity of the study sample.

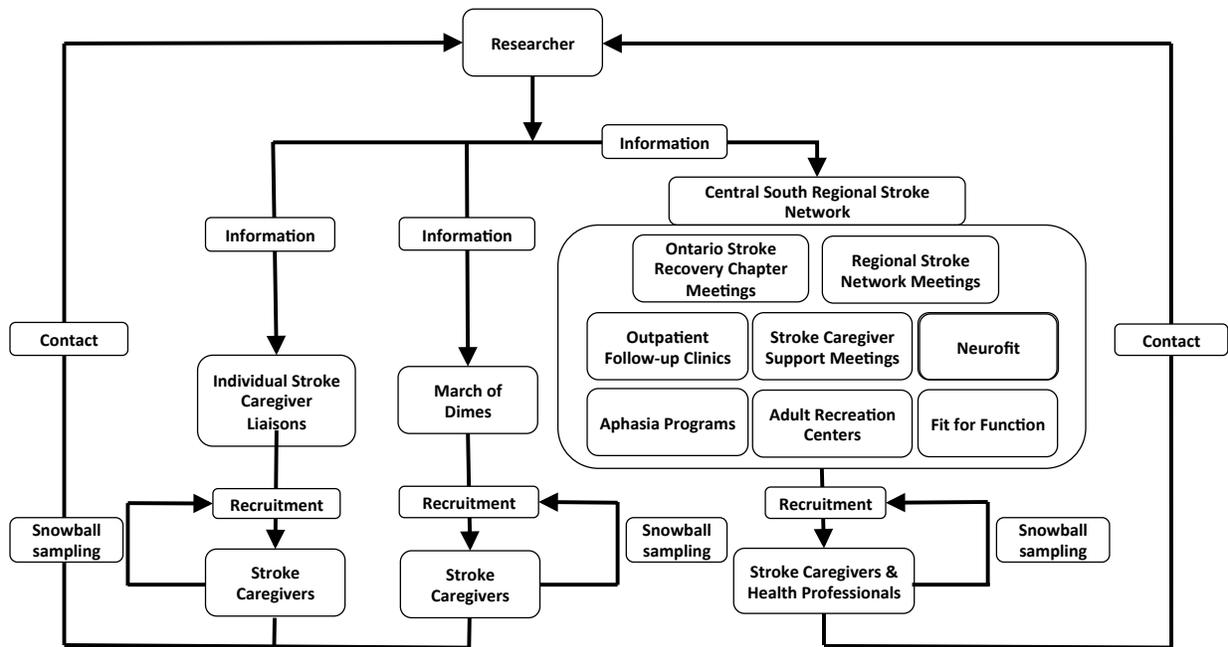


Figure 3. Recruitment strategy. This figure illustrates how the recruitment of stroke caregivers and health providers proceeded.

Data Collection

Interviews.

Consistent with the ID approach, in-depth interviews were conducted with all study participants (Thorne, 2016). Every effort was made to schedule interviews at a time that was convenient for the study participants. Participants could choose to participate in the interview in three ways: in person, via telephone or using Face Time. Most interviews were conducted through in-person interviews. The process of data collection and analysis proceeded in an iterative manner allowing for the development of new themes and ideas as the study proceeded (Thorne et al., 2004). All interviews were audio-recorded and subsequently transcribed prior to data analysis. The interview process entailed collecting basic demographic information (e.g., age, gender, employment status, date of stroke for stroke survivors, dwelling type, chronic health conditions) from the stroke caregiver participants (Appendix B). The first three alphanumeric symbols of participant postal codes were collected to categorize participants as either rural or urban dwelling based on their postal codes (Canada Post uses a “0” in the second position of the postal code to signify a rural community). This was followed by open-ended questions specific to the participant being interviewed (stroke caregivers or health providers).

Interview questions were developed based on the findings from the literature review and the RC – MCC framework (Grembowski et al., 2014), which provides a visual depiction of the factors that influence the needs of patients and caregivers and those factors that influence the availability of services (Appendix B & C). For example, questions were related to: (a) the caregiving role, e.g. “Can you tell me about what supports you provide?”; (b) social support, e.g. “Can you tell me about how being a caregiver has affected your social circle?”; (c) the stroke survivor, e.g. “Can you explain how your relationship with (name of stroke survivor) has been affected by becoming a caregiver?”; (d) health system and community resources, e.g. “Can you

tell me about your experience in accessing and using services?”; (e) the need-services gap, e.g. “Can you tell me about a time when you tried to access services?”; (f) the caregiver’s health, e.g. “Can you discuss how your health has been affected by your role as a stroke caregiver?”; and (g) contextual factors (economic/social/physical), e.g. “Can you tell me about something in your life that has had the most influence on your role as a caregiver?” Each of these questions helped explore the caregiving experience and the factors influencing their access and use of formal services (Appendix C).

The interview questions were piloted with one stroke caregiver and one health provider. I then met with my supervisor, discussed the findings from the pilot interviews, and revised the interview guides to ensure adequate capture or richness of information related to complexity and multiple chronic conditions. Based on this review process, one additional question was added to the stroke caregiver interview guide: (a) what is it like managing the complexity of multiple chronic conditions (in stroke survivor) as a stroke caregiver? Two questions were added to the health provider interview guide: (a) can you tell me how multiple chronic conditions in addition to being a stroke survivor affects the caregiving role? (b) Can you tell me how having multiple chronic conditions as a stroke caregiver affects their role?

Consistent with the ID approach, additional data were collected using ecomaps and field notes (Thorne, 2016). Quantitative information on formal homecare used in the last six months was collected from caregivers as well as whether they had other chronic conditions. Additional clinical data were collected about the stroke survivor, including the date of the patient’s stroke, the type of stroke, as well as ongoing health challenges and the number of MCC.

Ecomaps.

Data collection via semi-structured interviews with caregivers was enhanced through the use of ecomaps which involve the development of a pictorial representation of the relationships between an individual and the people in their environment (Hartman, 1995). Ecomaps can be used to help explain and understand the structure, size and function of the network and individual connections (Ray & Street, 2005). For the purposes of this research, ecomaps were used to depict the data and inter-relationships between caregivers, stroke survivors and health providers as well as community-based services. The process entailed jotting the details of the interviews in a large 9 x12 inch notebook and was used across all types of interviews: (a) in-person, (b) via Face Time or (c) via phone. The visual representation of the data was then corroborated with the data collected through the interviews to provide a more in-depth representation of the study findings (Figure 4) (Ray & Street, 2005; Rempel, Neufeld, & Kushner, 2007).

Field Notes.

From the start of the research process and throughout the study I kept a book of field notes. This process enabled me to make detailed notes on the research process, including documentation of meetings with my supervisor and committee, the data collection process and the process of analyzing the data. As the study proceeded, I also made notes on my thoughts, ideas and reflections in accordance with Thorne (2016). This practice helped me to situate myself within the research process and provided an opportunity to understand and reflect on my ongoing thought processes pertaining to the study. It also enabled me to immediately reflect on participant interviews as they occurred and to make note of the key ideas that emerged from the interviews (Gibbs, 2012). Furthermore, using field notes served as an audit trail so that I was able to look back over the course of the study and corroborate my activities and findings. My

personal and professional perspectives influenced these notes and, therefore they represented subjective and objective information pertaining to the study (Mulhall, 2003). Field notes were written as summary narratives soon after each interview and thereby constituted one of the first steps in the qualitative analysis (Gibbs, 2012). Field notes were also kept during the process of data analysis including during coding, thematic development and interpretations of the new findings.

Data Management

All interviews were audio-recorded and identified by a numeric code. The master list of codes and names was kept in a locked filing cabinet in the School of Nursing at McMaster University. Ecomaps were scanned, identified by numeric code, encrypted and stored in a password-protected computer. The hard copies of the ecomaps were also stored in a locked filing cabinet in the School of Nursing at McMaster University. The transcripts were entered into NVIVO 12.0.0, a software tool used to assist in analyzing qualitative data (QSR International Pty. Ltd., 2014). The use of NVIVO enables both storage and analysis of the transcribed data by allowing the researcher to quickly and easily conduct accurate searches and coding of the data (Welsh, 2002).

Data Analysis

Consistent with a constructivist theoretical perspective, study data were analyzed using inductive reasoning, moving from specific instances to a generalized conclusion. Furthermore, I acknowledge that the experiences of participants are socially and experientially situated and that my own perspective influenced the findings such that the final results are a co-creation of our respective understandings (Hunt, 2009; Thorne, 2016). The RC – MCC framework (Grembowski et al., 2014) was used to interpret the data through a lens that recognizes that

access and use of formal health and social services by stroke caregivers is a result of the complex interplay between multiple contextual factors.

In accordance with the flexibility of ID, Thorne (2016) suggests that researchers may seek guidance from other coding techniques to guide their analysis. As a result, I followed Thorne's suggestion and sought additional analytic guidance from both Saldana (2013) and Morse (1994). Saldana (2013) provides direction about the use of codes and coding techniques; Morse (1994) provides direction about cognitive processing whereby the researcher proceeds through a set of cognitive steps that facilitates the interpretive description process. Immediately after I conducted the interviews, I used the ecomaps created during the interview and my reflections pertaining to the interview to create a summary page of notes. On this page I described broad thematic patterns that captured the main points emerging from the interviews (Cresswell, 2007). Once the interviews had been transcribed, I re-read the interview transcripts several times to explore the data for overarching ideas and images of the data. I then added those initial impressions to the data sheets made immediately following the interviews; a step Morse (1994) calls comprehending. This process of reflecting and re-visiting the overarching themes or comprehending continued throughout the coding and thematic development stages of the analysis.

According to Saldana, a code is: “a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data” (Saldana, 2013, p. 3). In developing an early version of the coding list, my supervisor and I coded two transcripts using open coding also called line-by-line coding, to pull the data apart and look for “similarities and differences” (Thorne, 2016, p. 159). We then reviewed our results to ensure broad agreement on the coding list (Saldana, 2013). Members of

my supervisory committee also reviewed selected transcripts at this early stage to ensure that the codes were representative of the data. The preliminary coding list and any areas of broad discrepancy in coding were discussed with the research team and resolved before I moved forward to detailed coding using computer software.

The next step in coding was conducted using NVivo 12.0.0, (QSR International Pty. Ltd., 2014). Using guidance from Saldana (2013), I began coding the data using a step-wise process known as first and second cycle coding. First cycle coding entailed using simple, explicit codes to categorize the data (e.g., loss, transportation and communication). I used the technique of structural coding in this step, which involved the use of my research questions to categorize “comparable segments’ commonalities, differences, and relationships” (Saldana, 2013, p. 84). In select instances, simultaneous coding or the use of two or more codes for the same section of transcript was employed (Saldana, 2013). This was done in situations where the transcript passage contained particularly meaningful information that potentially represented more than one main code. As coding proceeded, the approach was tailored to accommodate individual variation among interviews. For example, in some instances I began coding by sentence or a partial sentence but then found that in order to capture the true meaning represented by the code I needed to code large units of information such as a couple of sentences or a paragraph (DeCuir-Gunby, Marshall, & McCulloch, 2010). Using NVivo and saving multiple versions of the analysis ensured that the steps I undertook were documented and available for review by my committee.

After all transcripts were initially coded I began a second cycle of coding to take the codes identified in the first cycle of coding and group them according to a concise list of themes (Saldana, 2013). Themes encompassed a brief sentence or phrase that contained answers to the

research questions and were represented by several codes. As the analysis proceeded, constant comparative analysis was used to compare coded segments of one transcript with other caregiver and health provider transcripts. This helped to identify possible connections and conceptualizations between different portions of the data (Thorne, 2000). According to Morse (1994) this step is called synthesizing, a process whereby significant and insignificant aspects of the data are separated. This is akin to beginning to recognize patterns in the data. Pattern recognition is an important aspect of ID and allows one to “characterize the phenomenon that is being studied” by exploring the commonalities and differences between themes (Thorne et al., 2004, p. 4).

I subsequently explored patterns across cases to see if they persisted and whether it was possible to make any generalizations. During this phase, I looked at codes and themes checking for similarities in the experiences of multiple stroke caregivers, for example, for a recurring theme of being unable to pay for services. At this stage, I also used the findings from ecomaps and the field notes to help corroborate and clarify thematic development. This process of pattern recognition was also done across health providers and then in a separate process, across stroke caregivers and health providers. A further step used during the analysis was that of identifying negative cases in the data. Negative cases would be opposing perspectives or findings pertaining to an emergent theme. This was done to ensure that I was providing a full reflection of the data and to determine if these negative cases were outliers or opposing positions that should be represented in the final data (Lincoln & Guba, 1985). Throughout the analytic process, and directly following meetings with my supervisor and supervisory committee I kept a memo book, also a part of my field notes, to document the proceedings of our meeting and also recorded my

thoughts or ideas arising from the discussions that were then used to further refine and organize the data (Thorne, 2016).

Consistent with the thoughtful clinician perspective (Thorne, 2016), data from health providers was used to corroborate or contrast the experiences of stroke caregivers and the healthcare providers, and to situate the findings within the body of knowledge related to health and social service provision to stroke survivors and their caregivers. The health provider perspective strengthened the study findings and helped to identify gaps or shortcomings in service provision to adults with stroke and their caregivers. At the end of this step I was able to draw links between the emerging patterns and concepts within the data (Morse, 1994).

Finally, one of the final steps of data analysis was the use of selective or theoretical coding to delineate a central set of codes; these were the umbrella or backbone for the rest of the codes (Saldana, 2013; Thorne, 2016). This step was done in collaboration with my supervisory committee whereby we discussed each of the central codes and clearly delineated how they would contribute to answering the research questions. The additional steps of theorizing and re-contextualizing cognitive (Morse, 1994) were then used. Theorizing, entailed proposing explanations for the data. This is not theorizing in the sense that would be expected by grounded theory research but rather is an iterative process of “speculation and conjecture, of falsification and verification, of selecting, revising, and discarding” ideas pertaining to the themes identified in the data (Morse, 1994, p. 33). It is also referred to as the “sorting” phase of the analysis where significant findings were teased apart from those that did not contribute to a valuable description of stroke caregivers’ experience in accessing and using formal health and social services as well as the factors that influenced their access to and use of these services.

As thematic development began to take place, themes pertaining directly to the caregivers were corroborated using the coded data from the health provider interviews. The two perspectives were valuable in order to better understand the experience of accessing and using formal health and social services. During this process of coding, my own personal perspective regarding stroke management and stroke caregivers was frequently revisited, since it is an important influence on the relationships found in the data. This was done to acknowledge and account for any ongoing influence this perspective may have on the data (Thorne, 2008).

The final step in the analysis and in cognitive processing outlined by Morse is re-contextualizing, where the emerging description of the experience of stroke caregivers from the data analysis was adapted so it could be applied to other practical settings or other populations (Morse, 1994). This stage is described in the discussion section of the dissertation. At this stage I engaged in dialogue between existing theory or knowledge and what has emerged from my data as I sought to situate the findings within an appropriate context (Thorne et al., 2004). To this end I discussed where the study findings are situated within the current literature on stroke management and the issues faced by stroke caregivers. New findings were either corroborated with the existing literature or provided new insights for the field of stroke research. I also situated the study findings with regard to the framework and discussed the framework's utility in informing caregivers' use of services and in identifying the factors that influence their use of services. This section included discussion of the strengths and limitation of the framework.

Study Quality

Eight criteria were used to ensure the rigor of the study: (a) epistemological integrity, (b) representative credibility, (c) analytic logic, (d) interpretive authority, (e) moral defensibility, (f) disciplinary relevance, (h) contextual awareness, and (i) probable truth (Thorne, 2016).

Epistemological integrity.

When assessing the merit of qualitative research, it is necessary to look for the alignment between epistemological stance, study design and study findings (Thorne, 2000). Findings which are in contradiction to the study's guiding principles raise doubts about the study integrity and suggest that the researcher may be biased by prior experience or perspective (Thorne, 2016). Therefore, as the researcher, I must be knowledgeable and clear about the underlying assumptions that are guiding my research approach and ensure that the subsequent research questions and results are compatible with this approach. In accordance with Thorne (2016), I clearly outlined my pre-existing assumptions prior to the development of the research, as outlined in chapter one and sought to be transparent about the extent of their influence throughout the development of the research questions and interview guide. I also stated the assumptions underlying the RC – MCC framework (Grembowski et al., 2014) and how this framework influenced the study design, data collection and study findings. I have adhered to the principles of ID by conducting the study with the goal of increasing understanding of the experience of stroke caregivers so that the new knowledge can inform future clinical practice. There has been clear explanation of study processes such as the use of first and second cycle coding, the use of open coding, constant comparative analysis and the inclusion of the thoughtful clinician perspective.

Representative credibility.

To ensure representative credibility, the theoretical claims made by researchers should conform with the way in which the subjects being studied are sampled (Thorne, 2016). For example, in my study, sample size was projected to be between 25 and 35 subjects, sampled through techniques such as purposive and snowball sampling, in accordance with ID approaches.

The study ultimately included 40 study participants that were sampled using these approaches. Participants were recruited using a broad range of recruitment sources. Sampling for stroke caregivers sought to obtain diversity in characteristics such as age, gender, and employment status. Sampling for health providers sought to obtain diversity in profession and geographic area. Furthermore, the results of the study are expected to accurately reflect the experiences of the stroke caregivers in accessing and using formal health and social services. Every effort was made to ensure that the findings of the study were representative of the caregivers' experiences by triangulating multiple data sources (in-depth interviews, ecomaps and field notes), iterative data collection and analysis and using multiple investigators to review transcripts (Thurmond, 2001).

Analytic logic.

In qualitative research there is an expectation that there is a clear logical flow of reasoning and decision-making (Thorne, 2008). This means that explicit statements of action and results must be made and they should make logical sense (Thorne, 2016). To this end, this research demonstrated analytic logic in a number of ways: (a) the dissertation demonstrates that the research questions arose from a comprehensive literature review indicating the need for the study and gaps in the knowledge base; (b) any decisions or changes in the way in which the study proceeded, for example, a change or addition in sampling strategy (e.g. snowball sampling) or the addition of interview questions (done after initial piloting of the interview guide), was clearly documented in the final research report; (c) study findings were corroborated by direct quotes from the in-depth qualitative interviews with study participants; (d) the study results were situated within the academic literature demonstrating how new knowledge has been generated; and (e) the information from field notes, interviews, eco-maps and research meetings was

transparent in the final research document to ensure that the reader can understand how the resultant findings evolved through a logical process of reasoning.

Interpretive authority.

When reading the findings of a study it must be clear to the reader that the author is a credible and honest researcher. This means that there must be actions taken to ensure that the study findings clearly represent the research and are not adversely influenced by the researcher's own biases (Thorne, 2016). I used a number of strategies to ensure interpretive authority in this study including: (a) clearly situating my perspective and professional experience in terms of the influence it may have on the research prior to data collection, (b) stating my underlying assumptions at the start of the study, (c) using investigator triangulation of the data, (d) maintaining field notes, (e) providing an audit trail so that the research can be transparent and potentially replicated (e.g. recruitment log), and (f) using rich description and quotes from study participants to corroborate the study findings. These efforts are broadly recognized techniques of increasing validity in qualitative research (Whittemore, Chase, & Mandle, 2001).

Moral defensibility.

Applied health sciences research should be conducted in the hopes of furthering knowledge such that in time there will be gains in peoples' physical and psychological health while alleviating suffering or reducing harm (Thorne, 2016). In light of this perspective, this study was developed and informed by peer reviewed literature and explains the experience of stroke caregivers as they access and use formal health and social services. The findings of the study are well situated to inform practice and policy related to the use of services by this population. Knowledge of the factors influencing access to and use of formal services can be

used to inform practice and policy regarding strategies to improve their use, ultimately to improve stroke caregiver outcomes.

Disciplinary relevance.

Situating research within the discipline where it will be conducted and disseminated is of paramount importance in ID (Thorne, 2016). This means that the research should clearly reflect a relevant nursing practice issue. There should also be a demonstrated knowledge gap pertaining to the issue in the nursing literature. I designed this study to increase understanding of the experiences of stroke caregivers in accessing and using formal health and social services. An extensive review of the literature was conducted to identify a knowledge gap pertaining to community-based family and friend stroke caregivers' experiences in accessing and using formal health and social services. Nurses provide direct care and education to stroke survivors and their caregivers thus clearly situating this topic within the scope of the nursing discipline. Best practice guidelines for stroke management speak to the importance of community reintegration and long-term outcomes for stroke survivors and also serve to situate this research within the broader field of stroke management (Lindsay et al., 2008). The literature review also identified issues related to caregiver burden and the need for education and support for stroke caregivers, topics that also fall within the scope of nursing practice (Andrew et al., 2015; Camak, 2015).

Contextual awareness.

Thorne (2016) indicates that contextual awareness, the influence of the environment in which researchers live and practice, has a direct impact on the way researchers conduct their research. Therefore, research findings will also be influenced by these contexts and must be situated within them. In doing so the researcher will acknowledge that the study findings may only be valid within the aforementioned contexts (Thorne, 2016). In conducting this study, I was

acutely aware of the context of stroke care in the study region, and acknowledge its influence on the services available to and used by stroke caregivers.

Probable truth.

A final aspect of study quality is the notion of probable truth, the idea that the results of the study may be the foremost example of the truth currently available (Thorne, 2016). As the primary researcher, I have made every effort to present the best available knowledge arising from the study, but also recognize that in time this truth could be either validated or disproved. To ensure that the study results represented the probable truth, I used strategies such as triangulating the data from the transcripts, field notes, and ecomaps (Guba & Lincoln, 1994). I also maintained a comprehensive audit trail that documented the meetings and discussions I had with my supervisor and committee members as well as the stages of analysis such as first and second level coding. This enabled me to return as necessary to different stages of the analytic process and see how my perspective or interpretation of the findings changed over time. A further strategy used was that of identifying negative cases in the data to ensure that I was providing an accurate reflection of the data (Lincoln & Guba, 1985). For example, in the case of social supports and finances, some stroke caregivers experienced these as facilitators to the use of services where others experienced these as barriers, so I explained these differing perspectives in the results. Ultimately, the end goal of the researcher is to create meaning that can inform and facilitate growth of knowledge that is open to substantiation (Thorne, 2016).

Ethics

The study received ethical approval from the Hamilton Integrated Research Ethics Board (REB 2770) and followed the guidelines stipulated by the Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans (Canadian Institutes of Health Research, Natural

Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2013). Written informed consent was obtained by the PI before study enrolment when the interviews were conducted in person and implied consent was obtained when the interviews were conducted via phone or Face Time. The study purpose and explanation of the study processes were explained to all potential study participants. Study participants were informed that they were able to withdraw from the study at any time and could refuse to answer any questions. If during the course of the interviews, caregivers experienced distress or discomfort with the conversation they were able to decline to continue with the interview, and all of their data was destroyed. If stroke caregivers expressed an interest in accessing any services, they were referred to their local chapter of the Caregiver Support Network and/or the local Community Care Access Center. Participants were also able to re-schedule their interview at another time. In acknowledgement of the participants' involvement in the study, a \$10.00 honorarium was offered to each participant.

All participant data forms were kept in a locked filing cabinet and all personal identifiers were removed from the data forms before storing. Participant interviews were identified by numeric code and transcribed to document format. The two transcriptionists signed a confidentiality agreement. All transcribed data and demographic data pertaining to the study was kept in a password protected and encrypted computer. The original data collection forms will be kept in a locked filing cabinet at McMaster University for ten years.

Chapter 4

Results

Introduction and Overview of Chapter

The following chapter presents the findings of this interpretive description study. The demographic characteristics of the participating stroke caregivers and health providers are described. To address research question one, the context of caregiving for stroke survivors is presented with supporting quotes. This section provides an understanding of the contextual circumstances that influenced stroke caregivers' health and social service use. Then, addressing research question two, caregivers' experiences in accessing and using formal health and social services are discussed. Finally, addressing research question three, the factors that influence stroke caregivers' use of formal health and social services are described.

Direct quotes from study participants are used to illustrate the themes. Quotes from health providers, representing what Thorne (2016) describes as a thoughtful clinician perspective are integrated into the description of themes. Stroke caregivers' quotes are denoted with (SCG) followed by a unique study identification number and those from health providers are denoted with (HP) and their unique study identification number.

Characteristics of the Sample

A total of 22 stroke caregivers participated in the study. No stroke caregiver participants withdrew from the study. Participating caregivers were an average of 62.9 years ($SD=9.7$) and about two thirds (63.6%) were female (Table 3). All caregivers were Caucasian except one who was of Asian descent. Most caregiver participants used services within the catchment of the Central South Regional Stroke Network, which includes south western Ontario. Almost one half were receiving formal services and 42% of participants who reported household income had

annual incomes less than \$40,000. Most of the participants (86.4%) were spousal caregivers. About one-third (36.4%) of the caregivers were employed. The mean length of time spent as a stroke caregiver was 30 months ($SD=14.0$ months). Most stroke caregivers lived in an urban setting (86.4%) and reported an average of 3.1 ($SD=2.1$) chronic conditions.

The caregiver participants cared for a total of 21 stroke survivors (one stroke survivor was cared for by two parent caregivers) (Table 4). Most (86.4%) of the caregivers were living with the stroke survivors. The average age of the stroke survivors was 63.4 years ($SD=12.1$), and 61.9% were male. The stroke survivors had an average of 4.4 ($SD=2.1$) chronic conditions.

A total of 18 health providers participated in the study; 77.8% were female (Table 5). Over one-half (55.6%) of the provider participants had a graduate degree, 27.8% had a college diploma or certificate, and 16.7% had an undergraduate degree. Just over one half (55.5%) of the providers had been practicing in their respective professions for 16 or more years, and one-half had practiced in their current position for three years or less. Provider participants included: five registered nurses (one clinical nurse specialist, one visiting nurse, and three stroke prevention clinic nurses), one occupational therapist, two speech language pathologists (SLP), three social workers, one therapeutic recreationist, one kinesiologist, two personal support workers (PSW), one family physician, one geriatrician, and one neurologist.

Table 3

<i>Characteristics of Stroke Caregivers</i>	
Variable	<i>n</i> (%)
Age (years) ^a	
40 – 49	1 (4.5)
50 – 59	5 (22.7)
60 – 69	10 (45.5)
70 – 79	4 (18.2)
80 – 89	2 (9.1)
Sex	
Female	14 (63.6)
Male	8 (36.4)
Geographic Location	
Urban	19 (86.4)
Rural	3 (13.6)
Household Income (\$ CAN)	
≤ 19,999	2 (9.1)
20,000 – 39,999	6 (27.3)
40,000 – 59,999	3 (13.6)
≥ 60,000	8 (36.3)
Prefer Not to Answer	3 (13.6)
Employed	
Yes	8 (36.4)
No	14 (63.6)
Relationship to Stroke Survivor	
Spouse	19 (86.4)
Parent	3 (13.6)
Receiving Formal In-home Services	
Yes	10 (45.5)
No	12 (54.5)
Type of Service	
Homecare support ^b	8 (36.4)
Other	2 (9.1)

Notes. $n = 22$, $\bar{x} = 62.9$, $SD = 9.7$, ^bvia Local Health Integration Networks

Table 3 Continued

Characteristics of Stroke Caregivers

Variable	<i>n</i> (%)
Duration of Caregiving (months) ^a	
0 – 12	2 (9.1)
13 – 24	8 (36.4)
25 – 36	2 (9.1)
≥ 37	10 (45.5)
Number of MCC (number) ^b	
0 – 1	6 (27.3)
2 – 4	12 (54.5)
5 – 7	3 (13.6)
8 – 10	1 (4.5)

Notes. *n* = 22, MCC = multiple chronic conditions, ^a \bar{x} = 30.0, *SD* = 14.0, ^b \bar{x} = 3.1, *SD* = 2.1

Table 4

Characteristics of Stroke Survivors

Variable	<i>n</i> (%)
Age (years) ^a	
30 – 39	1 (4.7)
40 – 49	1 (4.7)
50 – 59	6 (28.6)
60 – 69	8 (38.1)
70 – 79	4 (19.0)
80 – 89	1 (4.7)
Sex	
Female	8 (38.1)
Male	13 (61.9)
Number of MCC (number) ^b	
0 – 1	1 (4.7)
2 – 4	11 (52.4)
5 – 7	8 (38.1)
8 – 10	1 (4.7)

Notes. *n* = 21, MCC = multiple chronic conditions, ^a \bar{x} = 63.4, *SD* = 12.1, ^b \bar{x} = 4.4, *SD* = 2.1

Table 5

Characteristics of Health Providers

Variable	<i>n</i> (%)
Type of Health Provider	
Registered Nurse or Clinical Nurse Specialist	5 (27.8)
Physician (General or Specialist)	3 (16.7)
Occupational Therapist	1 (5.6)
Speech Language Pathologist (SLP)	2 (11.1)
Social Worker	3 (16.7)
Therapeutic Recreationist	1 (5.6)
Kinesiologist	1 (5.6)
Personal Support Worker (PSW)	2 (11.1)
Sex	
Female	14 (77.8)
Male	4 (22.2)
Age (years)	
≤ 30	3 (16.7)
31 – 40	7 (38.8)
41 – 50	1 (5.6)
51 – 60	5 (27.8)
≥ 61	2 (11.1)
Years Employed in Field (years)	
≤ 3	3 (16.7)
4 – 10	4 (22.2)
11 – 15	1 (5.6)
16 – 20	3 (16.7)
≥ 21	7 (38.8)
Level of Education	
Diploma or Certificate	5 (27.8)
Undergraduate Degree	3 (16.7)
Graduate Degree	10 (55.6)
Years in Current Position (years)	
≤ 3	9 (50.0)
4 – 10	5 (27.8)
≥ 21	4 (22.2)

Note. *n* = 18

Data from the qualitative interviews revealed that caregivers fulfilled many roles such as providing support with activities of daily living (ADLs), such as overseeing tube feeding, and transferring and bathing the stroke survivor. In cases where the stroke survivor was less physically disabled caregivers provided support primarily with instrumental activities of daily living (IADLs), for example, managing transportation, facilitating attendance at rehabilitation and stroke management appointments and assisting with finances. In some cases, caregivers provided extensive support with both ADLs and IADLs.

Many of the stroke survivors had physical disabilities that meant that they were not able to live or function independently without support with their ADLs. Some stroke survivors also had conditions such as aphasia or cognitive changes that made it challenging for them to complete IADLs. Overall these stroke survivors had care needs necessitating consistent, prolonged support from caregivers and formal health and social services.

The Context of Stroke Caregiving

The catastrophic nature of stroke. “Your life has turned upside down”

The shocking and unexpected nature of a stroke and its subsequent effects on the caregiver and stroke survivor became evident early in the process of conducting participant interviews. Although the caregiver participants had cared for the stroke survivors for an average of two and a half years, they continued to exhibit dismay, distress and immense sadness when discussing the occurrence of the stroke. For example:

When that first happened? He was going to retire. I had been after him to retire from his job. And he loved his job. But I could see that the stress was getting to him. And by the day, daily the stress was getting to him. So, he finally admitted that he would retire. He sent out notifications to his 400 clients that he was going to retire. He was a financial

advisor. Ok. They all wanted to see him. Because they all thought, “Oh my God, I got to have an appointment with him before he leaves.” And that just put him right over the edge. Too much stress for him. And so, he had his stroke two days before he retired.

(SCG 04)

In this particular case, the caregiver exhibited profound remorse over the events that preceded her husband’s stroke, as if reliving it and wishing she could have changed those events. But her remorse was also for the loss of the life they had yet to experience in retirement. Another caregiver echoed this:

So, looking at that down the road and life-time thing, even though I’m going to make sure it’s ok for us. That’s depressing. Yeah that pulls you down. No for our retirement, for our older age, for our golden years. This is not what we thought. (SCG 05)

Many caregivers had similar experiences, describing how they were living with the daily challenges associated with the stroke but also feeling enormous doubt and insecurity about their futures. Other caregivers acknowledged that the sudden occurrence of the stroke led to an abrupt change in the way they lived their lives. One caregiver said, “[our life] has turned upside down” (SCG 09) and another said:

Yeah, pre-stroke. So, we didn’t, you know, that was our life. I worked all the time and he worked all the time. Our kids, you know, we were involved in their sports and all that kind of stuff, but and then all of a sudden, he’s home 24/7. (SCG 10)

For a considerable number of the participants, the dramatic change in the way they lived their lives continued indefinitely. While the majority of stroke survivors did make considerable gains in their health, they continued to cope with life-altering deficits that limited their capacity for

self-care and engagement in their usual daily activities. This meant that not only did caregivers have little or no time to prepare themselves for the catastrophic event of the stroke, they also had to make significant changes in their ongoing daily lives. In the case of the preceding quote, the caregiver was working full-time and continued to do so after her spouse's stroke. She also had school age children at home, which added a further layer of complexity to her caregiving role. Other caregivers echoed the effect that the surprising and tragic nature of a stroke had on both the stroke survivor and caregiver. For example, one said, "I couldn't believe it. I kept thinking this is, I don't believe this was happening to us." (SCG 21)

The catastrophic nature of stroke was particularly prominent for caregivers of stroke survivors who experienced vascular cognitive impairment as a result of the stroke. One caregiver who cared for her husband who had suffered multiple strokes, eventually leading to cognitive decline, commented, "It's been a tough ride. It's been tough. You keep thinking, 'It's getting better, it's getting better,' and then sure as shit it turns bad again." (SCG 04) Each time this caregiver thought she was finding a way to cope with her situation, conditions changed leaving her feeling out of control, stressed, and exhausted.

Health providers also commented on how the occurrence of stroke led to a dramatic life change for caregivers, for example, "this was survival. 'How am I going to get groceries? How am I going to get to appointments?' How much supervision does this person need?" (HP 01) Providers had a clear understanding of the life-altering ramifications of stroke on caregivers and noted that the stresses often persisted over time.

While caregivers were not only new to this sudden role change, they may also have been struggling to assume a role that could be likened to that of a parent to a child. Unlike in cases of dementia where a person's decline is likely to be more gradual, there was no time for caregivers

to mentally or physically prepare for the sequelae of the stroke. Providers discussed the significant and sudden relationship changes that could take place when a stroke occurred with one provider saying:

I find it tends to become, especially if there's a large cognitive deficit, it tends to become more of a caregiver patient role, than the way it used to be. Parent-child role. Ok. Sometimes it gets better, sometimes it doesn't. But definitely there's a permanent change. Pretty instantly where you go from spouse to caregiver. (HP 10)

The shocking occurrence of stroke also led to some significant changes in the way caregivers and their families lived their lives post-stroke. For example, one caregiver talked about how their lives changed after her husband's stroke:

Yah I think in some ways it has [changed]. One thing we do, and the speech therapist laughs a lot. But I said we review the day when we go to bed. He does a day in review. And he starts with, you know, getting up and whatever he does. And tries and puts it in sentence forms, that kind of thing. Then we pray. And we didn't do that before. Sorry. *emotional - crying* (SCG 01)

This quote captures some of the key aspects of living with a stroke for both the caregiver and survivor: the life changing event she and her husband endured, the ongoing challenges related to communication, affecting both the caregiver and survivor, as well as the need for ongoing solace and support that they sought through their faith. When I interviewed this caregiver, approximately three years had passed since her husband's stroke. The depth of her feelings coupled with their journey of living with and managing the effects of a stroke was an ongoing and dominant focus of their lives.

Stroke Caregivers' Experiences in Accessing and Using Formal Health and Social Services

Overall, interviews with caregivers and health providers suggest that caregivers used some key formal health and social services. They accessed services such as counselling, family physicians, attending caregiver support groups and health related programs such as those offered by local YMCA organizations (Table 6). While caregivers made limited use of formal health and social services for themselves, many of the stroke survivors used formal in-home services and community-based services. Caregivers reported that the services the stroke survivor received were beneficial, and enabled the caregivers to take time away from their caregiving role, engage in caregiver-related tasks outside of the home, and learn more about stroke care. Examples of services used by stroke survivors included homecare services such as personal support workers and occupational therapy and community-based programs such as speech language pathology, physiotherapy, and targeted programs offered through the YMCA or recreational/rehabilitation programs provided by independent organizations (Table 6).

In exploring caregivers' experiences in accessing and using formal health and social services, three main themes emerged from the analysis. These were: (a) caregivers reach a tipping point, then cry for help, (b) services were worth the caregivers' work to access them, and (c) services for stroke survivors benefitted caregivers and stroke survivors alike. Each of these themes will be discussed using supporting quotes from participant interviews in the following section.

Table 6

Services Accessed by Caregivers and Stroke Survivors

Services accessed by Caregivers

Family Physician

Counselling

Caregiver Support Groups

Exercise and Health Related Programs

Services Accessed by Stroke Survivors that Benefitted Caregivers

Homecare Services (e.g., PSW, OT)

Community-based Programs

 Speech Language Pathology

 Physiotherapy

 YMCA Programs

 Adult Recreation and Therapy Programs

Caregivers reach a tipping point, then cry for help. “He’s given me medication to help me cope”

Caregivers were committed to their caregiving role, which, was often time consuming, and exhausting. As a result, they tended to relegate their own health needs to the background. This often meant that they sought the services of their family physician only when they could no longer ignore their own health needs. In these instances, caregivers often accessed their family physician for treatment in the form of medications, as stated by one SCG, “I’ve been back to him and he’s given me Lorazepam to calm the anxiety. My anxiety.” (SCG 04) The caregiver reached a point where she was no longer able to sleep or function in her daily life and the immediate solution was a medication. However, this may not have addressed the underlying factors contributing to her anxiety. Another caregiver said, “I ended up on a little pill because I

couldn't make a decision.” (SCG 15) Again, the caregiver reached a point of severe distress and needed to see her physician urgently. In these situations, caregivers used the services provided by their family physician as a coping strategy. If caregivers felt unable to take time away from caregiving to attend counselling, then taking medication was an immediate solution that did not further complicate their lives. In other instances, caregivers approached their family physician for any type of help, for example one caregiver said:

It was all about, I had no help. And then the doctor said, “The only thing I can suggest to you is call March of Dimes. They might have some resources.” So that was my first outreach for help. And that was maybe five months into it. So, by then I was a real basket case. *laughter* But as time went on...Yah he did. My doctor did [refer me to counselling]. (SCG 04)

This quote captures the desperate circumstances of the caregiver and the fact that for five months the caregiver had been managing without any formal support. The physician may have referred the caregiver to March of Dimes because he/she was not aware of other available services and supports. The onus to reach out to March of Dimes was placed on the caregiver although it was clear that the caregiver was at a breaking point, something the physician was able to address through a referral for counselling services. Furthermore, the caregiver exhibited a need for services to assist her in her caregiving role as well as a need for services to manage her own health.

In another instance the caregiver herself approached her physician for a referral to counselling:

So, I had to see my own doctor for a particular reason and I said “I think I need to see a counsellor.” And as soon as I start talking in a safe place I start crying. So, then I started

to tell her what was going on and she says “Holy man, of course you could, we have in-house counselling. Let me give you a referral.” So that’s how that happened. (SCG 02)

In this instance the caregiver did not know where else to turn and when she was at her wits end she approached her family physician. Her trusting relationship with her family physician enabled her to express her strong feelings and her physician to understand the gravity of her situation. However, not all caregivers had access to a family physician leaving them without a key point of contact for services in the community and not all felt comfortable approaching their family physician.

Some family physicians responded to caregivers’ need for help by working through their issues and providing some of information that the caregivers were lacking. For example, one caregiver described how her physician, “addressed all the items on her list” until she felt comfortable as she was unsure of where to turn for answers. (SCG 01) Some caregivers initially avoided using the services of their physicians because of stoicism, or because they were overwhelmed and making an appointment meant one more issue they needed to address. As one caregiver said, “our life has been nothing but therapy and doctor’s appointments and specialist appointments and it’s just been a nightmare.” (SCG 04) However, once caregivers had connected with their family physician it was not uncommon for them to continue with regular interactions whereby the family physician monitored their health. For example, one caregiver said, “oh yes. Yes. And I’m still going [to family physician].” (SCG 04) Another said, “we’ve got a doctor that will come to our home.” (SCG 06) These ongoing visits with their physician provided caregivers with access to respite or counselling to help them in their caregiver role and in instances when caregiver and stroke survivor shared a family physician, they both benefited from the recurring appointments.

Physicians described their role in connecting caregivers to other suitable services. In some cases, being part of a family health team made the referral process more expedient for the caregiver. For example, one health provider said:

You bring them in to talk about mood and coping specifically or we have access to a social worker that's here. We're part, we're the family health team too. So, we have psychiatry if necessary, too. (HP 10)

In this example, the health provider was situated within a family health team thereby providing the optimal setting for caregivers seeking assistance but this was not the norm for all caregivers. This health provider's comment captures the gravity of the situation some caregivers are dealing with but it also illustrates how the family physician was seen as the central point of access to community services. Yet in many instances, caregivers seemed unsure about approaching their family physician for help, maybe because they did not identify being overwhelmed as a medical issue or they may have been wary of being perceived as incapable by the physician.

Services were worth the caregivers' work to access them. "Programs have been a great help for me"

A number of caregivers discussed how formal health and social services such as health and exercise programs benefited their health. These caregivers were able to engage in exercise programs because the stroke survivor was concurrently engaged in a stroke-related rehabilitation program. The parallel timing of these programs served as both respite and an opportunity for health promotion for the caregiver. One caregiver discussed her regular attendance at an aqua fit program stating that:

The ‘Y’ has definitely helped me with the Aqua Fit programs that I go to three times a week. The two times Monday and Friday, when [husband] has his Neuro Fit it’s at the same time... But it was a fight to get the respite. (SCG 06)

This caregiver also alludes to the challenges experienced by caregivers in trying to access services in an efficient way and finding support for their own health and well-being.

Another caregiver talked about going to the gym, “I go to the gym a couple of times a week and I’m only gone for just over an hour.” (SCG 02) Her quote illustrates that even though she benefited from going to the gym, her experience was less rewarding because she felt ongoing pressure to make sure she was away from her spouse for a limited amount of time. Another caregiver spoke about attending the Neuro Fit program with her spouse at the YMCA and going earlier so she could also participate in exercise, “yeah we like to go a little earlier so we both can work out.” (SCG 14) These caregivers valued the services but had to make extra effort or allowances in order to participate in them.

Health providers also recognized the value for caregivers, in addition to stroke survivors, to have time to engage in healthy behaviours. For example, “[they can benefit from] some time apart, and do maybe a little social work, separately for both parties. Exercise for both parties.” (HP 06) But they acknowledged that caregiver engagement in activities was often dependent on additional support such as having the opportunity to engage the stroke survivor in an activity or having somebody stay with the stroke survivor in their absence. Despite these positive examples of caregivers engaging in formal exercise programs and having respite from their caregiving roles, few other caregivers discussed engagement in these types of programs.

One provider indicated that support groups are underutilized, “I think that is available [stroke support groups]. [But] I think [they’re] underutilized by the older and more severely

affected caregivers.” (HP 14) The provider is alluding to the challenges that caregivers face in making use of support groups such as caregiver acceptability of the group or costs associated with attending support groups. Caregiver acceptability could be influenced due to fact that support groups are often conducted without health provider oversight. In these situations, the caregiver may be required to self-refer to the group, potentially adding to their load. If the group is run by a health provider there is more likely to be a direct referral process from other stroke related services. Furthermore, caregivers may be more willing to engage in a group that offers oversight and resources to meet their own health needs and a health professional would be well-placed to follow-up with caregivers on an individual basis after the group program. Attendance was also constrained by transportation challenges such as discomfort with night driving or an inability to add one more commitment to their day. Providers described how support groups fulfilled the role of friends and family for isolated caregivers. For example, one provider described a caregiver’s participation:

So, I don’t think he was an academic, and boom your wife is in the hospital and everyone is throwing this medical jargon at you, and you don’t know what they’re saying. And you’re going ‘what is a stroke?’ So, he showed up at our meeting, this one night. And my whole group came together to listen to him. Ok. And it was like they became his family. So, this man showed up faithfully every month. (HP 04)

Caregiver support groups were in some cases pivotal sources of support for caregivers, providing empathy and sharing in the journey of caregiving for a stroke survivor. This group was led by a health provider however some groups were peer-led. This meant that the goals and processes varied among groups with provider-led groups supplying clinical support and peer-led ones

providing more practical and social support to caregivers. One provider explained the challenges for younger caregivers:

Very few [younger caregivers are accessing services]. I'd say in our population, it's a problem. There's a demographic issue, we're seeing younger people with strokes. The caregivers are working. They're in jobs. They're exhausted. We used to do more programming for caregivers. Fewer people are able to attend. So, it's a real issue. (HP 07)

Underutilization was perceived by health providers as a factor in the decrease of potentially helpful services. Thus, it is critical that those who develop, and fund services understand the factors contributing to this situation. While it may appear that it is not that caregivers do not want services, their use of these services is constrained by factors beyond the services themselves.

About a quarter of caregivers received counselling services from social workers or psychologists, usually after being referred by their family physician subsequent to asking them for help. Counsellors provided perspective for caregivers who often felt torn in multiple directions: caregiving, attending to the needs of other family, looking after their homes, juggling employment and taking care of their own needs. The experience of accessing and using counselling services was for the most part helpful and empowering for caregivers although most caregivers did not access counselling until they reached a tipping point and were overwhelmed by their life situation.

Caregivers detailed how using counselling services supported them in taking care of themselves. One participant stated:

Actually, it was the counsellor that I saw and he said "What if somebody came to you today and said, we're going to Europe for two weeks and we want you to come. What

would you say?” I’d say, “Well I probably can’t do that.” I’d have to figure out what to do with (my husband) and he said, “That’s not the answer you’re supposed to give me. You’re supposed to say I will make it happen.” And so that’s been very helpful. (SCG 02)

This caregiver described how counselling services helped her find perspective and take needed breaks from her caregiving role to reduce the likelihood of burnout over time. For many caregivers there was not one dominant issue that led them to seek counselling but rather an accumulation of demands and responsibilities that were often unrelenting and ever present.

The opportunity for individual engagement with providers was invaluable for caregivers and enabled validation of their own needs. In some cases, they felt they could not voice their true feelings if the stroke survivor was also present which left them feeling frustrated and invalidated. The social worker in the preceding quote worked with both caregivers and the stroke survivors they supported, thus ideally positioning her to understand the daily challenges caregivers were experiencing.

Providers recognized the value of counselling and advocated for, and helped caregivers access these services. For example, one provider discussed her role in referring caregivers to counselling services, “sometimes you need to bring in social work if the family needs counselling.” (HP 15) Providers also described counselling caregivers to ensure self-care, “I’m trying to teach them all the time. No, no, you’re number one. The person with the stroke isn’t, you’re number one.” (HP 04) For caregivers having the permission to take time for themselves and the acknowledgement of their role helped them feel supported. Health providers fulfilled a valuable role in helping caregivers feel secure and able to take care of themselves. Most caregivers were dedicated to caring for their loved one and wanted to continue in that role.

However, they also felt conflicted and experienced guilt for wanting time and space away from the responsibilities of caregiving. Counselling by providers was able to provide some of the ongoing support that they needed. These providers were also able to refer caregivers to secondary services such as financial guidance or further in-home services depending on the scope of their professional positions. In some instances, the counsellor also referred the caregiver to health-specific services such as their family physician for further assessment and treatment of the caregiver's health needs if they felt it was warranted.

Services for stroke survivors benefitted caregivers and stroke survivors alike. “His participation in the program relieved some of my stress”

Caregivers readily acknowledged that they benefitted from the services provided to the stroke survivors. For example, stroke survivors commonly participated in sessions offered by a speech language pathologist (SLP), even after considerable time had passed since the stroke. Caregivers who were unable to communicate effectively with stroke survivors became frustrated, despondent and were at risk of developing depression but when caregivers were able to participate alongside the stroke survivor in SLP sessions, they learned new tools and strategies to communicate with the stroke survivor. They also increased their knowledge and understanding of how a stroke could affect the speech and communication ability of the stroke survivor. These educational opportunities served to support them in their caregiving role and helped alleviate some of the frustration and despondency they experienced.

Attendance at SLP appointments varied among stroke survivors for example:

For three months he had speech therapy three times a week, and then it was reduced to two times a week. And then later it was reduced to once a week and now he goes to the Seniors Activation Maintenance program. (SCG 01)

The reduction in attendance at SLP programs usually corresponded with recovery gains made by the stroke survivors. In these instances, the caregivers also tended to benefit the most in the earlier stages of the programs where they learned strategies to communicate effectively with their loved one. A provider detailed this with, “the patients that would need my services would be those that had had a stroke and have aphasia. So their caregivers need a lot of support in terms of education.” (HP 02) Other stroke survivors continued to attend SLP appointments on an ongoing basis, for example, “he goes to speech therapy once a week” (SCG 21) Or, “we go on Monday’s, kind of the same type of thing through the aphasia program.” (SCG 15) Stroke survivors also attended multi-functional programs, which included SLP services such as, “and then he came to [facility name] for aphasia, a group.” (SCG 07) Although some caregivers attended the SLP appointments with the stroke survivor, others used this time for themselves as evidenced by one SLP who said:

We’ve got some who, you know are just working to make a living, and many who “this is my respite, I need my time.” So while the survivor is here they need a break. (HP 07)

The stroke survivors’ use of SLP services enabled the caregiver to take time for themselves while also being able to feel comfortable that the stroke survivor was well cared for during that time period.

Stroke survivors attended specific programs that provided rehabilitation and exercise offered through their local YMCAs. These programs were typically one hour in length, and provided structured guidance designed to support stroke survivors and others managing neurological conditions. Caregivers’ perceived that their use of these programs helped both the stroke survivors and themselves. For example, “because it [YMCA program] helps her with her walking and exercise so it was free... Best thing they ever did get. That was very good, very. ...

she still goes.” (SCG 21) The caregiver explained how the stroke survivor made valuable rehabilitation gains through participation in the program, which reduced the demands on the caregiver. Her participation in the program also helped the caregiver by providing respite and easing financial pressure because the programs were provided at no cost.

Caregivers also connected with other caregivers while the stroke survivor attended programs, for example one caregiver said:

It’s just so refreshing coming here and there’s a couple of women that are caregivers in my husband’s group and it’s just so refreshing to talk to them...and to just give each other positive thoughts. (SCG 04)

These interactions with other caregivers provided emotional support and enabled caregivers to speak with people who were experiencing some of the same issues they were. Caregivers valued the positive setting embodied by the YMCA where the staff was encouraging, and the environment was welcoming for all ages and abilities.

Just under one-half (46%) of stroke survivors and caregivers were receiving in-home services for both themselves and the stroke survivor. Of those receiving in-home PSW services, 80% received home care services through the Local Health Integration Networks (LHIN). The PSW assisted the stroke survivor with activities of daily living such as washing, dressing and mobilization. PSWs provided support to 41% of these stroke survivors, thereby enabling the caregivers to gain respite time that they used for themselves, to complete tasks, socialize and attend appointments. For example, one caregiver said, “they will walk him twice a week [it’s very helpful to have that time for me].” (SCG 09) PSWs providing personal care for stroke survivors also provided physical respite for caregivers, supporting them to continue in their caregiving role even if they had their own physical limitations:

PSWs come in five days a week for breakfast and lunch. Yah, they get her up and get her breakfast and she sits [at] her table for a while and then every other day, she takes a shower, so they go in and help her. (SCG 08)

PSW support help to free caregivers' time and energy so that they were able to attend their own appointments such as trips to their family physician, counselling or health promotion activities such exercising. Support was provided in varying amounts, with some recipients receiving daily care and others receiving care once per week. For example, one caregiver described how a three-hour period of respite enabled him to complete weekly errands, "you know my three hours is spent going multiple places and shopping possibly. And doing other things like car appointments, dentist appointment that I don't want to take [stroke survivor] with me." (SCG 20) Having this support enabled the caregiver to engage in activities that were difficult to do with his spouse.

Providers also highlighted the value of PSWs in supporting caregivers. For example, when caregivers' sleep was compromised:

Sometimes if the caregiver can't sleep at night we'll order something called eShift or the PSW sleeps with the client... PSW watches over them all night long so the caregiver has confidence someone is with their loved one and they can get rest. (HCP 15)

In other instances, the PSW's assistance enabled the caregiver to participate in social activities, for example one PSW said:

I've definitely provided lots of respite, so like a few hours, four hours, five hours where the caregiver could just go out and do what needed to do, shopping or go out with family. (HP 16)

Providers also commented on how they actively explored options to increase or implement respite for caregivers if they felt the caregiver was overwhelmed, for example, “sometimes it might be is there any way that you can get more respite for the family.” (HP 11) Health providers recognized how beneficial respite was for caregivers, as one provider said, “[it’s so important] just giving lots of time for the caregiver to get away.” (HCP 08)

Stroke survivors’ participation in community-based programs also benefited caregivers by relieving some of their stress, for example:

[The community program] took part of the stress. [Your husband went to a community-based adult day program that offers programs for adults with conditions such as stroke]?
Yes, in the day time. (SCG 19)

Community programs were often positive resources for caregivers especially if they felt that the stroke survivor was well cared for; this enabled them to take full advantage of the respite without adding undue worry to their load. Overall, community-based adult recreation and therapy centers benefited both caregivers and stroke survivors.

Summary: Findings from interviews with stroke caregivers and health providers suggest that caregivers benefit from a number of formal health and social services. Caregivers tended to address the stroke survivors’ needs ahead of their own, meaning that they used the services of their family physician only when they had reached a crisis point and were no longer able to cope with their caregiving role. Furthermore, services were worth caregivers’ work to access them, particularly health promotion programs and support groups. Caregivers and stroke survivors alike benefitted from services used by stroke survivors, including rehabilitation programs like SLP, homecare services such as PSWs and those offered by YMCAs. These programs and services provided the caregiver with respite, information and support in their caregiving role.

Factors Influencing Stroke Caregivers’ Use of Formal Health and Social Services

Nine themes emerged from the data regarding factors influencing stroke caregivers’ use of formal health and social services:

1. Emotional toll of caregiving – “Nobody can fix it, nobody can make it better”
2. Losses experienced by caregivers influenced their use of services – “There was nobody to relieve me”
3. Caregiver responsibility enormous – “I have to do everything”
4. Social support networks – “They deserted us, they just don’t come around”
5. Limited information and lack of suitable services – “There’s a year-long wait list”
6. Trust – “He’s breathing, but is that good enough?”
7. Challenged to take care of my own health – “How can I find the time?”
8. Finances – “You have to pay, well we can’t afford \$50 or \$75 twice a week” and
9. Transportation – “I have never driven...I don’t like driving”

The following table outlines these themes and their corresponding sub-themes and is followed by an in-depth discussion of each.

<i>Factors Influencing Caregivers’ Use of Formal Health and Social Services</i>	
Theme	Corresponding Subthemes
Emotional toll of caregiving	- Not applicable
Losses experienced by caregivers influenced their use of services	- Loss of my social supports - Loss of my partner relationship - Loss of my very identity
Caregiver responsibility enormous	- Many daily tasks - Sense of duty - Responsibility for the stroke survivor’s safety

Table 7 Continued

Theme	Corresponding Subthemes
Social support networks	<ul style="list-style-type: none"> - Social networks were avoidant - Social networks rallied
Limited information and lack of suitable services	<ul style="list-style-type: none"> - Insufficient information on services - Challenges with service availability
Trust	<ul style="list-style-type: none"> - Difficulty trusting that I can leave my loved one alone - Struggling to trust the providers caring for my loved one
Challenged to take care of my own health	<ul style="list-style-type: none"> - Limited time and coping ability - Few services - Limited attention given to caregiver health
Finances	<ul style="list-style-type: none"> - Paying out-of-pocket for services - Reduction in income and employment - Navigating financial assistance systems - Benefits of financial stability
Transportation	<ul style="list-style-type: none"> - Taking on the stressful role of a driver - Access to subsidized transportation

Emotional toll of caregiving. “Nobody can fix it, nobody can make it better”

The emotional toll of caregiving resonated throughout the analytic process as one of the primary factors influencing stroke caregiver use of health and social services. Caregivers had been providing care to stroke survivors for an average of 30 months and in most situations continued to provide substantial ongoing support. Despite common experiences of the physical

effects of caregiving, such as the development of overuse injuries or gaining weight because of reduced time and opportunity for exercise, these effects were deemed relatively minor compared to the deep and often painful emotional consequences of caregiving. Caregivers contrasted their raw emotional experiences with the effects of caregiving on their physical health:

Yeah from the physical standpoint, as I say, I was always blessed to be physically fit and strong enough that I can do those chores that it didn't bother me. You know and that was good. But the emotional side was pretty tough for a while. (SCG 17)

They perceived their emotional health was directly related to their ability to cope with their caregiving role. For some, the emotional toll of supporting their loved one around the clock wore them down, but for others it was dealing with specific situations that they found particularly challenging. For example, one caregiver said:

It was always my huge fear when he would drive, because he would steal the car and he tried to take the Winnebago one time, it's 35 feet long. Like, there are kids on the street. I was just terrified. I would have to constantly hide car keys. (SCG 10)

The ongoing fear that the caregiver experienced each day as she left for work was overwhelming. Her spouse's erratic and unpredictable behaviour meant she always had to anticipate new potential issues or challenges. Each day she worried about returning to her home unsure what her spouse may have done in her absence. With time, the unremitting levels of stress such as that experienced by the aforementioned caregiver led them to access services, such as counselling or their family physician. Other caregivers echoed sadness and uncertainty as they struggled to adjust to what was clearly going to be a long road with an unpredictable future. For example, one caregiver said:

He's seventy-five-years-old. He's so positive. I keep saying this. He said to me the other day, he said, "You worry too much, you've got to quit worrying." He says, "I'm seventy-five-years-old." And he said, "I don't have any control over what's going to happen, so I'm going to enjoy myself when I'm here." [crying] Yeah. It's easier said than done though. (SCG 04)

The persistent nature of being a caregiver for a stroke survivor and the uncertainty of what the future would hold served to wear caregivers down over time, leaving them with little resilience or positive outlook on their future. Caregivers also shouldered an emotional burden related to being a care provider rather than a life partner. For example, this caregiver remarked:

And you know now I'm kind of like his wife, his friend and then you know telling him what to do. So that's what I find hard cause I'm trying to help him and...I don't know what he sees me as, like a monster or something but you know he has to do [his exercises]. (SCG 09)

The caregiver resented her position as taskmaster over her spouse. She felt torn between wanting to help her spouse and yet having to be the "bad guy." Caregivers often longed to have someone else take over for them so they could return to being "just a spouse" but they felt that there were few services that could fulfill this wish. Day programs could be helpful but came at a cost and were not always suitable for the stroke survivor.

Health providers echoed the caregivers' experiences of the heavy emotional toll with similar stories of their own. One provider said:

Recently a patient's wife called me and she broke down on the phone and I said, "You know your husband is really lucky to have you. You're such a great support for him." And I hear this a lot they'll say "well I don't think they realize that, or recognize that."

And I don't know if it's because some patients who've had more significant strokes, I don't have that insight. I don't know. But some of them feel like they might be okay in the caregiver role, but they maybe don't feel appreciated. That's one piece. (HP 09)

Health providers recognized the complicated nature of caregivers' feelings around their caregiving role and sought to provide them with confirmation that accessing services was the right course of action to take. While all caregivers willingly supported the adult with stroke, the emotional cost of providing that support in the absence of affirmation was not enough for all caregivers to feel valued and emotionally happy. Health providers spoke of the challenges that caregivers experienced in accepting their new reality, for example one provider said:

I mean even three years out or five years out [after the stroke] for some of our caregivers like that acceptance still isn't quite there yet, they still want things to be the same and a lot of it is trying to figure out what that sort of normal is and to accept to make use of that. (HP 12)

Acceptance of this new reality remained challenging for caregivers despite the passage of time. Caregivers struggled with these complex emotional issues over long periods of time. Asking health providers such questions indicated that caregivers hadn't fully grasped or perhaps accepted the resultant effects of the stroke and suggested that they required further education and support to deal with the ramifications of the stroke on both the adult with stroke and themselves.

The act of caregiving for a stroke survivor can be all consuming and physically and emotionally draining. Caregivers used services that helped them in their caregiving role and often accessed these services as a necessity of coping rather than to optimize their health or deal with loss. Providers also acknowledged, "but we know that a stroke impacts the caregiver equally, right? In terms of such a devastating event." (HP 03) Complexly interwoven with the

grief related to the stroke, were the aspects of hope and recovery. Providers were focused on optimizing the health and assisting the caregiver and survivor in coping with the deficits related to the stroke. This may mean that the grief associated with the resultant losses due to the stroke was not addressed, particularly for the caregiver.

Summary: Overall, many caregivers were troubled by their emotions, expressing feelings of guilt, anxiety and despair. These pervasive and continuing feelings led caregivers to access the services of health providers such as their family physicians and social workers for counselling but those services were most often accessed as a last resort. Few caregivers accessed services such as gyms or YMCAs as a means of coping during the moments when their emotional pain was greatest and often those that did, were directed to the service by a health provider.

Losses experienced by caregivers influenced their use of services. “There was nobody to relieve me, no one to talk to”

Another factor influencing caregivers’ access and use of health and social services were the many losses they experienced in their lives when they became a caregiver to a stroke survivor. These included: (a) loss of my social life, (b) loss of my partner relationship, and (c) loss of my very identity.

Loss of my social life. “Everything revolves around providing care”

Many caregivers who provided extensive and enduring support to stroke survivors experienced loss of their social networks. Caregivers spoke of loss in a raw, visceral way, “well on my bad days, I think I don’t really have a life.” (SCG 06) This caregiver’s quote speaks to the potentially all-consuming nature of becoming caregiver to an adult with stroke. Loss, for the caregiver, included loss of her freedom to do regular daily activities such as taking care of her own health by exercising or getting together with a friend for coffee. Her day-to-day activities

were dictated by her husband's needs and the constant obligation she felt to be available to help him day and night. She experienced enormous pressure to be "on" when she was most tired. This happened at night, when she had to physically assist her husband with transfers into and out of bed, toileting and overseeing his tube feeds.

Providers corroborated this loss experienced by caregivers, "challenging with time, feeling that they don't have a life anymore. That everything revolves around just caring for this person and making sure all their needs are met." (HP 05) Some providers saw the caregiver over a period and then drew on this experience to create a holistic perspective of effects on caregivers' lives in the long term. For example, one provider recounted:

This particular lady that I'm thinking about did [decline over time]. She was actually someone, that when I first met her was so together, 'We're going to beat this thing.' And I thought to myself. 'Wow you're doing too well.' Cause this is the long haul. And I saw her kind of spiral downwards over time. When she realized what...was involved. What she was in for and it really is a long haul. (HP 02)

The pressure and all-consuming nature of the caregiving role left caregivers feeling exhausted and overwhelmed. But the pressure they put on themselves to be competent, selfless, and committed caregivers hindered them in seeking help from formal services such as respite or specialized day programs. For them, loss of their social life was a necessary result of being a dedicated caregiver. Although caregivers acknowledged the loss of their social life, they felt that asking for help was to admit failure or to potentially demonstrate an inability to cope on their part. For example, "I don't know that I ever reached out...because you see I am woman, I am strong...you can't break down." (SCG 02) In situations where the stroke survivor had extensive care needs, the caregiver may have felt that admitting the need for help was to risk their loved

one ending up in long-term care, something they desperately wanted to avoid. Loss of their social life increased caregiver access of services but only after they had reached a maximal point of stress. Before that point, caregivers persevered hoping their situation would improve. Failing that, they turned to the help of health providers such as physicians and social workers.

Loss of my partner relationship. “He is more my child than my husband”

Some caregivers felt that they had lost their relationship with their spouse due to the cognitive and physical effects of the stroke, meaning they could no longer relate as partners. Due to the emotional toll of this loss, some caregivers accessed services such as counselling or sought out respite opportunities so that they could receive valuable support from friends. One caregiver described the deep and overwhelming loss of her relationship with her spouse after he experienced his stroke:

That [our relationship] has changed in ways, good and bad. I have to be honest and I would never tell this to [husband] at this stage of the game. He thinks he’s 100% himself because he has his memory. His memories were not changed. But he doesn’t have the same cognitive abilities that he had before. And I miss them. I love him dearly with all my heart. But I have to say [husband] is a child more than he is a husband. *crying* And I would never say that to him because it would break his heart...I did lose my husband on December 20th, I did. (SCG 06)

The deep, heart-wrenching loss of the relationship with her life partner was something she continued to face every day. But unlike in situations where a spouse dies, in her case, her spouse was very much alive. There was no formal acknowledgement of what she lost or a completion of mourning rituals that would commonly accompany a death. She continued to live her life with her husband, albeit radically changed, all the while quietly mourning the loss of the

person she had married. This loss, as overwhelming as it was to her, was to the outside world largely invisible. The caregiver felt she should be grateful that her husband was alive and that she was able to care for him in her home. She made it clear how much she loved her husband and her distress in the loss of her life partner, as she knew him. However, she did not seek counselling to help her manage her intense feelings of sadness that accompanied her loss because of the fear of harming her spouse even more.

Providers also identified the loss of partner relationships as an issue that could influence use of services with the change in relationship potentially leading to feelings of grief and loss for the caregiver. For example, one provider said:

They've gone [to] more of a caregiving role as opposed to, you know, the role of being a partner and being, you know, what's the word I'm looking for? No longer a partnership...It's like the parent-child relationship. (HP 17)

One health provider acknowledged that some caregivers experienced a loss of their partner relationship but when asked whether they felt caregivers reached out for help such as counselling the provider replied, “not, no, not generally. We've only had a couple that have, you know.” (HP 17) There is acknowledgement by health providers that caregivers are suffering and potentially struggling as a result of the losses they have experienced by becoming a caregiver. However, there was a lack of critical reflection by health providers about the possible provider roles in being proactive so that caregivers did not have to do the work of reaching out for help.

Loss of my very identity. “I am no longer an independent person”

For some caregivers, the commitment, sacrifice and all-encompassing role of being a caregiver left them feeling as though they had lost their very identity. The magnitude of the loss

often influenced their choice to use services such as counselling or respite, thus enabling them to have some time and space for themselves.

The ecomap based on the interview with SCG 04 (Figure 4) illustrates this type of loss. These included: (a) her belief that she had lost her identity, (b) her anxiety, (c) concerns about leaving her husband alone, (d) having providers in her home was overwhelming, and (e) that she was living day by day. This ecomap enabled me to immediately capture the caregiver's intense experience of loss; later corroborated by analysis of the full transcript. The following quote captures the profound experience of the caregiver featured in the ecomap:

And I go out to lunch with my friend, first thing on the plate is, 'How's [he]?' Ok.
'Is he still going to the therapy? And what do the doctors say? Is he ever going to get better?' And I'm like, when I was talking to my husband about this, I come home one day and I was just in tears. And I said, like, I've lost my identity. (SCG 04)

The caregiver in this example desperately wanted some time away from caregiving and to be acknowledged as a person with her own needs. Those around her constantly reminded her that her needs were no longer important, causing her great anguish and pain.

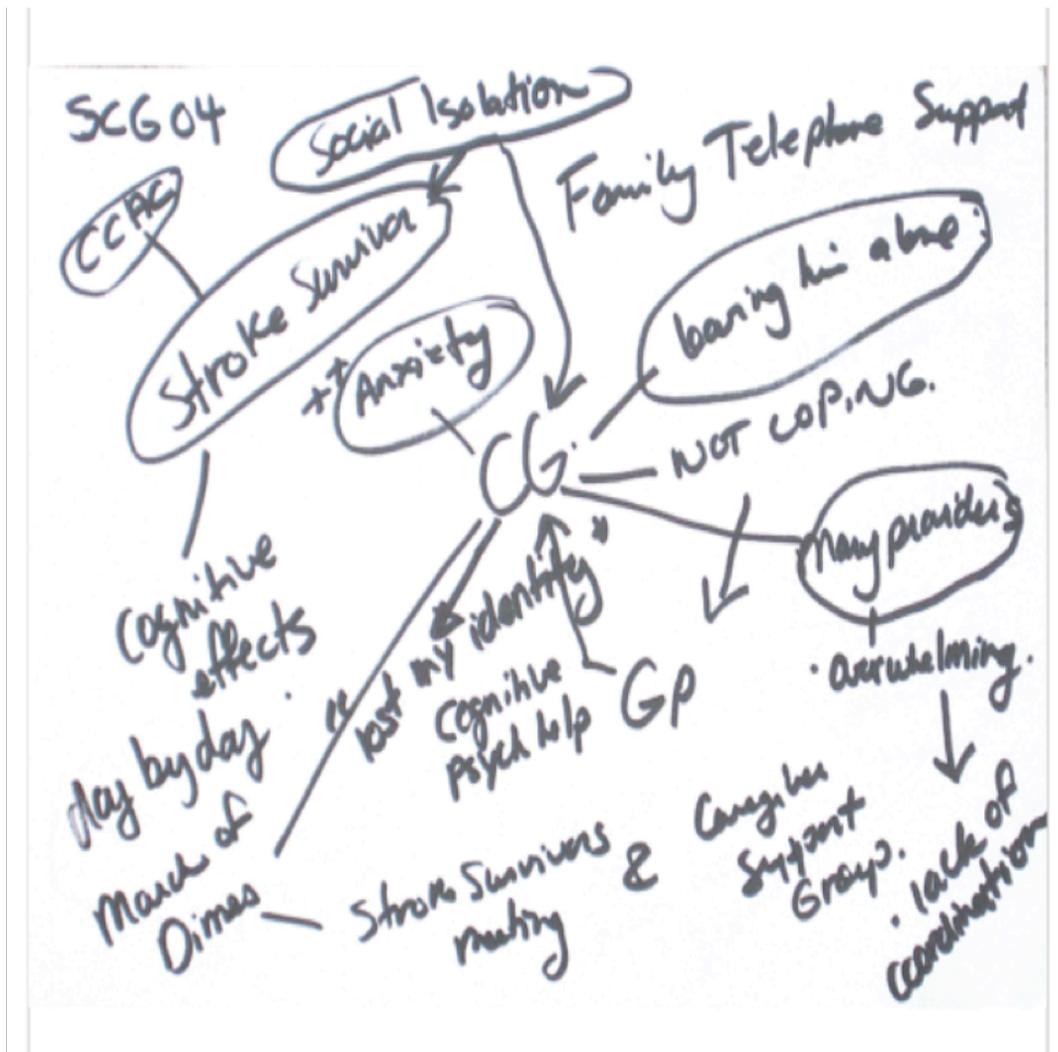


Figure 4. Ecomap from in-depth interview with caregiver participant SCG 04

Health providers were eager to help caregivers, which often meant helping caregivers solve problems through providing education or referral to services and supports, “most of the time you are able to link them [to educational resources or a health provider] or provide a suggestion.” (HP 09) “[We try to] provide as much information as they want and they need [to help them manage their caregiving role and cope with their feelings].” (HP 03) But some problems resist resolution and the caregiver’s quote captures a deeper and more profound sense

of loss that cannot be easily helped by education or a brief consultation. As another provider discussed, caregivers continued to grieve the loss of their partners and the lives they had known prior to the stroke, “some caregivers come into a session and I would say, constantly grieving. So why is he like this. What’s happening? And asking the same questions over and over again.” (HP 02)

This quote illustrates the sense of loss of identity and the caregiver’s need for that to be acknowledged by others. In this case, the caregiver perceived that she had lost her identity as a woman, wife and independent person. She believed the people around her no longer consider her for her own sake but rather just in the role of a caregiver to someone who had experienced a severe stroke. The quote captures her resentment and frustration but perhaps also her own discomfort in her need to be acknowledged for her own qualities as a person, not just as provider to someone else. Her psychosocial challenges led her to access counselling services to try and help her manage her intense feelings of abandonment. Caregivers’ experience of fragility and the need to be recognized as a separate and valued person, reflects their need for validation from others about who they are, not just for the roles they enact in their lives. The prolonged effects of caregiving appear to diminish this sense of self as a valued individual in society and in their own social networks.

The experience of feeling as though one does not matter anymore, as an individual person is deeply emotional, hurtful, and definitively tied to self-worth as evidenced by the following quote, “[I’m] trying to continue on my life...because I’ve lost my self-worth.” (SCG 04) In this situation, the caregiver’s profound sense of loss of identify affected her ability to cope with her role as caregiver and led her to access the services of her family physician who continued to see her on a regular basis years after her spouse’s stroke.

Health providers acknowledged and shared their understanding of the losses related to sense of self that some caregivers experienced, stating the importance of this, “yeah, and empathy. Just trying to empathize with them in a really, and being transparent and honest, that this is a really horrible situation. Right and just trying to be with where they are at the time.” (HP 03) While some caregivers did access services to help them deal with their emotional pain, there was a general tendency for them to suffer in silence as these caregivers explained, “getting counselling. So, why didn’t I? Maybe I didn’t want to admit it.” (SCG 02) “you just kind of deal with it.” (SCG 14) There was little indication that the training and expertise of most providers were enabling them to truly and fully confront and help with the immense loss of self that caregivers were going through.

Summary: Caregivers experienced many types of loss as a result of their caregiving role. These losses included loss of their social life, partner relationship and self-identity. Losses acted as both a barrier and an enabler to caregivers’ access and use of formal health and social services. In some instances, losses encouraged caregivers to access and utilize services that included their family physician, social work, counsellors, respite services and day programs. However, in other situations, losses, such as loss of their social network, hindered caregivers’ use of services because the enormous amount of time spent caregiving meant they were no longer able to engage in health supporting behaviours and activities. This in turn led to the loss of their social networks. Furthermore, when a caregiver felt they had lost their partner due to the effects of stroke they tended to suffer in silence rather than seek out supportive or counselling services.

Enormous caregiver responsibility. “I have to do everything”

Providing ongoing support to stroke survivors necessitated that caregivers take on a tremendous amount of responsibility. As discussed in the context of caregiving, all caregivers

had incurred a dramatic change in their lives that thrust them unexpectedly into a caregiving role. The weight of these caregiving responsibilities was evidenced in three sub-themes: (a) many daily tasks, (b) sense of duty, and (c) responsibility for the stroke survivor's safety. These responsibilities presented barriers such as having a lack of time, energy and the necessary supportive resources needed for caregivers to access services and supports for their own benefit. Although caregivers experienced enormous responsibility in their caregiving roles, there were also instances where formal health and social services were able to successfully support them.

Many daily tasks. "I have to do everything and I'm only one person"

Most caregivers engaged in multiple daily tasks to support the stroke survivor. On top of providing extensive personal care, they assisted stroke survivors with rehabilitation, for example one caregiver said, "so I, instead of taking him to a massage therapist I do his massage. I massage his legs." (SCG 03) Beyond supporting them with their activities of daily living they also provided for and ran the household. The following quote provides an overview of one caregiver's role, "oh, I still do, I have to do everything. Yeah. Everything, ok. I have to do the finances. I have to do the groceries. I have to do the cooking, the cleaning. Everything." (SCG 04) This caregiver was in her 70s and continued to provide ongoing and substantial support to her spouse one-year post-stroke. This caregiver did not have daily PSW assistance, as her husband was able to wash and dress himself. The magnitude of her daily caregiving role left her with little time or energy for accessing formal health and social services that she may have benefited from such as structured exercise programs or counselling. Furthermore, the ongoing pressure she felt to fulfill multiple roles such as spouse, caregiver, financier, and household manager left her feeling vulnerable, despondent and at risk for developing anxiety and depression.

Another caregiver voiced her experience in fulfilling multiple responsibilities, “yeah you have to do everything yourself...you know and I had to run to work, I had to run to an appointment; I didn't have a computer, I have to run to my daughter's place, and then you got to run back to unemployment [employment insurance benefits office]... Well I'm only one person.” (SCG 09) The caregiver's frustration with her competing priorities was palpable, illustrating how easily the caregiver's health needs became eclipsed by their caregiving role. These caregivers accessed limited services because they had little opportunity among their competing priorities to learn about what was available to support them and to make use of any of those services.

In addition to the overwhelming responsibility they held, caregivers also commented on their high levels of fatigue and lack of time that was associated with their caregiving responsibility. For example, one caregiver said:

Sometimes I look forward to just Sundays. Right [because] she goes to her daughters and it's me time. Right so I do whatever the hell I want, I don't have to answer to anybody, I don't have to worry about anything. If I want to go across the street up there, or across the street over here or if I want to go to sleep, I can just go to sleep right? It's kind of nice, it's my time, right? Which is restful. (SCG 22)

Caregiving for most of the caregivers was around the clock with little opportunity for breaks or “me time.” Even though caregivers were not always actively engaged in caring, having to be responsible for another's well-being could be likened in some regards to caring for a child. They wanted to provide the support, and they loved the stroke survivor but there were limited opportunities for breaks, which was exhausting, particularly over extended periods of time. As the caregiver above mentioned, his only time for himself was on Sunday afternoon, not a time conducive to attending appointments.

In one particular instance, the caregiving responsibility went beyond the stroke survivor to include other family members. For example, one caregiver was supporting her adult daughter who had had a stroke and her older adult husband who suffered from dementia. In her situation, she was caring for two people, “in two different locations. Three years. Yeah, I ended up on a little pill because I couldn’t make a decision.” (SCG 15) This particular caregiver took on caregiving for two people until she could no longer cope with the load. Due to the strenuous and all-consuming nature of this caregiver’s role she had limited time or energy to meet her own care needs. She couldn’t even get to see her family physician until a family member stepped in and strongly recommended, she see her family physician for support and guidance. It was only then that she began taking medication to help her cope with her anxiety. Attending a support group, seeing a family physician or taking time to engage in a program to support her health was not feasible without additional supports.

Interviews with providers acknowledged that time constraints and limited availability of respite influenced many caregivers’ use of services, “you know, I talk to a lot of people who would love to come to my caregivers’ group but they just don’t have time...And they’re the ones that need it the most.” (HP 04) Access to health and social services by caregivers is complicated by many factors, but for those who have many competing responsibilities, time, energy and the suitability of services are important factors that cannot be easily addressed.

Providers explained:

Because caregivers are overwhelmed. They are doing everything now... the finances, the grocery shopping, generally, they’re in charge of the socialization. Factors that make it challenging for caregivers’ time [to use services]. They can’t leave the person alone.

(HP 04)

Providers also acknowledged that caregivers' responsibilities left them vulnerable:

I think it makes them more stressed out because they have more on their plate with less support unless there's a lot of family support. So, you find a lot of times they're more likely to get sick. (HP 15)

Caregivers' extensive and often overwhelming responsibilities, which took their time, energy and resources, served as a significant barrier to accessing and using formal health services that could have supported them in their caregiving role and in the management of their health.

Sense of duty. "You feel like you're responsible for their life"

Common across caregivers was their sense of duty, which meant that they tended to own the role of caregiver as a matter of course often seeing it as something they had no choice in or for which they had no expectation of help. As one caregiver said, "some days I'm, 'oh, my God I just can't do this anymore.' And other days I'm, 'well this is your life and accept it and we'll deal with it and we're not that bad.'" (SCG 04) The ongoing responsibility tended to wear caregivers down particularly when they realized that their loved one was likely to make small gains in their health with time. The time spent caring for the stroke survivor meant that there was little time and energy for them to access services for themselves. Often, they put off asking for additional help such as respite because they felt it was just expected that they should take on the responsibility. It didn't necessarily occur to them to ask for help. For example, one caregiver talked about her perspective as a caregiver:

A little bit of respite services or support even if it was just an hour a week, would have been appreciated for being able to go out and get the groceries, or go have a coffee with a friend and not be feeling selfish because a caregiver has an overwhelming sense of,

what's the word, responsibility. Like you feel like you're responsible for their life even though, you know you're not. But you feel like you are. (SCG 07)

This caregiver struggled to *turn off* from her caregiving role, shouldering the expectations of always being available to support the stroke survivor. She perceived that she needed help but at the same time was conflicted by her need to be everything that the stroke survivor needed. This sense of obligation often prevented caregivers from using formal services such as respite. They felt like they needed to be that specific person who was always available for the stroke survivor or they felt a sense of guilt in taking time for themselves. Caregivers needed permission to take a break from caregiving. A health provider stated, “we wish we could call them.” (HP 02) But in most situations this did not happen and health providers themselves were not always well prepared to deal with caregiver challenges.

Responsibility for stroke survivor's safety. “I worry, she fell a couple of times”

An integral part of the great responsibility that caregivers felt was their role in their care recipients' safety in the home environment. This sense of responsibility led them to live with a level of chronic angst that hindered them in using services that were designed to help them. For example, “yeah, but I just don't like leaving her alone because at first she fell a couple of times.” (SCG 21) Providers confirmed that caregivers were tentative to access services on their own behalf because of their concern for their care recipient's safety. For example:

Worrying about their spouse or the person that they've left there, that nothing is going to happen while they're gone, trusting the PSW that might be with them or setting up a system so they can actually leave if they don't have other family members close by that makes it practically impossible. (HP 13)

Their reservation in accessing health and social services in these instances was strongly connected with their concern for the safety of the stroke survivor they were supporting. Services could be available but unless there were supports in place for the stroke survivor that the caregiver was comfortable with, the caregiver would not access them.

Summary: Caregivers of stroke survivors frequently experienced an enormous sense of responsibility in their caregiving role, which could be overwhelming. Because of their challenges, most were not able to access services that would support them or help manage their own health such as having respite care or attending health promotion activities because of their limited time and resources. Furthermore, caregivers were conflicted over using services; they knew they needed the help but were reluctant to accept it. This theme demonstrates the interrelationships between other thematic constructs such as finances and social supports. When caregivers were able to pay out-of-pocket for respite or have friends and family spend time with the stroke survivor then they were able take a break from the enormous responsibility they had. However, caregivers spoke more commonly about the lack of supports in their lives rather than the positive ones.

Social support networks. “They deserted us, they just don’t come around”

The availability of informal support influenced caregivers’ use of formal health and social services. Caregivers encountered varying experiences with their social networks following the stroke of their family member. The two sub-themes identified were: (a) social networks were avoidant, and (b) social networks rallied to support caregivers.

Social networks were avoidant.

Several caregivers exhibited sadness and dismay as they explained how they felt they were abandoned or avoided by friends who had previously been central pillars in their lives after

their loved one's stroke. For example, one caregiver said, "they deserted us. They just don't come and visit. And I just don't know if they know how to deal with this or not, I don't know. No, a lot of people they just don't come around." (SCG 08) Another caregiver said, "no family and like I say friends were scared. They didn't want to deal with it." (SCG 04) The caregivers alluded to the difficulties that some people may have had in relating to the stroke survivor especially if they had aphasia or pronounced physical or cognitive deficits. This perspective was echoed by another caregiver who said, "it seems that most friends are fair-weather friends if you want to call it that. A lot of friends don't know what to do, don't know what to say, so they just don't." (SCG 20) The caregiver spoke to peoples' discomfort and insecurity in facing the stroke survivor and family. Interviews with providers echoed the caregiver experiences, "I mean one of the biggest things that I hear from both our participants and from our caregivers is our friends don't come around anymore." (HP 12) And, "yeah unless you already have a very good network that's already in place, you're going to lose it. Which is really unfortunate, that's just how society works sometimes." (HP 13)

The resultant effects of this avoidant behaviour by friends and informal supports often meant that caregivers were more reliant on accessing formal health and social services to assist them in caregiving. Instead of friends and family providing caregiver relief the caregiver may have had to access formal in-home respite. However, formal respite was either significantly constrained by its availability in the health system or was paid out-of-pocket. As one provider said, "so really if they don't have helpful family or friends, they're really stuck. You know, they're just depending on the few hours a week that they get from CCAC [LHIN]." (HP 04) Some caregivers used day programs and organized initiatives to find respite and although many of these alternatives were partially subsidized, they became costly over time.

An additional challenging aspect of caregivers' social support networks was being told by well-meaning people to seek help from friends and family yet finding that there was a lack of services to meet the caregiver's needs. One caregiver commented that, "yes and I know that some people say that you should reach out and ask for help but, every time I did, I didn't feel the help was there except for from the therapy team." (SCG 07) This caregiver's experience exemplifies some of the social difficulties faced by caregivers. The support provided by the therapy team was instrumental in helping this caregiver manage the earlier stages of her spouse's stroke recovery. However, later in the recovery process she was no longer able to turn to those services for support as her spouse had been discharged from those services. Health professionals echoed the experiences described by caregivers. For example, one commented, "relationship loss is absolutely huge. Huge. Ok. And for caregivers as well. It becomes a very quiet lifestyle. Ok. Very lonely. Very isolated." (HP 07) Another HP said:

So, we often find that, we'll get phone calls actually, like after discharge, from patients and their caregivers. You know, they're feeling very, alone right? Alone in the community and just like I said before, feeling very supported here and then not having that at home. And feeling very isolated and very alone. (HP 03)

In these instances, caregivers found support through formal caregiver support programs where they were able to connect with people managing similar circumstances. These connections substituted for social networks and enabled caregivers to build new social connections.

In a further example, a caregiver spoke about how her social life had been altered as a result of becoming a caregiver. She described how, "it's [social life] falling away because I can't go out on my own." (SCG 19) Her caregiving situation made it impossible to leave her house unless the stroke survivor was in the care of someone else or accompanying her, which severely

constrained her ability to socially engage with friends. In this example, the caregiver needed to access formal services such as respite in order to have a social life. Her social isolation increased her risk for declining health and her inability to leave the house made it challenging to access formal services such as going to her family physician or attending a caregiver support group.

Having an avoidant or limited social network resulted in caregivers feeling unsupported and isolated in their caregiving role, often resulting in mental health issues such as anxiety and depression. A participant interview exemplified this potential situation with:

We don't have a whole lot of friends. So I was totally left on my own. Didn't know what to do... How to handle him when he was peeing in the kitchen. Not knowing where he was. I couldn't leave him. And I had no help what-so-ever. I just about had a nervous breakdown. (SCG 04)

The caregiver's experience eventually led her to access the services of her family physician to find support and medication to help her cope. Health provider interviews also corroborated the importance of peer support particularly for those caregivers who were isolated, "so definitely I think peer support is key for caregivers as well as for the person after the stroke." (HP 01)

Another interview with a provider described a situation of how one caregiver joined the support group she was leading:

A young man showed up one night for my meeting, crying his eyes out, just crying, he said he had no one to talk to. He didn't know what to do and somehow, he found that I run this group. And he was a caregiver. Well his wife had just had a stroke. Fifty year-old wife...He had no children, didn't seem to have any family support. Nothing. So somehow, he found this resource showed up at our group crying his eyes out. (HP 04)

It was not uncommon for caregivers to become isolated with negative ramifications for their health and ability to provide supportive care. However, formal health and social services played a valuable role in helping these caregivers manage, find support and continue in their caregiving journeys.

Social networks rallied.

A feeling of social isolation although common was not ubiquitous among all caregivers who participated in the study. Some caregivers described how their social networks rallied to support them in their caregiving role enabling them to take time to use formal health and social services that were focused on health promotion. For example, one caregiver said:

Oh yeah, we had a very supportive system with our closer friends they were calling all week, wanted to make sure how the progress was, and you know if there's anything they could do for us and that type of thing. So yeah that was good. (SCG 17)

It was not easy to discern why some caregivers were well-supported by their social networks while others were less supported. But those caregivers who had strong, close networks prior to the stroke appeared to fare better than those who were more insular or constrained by their life situation. Another caregiver said, “the social support from the community as a whole, was outstanding.” (SCG 07) As in the previous example, a strong social network preceding the stroke resulted in a generous support network post-stroke. In another example, a caregiver's daughter, who lived at home with him, was able to provide daily respite in the evenings for him. The extra respite she provided outside of the formal services he received was crucial in helping him cope with his responsibility, “(she) gives me relief. So, after dinner I can sit down and watch baseball, and she kind of takes care of her ‘till bed time.” (SCG 16) This meant that he could let his guard down and go outside of his caregiving role, if only for an hour or two each day.

Providers also alluded to the willingness and availability of family members to provide respite as a valuable part of supporting the caregiver. This respite gave the caregiver an opportunity for social engagement outside of their caregiving role. For example, one provider said, “where I see things more successfully done is, is there family around that can pitch in and give the caregiver some help and sometimes just respite a few days away is important.” (HP 14) In these instances the support provided to caregivers by their social networks enabled them to access services that supported their health such as attending fitness programs, attending support groups or a dentist appointment. For example, one caregiver said, “Friday's when I get groceries, his sister comes and sits with him. Well if I wanted to go [to an appointment] like I say I just call family and then they come sit with him.” (SCG 09) In other situations, the support of social networks enabled the caregiver to go to appointments with their care recipient, for example, “we have to go to London to see his cardiologist and he doesn't like me driving on the highway. And they [family] would take me.” (SCG 03) In that instance, the social network facilitated the caregiver's participation in her spouse's use of formal health services.

In another scenario, a study participant discussed how a provider facilitated her informal meeting with another caregiver that subsequently led to connecting her with a formal support group:

So, then she hooked me up with a woman who her husband had had a stroke and was very similar. Their son was in university and that kind of thing. So, I went, and I met with her a couple of times. And then I started going to the [name of place] support group, the caregivers support group which was really, really helpful. I just had a hard time getting there. (SCG 10)

The caregiver found camaraderie and support through speaking with someone who had encountered similar experiences. It provides an example of how providers are well-positioned to connect caregivers to other caregivers thereby facilitating peer support.

In another example, caregivers using a formal support group became friends and then continued to support one another in informal social situations, thereby demonstrating the value and friendship that transcended the context of a formal support group:

And because of the social aspect, actually we have had a bunch of them [other caregivers] here, oh, a couple of months ago for dinner and we were able to park the men in the family room with the TV and the ladies went in to the dining room and we shut the door. And we had a new girl, new couple joining us and we said, “ok [name] just so you know, it’s safe here. These walls have heard a lot of stuff.” (SCG 02)

From this quote, the power and value of peer support becomes clear. Caregivers of stroke survivors experienced immense and complicated feelings associated with their role and regarding their greater life circumstances. The safety and empathy borne out of sharing their experiences of similar albeit individual journeys with their peers was very valuable for helping caregivers cope with their caregiving journey.

Summary: The explanation for why some caregivers had a strong social support system and others did not is neither straightforward nor easily addressed whether they are a caregiver or not. However, what clearly emerged from the caregiver and provider interviews is that those caregivers who had limited family supports and who were providing extensive amounts of care to a stroke survivor faced the potential of developing social isolation and caregiver burden. In these situations, caregivers would have benefited from health and social services such as respite and opportunities to meet with counsellors. However, there was limited information on these

services and few services available for caregivers to meet their needs. A considerable number of caregivers who participated in this study described a reduction, loss or change in their social support networks as a result of becoming a caregiver. Alternatively, some caregivers also reported positive experiences with their social networks with friends and family providing emotional support as well as providing much needed respite for caregivers to take time away from their caregiving role.

Limited information and lack of suitable services. “There’s a year-long wait list”

Other factors influencing access and use of formal services were: (a) insufficient information on services and (b) challenges with service availability. Each of these aspects will be discussed in relation to their influence on caregiver access and use of formal health and social services.

Insufficient information on services. “I had to learn everything”

Most caregiver participants indicated that they had insufficient information about available services and how best to access them during their caregiving journey. One caregiver explained:

You know and these people are professionals it's like you know when you start a job at a factory nobody really wants to tell you [that you] have to learn that and that's what I found, I had to learn everything. And you know people oh my God they just tell you “oh well you can get disability.” No, you can't. (SCG 09)

Not only did caregivers experience challenges in accessing services that they knew about such as disability, they also struggled to find out what other services were available to support them. For example, “we didn't know, we didn't know if there was any help out there because nobody said there was any help out there.” (SCG 15) And, “I just want to back up and say that when I was at

home looking for help, I was able to sit on the computer and try and find things. And that was the whole issue, trying to find things was very, very difficult.” (SCG 02) And, “not a lot of direction or information was given.” (SCG 07) One caregiver went on to discuss how she developed her own information manual subsequent to her experiences:

I kind of made up my own little booklet of help and so on. And what was out there. And what wasn't out there and that kind of thing. Of which I passed on to a good friend of ours when he had a stroke, just a year later. (SCG 02)

Navigating government related organizations was particularly challenging for caregivers, “my finances, trying to negotiate the myriad of government agencies has been a challenge.” (SCG 20) Struggling to learn about and access community services consumed considerable amounts of caregivers' time, added to their stress and took away from their opportunity to directly support their loved one or care for themselves. Social work, a role well-placed to support these caregivers, was often not available to them in the community.

Providers interviewed were only familiar with stroke navigators in an inpatient setting, “the stroke navigators that I've known about they're usually just for hospital.” (HP 04) Further discussions with providers demonstrated that there was considerable misunderstanding among caregivers about the capacity of the LHIN to meet their needs. For example, one provider said:

So, you know, they're [caregivers of stroke survivors] just so angry that they're not getting the services that they think they deserve and you know, I did have them [CCAC representative] come and talk in one of my groups and I felt really sorry for the lady that came in. Oh, from CCAC. I thought they were going to shoot her, you know. Because they were angry because, you know, “I didn't get it.” You know, whatever, so. There's a lot of anger and misunderstanding about what they provide. (HP 04)

Another provider spoke about the value of having a resource person for caregivers to contact for information on availability and accessing services:

Some of it is also people don't know what's out there, and they don't know what questions to ask. I think it would be really helpful if people had someone to call. And we do have patients call us, many times that's happened to me, one month later, two months later, three months later and I know that help the in-patient team to think, "Ok I don't know, I'm not your patient anymore but I don't know what to do." Or, "What do you think about, who should I call or what service is needed." So, we, every team I've been on has identified that as a need. (HP 02)

Some health providers recognized that there is a lack of information about resources for caregivers and that caregivers value someone to speak with rather than being left alone to find out about resources in a book or on the internet.

While some caregivers struggled to find suitable services, there were also caregivers who were very thankful for the support they had received along the way. For example, one caregiver said:

But we've had such beautiful people walk into our lives trying to help (husband) that you realize that it's a good world. There are a lot of good people out there. And you don't realize that as much when you're not in need. But when you're in need and your needs are being met by these lovely people then you think, my God, the health care profession is working. (SCG 06)

Thus, when the system is able to respond to meet the needs of stroke survivors and their caregivers, caregivers are grateful and willingly acknowledge the value that they receive from

the publicly funded health system. Caregivers are then more likely to reach out to service providers when they need help going forwards.

Challenges with service availability. “These programs are for seniors, she’s not a senior”

Stroke caregivers expressed frustration about the lack of services available to meet their needs and the needs of the stroke survivor. For example, they spoke about the lack of services available for younger stroke survivors and their caregivers in the community. These limitations affected stroke caregivers’ ability to remain in employment and engage in other aspects of their lives. One stroke caregiver discussed her experience in trying to access programs for her spouse:

You know and then after the hospital that [rehab] ended cause you're only so long.

Then they sent us to [place name] but then we found out about this government place

well I'd tried before but you know you had to be 65 well what about the people that are younger? That are having these strokes, they have you know? And I said to the lady

"look I don't want to be rude but," I said "you've got three exercise classes for people who are over 65. I mean I don't want to be rude, they've almost got their foot in their grave,

like why aren't you helping this, like he could've maybe been back to work.” (SCG 09)

The caregiver was clearly frustrated by the lack of available programs for younger adults with physical and/or cognitive deficits related to stroke. Because of the program inclusion criteria, the stroke survivor could not attend, thereby losing out on an opportunity for rehabilitation while the caregiver lost out on valuable respite time. This sentiment was echoed by another caregiver, “also a lot of the things that are available for disabled people are for seniors, [Name]'s not a senior.” (SCG 20) This caregiver was also discouraged by the lack of supportive programs available for younger adults. In both examples, the stroke survivors were in their fifties. These

caregivers were left paying out-of-pocket for private in-home respite, which was often unaffordable.

A health provider described a perspective of another younger caregiver:

I'm just thinking of one recently, a caregiver, she went to a caregiver support group I don't think it was for young stroke survivors though. It was specifically for caregivers and she said she was very young; she was the youngest person there so she couldn't quite relate. (HP 09)

This quote draws awareness to the importance of relating to others in order to feel supported, suggesting that the needs of younger caregivers and stroke survivors may be different than their older counterparts. Another provider spoke to the challenges of caregiving while employed, “so that stress of getting and wanting to get to work and actually needing to get to work because they needed the money and then there is all these appointments.” (HP 02) Caregivers are torn between multiple roles, providing ongoing care to the stroke survivor while at the same time working to support their family. Most of these caregivers had few options, they could not afford full time respite and they could not afford to leave their jobs; this left them in a very stressful position.

The limited availability of counselling and psychosocial supports to meet caregiver needs emerged as another aspect of caregivers' struggle to find suitable services. Caregivers early in their caregiving journey were often looking for guidance on how to manage specific situations with the stroke survivor. As one caregiver said:

And I just kind of sat there and blubbered away and cried. “What do you guys do?” “Oh, well, I just you know...” No specific guidelines. I needed more yeah. And I don't know whether I would have got it from a professional person. But if it was a professional

person, if I ever had to go to a professional person again, I would love to speak to somebody who is familiar with the stroke situation. (SCG 04)

The caregiver was referring to her experience in consulting with a caregiver support group and a counsellor. In the case of the caregiver support group, she felt the group was more geared to socializing and less towards providing direct caregiver support, something she needed at that point in time. In the case of the counselling, she wanted concise, focused support to cope with the acute stress brought on by caregiving for a spouse who had significant cognitive deficits. The caregiver felt that her time and energy were wasted trying to explain her situation to the counsellor. She believed that someone more familiar with stroke would have understood her position at the outset thus enabling her to focus on her needs rather than requiring lengthy pre-emptive explanations. The value of familiarity with the stroke experience is captured in the next quote by another caregiver:

So, when he had his incident and when she [another stroke caregiver] comes in the store sometimes we can just kind of share stories. You know? How was your week? What did you go through this week? You know those types of things. So, I find with people like that that have been through it and I think she's a very positive person the same as me. You can help each other instead of being around someone who whines and thinks they're the only ones that are going through it so...you're not alone in it. (SCG 17)

This caregiver is referring to the power of peer support, something he discovered through the context of his work that brought him into regular contact with another caregiver. Over time they shared their experiences and proved to be a powerful source of support for each other.

These examples demonstrate the value of appropriate support and exemplify how frustrating incompatible support can be for caregivers. It is important to acknowledge that caregiver needs

may be quite distinct at different phases of their caregiving journey and that support is highly context dependent.

Health providers discussed issues with the lack of follow-up with the caregiver in the community setting. For example, one health provider discussed a specific situation as follows:

So, the couple that I told you about that had the dynamic pre-existing to the stroke and that, were probably financially challenged and challenged in other ways, that particular caregiver really could have used some ongoing support...And that wasn't there for her. (HP 02)

This health provider suggested that the caregiver would likely be struggling when the stroke survivor returned to the community but acknowledged that the system was unable to reach out to the caregiver. This could speak to a number of factors such as the lack of time and availability of staff and resources to follow-up with caregivers, but it could also suggest that caregivers are not usually included in the circle of care. Clearly, caregivers have supportive requirements at many stages of their caregiving trajectories. There are likely to be a number of support options to meet caregiver needs but having a full and rich understanding of the stroke experience emerged as an extremely important starting point for providing the support caregivers need and want.

While some caregivers were interested in attending supportive programs such as caregiver support groups, they often found that they were constrained by the scheduling of these groups. For example, one caregiver said:

It is what it is and one thing that would help, I know there's caregiver sessions, and we go to [name of organization] sometimes so they have caregiver sessions. But they're at a time when I can't get there because [Name]'s not being looked after... So, what would be

handy is if they had a caregiver session and a session [for stroke survivor] at the same time. (SCG 20)

This caregiver provided extensive support to his spouse and could not leave her at home unattended, so attending a support group was out of the question unless it corresponded with a program for the stroke survivor. Another caregiver spoke to the challenges in managing the scheduling of PSWs for service:

But I don't get [PSWs] like on Sunday, this summer, I, because of the PSW's being new and weekends and saying "well we can't send somebody till nine o'clock to put him to bed, you know we'll send somebody at noon" (uhm) I've been sort of cancelling like weekend by weekend, because if you cancel and say "don't send them for the rest of summer" you never see them again. (SCG 19)

The caregiver had learned strategies to optimize services that met her needs without jeopardizing the service availability.

Healthcare providers spoke to the wait times for programs that left caregivers with little opportunity for optimism, for example:

The other gap is that people have to wait on a waiting list for an adult day program. A good example is I've got somebody right now that I want to attend [program name]. We identified there's going to be a large caregiver burden. This particular patient relies on her husband for everything. And he's going to burn out. But there's a year waiting list to get into an adult day program for her. (HP 05)

Adult day programs fulfill a valuable support and rehabilitation role for stroke survivors while at the same time giving caregivers important respite time. In order to support caregivers in their caregiving they need legitimate supports that they can count on to deliver when they need them.

One provider further highlighted the challenges experienced by caregivers in finding respite either through day programs or formal respite services, “one of the challenges in our area is just access to respite beds, there's not a lot of them. So, they book up quickly and it can be a challenge to actually be able to use them.” (HP 12) Another provider described further issues in accessing respite for caregivers:

So, when we're looking at formal supports to support self-care there's really, there's honestly really, I can't really think of [any]. Other than respite. The very small respite, like through CCAC [now LHIN] and through Victorian Order of Nurses, which usually I think, is at a cost as well. (HP 03)

Caregivers experienced considerable obstacles in accessing available programs and coping with the scheduling of services such as in-home respite or community programs. These challenges added to their burden as caregivers and reduced their opportunities to manage their own health and engage in employment.

Summary: Overall there was limited information on the types of services available to caregivers. This was compounded by the lack of suitable services to meet their needs. There were caregivers who were eager to access services, but they felt unsure about how to do this or even whether the services were available for them. Providers indicated that caregivers needed assistance in accessing services but that there was also a shortage of services to meet their needs. Younger caregivers and the stroke survivors they supported also had limited services to meet their needs such as age appropriate day programs and relevant support groups. There was a dearth of stroke specific counselling available to support caregivers and accessing available supports was made challenging by difficulties in obtaining respite. Scheduling of support programs and in-home services also presented challenges for caregivers.

Trust. “He’s breathing, but is that good enough?”

Caregivers of stroke survivors struggled with issues of trust, which hindered their ability to access and use health and social services. Two central sub-themes were identified: (a) difficulty trusting that I can leave my loved one alone and (b) struggling to trust the providers caring for my loved one.

Difficulty trusting that I can leave my loved one alone. “He took his morning meds, he thought it was time for work, it was evening”

A common experience among caregivers was their difficulty trusting that if they left their loved one alone they would still be all right when they returned home. So in these situations caregivers were likely to forgo using services they could benefit from such as attending health-related appointments or engaging in health promotion activities. In some instances, the caregiver had a negative experience that eroded their ability to trust, for example one caregiver recounted:

Like I had one thing happen to me and it never left me. When he had his first stroke, where his mind went, he slept a lot and he was sleeping on the couch, and I said to him “(husband) I’m just going to run to the store. I’ll be gone for just a few minutes.”

Because remember, he didn’t know how to tell time. “I’ll be gone for just a few minutes. I’m just going to pick up something for breakfast.” I came home, like honest to God, 15 minutes later, he’s in the kitchen, he’s got a tie kind of half on over his pyjamas... Ok. He thinks he’s getting ready to go to work, and he’s making breakfast. And he always made the coffee in the morning. So, he was trying to make coffee. But it wasn’t going right at all. He had his tie on. I said, “what are you doing?” And he said, “I’m making breakfast for us.” I said (Husband), “it’s 8 o’clock at night.” Of course, the minute I say

something to do with time I know it doesn't register. It's just the way we live. We just we live, and he said, "but don't worry I've already taken my morning meds." (SCG 04)

The caregiver's ability to trust in safely leaving her loved one was challenged on many levels in the aforementioned scenario. Not only had the stroke survivor confused the time of day but he had also engaged in two potentially life-threatening activities: (a) taking his morning medications at night, and (b) his struggles in using an appliance that could potentially be a fire hazard.

Moving forward, although the stroke survivor continued to make gains in both his cognitive and physical abilities, this did not alleviate the anxiety and struggles with trust that the caregiver experienced. While in-home respite would have helped support her to access services such as counselling, these were not offered to her. She therefore felt that she could not leave her loved one alone to address her own health needs.

Another caregiver stated, "well I think the biggest thing is you lose your independence." (SCG 20) He could not leave the house unless his spouse was under the watchful care of someone he trusted. His biggest fear was if something happened to his spouse while he was out and that his wife could not call for help. Although the caregiver had experienced an extreme loss of independence, he was somewhat reluctant to make use of services that could have helped him. His reticence stemmed from wanting his spouse to have the best possible care that met her specific needs and his anxiety associated with leaving her in the care of others. The caregiver's extreme commitment to caregiving meant that he did not access services such as a support group or respite that would have enabled him to have more social engagement outside of his home.

Another caregiver described her concerns about trusting that she could safely leave her loved one alone, particularly at night:

But my fear as far as sleeping at night, it's a little bit better now. It's not as bad, but every once in a while you'll get this well I wonder if he's okay. But you know you're watching and yeah, he's breathing but is that good enough? Because he isn't going by himself. Because that's just not the way it's going to be right? If he's going to die, I want to be there when he does. (SCG 14)

The caregiver in this instance had an extremely unsettling experience when her spouse first had his stroke. He had the stroke while sleeping such that the caregiver did not recognize the signs of stroke and her spouse went untreated for a long period of time. This experience was extremely traumatic for the caregiver and although her husband had recovered to a great extent, she still could not trust that he would be all right in her absence. Although the caregiver was determined that her life would return to normal, she was left with lingering trust issues about her husband's safety. She did not confide this fear to a health provider and essentially suffered in silence.

In another example, the stroke survivor was quite young and had severe aphasia. The caregiver spoke to his experience:

In the beginning I told her don't do laundry because it makes me nervous. She [needs] someone while she's out of the apartment, right? But then you know, I can't keep her confined, she wants to have freedom and still feel useful, right. (SCG 22)

The caregiver recognized that his trust issue was his own obstacle and he understood how it was affecting the stroke survivor's ability to recover but as in previous examples he did not vocalize these concerns to a health provider and sought to overcome them alone.

Providers recognized that trust was a challenge faced by many caregivers, for example one said:

And now I'm bringing my loved one home, like at least when they were in the hospital, I knew they were safe when I wasn't there. But now we're home and how do I get to work but not worry. And who comes and checks on him. Or does someone need to be with him, can he be alone? (HP 02)

This provider understood that caregivers felt torn between the demands of employment and caregiving, often times left feeling stressed and anxious. In some instances, the stroke survivor could no longer work and the caregiver needed to continue working in order to support their family. Work was not optional for them and this placed them in a conflicted position; the demands of employment juxtaposed with the fear they had about leaving the stroke survivor at home alone.

Struggling to trust the providers caring for my loved one. "People say why don't you put her in a home for a week and I can't do that"

Caregivers also struggled to trust in the providers who were caring for the stroke survivor. If the caregiver did not trust the service provider, they were less likely to use the services and were, therefore unable to benefit from the respite that these services could provide. Through one example it became clear that support groups designed to help caregivers, were more akin to a luxury not a priority, and frequently underutilized as one caregiver said, "[I'm] not able to go to the support group...Because of the fact I can't get support, trusted support for [Name] at the same time to do that." (SCG 20) Clearly having trust was more important for the caregiver than the benefit he felt he would get from going to the group and worrying about his loved one. In another example, the same caregiver spoke about accessing respite services offered through facilities such as long-term care homes:

A lot of people say well why don't you just you know put her in a home for a week and I can't do that. I mean, and people say well you could just hire somebody to, well yeah, I can but it's not as simple as that. Again, it's the trust factor. (SCG 20)

His greatest concern was that his wife was well cared for and had suitable programs to engage her while in respite. Because she had severe aphasia and was not ambulatory, he was very concerned about whether her care needs would be sufficiently met. He could not bring himself to try the services and therefore incurred a much greater caregiving burden himself.

Subsequently he also had very limited opportunities to access services to meet his own health needs, such as attending routine medical appointments or to engage in health promotion activities.

One health provider indicated that respite is only effective if the caregiver trusts the quality of the service. For example, one provider described:

Because it's... like somebody can drop their stroke survivor off here during the day program, but if they still don't feel comfortable their respite time isn't going to matter. Or if you've got that personal support worker or whoever coming in to their home and they're still not 100% comfortable with that person, and they don't take that time to build that rapport, that respite time isn't... they're going to spend it worrying. They are going to spend the whole time at the grocery store worrying, or they're not going to be able to actually get something out of that. (HP 06)

In interpreting the above quote, it is possible that a caregiver's lack of trust or comfort in using respite services could actually lead the caregiver to worry more rather than having the intended break that the service was intended to provide.

Further interviews with providers corroborated the challenges experienced by caregivers in trusting health and social service providers. One provider said, “I think general levels of trust. They must trust people to burden somebody else. And to be quite honest some caregivers can’t seem to trust anybody.” (HP 08) This quote demonstrates the magnitude of the issue regarding trust in services for caregivers. Some of their distrust may have arisen from a basic desire to have the best of care for their loved one, but guilt could also have contributed. Perhaps they felt if they were always with their loved one, they could prevent another stroke occurring, something many caregivers feared. In some instances, the lack of trust was borne out of prior experience. As one provider said:

I’ve seen some huge breaches of trust and that makes it really challenging for some caregivers. It’s just very unfortunate when it happens, the personal support worker is very much an unregulated profession so you’re going to get good ones, you’re going to get bad ones, you’re going to get good ones that also overstep their bounds because they don’t recognize those boundaries as well, you’re going to get bad ones that don’t even know what boundaries are, don’t care. (HP 13)

However, despite the issues of trust caregivers experienced, they were also thankful for the supports that they were able to access and acknowledged how they helped them in managing their own health and supported them in their caregiving role, for example:

Well as I said, [place name], I feel like it's a breath of fresh air when I take [Name] to [place name]. I know the people are going to look after her, I know that she's going to be cared for properly, I know that they actually care about her. Yes, and it just puts my mind at ease and I'm able to go and do some things while she's there. (SCG 20)

This quote highlights the value of trusted services and emphasizes how important it can be for enabling caregivers to take much needed respite.

Summary: To a large extent, caregivers experienced challenges in trusting that they could safely leave the stroke survivor they were supporting at home alone even after considerable time had passed since their stroke. Furthermore, they also grappled with trusting health providers' ability to sufficiently support the stroke survivor in their absence. These two areas of trust significantly impacted the caregivers' ability to access and use health and social services that were designed to support them.

Challenged to take care of my own health. “How can I find the time?”

Another factor that influenced caregivers' use of health and social services was their struggle in trying to manage their own health while also supporting a stroke survivor. Sub-themes included: (a) caregivers had limited time and coping ability, (b) there were few services to enable caregivers to take time away from their caregiving role to engage in health-related activities, and (c) there was limited attention given to the importance of caregiver health. Each of these factors served to constrain caregivers' ability to use health and social services such as attending medical appointments and counselling sessions as well as engaging in health promotion activities such as exercise at community health centers.

Limited time and coping ability. “She had been neglecting to look after herself”

An important limiting factor on caregivers' ability to take care of their health was time, which hindered them in using services related to health management and promotion. For example, one caregiver said, “well I could probably exercise more but I don't really find the time.” (SCG 16) Caregivers were discouraged at being unable to attend appointments to manage their health but unsure of how to change their situation. One health provider recounted a tragic

situation where although the caregiver was attending a support group, she was neglecting her health in other aspects due to having limited energy and coping ability:

Well, another lady who came to my caregiver group for years, her husband had a stroke with aphasia. I was doing home visits with them because her health was really going downhill. She had terrible pain. And, I remember going in there one day, one evening, I was doing the home visit and she couldn't move. Like she wasn't moving off the sofa, and the guy was in a wheelchair and... How is this working? I said, "Look there's something." Cancer was crossing my mind, because she wasn't eating and she was losing weight. I said, "Look you have got to go see the doctor and have them investigate this back pain. You have to do it." So, she had basically had been avoiding looking after her own health. She neglected herself. So, it ended up that she was full of cancer and she died before, then he went into a retirement home then he died. (HP 04)

For this caregiver, her number one concern was that her spouse was being adequately cared for and she spent much of her time and energy seeing that this was so. Her own health needs came a distant second and she paid the ultimate cost with her life. By prioritizing their caregiving demands over their own health, caregivers are frequently left with little time or energy to engage in health supporting behaviours such as accessing health and social services for their own needs. In the aforementioned case, it was a provider delivering service to the stroke survivor who drew attention to the caregivers' health, not the caregiver themselves who actively sought out health services.

Caregivers frequently discussed how their own health had declined because their caregiving role limited their ability to attend their own health-related appointments. For

example, one caregiver when asked whether there were changes she wanted to make to improve her health said:

And I'm thinking, this is what I've started working on recently, is to try to look after myself better. I think you might hear this in all your interviews, is people will say to me "you have to look after yourself." Have you ever heard that before with your clients? I have heard that. You've got to look after yourself. And I'm like, "how can I look after myself?" That is, I don't know how to get myself through it. It's almost like I pretend that I'm... that it never happened. I'm just going to give myself a day. And you're hoping. Or I pretend none of this happened and just try to be like I was before. (SCG 04)

The caregiver was overwhelmed by her role as caregiver and just thinking about how to manage her own health let alone access services seemed an insurmountable goal. Many caregivers were cognizant of how their health had been affected by caregiving and aware that looking after their health was important but they struggled to identify how they could change their status quo. For example, one caregiver said:

I know that it's not something I'm just going to be selfish, I realize I have to take care of me, and that's what I've been trying and I think, where the blood pressure is you know going up and down because yeah, I'm torn between the two. (SCG 19)

Few caregivers discussed seeking help or additional support to enable them to exercise or attend appointments. More often, they tended to be resigned and despondent about their situation.

Other caregivers who felt that their health had declined or was relegated to the background because of their caregiver role echoed this experience. Self-care requires time, energy and an ongoing commitment, something caregivers of adults with stroke had little left of after their caregiving roles were fulfilled.

Few services. “How do they attend exercise programs when there is no one to care for the adult with stroke”

Another contributing factor to the difficulty caregivers experienced in taking care of their own health was the limited availability of services such as respite that would give them the valuable time and space to engage in health supporting behaviours. In many instances respite was available once per week and that time was allocated to attend to tasks of daily living such as banking, groceries and other household chores. For example, “you know my three hours is spent going multiple places and shopping and doing other things like car appointments.” (SCG 20) Few caregivers were able to use the respite they had to take care of their own health because the amount of respite was too limited. Some expressed frustration at being told to take care of their health without any additional support. For example, one caregiver said:

I would like to lose 40 pounds, I would like to lose all this grey hair, and these wrinkles. Some people go, my God, you’ve aged. And I go yeah come and live in my life for the last four years. (SCG 10)

The sense of responsibility the caregivers felt towards their care recipients was profound, but it also made it difficult for them to use the limited amount of respite available to support their own health. This was corroborated by a health provider who said:

I’ve heard caregivers say that suggestions are made that they need to exercise, or they need to be more active, or they need to go to the gym, or they have to go to physio and they need all of these other appointments. But how do they get to these appointments and how do they do these things when there is somebody at home that needs somebody there with them? (HP 06)

Health providers recognized that caregivers had many competing priorities in their lives demanding their care and attention, but they didn't have any easy answers to their dilemmas. They did however highlight the importance of attending to caregiver needs so that they could successfully continue in their caregiving role:

So if we want to keep people in their home longer which I think is the right thing to do, I think we need to make sure that things like ease of access to supports is there consistently, a support for caregivers, respite programs, to really help that caregiver take that time for themselves, like we're asking them to do a lot that health care professionals would have done you know 15 or 20 years ago. (HP 12)

Providers acknowledged that the health system has changed over time and that caregivers have taken on increasingly more responsibility while the system has done little to improve the services provided to caregivers. Health providers further discussed the importance of increasing respite services for caregivers, for example:

I think that there should be more, free accessible programming. So, like respite would be number one, specialized to stroke for sure, guaranteed respite. Coming in, I would say, in a perfect world, multiple times a week. (HP 03)

Providers understood that one hour per week of respite did not sufficiently support caregivers to care for their own health and use services such as health and fitness facilities. They noted that, “respite is very important” (HP 08) as an integral part of a care plan when a stroke survivor returns to the community. As one provider said, “you know, you're only allowed so many hours of x, y and z and that is not cutting it...and they can't leave their loved one at home.” (HP 09) When caregivers cannot leave the house it is very challenging for them to engage in any health supporting behaviours be it formal exercise programs, seeing their family physician or attending

regular counselling sessions. There are clear inter-relationships between this subtheme on limited services to enable caregivers to engage in health supporting behaviours and the previous main theme of limited information and lack of suitable services. The deficiency of suitable services impacted caregivers on various levels and in multiple aspects of their lives. For the purposes of this section service availability was explored as it related to caregivers' ability to look after their own health.

Limited system wide attention given to the importance of caregiver health. “The caregivers aren't our patients”

Constraints in the health system play an integral role in influencing caregivers' ability to take care of their health and use services that could help them. Health providers who are caring for adults with stroke are often tasked with assessing the caregiver for their ability to support the stroke survivor when they return to the community. It can be difficult for health providers to determine when a caregiver can take on or continue with caregiving especially since caregivers are often considered to be outside of the stroke survivors' circle of care. One provider said, “part of it is these [stroke survivors] are patients that need care and we have “x” number of dollars and the caregivers aren't our patients.” (HP 02) If the caregivers are incapable of providing care for stroke survivors, then ideally systemic supports such as PSW services are put in place so that the stroke survivor may remain safely at home or they are directly referred to an alternative level of care such as long-term care.

Once stroke survivors have been discharged from the acute care stroke management services and have returned to the community setting, health providers have fewer opportunities to assess their needs because they may have only one point of contact with the stroke survivor and their caregiver via their family physician. Because most stroke survivors had experienced

their stroke more than a year previously, they had few stroke related appointments. Furthermore, caregivers may be less likely to readily access their family physician because they are very busy with caregiving and may think that appointments are meant for medical care, rather than services relating to respite or health promotion activities. Therefore, services are not provided proactively to caregiver. Interviews with health providers substantiated this perspective with one explaining that:

So, we would generally follow people for two or three visits after the hospital unless there are issues that could not be helped by the family doctor. And typically, the issue would be like blood pressure control...Usually that's sorted out by three to six months. We generally, and I think I speak for most of my colleagues, don't follow patients longer than three to six months unless there are problems. (HP 14)

In this quote, the provider is referring to the care trajectory of the stroke survivor but each time the stroke survivor has a follow-up appointment, it presents an opportunity for the caregiver to also connect with members of the health team such as nurses and physicians. When the stroke survivor no longer attends regularly scheduled follow-up appointments with the stroke team, there are fewer opportunities for the caregiver to easily connect with formal health providers.

Health providers talked about the gradual decline in health that can affect caregivers over the long-term, “they get um, depressed. They get anxious. They’re worried all the time, about their loved one and their health suffers.” (HP 05) Providers clearly identified and understood the difficulties caregivers were facing but they acknowledged that the answers such as increased respite, improved advocacy for caregivers and inclusion of the caregiver in the circle of care were difficult to achieve within the current health and social context. One provider remarked:

I think that's a very fair observation and the take care of yourself is a, it's a superficial comment. On the other hand, it's difficult to learn enough about the caregiver sort of medications and whatnot to ... We can't be the caregiver's doctor, general doctor. (HP 14)

These health providers couldn't supply the services that caregivers needed. But the caregivers didn't have the time or resources to access the services at another time so more often than not they went without the service.

Health providers who cared for the stroke survivor recognized the importance of including and checking in with the caregiver but also felt constrained by the scope of their professional role. The providers' perspective speaks to the complexity of supporting caregivers to take care of their own health while being caregivers. This complexity is shaped by an interaction between many factors: the social and personal characteristics of the caregiver, the caregiver and stroke survivor's living situation including their financial stability, employment status and proximity to services and systemic issues such as respite hours, in-home service provision and availability of subsidized community programs.

Further complicating caregivers' access to and use of services was the limited priority given to assessing the needs of caregivers by current care models for adults with stroke. Providers explained that their clinical focus and time constraints limited them to focusing solely on the stroke survivor. Caregivers were not routinely assessed for specific needs they may have had. For example, one provider recounted their experience with considering caregivers:

We don't explore it. So, I mean some caregivers do, like they'll call me and they might say to me, you know, "I'm having a really difficult time coping." Yep. But essentially it comes from them... I'm realizing you know, in these appointments with patients we

don't delve deep into the needs of the caregiver. Because of our time too, right? So, we have half an hour and we're doing blood pressure... it's very clinical. (HP 09)

The providers were aware that caregivers could have benefited from assessment and support in accessing services but they also recognized that systemic constraints such as a lack of time, personnel and funding made this very difficult to achieve. Perhaps health providers are also experiencing fatigue in their role as advocates, particularly if they feel that their efforts do not amount to change.

Summary: On the whole, caregivers found it very taxing to manage their own health while caring for a stroke survivor. The overall pressures of their caregiving role coupled with the other demands in their lives left them with limited time, energy and coping ability that constrained their ability to access services that would support their health. Furthermore, limited availability of respite services and limited systemic responsiveness to caregiver needs further hindered caregivers' ability to manage their health and use health-supporting services.

Finances. “You have to pay, well we can't afford \$50 or \$75 twice a week”

Finances were identified as an important factor that influenced use of formal health and social services. Four sub-themes were identified: (a) paying out-of-pocket for services, (b) reduction in income and employment, (c) navigating financial assistance systems, and (d) the benefits of financial stability.

Paying out-of-pocket for services. “We're on a fixed income, we can't afford that”

Once the stroke survivor returned to their homes and communities after stroke, they began to incur out-of-pocket expenses accessing a variety of health and social services. For some caregivers, the financial changes they experienced as a result of caring for a stroke survivor led them to seek out services such as in the example below:

So that's hard watching him want to do the things he used to do. Driving is a big thing, right. He tries to steal the car. Oh, yeah, when he was in the hospital he had a lot of impulse buying. So, buying my new bedroom suite, a \$4,000 fridge. Yeah, and a Winnebago. Like, we have triple and quadruple of everything. I have given up. I used to try and keep track of receipts and all the purchases and return them. And now, I'm just, my therapist has said why put that stress on? You know? He's going to figure out, oh I don't have any money because I've spent it all. I've actually had to, you know, limit the credit card. (SCG 10)

This quote speaks to financial loss in concrete terms such as the spending of the caregiver's money through the impulsive actions of her spouse. In this example the caregiver's husband had experienced cognitive changes as a result of the stroke, which led to his impulse control issues. The caregiver lost not only some of her financial stability but also the ability to reason with her husband on the matter of finances. In her situation, the change in her finances was so extreme that she experienced great anxiety and paid out-of-pocket for the services of a counsellor. The counsellor was able to provide her with reassurance that this situation could be controlled, recommendations for reducing her stress levels and strategies for managing the financial and personal loss.

When I asked one caregiver if he paid out-of-pocket for any services for either himself or the stroke survivor, he said:

Okay I take her to [a day program]. So, we pay for that. I take her to a group physiotherapy exercise program once a week, so we pay for that. I take her to a foot care specialist chiroprapist, so I pay for that. (SCG 20)

The caregiver in this example had taken early retirement to care for his wife and was managing her care on a fixed income. Due to their limited household income, the weekly care costs were acutely felt. Although some services and programs such as the day program were subsidized, the cumulative nature of the costs quickly depleted their monthly budget.

Caregivers were pragmatic about the financial costs associated with accessing care, “I tried, I couldn’t find a lot of additional services that were accessible unless they were at high paid cost.” (SCG 07) Caregivers acknowledged that their options for accessing support in their caregiving role were constrained by their finances but they often felt that there was little course of action they could take. Other caregivers echoed these financial worries and constraints on their ability to use programs and services. One caregiver said, “you’re looking at \$25 a day, you know. I think how you are going to support it, wow.” (SCG 08) This caregiver and his spouse were referring to the cumulative costs of attending day programs, which included transportation, program costs and lunch. In that situation, the stroke survivor, who was in her early fifties, was unable to work and her spouse, her primary caregiver, was also unable to work because of cancer and its associated treatment. These costs, although small in isolated increments, given their diminished household income, were beyond their financial capabilities.

Another caregiver made further reference to the financial pressures associated with attending appointments:

Um, finances for the travel, the gas, the parking, and \$20 every visit sometimes it was three times a week, that’s you know \$240 a month. You know, so much was reimbursed and there are maximums for this and maximums for that but... working within the budget and it was difficult. (SCG 07)

Providers also identified that out-of-pocket expenditures influenced service use. They noted that the costs associated with attending programs constrained service use and they commented on the paucity of available funding streams to support caregivers and stroke survivors. For example, one provider commented:

Well, so, those ones [caregivers], must be very careful about every penny they spend. Coming to our day program or aphasia program there is a cost. And some of them do limit it; limit their attendance because of the affordability. And we're pretty cheap. We're six bucks for a half day. But if you're on Ontario Disability Support Program...It's gone pretty fast. Six bucks a week, yeah and then on top of that it's the transportation, is another six bucks each way. So that's an \$18 day for half a day. Half a day. So that's a big deal. It's a real big deal. (HP 04)

Much like the caregivers, providers readily acknowledged how financial constraints limited access to services and programs but they also struggled to identify suitable solutions. Another provider identified gaps in the system:

The social worker comes in and kind of sees where everybody's at and will refer for social services but you don't have counsellors available for families that's like supported by the system. They've got to pay for it and they can't afford it most times. A lot of these patients are on pensions, right? Your average stroke patient is a pensioner so they don't have the funds to go out and get regular or even a couple of sessions of counselling if they've got to pay for it. (HP 15)

This provider discussed the lack of available funding for counselling for either the caregiver or the stroke survivor. She also identified systemic barriers such as the limited availability of social workers within the community setting as a contributing factor to their out-of-pocket costs. Most

caregivers had to pay privately for counselling services, unless their family physician was situated within a family health team with access to social work or a psychiatrist.

Reduction in income and employment. “He had to leave his job”

Caregivers and their care recipients often encountered significant reductions in their household income following the stroke. The decreased income experienced by families was usually directly related to a change in employment or reduction in level of employment by either the caregiver or the stroke survivor. For example, “so financially we were... Now I’m not working, now he’s not working.” (SCG 08) Their financial predicament significantly affected their choice to access services that came with an associated cost such as day programs. Although the average age of caregiver participants was 63 years, almost 60% of caregivers and 48% of stroke survivors were under the age of 65 years and 36% were still actively engaged in employment.

Another caregiver commented, “yeah and he made good money cause he's a truck driver so I didn't have to work. Yeah [he had to leave his job].” (SCG 09) In some instances the stroke survivor was forced to leave their employment due to their health, in others it was the caregiver. For example, “[I had to leave my job] which mostly because I just couldn’t cope any longer.” (SCG 02) Ironically, some caregivers left employment because of the toll of their caregiving role on their health, but this change may have added to their stress as they subsequently faced increased financial pressure and fewer resources to pay for additional help such as respite or private counselling.

Health providers cited similar examples of how loss of employment negatively affected the ability of caregivers and stroke survivors to access health and social services. For example:

Yah, absolutely, so, I'm just thinking of a patient who is not living in [place]. Just outside of [place], he couldn't work anymore. And his wife who was his caregiver, I believe she was working part time, or didn't have a high paying job. So, they couldn't afford to live where they were living any more, with driving in for appointments, they actually had to give up their home. They moved into an apartment. (HP 09)

In that instance, the costs associated with transportation to appointments forced them to leave employment and relocate. While the above quote is an exceptional example, it emphasizes how the financial repercussions of stroke can greatly affect both the caregiver and the stroke survivor particularly those in younger cohorts. For the caregiver, the emotional ramifications of losing her job and her home could place her at risk for health issues particularly related to mental health thus increasing her need to access health services. But necessities such as accommodation, food and access to basic services came first and foremost; access to non-essential supports for the caregiver were eclipsed by their need for basic living. This meant that caregivers could not pay for more than basic PSW support to give them respite. Accessing the services of a social worker either for guidance in navigating financial assistance or for counselling was not possible. Even costs associated with transportation and parking may have limited some caregivers in making an appointment with their family physician for a check-up or to discuss their caregiving role.

Other providers commented on how some caregivers were forced to reduce their employment to manage all aspects of caregiving. For example, “there have been caregivers that have had to take time off work and be on a leave of absence in order to facilitate [caregiving].” (HP 05) As in other examples, the overall reduction in household income left caregivers with limited income to access more than funded services provided.

Another provider commented on the cumulative adverse effects of the stroke with many caregivers and adults with stroke working to define a new functional norm but also coping with a loss of employment. For example:

The impact is significant because the losses of the person with a stroke, impact of a stroke, are so significant. So, not only the loss of ability but the loss of bringing in income to support the family. (HP 07)

If a family is struggling to meet the daily costs of living such as food, rent, and medications, then it is unlikely that caregivers will be able afford a day program or join a gym to help manage their own health. An interview with a provider is an example of how financial constraints related to a forced leave of absence from employment constrained a caregiver and his care recipient from accessing multiple services:

He's not working anymore. There's, I don't think there's any obvious pension. They had to start looking into CPP disability. And even that was challenging. I don't remember the specifics of it but it didn't go as smoothly as it should have and there were many months where nobody was being paid for anything. And that was challenging for them. (HP 10)

The caregiver was unable to continue working while he was also caring for his wife, which meant a drastic drop in income but also a limited ability to access services that could have helped them such as respite or day programs because many of these programs were paid out-of-pocket. In another instance, the stroke survivor, who was the sole income earner, had to leave his job as a result of his stroke at the age of 56 years. He and his wife struggled to pay for his basic medications and had nothing left over to pay for supportive programs or transportation to attend programs.

Navigating financial assistance systems. “There were so many steps, it was overwhelming”

Another aspect of the financial costs associated with caregiving for a stroke survivor was related to financial assistance. Some caregivers experienced challenges as they attempted to access financial assistance. Caregivers and adults with stroke sought financial assistance through avenues such as workplace disability programs, Ontario Disability and Support Programs and government funding sources designated for supportive equipment such as wheelchairs or lifts. One caregiver indicated that:

My finances, trying to negotiate the myriad of government agencies has been a challenge and I've learned who to contact about things like disability tax credit and stuff like that.

(SCG 20)

The caregiver displayed resourcefulness in learning how to navigate financial systems, but this process could have been assisted by a social worker. As mentioned previously, access to social work in a community setting is extremely limited so these caregivers were often left to their own devices to optimize publicly funded supports. In another scenario, the caregiver was trying to gain access to basic services for the stroke survivor, not for services specific to themselves.

When I asked him how the system could better support him he suggested:

Yeah if it was, it would be like subsidizing care for kids, just the kind of model I'm thinking of. You know if, and it would be based on your income and it would be based on your need and all that stuff. But that would help too and then I'd be able to do things and know that she's being looked after. (SCG 20)

The caregiver was discussing the notion of geared-to-income supportive services, something that would be well-placed to support those caregivers and stroke survivors who were forced to leave

jobs but had still faced ongoing supportive and health management costs, particularly those associated with attending community programs.

In some situations, the caregiver or the stroke survivor had received financial guidance and support from a social worker prior to returning home but once the stroke survivor was at home, the caregiver was generally left to navigate the financial aspects of care and services alone. Another caregiver discussed similar financial challenges:

No services, no supports. Because he was already on disability, anything he needed we had to pay for and then apply for it back. Or apply and wait. So, there was a financial restriction there too. Both of us being on lower budgets at the time. And there wasn't a lot of supports offered in the financial department. (SCG 07)

Completing applications for reimbursement fell to the caregiver, adding to her load. In a hospital setting, a social worker would be able to offer guidance and assistance in navigating financial matters such as funding and reimbursements. However, in a community setting there are few supports for service navigation. Another caregiver could not find a suitable day program in her area, "but there's nothing, there's nothing here in [place]... you have to pay, well we can't afford 50 or 75 dollars twice a week." (SCG 09) In instances like this, the caregiver and the survivor went without the service because she couldn't find any services that were affordable for them. This meant the caregiver was not able to have respite from her caregiving role. In her situation, her spouse was relatively young and the available programs were geared to older adults with cognitive issues and not suitable for his needs.

Health providers and caregivers alike identified significant challenges in navigating supportive financial assistance which included having to complete large amounts of paperwork to access funding for equipment or in order to be reimbursed by insurance companies for costs

they had already incurred. Once the stroke survivor was situated in a community setting, there was little to no assistance available to support caregivers as they navigated supportive financial programs.

Although many caregivers faced challenges in accessing health and social services due to financial issues, some caregivers drew parallels between having financial stability and its role in facilitating their access to services. For example, one caregiver said:

I don't know what somebody would do if they [couldn't leave the house because] I was able to get out and socialize, and get away from [caregiving] because I could afford to pay for someone. I don't know how other people manage, we are lucky. (SCG 18)

In this case, the caregiver paid for respite so she could comfortably go out while knowing that her loved one was well cared for. The break she had from around the clock caregiving also meant that she was less likely to experience caregiver burden over time. The caregiver's quote also illustrates the important role that the social determinants of health had in facilitating access to services.

Overall financial well-being was also a key factor in the capacity for travel and engagement in recreation despite living with ongoing limitations from a stroke. As one health provider said:

I do know a couple of caregivers who have said "to heck with it." They've had a stroke and "we're still going to travel. We're still going to go to Australia. And we're going to go on a cruise, we've been to Florida." I can think of two different caregivers who recently, that didn't let any of that stop them. (HP 02)

This quote captures the desire and motivation of many caregivers and families to make the best of their respective situations whatever that may look like for them. Although many caregivers

discussed how financial constraints affected their ability to access services, other caregivers considered how fortunate they were to be able to afford services such as respite. Access to health and social services was challenging for all community caregivers but those with greater financial means had considerably more options to meet their needs. One provider's summation of a caregiver's ability to manage caregiving over time can be seen in this impactful quote:

Oh, that's a tough one, because I think everything differs. I think so much depends on the compassion of the caregiver. You know I think there were two really; there are two major determinants. There's the health of the caregiver and how much money they have. I don't think there's ever enough money to provide all the support.
(HP 08)

The health provider's comments capture the importance of finances in enabling caregivers and their care recipients to access health and social services that will support them in their caregiving role.

Summary: Stroke caregivers' ability to access and use formal health and social services was influenced by finances in several different ways. They incurred personal costs to access services for themselves such as counselling, day programs, and respite care. Caregivers and stroke survivors also experienced changes in income either due to the stroke itself or from the demands of their caregiving role. Furthermore, they faced challenges in navigating a complex system of financial supports. A small number of caregivers spoke of their fiscal stability being an enabler to access resources, services and programs that supported them in their caregiving journey. However, overall, monetary matters tended to limit rather than facilitate access to and use of formal health and social services.

Transportation. “I have never driven; I have a license but I don’t like driving”

There were two key issues relating to transportation that affected caregivers’ ability to access health and social services: (a) taking on the stressful role of driver, and (b) lack of suitable accessible and subsidized transportation options.

Taking on the stressful role of driver. “He always says I’m going to hit something”

For some caregivers, assuming the primary role of driver was extremely stressful and challenging. They had taken on this role because their loved one was either still recovering from their stroke or no longer able to drive because of their stroke. Two caregivers became the primary driver in the household for the first time in their lives. In one example, the caregiver said:

The other difficulty is, I [have] never driven. I have a license but I don’t like driving... I grew up in Hong Kong and we have very good transit. So... I never ride bike or anything. My spatial perception isn’t very good. So, he is very scared. Like since he’s been sick he’s very afraid of everything. So, his vision was very poor, so that compounded the problem. So, every time I make a turn or something he was saying, “Oh you going to hit something.” Or, “You’re going to get into an accident” ... That was very stressful. (SCG 03)

Assuming the role of driver in the household was a monumental adjustment for this caregiver and her care recipient. Prior to her spouse’s stroke she did not drive at all but following the stroke she was required to drive him to many appointments such as ongoing outpatient rehabilitation, family physician and specialist appointments. Driving was a necessity for her spouse to access the health services he required as part of the ongoing management of the effects of his stroke. Taking on that role would have been trying under normal circumstances, but to be

thrust involuntarily into that role while also dealing with the stroke survivor's care needs was extreme for the caregiver and had a negative impact on her own health. In that situation, the caregiver became the primary driver because she loved her spouse and wanted to support him. While it may be logical to expect a caregiver to adjust with time to taking on the role of primary driver, this was not necessarily the case. The spouse of another stroke survivor recounted:

All the driving, and I hate that. I have to say that that is one part of the caregiving that I've really not adjusted to because I love to sit in the passenger seat and just look at the scenery. And I find that that's stressful. I have to say that for me, driving has always been a bit stressful and I'm not too fond of that. (SCG 06)

Nevertheless, this caregiver was determined to do what was necessary to bring her husband home rather than to long-term care even though he had extensive care needs that necessitated many appointments and appreciable amounts of driving. The caregiver felt a strong obligation to provide the necessary transportation required to access services although it caused her additional stress, anxiety and contributed to her overall load as a caregiver.

Issues around driving at night and parking related challenges contributed to the stressful nature of driving for caregivers and impacted their ability to access and use health and social services in a number of ways. These include limiting their opportunity to participate in support groups, reducing their access to rehabilitative services that also served as respite, and adding to caregivers' overall burden. One caregiver discussed the challenges associated with driving, which included the issues of parking and night driving:

Yeah, I drove every day and parking and that, it was quite an experience. I just don't like driving at night that much. We don't go out very much at night. But don't forget we are getting old. (SCG 21)

Given that many caregiver support groups met in the evenings, this caregiver was no longer able to use this service. In most cases caregivers' role as primary driver included taking their loved one to many appointments and later in the recovery process to day programs and ongoing therapy. Driving in this role necessitated navigating parking lots and parking ramps that could pose difficulties for someone unused to driving in those conditions. This particular caregiver remarked on how she felt her age affected her comfort level with driving especially at night. Given the average age of 63 years of the caregivers in the study, this could mean that other caregivers were similarly affected.

Providers talked readily about the challenges that driving presented for caregivers particularly when driving became a new or different role than the caregiver was familiar with. For example, one provider commented:

I can think of many cases where um, this is going to be stereotypical, but like an elderly couple maybe where the wife didn't drive and the husband, and he was the main driver. Or situations where the spouse, where maybe the family was concerned and because maybe mom had some cognitive changes and, you know dad was the driver. (HP 01)

In that scenario, the provider is referring to situations where the stroke in one family member serves to expose the health issues in the other spouse. Such a situation draws to light the scope of the caregiver role and highlights the importance of the caregiver's health and their ability to manage their own health while assuming a caregiving role.

Access to subsidized transportation. "We're in a dead zone, there is no service"

While subsidized transportation can help facilitate access to formal services, not all people have access to this benefit. For example, when talking about potential services to transport her husband one caregiver responded, "ah, distance yes. I wish I could get a service, a

drive to [husband]’s day program, but apparently we’re in a dead zone or something.” (SCG 06)

She was referring to the fact that she lived in a rural area that fell on the border between two jurisdictions, which complicated gaining access to services such as DARTS (Accessible Transportation Service) or Wheel Trans to assist with transportation. Furthermore, using public transport or even subsidized transport was not an option for all stroke survivors. For example, another caregiver spoke about the challenges she faced in getting transportation services for her husband:

We got him into [program], and then [name] is going to help drive him, and stuff like that because he didn’t have transportation and I also had to be at work, here in [location], and he didn’t qualify for, what is it? Wheel Trans, or whatever....

Because he was ambulatory, and he could walk the 75 metres or whatever the assessment is but cognitively, he’d walk out in front of a car. (SCG 10)

In that situation there were services available, but the stroke survivor’s circumstances of being physically able though having a cognitive handicap meant that they could not take advantage of them. In this instance, the caregiver was left struggling to find an alternative form of transportation, which often did not exist, or meeting the transportation requirements themselves.

This caregiver’s experience was echoed by a provider:

So, I mean in terms of efficiency for the patient and family, not always ideal. And also, a patient has to be cognitively able to ride alone. Right. It’s very rare, there are I think exceptions where I think, like if a spouse or family can go with the patient, but there’s always a big question around can the patient ride alone. And again, a huge part of our population is not able to ride alone. (HP 03)

This provider had extensive experience with stroke survivors and those who had experienced traumatic brain injuries. She pointed out how people with cognitive limitations can end up being marginalized by the constraints of the services available.

A social worker who supported caregivers and stroke survivors who lived in urban and rural regions commented:

Yes, transportation is something that takes up a lot of my time. In our area there are some good accessible transportation programs, but they really need to be booked in advance. They're not always consistent either like before I got on the phone with you, I was trying to figure out how somebody was going to get to our program this afternoon because the volunteer driver couldn't make it. So, in our regions it really is a challenge for transportation. There's the sort of municipal...and then there's other organizations like [volunteer organization] that provide volunteer drivers to get people to programs and back...Usually they can get a ride, but if they can't get a volunteer to drive people then you're sort of out of luck. (HP 12)

This provider identified the various options available for transporting stroke survivors, the challenges of scheduling transportation in advance, and working with volunteer drivers. These options can be very important in helping adults with stroke attend programs and providing valuable support to caregivers. However, they can also be an enormous source of stress and uncertainty for caregivers, particularly for those who have their own constraints related to driving such as health conditions, limited family support and potential constraints related to their employment.

These data suggest that managing the transportation needs of a stroke survivor in a community setting is often complex and requires adaptable and creative solutions. In many

situations it is the caregiver that bears the brunt of meeting the transportation needs of the stroke survivor, at considerable cost to their time, energy and well-being. This cumulative toll on the caregiver places them at greater risk for burden but at the same time constrains their ability to access services such as counselling or to engage in health promotion activities that would help support them in their caregiving role.

Summary: Transportation arose as an important issue affecting caregivers at many levels. Due to constraints surrounding access to and availability of accessible transit, caregivers shouldered a greater burden in driving their care recipients to appointments and programs. Consequently, their available time was reduced leaving them with fewer options of attending appointments during business hours to fulfill their own needs. Overall, reduced time and waning energy meant that caregivers might have been less likely to access services such as caregiver support groups, health maintenance programs such as physiotherapy or alternative therapies and in some situations, they may have failed to use basic funded services such as their family physician.

Chapter 5

Discussion

The aims of this qualitative ID were to: (a) describe the context of providing care to stroke survivors within which to understand their access to and use of services, (b) explore family and friend stroke caregivers' experiences in accessing and using formal health and social services, and (c) identify the factors that influence stroke caregivers' use of formal health and social services. To my knowledge, this is the first Canadian study to explore: (a) stroke caregivers' experiences accessing and using formal health and social services, and (b) the factors that influence stroke caregivers' use of formal health and social services six months to five years post-stroke. Furthermore, the study findings provide a long-term perspective (mean 30 months, $SD=14.0$ months, after stroke) on service use and the stroke recovery trajectory that is underrepresented in the stroke literature to date (Bakas et al., 2014).

These findings extend the literature by using a conceptual framework (Grembowski et al., 2014) to develop and guide this qualitative study and to situate the study findings. Furthermore, the research included not only the perspectives of stroke caregivers, but also those of multiple health providers. Providers' viewpoints further substantiated the study findings and fostered greater clinical understanding and relevance of the findings. These findings make several important contributions to the understanding of service access and use by stroke caregivers with the results informing the three main areas of study focus. Although caregivers expressed a need for support, formal services were underutilized. There is a need to understand this paradox in order to better meet the needs of this population. This understanding is critical for policy-makers, healthcare systems and providers to understand and use as the basis for addressing caregivers needs. Consistent with ID, the discussion will not only explore how the results of the

current study are supported by the findings of others but will also highlight how the current results expand, refine and deepen the meaning of the original literature (Thorne, 2016).

First, findings provide evidence about the ways in which the catastrophic nature of stroke negatively impacts caregivers and strongly influences their access to and use of formal health and social services. Secondly, the study findings improve our understanding of the experiences of stroke caregivers in accessing and using formal health and social services, with findings demonstrating that: (a) caregivers reach a tipping point, then cry for help, and (b) services for stroke survivors benefitted caregivers and stroke survivors alike. Third, this study makes an important contribution to our understanding of the factors that influenced caregivers' use of services including: (a) losses experienced by caregivers acted as a barrier or an enabler to their use of services, depending on the context; (b) caregivers' access to and use of services was strongly dependent on the ability of their social networks to support them; (c) availability of finances and transportation are key determinants to service use by caregivers; and (d) trust in health providers and trust that the stroke survivor will be safe despite the caregiver's absence strongly influences caregivers' decisions to use services. Each of these main findings will be discussed below in relation to the literature with an emphasis on how the study findings expand the knowledge base on stroke caregivers' access to and use of formal health and social services.

The RC – MCC framework (Grembowski et al., 2014) was used to guide the development of the questions in the interview guide. Once data analysis was completed, I mapped the findings onto the RC – MCC framework. This mapping helped to increase understanding of the factors that influence the misalignment in caregivers' needs for services and their access to and use of these services. The outcome of this mapping process may help to inform service delivery models for stroke caregivers and to guide caregiver assessments.

Subsequently, I reflected on the strengths and limitations of mapping the study results onto the RC – MCC framework. This chapter also includes implications of the study findings to inform nursing practice, education, policy and future research and will conclude with a brief discussion of the strengths and limitations of the research.

The Context of Stroke Caregiving

The current study provides understanding of how the catastrophic and sudden nature of stroke can impact stroke caregivers and provides a context within which to understand their access to and use of services. This study determined that the catastrophic and sudden nature of stroke left caregivers shocked and often ill prepared to assume a caregiving role. Caregivers did not expect that the stroke survivor would experience a stroke, and had no time to prepare for its occurrence. When the stroke survivor returned home there was often little to no time for the caregiver to adjust. At this point, caregivers often had limited opportunity to prepare and a paucity of information about formal community-based supports for themselves or the stroke survivor. During the stroke survivor's hospitalization, a team of health providers cared for the stroke survivor around the clock. Initially in the community, stroke survivors received outpatient rehabilitation. However, within a prescribed timeframe of usually less than six months, these services were discharged. At this stage, many caregivers had limited formal supports and a tremendous number of caregiving responsibilities, often leaving them overwhelmed, exhausted and distressed. These findings are consistent with the findings of a literature review which determined that caregivers have many unmet needs in the community including a need for better preparation for the caregiving role, more access to respite and a need for emotional support (Lutz & Camicia, 2016).

The findings from the current study suggest that caregivers were shocked by the initial stroke and overwhelmed by the ongoing caregiving responsibilities. Therefore, they struggled to “take a step back” and recognize that they may have needed help, possibly failing to seek any help, or doing so only at a point of serious crisis. At the same time, though the acute phase of stroke had past, the caregiver continued to experience many ongoing caregiving demands which hindered their ability to access and use the services they needed for themselves. These findings are consistent with Simon et al. (2008) who reported that although stroke caregivers reported psychological distress, they did not necessarily use any formal supports in the community. In the current study, services were sometimes available but nevertheless not used because of issues such as bad timing, limited transportation or a lack of respite care for the stroke survivor. The results from the current study suggest that the caregivers’ lack of preparedness and insufficient information on services may contribute to their limited use of services, a finding consistent with the literature (Pindus et al., 2018).

The current study determined that 85.7% of stroke survivors who were associated with the caregivers interviewed, had at least three chronic conditions, which is higher than the 74.9% of stroke survivors with three or more chronic conditions reported in a previous study (Gruneir et al., 2016). Of the caregivers in the current study, 59.1% had three or more chronic conditions. However, despite the frequent occurrence of their chronic conditions, caregivers in the current study prioritized the needs of the stroke survivor over their own. Caregivers only acknowledged their own health issues when they strongly impacted their ability to provide care or meet the demands of their daily lives.

The current study also found that the catastrophic and sudden nature of stroke often left caregivers grieving over the loss of their prior lives and the future lives they had planned for but

now would never have; a finding also identified in the literature (Coombs, 2007). However, caregivers in the current study also experienced guilt about this grieving and their longing for their prior lives, because they felt that their focus should be on the stroke survivors, not their own health or wishes. Other feelings of guilt often involved the caregivers' perception that they had failed to foresee the stroke or recognize it when it had happened, which, may have resulted in a poorer outcome for the stroke survivor. These feelings of guilt were paired with uncertainty and fear that the stroke survivor would experience another stroke.

The catastrophic and sudden nature of stroke deeply unsettled the caregivers' sense of normalcy and predictability and placed them at heightened risk of caregiver burnout. Caregivers feared that their lives could further change for the worse in an instant. These feelings of guilt, insecurity and anxiety often meant that caregivers became preoccupied with their caregiving role and were less likely to reach out for help. Furthermore, the caregivers in the current study were supporting stroke survivors with significant care needs which left them with limited time to care for their own health and placed them at greater risk of caregiver burden. Recent work by Oliva-Moreno et al. (2018) suggests that risk of burnout in stroke caregivers increases with more caregiving hours, decreased patient quality of life, and greater severity of stroke at discharge. The findings of the current study provide additional explanation for the mechanisms that may underlie and cause these relationships to exist.

Caregivers' Experiences in Accessing and Using Formal Health and Social Services

Key new findings from the current study include: (a) caregivers valued and benefitted from the services they used but did not access them until they reached a tipping point, and (b) stroke survivors' use of community-based programs, such as therapy and day programs, were greatly valued by caregivers and supported them to manage the demands of their caregiving role.

Findings from the current study that are consistent with the literature include: about half of stroke survivors and stroke caregivers received some degree of formal service supports up to two years post-stroke (King & Semik, 2006), caregivers identified a need for more respite and counselling supports (King & Semik, 2006; Masry et al., 2013), and primary care was the first point of contact for stroke caregivers in the community (Hare et al., 2006).

Caregivers valued and benefitted from the services they used but did not access them until they reached a tipping point.

The findings indicate that the limited services that stroke caregivers used to support them in their caregiving role, were helpful. Caregiver participants frequently reported use of family physicians, counselling services, peer support and caregiver support groups. For example, caregivers were able to manage their symptoms of stress and anxiety by using the services of physicians and family health teams, which, with ongoing follow-up, helped them manage the demands of caregiving. Counselling helped caregivers cope with the emotional toll of their role and lifestyle changes. Both caregivers and health providers in the current study acknowledged the value gained in participating in counselling, particularly with regard to helping the caregivers find balance in their lives. In addition, through linking with other services such as respite and health promotion groups, caregivers were able to take a break from their caregiving role. These multiple types of support were instrumental in helping caregivers continue to provide ongoing care to the stroke survivor in their home environment.

Results from the current study indicated that some caregivers sought the help of caregiver support groups. Caregivers felt that the empathetic support received through the caregiver support groups was helpful, a finding consistent with the literature (King & Semik, 2006). Caregivers in the current study participated in support groups to meet a variety of their needs.

Particularly in the early stages of caregiving, caregivers were looking for information that included community resources (e.g. respite, support groups, day programs) and stroke management information, while later they were more focused on seeking social connection. These results speak to the fact that caregivers' needs and requirements change over time. Although caregivers' needs for information and emotional support were found to decrease with time since the stroke had occurred, they still remained high with new concerns arising at different stages. This finding is consistent with that of research conducted by Tsai, Yip, Tai, and Lou (2015) in northern Taiwan.

Some caregivers in the current study experienced support groups as a way to meet their need for social connectedness and relief from the isolation they experienced in their role as caregivers. The current findings enrich previous understanding of the value of support groups for caregivers and highlight that caregivers' needs change over time. Although the results from this study show that some caregivers did use support groups, both caregivers and health providers highlighted that caregivers' overall engagement with support groups was limited. This finding is corroborated by two studies on stroke caregivers, which determined that 20% and 18% of caregivers, respectively, used support groups (King & Semik, 2006; Simon et al., 2008).

Results from a qualitative study by Hare et al. (2006) in the UK suggest that lack of awareness of the existence of caregiver support groups is reason for limited caregiver engagement with these groups. However, the results from the current study indicate another reason for limited caregiver engagement with support groups, namely, the suitability of the group to meet caregivers' needs. Some caregivers were discouraged from visiting support groups because they were looking for more structured support to address specific questions or concerns they had. The informal nature of many support groups meant that they primarily fulfilled a

social support role but provided less of the information and resources that some caregivers wanted.

In the current study, about 20% of caregivers used counselling services. While this is a much higher rate of counselling service use than the 7.5% of caregivers who used counselling and psychiatric supports at 15 months post-stroke in one UK study (Simon et al., 2008), it is identical to the usage by caregivers (20%) in another UK study at two years post-stroke (King & Semik, 2006). The results by Hare et al. (2006) and King and Semik (2006) suggest that caregivers' need for counselling increases with time post-stroke. In the current study caregivers approached health providers only once they reached a tipping point and could not cope any longer in their caregiving role. The current study's findings also suggest that the potential caregiver need for counselling may remain high over time since stroke.

Findings from the current study suggest that caregivers were tentative about accessing and using services for their own health needs. Caregivers' initial reticence to reach out for services may stem from a perception that health providers are intended to support the stroke survivor rather than the caregiver. Further, caregivers tended to feel that their needs were not seen as important, as indicated by a qualitative study by Greenwood, Mackenzie, Harris, Fenton, and Cloud (2011) in the USA. In the current study, one caregiver sought out her family physician primarily for medication to help her sleep rather than to discuss her challenges as a caregiver. Caregivers tended to minimize their own health issues particularly related to their mental health which, made them less likely to use services. However, issues such as loss of sleep over time can precipitate illness and other complications in caregivers, something that health providers, particularly those in primary care, are well situated to address (Byun, Lerdal, Gay, & Lee, 2016).

While caregivers face challenges in reaching out to health providers in primary care, health providers in the current study also experienced limitations in their ability reach out to caregivers in the community. These health providers explained that their resources did not allow them to follow and support caregivers in the community, though the Canadian Stroke Best Practice Recommendations suggests that liaising with caregivers in the community is important (Cameron et al., 2016). A systematic review of qualitative studies by Pindus et al. (2018) determined that there was limited community follow-up by family physicians and community-based specialists post-stroke, though up to 18% of stroke survivors and caregivers required follow-up or re-assessment to maintain continuity of care (Pindus et al., 2018).

These findings of the current study suggest a misalignment of stroke survivors' and caregivers' needs for services and the services actually provided. This misalignment might be arising because services are provided in a reactive manner which places the onus for access to and use of services on the caregiver rather the health system. The reactive provision of services by the health system may have further contributed to caregivers accessing services on an 'on demand' versus a proactive basis. In a qualitative study, interviews with members of a family practice team indicated that they saw their roles as reactive rather than proactively supportive of caregivers, citing constraints on their time (Greenwood et al., 2011). This literature highlights the health system focus on acute care and billable services. Family practice team members also suggested that there were more appropriate health providers to meet caregivers' needs in the community, though they failed to clarify to which services or providers they referred (Greenwood et al., 2011). It is possible that if caregivers perceived this reluctance by health providers to care for them, this could increase their perception that their health needs are not important.

The current study also extends our knowledge and understanding of stroke caregiver service use with study findings demonstrating that caregivers sought services only once they reached a tipping point or crisis situation. At this stage, caregivers felt desperate enough to overcome their tentativeness in reaching out for help. Family physicians were often the first point of contact for caregivers seeking support for their caregiving role. This included obtaining medication to treat anxiety and insomnia as well as for referrals to other services such as social work or counselling. Although nurses in primary care would also be well-placed to support these caregivers, those interviewed in the current study engaged mainly with their family physician. These findings are consistent with research by Simon et al. (2008) who reported that visits to family physicians were the most commonly used service by stroke caregivers at 15 months post-stroke. The degree of stroke survivor disability was the strongest predictor of caregiver service use to meet their own needs, a finding echoed by Cameron, Naglie, Silver, and Gignac (2013), but 15 months was the maximal time post-stroke assessed in that study (Simon et al., 2008). The results from the current study suggest that once caregivers have initiated use of their family physician, they continued with ongoing physician appointments because it helped them cope with their caregiving role. This may indicate that caregivers have ongoing health service needs that could potentially be better addressed by other community-based health providers such as nurses or social workers. The importance of primary care as the first point of contact for caregivers is well recognized. A prior study in the UK has shown that 74% of stroke caregivers used the unspecified services of their family physicians at 15 months post-stroke down from 90% at six weeks post-stroke (Simon et al., 2008). However, the current study found that caregivers tended to wait until a tipping point or moment of crisis before reaching out to their family

physician. This finding suggests that there may also be important differences in availability of health services and providers for chronic disease management between Canada and the UK.

In addition, the current study findings highlight a lack of a centralized community-based support for caregivers. Although 46% of the stroke survivors received formal in-home services, caregivers did not identify the community care coordinator as a resource or support for them. On the contrary, caregivers were frustrated by the lack of coordination among community health providers. There were also systemic constraints such as lack of a community stroke navigator or community nursing role which limited opportunities for health providers to support caregivers in the community despite their interest and concern for caregivers' well-being.

Services for stroke survivors benefitted caregivers and stroke survivors alike.

An important finding of the current study was that caregivers valued the services provided to the stroke survivors. For example, when the stroke survivors participated in stroke-related rehabilitation programs, the caregivers were able to attend health promotion activities such as aqua fit or a fitness program. Physical activity helps caregivers cope with the demands of their caregiving role, as shown by a clinical review of meta-analyses conducted in the USA, which suggests that engagement in physical activity can positively impact caregivers' quality of life and help them manage their caregiving role (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). However, the current study adds to this understanding by providing evidence for the positive impact of a coordinated approach to service delivery on caregivers. This finding suggests that coordinated service delivery for caregivers and stroke survivors could be supported by initiatives such as the Guided Care Program for Families and Friends, by potentially reducing the time, resources and energy demands on the caregiver (Wolff et al., 2009).

Caregivers also discussed how they benefitted from talking with other caregivers about their caregiving experiences while the stroke survivor received services, emphasizing that it supported them in their caregiving role. Health providers in the current study corroborated the value of joint survivor-caregiver engagement in programs but recognized that there could be logistical challenges if the stroke survivor had complex deficits requiring a greater level of care. This finding is consistent with qualitative interviews with USA caregivers suggested that group-based programs can enhance regular engagement in physical activity and simultaneously provide social benefits to caregivers (King & Semik, 2006). However, the study authors did not address the challenge of organizing care for the stroke survivor while the caregiver is engaging in these physical activity programs.

Both caregivers and health providers highlighted the importance of PSW services in supporting caregivers in their caregiving role with just under half of stroke survivors (46%) receiving in-home PSW services. This finding is consistent with a mixed-methods study of 93 caregivers up to two years post-stroke who reported that 51% of stroke survivors used home care (King & Semik, 2006). The continuing use of PSWs by many caregivers and stroke survivors in the current study at an average 30-months post-stroke reflects the persistent care needs of the stroke survivors. Evidence for the persistent care needs of many stroke survivors is provided by a report from the Heart and Stroke Association (2017) that suggests that 30-40% of stroke survivors continue to live with a moderate to severe disability post-stroke. Similar levels of homecare use by stroke survivors and caregivers were also found in studies conducted in the UK and USA (Hare et al., 2006; King & Semik, 2006).

The current study extends the literature by increasing our understanding of the benefits PSW services, from the perspective of stroke caregivers. The main benefit for caregivers from

using PSW services was that the PSWs provided caregivers respite from their caregiving role. This respite enabled the caregivers to use other services such as health promotion programs offered by community agencies or attend their own medical or dental appointments. Health providers corroborated the benefits from PSWs to caregivers and sought varied options to increase respite for caregivers, particularly in situations where caregivers were overwhelmed. This study highlights the value of administering respite not just to relieve stroke caregivers from their caring duties but also to foster caregivers' engagement in health promotion activities.

However, caregivers also discussed the difficulty they had in obtaining respite service for longer periods of time. For some caregivers, constrained time limits on PSW service meant they did not have the support they needed to manage their own health needs such as attending medical appointments or engaging in group-based programs. While PSW services are often allocated to support both stroke survivors and caregivers, the systemic constraints make it challenging for caregivers to realize the potential benefits of the service.

Stroke survivors' use of community-based programs, such as speech language pathology, physiotherapy and recreational/rehabilitation programs offered by not-for-profit organizations benefited caregivers as well. While these programs were primarily targeted at the survivor, they also provided education, information and support to caregivers, services that caregivers indicated were often lacking (Hare et al., 2006; King & Semik, 2006; Masry et al., 2013; Pindus et al., 2018). Best practice guidelines emphasize the importance of engaging caregivers in a variety of ways (e.g. education, peer support, social engagement) in order to empower them as caregivers and to aid in the stroke survivors' community reintegration (Cameron et al., 2016). Health provider participants in the current study emphasized the value of these programs in supporting caregivers. A key finding of the study was that health providers explained how interactions with

caregivers who were participating in programs and initiatives provided an opportunity for further assessment of caregivers' health and needs. These additional caregiver assessment opportunities are particularly important because once the stroke survivor has returned to the community there may be fewer occasions for the caregiver to engage with health providers unless they actively seek out services themselves (Cameron et al., 2016; The Change Foundation, 2018).

Factors that influence stroke caregivers' use of formal health and social services

The current study also makes a valuable contribution to understanding the factors that influence stroke caregivers' use of formal health and social services. Key factors identified in the study included the caregiver losses, the ability of their social networks to support them, the availability of finances and transportation, trust in health providers and trust that the stroke survivor would be safe despite their absence.

Caregiver Losses.

Three specific areas of loss experienced by caregivers influenced their access to and use of formal health and social services: loss of social engagement, loss of their partner relationship and loss of their identity as an independent person.

Loss of social engagement.

Caregivers often became so consumed by supporting their loved one that they could no longer engage in social activities leading to the loss of social contacts. Loss of social engagement has been shown to negatively impact caregivers in their role by increasing their risk of social isolation and depression (Camak, 2015; Masry et al., 2013; White et al., 2007).

Interestingly, some caregivers in the current study indicated that the loss of social engagement was a factor influencing their use of services. The finding of the social benefits of peer support groups is confirmed by the results from several studies, (Cameron et al., 2013; Satink, Cup, de

Swart, & Nijhuis-van der Sanden, 2018), though findings from a cross-sectional mixed-methods study from the USA showed that caregivers make limited use of support groups (King & Semik, 2006). However, Cameron et al. (2013) noted the challenges that caregivers experience in accessing supportive services particularly if the caregivers are employed themselves and have constraints on their time.

Other forms of social engagement can also be of value to caregivers. Research by Mant et al. (2000) on an intervention for caregivers that included four visits by a health provider in the first six months in a stroke caregiving role determined that caregivers experienced significant psychosocial benefits from these interactions. These findings suggest that varied types of services have the potential to provide beneficial social engagements to caregivers, especially when caregivers' prior social contacts have been lost because of the high demands of the caregiving role. The current study adds greater detail to this literature through findings that stress the link between characteristics of the survivor-caregiver dyad and the social support networks. The findings also highlight how services such as support groups can meet the changing needs of caregivers throughout the caregiving journey. Early in caregiving, caregivers were looking for information and resources from support groups. Later in the caregiving trajectory, caregivers sought social connectedness with these groups, which was described as family-like support by a health provider in the current study. Implications for practice arising from these findings point to the importance of ongoing assessment and tailoring of services to meet caregivers' needs.

Loss of partner relationship.

Several stroke caregivers in the current study discussed losses and changes in their relationship with the stroke survivor. These findings are consistent with literature that has shown

that 48% of caregivers have experienced changes in their spousal relationships as a result of their caregiving role (The Change Foundation, 2018). For some caregivers, losing their prior relationship with the stroke survivor resulted in feelings of grief and unhappiness. To manage these intense and often overwhelming feelings, caregivers often chose to use the services of their family physician, counselling or respite so that they could have professional help, advice, medication and time and space to engage in activities outside of their caregiver role. A longitudinal cohort study on stroke caregivers by Simon et al. (2008) in the UK determined that when caregivers and stroke survivors had a good relationship, then caregivers were more likely to be satisfied with the services they were using. One could speculate that client satisfaction would thereby increasing the likelihood that caregivers would continue to use the service. But Simon et al. (2008) did not make direct linkages between the caregiver-stroke survivor relationship and caregiver service use.

The findings of the current study highlight that the painful loss of the partner relationship led some caregivers to seek services such as counselling or respite to help them deal with this loss. However, the current study determined that most caregivers shy away from admitting the loss of their partner relationship to health providers, their partner or themselves and therefore never reach out to the services that could help them with this loss. These findings suggest that stroke caregivers are potentially managing complex emotional feelings that may not easily be addressed by giving caregivers access to respite or medication. Critically, these caregivers need ongoing assessment to help identify the best course of action to help them balance their own feelings and experiences pertaining to their relationship alongside with the demands of their caregiving role.

The likelihood of experiencing a change or decrease in the quality of partner relationships post-stroke is documented in the literature. This includes a longitudinal, mixed methods descriptive study of caregivers' problems during the early post-stroke period conducted in the USA (King, Rourke Ainsworth, Ronen, & Hartke, 2010) and a longitudinal study of 63 stroke survivors and their caregivers' needs post-stroke conducted in Taiwan (Tsai et al., 2015). The results from these studies suggest that the quality of the caregiver-stroke survivor relationship may be impacted for at least three years after the stroke (King, Rourke Ainsworth, et al., 2010; Tsai et al., 2015). These results are consistent with the finding in the current study that caregivers' loss of their relationship with the stroke survivor may not be resolved over the study's mean post-stroke timeframe of 30 months.

Findings from the current study suggest that long-term changes in relationships may result following stroke and impact caregivers' decisions to use services particularly if the stroke survivor has high care needs. For example, a caregiver in this study who provided a substantial amount of care to her husband likened the relationship to that of parent and child rather than a partner. Although she loved her husband, she deeply grieved the relationship she no longer had with him. In response to this experience, she sought respite so that she could have a break from her caregiving role and engage in health promotion activities at her local YMCA. However, as this research suggests, determining service need in this case may be dependent on assessment of the caregiver rather than assuming that they will reach out to services.

Another caregiver whose relationship with her spouse changed profoundly after the stroke, sought counselling to try come to terms with her feelings of despondency. Recommendations for stroke caregivers in the literature highlight the value of counselling (King & Semik, 2006) although it has been recognized that psychosocial interventions alone are not

enough to manage all the complexities of caregivers who are experiencing multiple aspects of caregiver burden (Cheng, Chair, & Chau, 2014). Relatively few caregivers used counselling in the current study, constrained by a lack of respite, available counselling or knowledge of suitable counselling. Furthermore, counselling was often paid out-of-pocket unless caregivers had private insurance. Prior studies have explored relationship change and loss due to stroke, as well as the consequences of this for caregiver satisfaction with services. But the current study is the first to provide evidence that a change and/or reduction in the quality of the caregivers' relationship with the stroke survivor can increase caregivers' need for services, such as those offered by primary care and home health care. Furthermore, this study provides evidence that in some caregivers this loss leads to an increase in access and use of formal services.

Caregivers' loss of identity as an independent person.

Caregiver participants described experiencing a loss of identity after becoming a caregiver, which influenced their use of services. The scope of their caregiving role was challenging in that caregivers needed to engage in their normal activities such as socializing, household and community tasks as well as take care of their own health. For example, caregiver participants discussed how they were no longer able to socialize with their friends due to the demands of caregiving. In addition, many prior friends withdrew from providing support as the debilitating effects of the stroke continued to affect the survivor and the caregiver. These losses of friendship meant that caregivers could not identify themselves anymore through their role as friend and through other aspects of their prior identity, such as being an active participant in their community. Instead, their identity was reduced to their role as caregiver.

This loss of their previous identity put these caregivers at greater risk of experiencing stress and anxiety. When these feelings reached a critical point, the likelihood was high that the

caregivers reached out to counseling services or to their family physician for help. The connection between the loss of identity, ongoing stress and subsequent service use is consistent with a qualitative review on stroke caregiving burden and the role of nursing (Camak, 2015), a prospective cohort study on the psychosocial functioning of spouses of stroke survivors in the Netherlands (Visser-Meily, Post, van de Port, van Heugten, & van den Bos, 2008) and a qualitative phenomenology on stroke caregivers on the experiences of stroke caregivers in Australia (Masry et al., 2013). However, this literature does not address the effects of these experiences on caregiver service use. The current study expands on these prior findings by demonstrating how the feelings of being constrained, stifled and without their own identity led to a higher likelihood of caregivers' use of counseling and family physician services.

Health provider participants in the current study described the profound and constant grief experienced by some caregivers due to the demands of the caregiving role and the consequences to their sense of self. They noted that while information and education can help caregivers gain greater insights about their situation, this may not be enough to enable caregivers to move forward to attain better emotional health. The literature also describes the profound grief experienced by some stroke caregivers and the complete change in lifestyle that can accompany a stroke caregiving role (Visser-Meily et al., 2008; Young, Lutz, Creasy, Cox, & Martz, 2014). However, this literature provides little discussion of the subsequent impact of grief on caregiver service use.

The research also suggests that depression in stroke caregivers may persist and even increase with time (Gaugler, 2010; Visser-Meily et al., 2008). But, a longitudinal cohort study on stroke survivors and their caregivers by Cameron, Cheung, Streiner, Coyte, and Stewart (2011) demonstrates that it is not the amount of care provided by the caregiver that is the main

determinant of caregiver depression, but rather the level to which caregivers can continue to engage in activities that are important and beneficial to them. In the current study, some caregivers expressed how respite services were critical for them to continue engaging in activities they valued, such as engaging in fitness programs. However, though some caregivers in the current study described how they sought services in the community setting, they were often unsure of what services were available or how to go about accessing them. This finding is congruent with results from prior studies on stroke survivors and their caregivers (Hare et al., 2006; King & Semik, 2006; Masry et al., 2013; Pindus et al., 2018). The current research expands on these prior results by highlighting the beneficial impacts on caregiver wellbeing (e.g. participation in fitness programs) when caregivers succeed in accessing these services.

Caregivers' use of services was strongly dependent on the ability of their social networks to support them.

An important finding of the current study was the influence of caregivers' social networks on their use of services. While it is well documented in the literature that caregivers can experience a change in their social networks as a result of assuming a caregiving role (Lutz et al., 2011; Masry et al., 2013; Rigby et al., 2009; White et al., 2007), there is limited literature on the consequences of diminished social networks on caregivers' service use. Some caregivers in the current study described being abandoned by their social networks meaning that they did not assist them in caring for the stroke survivor. Caregivers were subsequently forced to access respite services in order to manage basic household tasks, complete groceries and banking or attend their own health appointments. The literature describes the loss of stroke caregivers' social networks related to their caregiving responsibilities (Andrew et al., 2015; Masry et al., 2013). A longitudinal cohort study of 53 stroke caregivers in the UK suggests that those with

fewer informal supports make greater use of formal services at one year post-stroke (Simon et al., 2008). But this is the first Canadian study to describe how caregivers diminished social networks can lead to increased use of formal services.

Findings from a cross-sectional descriptive stroke caregiver study in Hong Kong suggests that caregivers' perception of their social networks are greater than the actual network that ultimately provides support to them (Sit, Wong, Clinton, Li, & Fong, 2004). This finding is consistent with findings from the current study that found that the support some caregivers were counting on from their friends did not materialize. Importantly, while some caregivers in the current study were able to access formal respite to stand in for their diminished social networks, other caregivers were not able to do so. This disparity among caregivers was in part contingent on their current level of service provision or the stroke survivor's level of disability and in some cases depended on their ability to fund extra respite out-of-pocket. A small number of caregivers in the current study actively avoided accessing services that would meet their needs out of concern of upsetting the stroke survivor or appearing incompetent as a caregiver, a finding also noted in the literature (Danzl et al., 2013). This finding highlights the complexity of stroke caregiving and demonstrates that stroke caregivers' use of services is affected by many circumstances. Furthermore, it emphasizes the importance of a thorough assessment of the stroke caregiver with consideration of their relationship, their health and the greater context within which the caregiver and stroke survivor are living.

A small number of caregivers discussed how fortunate they were to have the support of strong social networks that assisted them with transportation or respite thereby facilitating caregivers' access to services. While the support of these informal networks meant the caregivers used less formal respite services, they were in turn able to use other services aimed

specifically towards their own health, such as attending their own medical appointments or engaging in community-based health promotion activities. Results from a Canadian qualitative study supports the notion that supportive social networks can provide respite to caregivers and help them continue in their caregiving role (White et al. 2007). However, while the literature suggests that the support by social networks can positively impact caregiver health (Steiner et al., 2008), the current study uniquely documents the relationship between social supports and caregivers' use of services.

Availability of finances and transportation are key determinants of service use by caregivers.

An important finding of the current study was that finances and access to transportation influenced stroke caregivers' access to and use of formal health and social services. While other studies conducted in the USA also determined that finances are an important limiting factor to access and use of services (King & Semik, 2006), this study highlights the importance of this factor even within a publicly funded health system such as in Canada. For example, caregivers frequently experienced a reduction in income or loss of employment related to their caregiving role or the survivor's stroke. This in turn meant that there were limited funds to pay for services such as day programs or counselling and to pay for associated costs such as transportation that would enable access to these services.

While a prior literature review of stroke caregiver burden provided evidence that stroke caregivers also face financial burden as a result of their caregiving role (Camak, 2015; Hickenbottom et al., 2002), this study suggests that financial hardship influences caregiver service use. In a survey study from Australia with its mixed publicly and privately funded healthcare system, Andrew et al. (2015) noted that increased personal expenses by the caregiver

were associated with increased stroke survivor needs. They also found that loss of caregiver income due to the caregiving tasks served as a barrier to caregivers' use of services such as respite (Andrew et al., 2015). In the case of the current research, three types of barriers related to finances were identified that affected service use. These included paying out-of-pocket for services, reduction in income, and difficulties in navigating financial assistance systems. Caregivers in the current study emphasized that many services in the community entailed payment for the services or for accessing the services. For example, they talked about the fees associated with day programs, community-based rehabilitation or exercise programs and paying out-of-pocket for respite. Although some of the costs related to these programs were subsidized, the programs' associated costs such as parking, transportation and food were cumulative and often hindered ongoing participation in the programs.

In the current study, loss of employment affected caregivers' household income in two ways: first, when caregivers themselves had to reduce their work hours to fulfill their caregiver role or second, when the stroke survivor was the primary income earner and could no longer work. In both instances the caregiver and survivor were of working age, a consideration, which must be considered when assessing the needs and required support of caregivers and stroke survivors in the community. There is a body of literature citing decrease or loss of employment as a factor that can exacerbate the burden experienced by caregivers (King, Ainsworth, et al., 2010; King & Semik, 2006; Pucciarelli et al., 2018) but these studies did not discuss the connection between employment and ability to access or use services and each study included shorter post-stroke timeframes than the current study. Although the financial costs associated with caregiving are well documented (Hickenbottom et al., 2002; Joo, Dunet, Fang, & Wang,

2014; Lai, 2012), the current research enhances understanding of how limited finances can negatively impact the ability of caregivers and survivors to access and use services.

Furthermore, this study also determined that caregivers experienced challenges in finding information about financial subsidies, such as disability support, day programs or equipment subsidies which, negatively impacted their use of services. These challenges included: needing access to computers, not knowing whom to approach for assistance, and simply not knowing that programs existed or were intended to support them, findings corroborated by prior studies (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Hare et al., 2006; King, Hartke, Lee, & Raad, 2013).

Health provider participants in the current study also identified limited finances as having a negative impact on caregivers' access to and use of services. This included the case of a family who lost their home as a result of stroke-related unemployment and the costs they incurred because of driving long distances to attend stroke-related appointments. The current study extends the knowledge base by capturing the perspective of health providers who were empathetic and knowledgeable about the financial issues facing caregivers, though ill equipped to help caregivers with these issues. As reasons for their inability to help caregivers with financial issues, health providers cited absence of community-based social work as well as difficulties remaining knowledgeable about services and programs. Both caregivers and health providers discussed challenges they experienced regarding accessing financial services that would provide disability and subsidies to support the costs of community-based programs. Although conducted outside of North America, research conducted in India suggests that financial stress affects the majority of caregivers and could negatively impact service use (Das et al., 2010). A systematic literature review of challenges, satisfactions and coping strategies of

stroke caregivers also mentioned finances as a common challenge, but did not make the explicit connection to reduced access to and use of services (Greenwood et al., 2009).

Adding richness to the results was the current study's finding that caregivers with good financial stability were more likely to access and use services. Caregivers in the current study discussed being able to pay for private respite to enable the caregiver to engage in social activities and being able to pay for equipment to facilitate travel. Findings of a nine-year cohort study by Chan et al. (2009) in the USA determined that stroke survivors residing in areas of higher median household income accessed more outpatient rehabilitation services; however, they did not assess caregivers' service access and use. The current study provides a more comprehensive understanding of the impact of financial stability on caregivers' access to and use of services in the Canadian context. Further, the study's findings suggest that practice and policy must consider the financial costs associated with caregiver service access and use and allocate funding to help address these costs.

Trust in health providers and trust that the stroke survivor would be safe despite their absence strongly influences caregivers' decisions to use services.

An interesting and new finding in the current study was that caregivers struggled to trust that the stroke survivor would be well cared for by health providers who were providing care in their absence. These health providers either came into the home or provided care at adult day programs. Some of the lack of trust felt by caregivers stemmed from limited continuity in service provision regarding homecare. Caregiver participants reported that especially during the early post-discharge phase multiple and changing PSWs came into the home. This meant that caregivers spent more time explaining the needs of the stroke survivor to the homecare worker and supervising the homecare worker to ensure they addressed the needs of the stroke survivor as

required, rather than benefiting from the respite. Furthermore, caregivers in the current study also identified unreliability among PSWs as a source of stress for them. If they were unsure of who would be coming to care for the stroke survivor, then they were less likely to leave the house.

Building trust between the caregiver-stroke survivor dyad and health providers takes time and consistency, particularly when the care recipients may be unsure and anxious. In the case of day programs, staff who were attuned to the caregivers' fears were able to take extra time communicating information and reassuring the caregiver about the quality and type of care provided. With time, these caregivers gained trust in the health providers and were able to benefit from these services. Some caregivers in the current study were able to participate in programs that ran at the same time and location as the stroke survivors' program. The benefits of such programming were that it enabled caregivers to better trust that the stroke survivor would be alright in their absence in part because of their proximity to the stroke survivor and regular encounters with the program providers.

Caregiver participants in the current study also discussed their fear and anxiety related to leaving the stroke survivor alone after their stroke. Their fears stemmed from the concern that the stroke survivor might experience another stroke in their absence or behave in a manner that would threaten their health or safety. This fear decreased the likelihood that these caregivers left the stroke survivor to make use of services outside the residence, such as attending a gym or attending a dentist or physician appointment. This finding is consistent with the literature, where caregivers report their fears associated with the stroke survivor experiencing another stroke (Hare et al., 2006; Townend, Tinson, Kwan, & Sharpe, 2006; White, Barrientos, & Dunn, 2014). The findings of the current study add to the body of knowledge by highlighting how lack of trust

in health providers and in the stabilized health of the stroke survivor hindered caregivers from using services for their own health.

Mapping of the Study Findings to the RC – MCC Framework

In the following section I will reflect on the application of the study findings to the RC – MCC framework (Grembowski et al., 2014). Data analysis revealed key themes in three areas: (a) the context of stroke caregiving, (b) stroke caregiver experiences in accessing and using formal health and social services, and (c) the factors that influenced caregivers' and stroke survivors' access to and use of formal health and social services. These key themes were then mapped onto the RC – MCC framework for the purpose of better understanding the application of the framework for guiding research on stroke caregivers access to and use of formal health and social services (Figure 5) (Grembowski et al., 2014). First, the caregiving context of the catastrophic nature of stroke was mapped onto the patient-caregiver dyad. Second, the caregivers' experiences of accessing and using services was mapped onto the services construct of the framework. Third, nine factors that influenced caregivers' and stroke survivors' access to and use of services were mapped onto six specific constructs of the RC – MCC framework (Figure 5) (Grembowski et al., 2014): 1) contextual factors – transportation; 2) social support – loss on so many levels, social support networks; 3) population health and inequalities – finances; 4) patient-caregiver dyad – trust, caregiver responsibility enormous, challenged to take care of my own health; 5) health – emotional toll of caregiving; and 6) community resources – limited information and lack of suitable services.

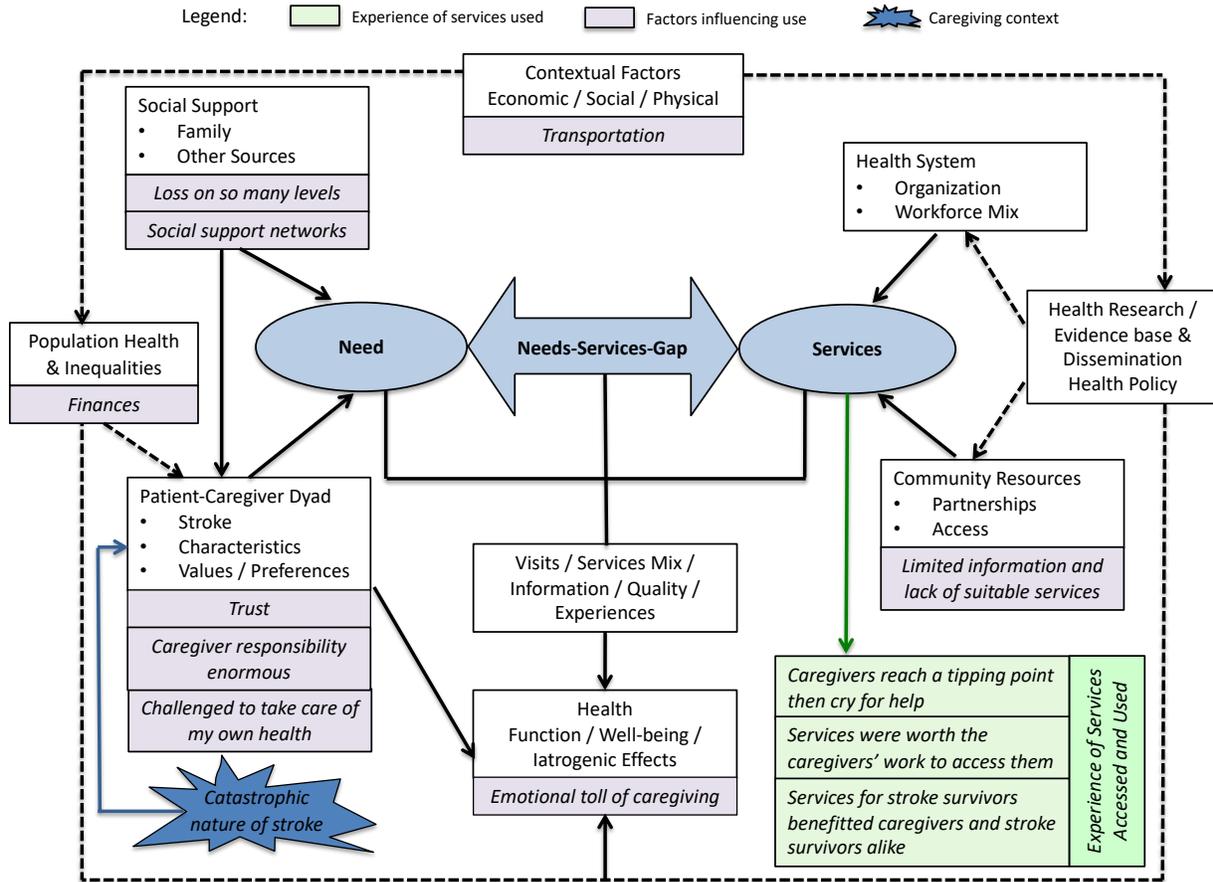


Figure 5. RC – MCC Framework with embedded study findings of context of stroke caregiving, stroke caregiver experience in accessing and using formal health and social services and the factors that affect caregivers' access to and use of services. Adapted with permission from D. E. Grembowski

The results from the current study help explain the needs-services gap of the RC – MMC framework. The results indicate that while some services are available that are important to stroke caregivers, these services are not always readily accessed by them suggesting a misalignment between service provision and service use. Reasons for this limited service access and use include challenges in obtaining information about available services and competing

demands on caregivers' time and resources due to their caregiving role. Additionally, some of the available services do not adequately meet the needs of caregivers at their specific stage of the caregiving trajectory (e.g. caregiver support groups). Furthermore, services used by the stroke survivors benefitted stroke caregivers illustrating the importance of considering the caregiver-survivor dyad during assessment and planning for service provision.

The findings from the current study also suggests that the sudden and potentially catastrophic nature of stroke has long-lasting impacts on caregivers' access and use of services. For example, although caregivers were frequently overwhelmed by their caregiving role they did not always use available services (e.g. respite) because of the challenges they faced in trusting that the stroke survivor would be safe in their absence. Furthermore, as a result of their traumatic experiences with a sudden and unexpected stroke, caregivers also required greater engagement with health providers before they could trust that the stroke survivor would be sufficiently cared for. Consequently, some stroke caregivers used fewer services than were available to them.

Other results from the current study inform the social support construct of the RC – MCC framework (Grembowski et al., 2014). The social networks of some stroke caregivers were strong and remained so over time after the stroke. These caregivers made less use of services that directly supported them in their caregiver role, because these functions were partially fulfilled by their social networks. At the same time, these caregivers were able to make greater use of other services such as those that promoted their own health. However, the social networks of many caregivers diminished through time because of the impacts of the stroke and the demands of their caregiving role, which limited opportunities for some social activities. These caregivers were left socially isolated and lacked supports that would facilitate their use of

services. Consequently, these caregivers were in greater need of formal services to fulfill their social needs and support them in their caregiving role, though they experienced challenges in accessing these services.

Strengths and Limitations of Using the RC – MCC Framework for this Study

Reflecting on the use of the RC – MCC framework to guide formulation of the research questions, to develop the interview guide and to map the study results, several strengths and limitations emerged (Figure 5) (Grembowski et al., 2014). Among the strengths of the use of the RC – MCC framework was its emphasis on inter-relational components that influence the patient-caregiver dyad (Grembowski et al., 2014; Zullig et al., 2016). The comprehensive nature of the framework takes into account the patient, the health system and community-wide contextual factors (e.g. social networks, finances, transportation) (Grembowski et al., 2014). This holistic perspective facilitated a systems approach to exploring a broad range of factors influencing access to and use of formal health and social services. The interview questions were developed to help answer the research questions (Grembowski et al., 2014). This facilitated collection of a rich dataset that was well-placed to inform a multitude of aspects of caregivers' experiences and factors that influenced their access to and use of formal health and social services.

A further strength of the RC – MCC framework was its strong emphasis on the needs-service gap in conjunction with the contributing factors that could influence this gap (Grembowski et al., 2014). The process of mapping the study findings onto the framework helped to illustrate the suggested finding that there was a strong misalignment between the needs of stroke caregivers and the services provided.

A further limitation in the use of the RC – MCC framework in this study is its unidirectional presentation of the relationships between individual constructs (e.g. the social support construct has a unidirectional relationship with the patient-caregiver dyad) (Grembowski et al., 2014). In addition, although the framework encompasses multiple constructs that influence the availability of services and the needs of the stroke patient-caregiver dyad, the framework is essentially also unidirectional in that all constructs directly or indirectly feed downstream into the health of the dyad. Therefore, the framework does not consider how various constructs in the framework relate to feedback loops or how the factors individually or in combination impact on service use. While the results from the current study frequently pointed toward interactions between multiple constructs of the RC – MCC framework, the absence of feedback loops provided a limitation for the mapping the study results onto the framework (Grembowski et al., 2014).

Implications and Recommendations

Nursing practice.

Study findings reveal several important implications and recommendations for nursing practice. The finding that caregivers benefitted from services but tended not to access them until they reached a tipping point suggests that they would benefit from a family-centered approach to care. This would entail including caregivers and stroke survivors in care planning and decision making about services to meet their needs. Currently caregivers are often providing care with limited support and lack of attention to their health and support needs. Family-centered care is a model of care increasingly used that recommends a collaborative approach among patients, their families and health providers in order to collectively to structure, administer and assess healthcare (Creasy, Lutz, Young, & Stacciarini, 2015). A family-centered

approach should be utilized at the beginning of the stroke survivor trajectory in order to address caregivers' health and needs in a systematic, proactive manner rather than waiting for a crisis to care for caregivers. Furthermore, there needs to be greater emphasis on the importance of bridging the whole family to the community following stroke to ensure that caregivers are also followed over time. Provision of care in the community needs to be addressed by the greater health system because currently although nurses are well-trained to support stroke caregivers, the system-wide constraints on homecare limits optimization of the nursing role in this population.

The nursing role in family-centered care should include determining whether the caregiver has the knowledge, skills, capability and resources to adequately care for the stroke survivor in the home environment (Creasy et al., 2015) and what additional services are needed to help them do so. However, findings from the current study suggested that caregivers did not see nurses as health providers who could help them, perhaps because in the community setting they had limited access to them. Instead, caregivers talked mainly about seeing physicians as the first point of access in the community. Caregivers should be assessed to determine their own needs for support, something nurses are well-trained to do (Donner et al., 2015).

Furthermore, health providers have a responsibility to engage the caregivers in meaningful dialogue on multiple occasions in order to continue to help caregivers and stroke survivors be successful in the long-term (Creasy, Lutz, Young, Ford, & Martz, 2013). Study findings suggest that health providers are well positioned to not only give caregivers information regarding existing services but also help them make links to these services, consistent with a recommendation in the 2016 Managing Transitions of Care Following Stroke Update (Cameron et al., 2016). But importantly nurse health providers must have opportunities to connect with

caregivers in the community setting, something that is significantly constrained within the current Canadian health system.

Moreover, this study found that caregiver needs related to information and services changed with time and suggests the need for ongoing assessment of caregivers which, is consistent with the findings of other studies (Masry et al., 2013; Pindus et al., 2018). Research suggests that the mental health of the caregiver, along with objective measures of caregiver load, predict caregiver burden in the long-term, so therefore it would be important to make supports like counselling available to stroke caregivers throughout the caregiving journey (Bakas et al., 2015; Krieger, Feron, & Dorant, 2017). Furthermore, interventions that include supportive counselling provided by a trained health provider has been shown to assist caregivers in better managing their caregiving role (Bakas et al., 2009; Brereton, Carroll, & Barnston, 2007; Visser-Meily et al., 2005).

Ideally caregivers should be assessed by nurses in the hospital setting prior to the stroke survivor's discharge home. This includes assessment of the factors that were identified in this study as influencing service use and developing targeted strategies to address any barriers to service use. Importantly, no single set of factors can explain service use so in order to meet individual needs a thorough and comprehensive assessment will be required in order to best tailor services. However, ongoing follow-up and assessment is also required in the community setting in order to evaluate coping over time and detect changes in the physical and psychosocial health of the caregiver once the longer-term impact of caregiving is realized, where home health nurses or those in primary care would be well positioned to intervene. The RNAO best practice guidelines for stroke highlight the importance of the nurse assessing and screening for caregiver burden as well as providing ongoing assessment of caregivers' needs, capabilities and learning

goals (Registered Nurses Association of Ontario, 2016). Yet there is little opportunity for nurses to connect with caregivers in the community setting. Funding by the health system needs to support community nurses in a health promotion and ongoing assessment capacity in order to best care for these caregivers.

Ideally assessment of caregiver and survivor would occur separately so that the each can speak honestly about issues such as stress or coping (Adelman et al., 2014). With regular assessments, targeted assistance can be provided before caregivers reach a point of crisis. Study findings also draw awareness to the stoic nature of many caregivers and the importance of education not just to counsel caregivers on self-care, but in order to provide them with emotional support and connect them with appropriate resources (King & Semik, 2006; Tsai et al., 2015).

A further recommendation arising from the study is that health providers tailor service provision to the individual needs of caregivers and stroke survivors in order to consider individual social, financial and environmental circumstances. This recommendation arises from the study finding that caregivers' unique psychosocial and environmental context had a strong influence on their ability to access and use services. Some caregivers were unable to use services due to costs associated with the programs and/or with transportation. Those caregivers would benefit from subsidies, financial advice provided by social workers, and information on stroke and support services, a finding documented in previous research (Fens et al., 2015; King & Semik, 2006; Masry et al., 2013).

Education.

Increasing education on family-centered approaches to care could benefit health providers and help address the gaps in service access and use by caregivers identified in the current study. Greater focus is needed on assessing caregivers' needs for care and care planning,

education on how to assess for caregiver burden and anxiety and how to connect them with community supports. Nurses and other health providers such as care coordinators, social workers, family physicians and rehabilitation specialists are ideally positioned to advocate for and educate other providers, caregivers and the public regarding some of the resultant cognitive changes that can occur due to stroke. These service providers are also well-positioned to advocate for increased respite for stroke caregivers particularly six months post-stroke when many of the stroke survivor's services have been withdrawn. The health system must acknowledge the nursing role as a pivotal part of achieving these educational goals and provide greater opportunity for them to practice in outpatient community settings.

A physician interviewed in the current study discussed his limited knowledge of community resources for caregivers, suggesting it would be helpful for primary care providers such as nurses and physicians to have better knowledge of community services for stroke survivors, their caregivers and families, a finding that was corroborated by the literature (Hare et al., 2006). Research also demonstrates that caregiver education on issues such as self-care and service access would be best-placed early in the community-based phase of the caregiving trajectory, as the caregiver is better able to grasp the demands of their caregiver role at that point (Cameron & Gignac, 2008). Generalized public education would also be well-placed to help allay some of the misconceptions and stigma surrounding stroke and aphasia that could result in the unintended isolation of caregivers and adults with stroke.

Programs and Policy.

The findings from the current study have several implications for Canadian healthcare policy and programs. The Canada Health Act states that the objective of Canadian healthcare policy is "to protect, promote and restore the physical and mental well-being of residents of Canada

and to facilitate reasonable access to health services without financial or other barriers" (Government of Canada, 1985, p. 5). However, the findings of the current study highlight the problems many caregivers of stroke survivors are facing in accessing and using services. These problems include the fact that many community-based services that would benefit caregivers are not covered financially and therefore must be paid out-of-pocket. The occurrence of a stroke can add to the financial constraints experienced by stroke survivors and their caregivers, making the use of community-based services unaffordable for some. These effects can be felt by older stroke survivors and their caregivers living on a fixed post-retirement income. But the effects can be even more pronounced for younger stroke survivors and caregivers whose household income may have dropped because of a loss or reduction in employment. At the core of this issue is the question of what constitutes reasonable access for stroke caregivers. For some stroke survivors and their caregivers' important services are out of reach. Improving access to services for these survivors and caregivers would require increasing access to financial aid, possibly through enhanced subsidies or income tax reductions, or by increasing the list of insured community-based services. However, the Act also refers to non-financial barriers some which were identified in the current study (e.g. lacking social supports, lacking information about services, psychological factors [i.e. trust in health system].) Addressing these barriers would require changes to healthcare policy so that stroke caregivers are recognized as an integral part of the circle of care for stroke survivors. However, attending to the service needs of caregivers should go beyond viewing them solely as caregivers of stroke survivors and rather recognizing them as individuals with health needs of their own that are directly impacted by their role as a stroke caregiver.

At a healthcare program level, beneficial changes to resource allocation could entail increased funding and rewards for family health teams who engage in regular and ongoing follow-

up assessment of stroke caregivers once a stroke survivor has been discharged from acute care services. There is increasing recognition of the importance of family-centered care (Registered Nurses Association of Ontario, 2015) as well as the need to include ongoing assessment and service provision to stroke caregivers (Cameron et al., 2016; Registered Nurses Association of Ontario, 2016). Therefore, in order to meet these identified needs, new proactive models of care that recognize and respond to the needs of stroke caregivers could draw from other models of care such as First Link, the program of support for caregivers of persons with dementia administered by the Alzheimer's Society. First Link has been shown to improve caregiver capacity for managing their caregiving role and has enhanced their awareness of community services and resources (McAiney, Hillier, Stolee, Harvey, & Michael, 2012). The new model of support of stroke caregivers would involve the development of a program that includes direct access for caregivers to social work as well as a team that includes nurses, family physicians, pharmacists and rehabilitation therapists. This type of program would facilitate caregivers' access to services such as counselling and respite while also supporting the recovery of the stroke survivor.

There would be value in increasing targeted funding for community-based rehabilitation and health promotion initiatives that meet the needs of caregivers and stroke survivors. Such programs could potentially include collaborations between community partners such as the YMCA or independent adult day programs with community nurses. Furthermore, the Ontario Ministry of Health and the Ministry of Long-Term Care are planning a new model of care delivery that involves the use of a team-based approach to care delivery (Ontario Ministry of Health, 2019). In this model, the patient would receive all services from one coordinated team, no matter what the type of service. Although, yet to be implemented, the initiative has the potential to address some

of the issues around fractured communication and lack of coordination between services that were identified in the current study.

Research.

This study has revealed several unanswered questions that suggest directions for future research. A next step for research could involve the development of an intervention to address some of the barriers to service use identified in the current study (e.g. respite, transportation, support group engagement and trust in health providers). This could be done in the form of a pilot study with the use of a coordinated approach to care for both stroke survivors and caregivers. Such an intervention for caregivers would include elements of assessment, information provision as well as opportunities for social engagement and health promotion activities. The current study identified a number of factors that influenced caregivers' access to and use of formal health and social services. Going forwards, research could explore how these factors are the same or different in other chronic care populations (e.g. dementia, MCC).

One of the potential questions for future research is: How does caregivers' access to and use of formal health and social service change over time? Much of the available literature investigates the immediate post-stroke time period with only very few studies collecting data on caregiver service use beyond one-year post-stroke (Hare et al., 2006; King & Semik, 2006; Simon et al., 2008). This type of study could be conducted using either a qualitative or mixed methods longitudinal design which would allow for use of standardized questionnaires to collect data pertaining to caregiver use of formal health and social services, psychological measures such as quality of life tools over time, as well as in-depth interviews to inform the quantitative findings.

A second potential question for future research arising from the current study is: What is the association between the factors influencing service use identified in the current study and the actual service use of caregivers and stroke survivors? This might involve the use of an observational correlational study that would entail collecting data on health and social service utilization and information on factors identified in the current study and looking at associations between the two data sets over time. The findings from this proposed study could be used in conjunction with the qualitative findings of the current study to inform the development of strategies to enhance the timely and appropriate use of services by caregivers to support them in their role.

The results from the current study indicated that for some caregivers, access to services such as fitness groups was facilitated when caregiver and stroke survivor services were delivered in parallel, at the same time and location. This finding raises the question whether it would be feasible to offer a broader variety of services to caregivers in parallel to services delivered to the stroke survivors. Therefore, a third research question could be: What is the feasibility and effectiveness of a program that simultaneously addresses service needs of stroke survivors and caregivers? Addressing this research question could involve the use of a pilot study to examine an intervention for caregivers that would include the provision of caregiver resources, financial information, an opportunity for caregivers to liaise with a community nurse or social worker, and a peer support group, while the stroke survivor is using a formal service such as a rehabilitation program. The study would assess feasibility measures such as participant recruitment and retention, program implementation challenges, and caregiver benefits such as decreased social isolation and anxiety. Caregiver interventions have demonstrated some success in helping caregivers manage the challenges of caregiving with reduced levels of caregiver strain, stress

reduction and better quality of life (Bakas et al., 2014; Mant et al., 2000). There is also some evidence that caregiver interventions are cost effective but further research is needed particularly in a Canadian perspective (Heslin, Forster, Healey, & Patel, 2016). The factors that influence caregivers' use of formal health and services identified in the current study are challenging to address as they are complex and involve the health system, government funding and policy, individual characteristics as well as the social determinants of health. Nevertheless going forward further research would be beneficial to increase understanding of how to facilitate stroke caregivers' health and coping particularly during the community-based phase of caregiving also known as adaptation (Cameron & Gignac, 2008). The current research along with the available body of literature has shown that caregivers could benefit from opportunities for community-based education particularly regarding how to access community resources and apply for funding, as well as opportunities for increased engagement with other stroke caregivers in the form of peer support.

Strengths and Limitations

The current study had several strengths and limitations. A strength of the study was its rigorous adherence to the ID approach. This included a rigorous analytic approach, the use of multiple data sources including interviews and ecomaps, and the use of several strategies to ensure the rigor of the study to address criteria of epistemological integrity, representative credibility, and moral defensibility.

Another strength of this study was the inclusion of a broad sample of caregivers and health providers to inform our understanding of caregivers' experiences with and the factors influencing their access to and use of formal health and social services within the Canadian context. Caregivers represented both sexes, a broad age range (42-82 years), various

relationships to the stroke survivor (spousal, child and parent), and a range of time as caregiver (6-49 months) although caregivers in the current study were a mean of 30 months into their caregiving role. This means that the sample is not representative of stroke survivors in the earlier phase of the stroke trajectory. This research was also able to realize the value of community partnerships in facilitating recruitment of a comprehensive sample of community-based stroke caregivers who were able to draw on extensive experience in accessing and using formal health and social services. Study participants were recruited from within the communities of Brantford, Burlington, Dundas, Hamilton, Grimsby, Guelph, Hagersville, Kitchener, Middlesex County, Paris, Scarborough, St. Catherine's, Stoney Creek, and Wellington County in Ontario and although the participants could speak to a variety of service use experiences and influencing factors, they were only representative of a limited region of Ontario.

Caregiver experiences were substantiated by a sample of health providers, providing a thoughtful clinician perspective, whose diverse practice expertise and understanding of stroke-related service provision added richness and additional perspective to the data set. Furthermore, the use of the thoughtful clinician perspective, contextual relevance and one-on-one in-depth interviews guided by open-ended questions was commensurate with interpretive description methodology (Thorne, 2016).

Limitations of this research include the use of single interviews often conducted a considerable time after the stroke caregiver started using services thereby necessitating caregivers to recall experiences spanning potentially long periods of time. A longitudinal study design may be better placed to facilitate experiential recall of access and service use over time in stroke caregivers. The study sample included mainly spousal caregivers with a nominal representation of parent stroke caregivers and no adult child caregivers. Every effort should be

made to include this important segment of the stroke caregiving population in future research samples. Furthermore, cultural and financial diversity within study participants was lacking, indicating the need for future research that includes these groups. This could potentially be addressed by using stratified sampling techniques based on cultural group, and socioeconomic and geographic boundaries.

Although more female (63.6%) than male caregivers (36.4%), were represented in the sample, men outnumber women in terms of stroke incidence at younger ages particularly in the ranges of 50-79 which was the age range of most study participants (Public Health Agency of Canada, 2017). Greater inclusion of male caregivers may better inform service provision and policy to all caregivers. Lastly the study sample included only health providers, albeit from multiple professions, but no social service providers were interviewed. In order to increase the depth of the information particularly regarding community-based formal health and social services it would be helpful to include some social services providers such as those employed at YMCAs or financial aid organizations.

Conclusions

This study has made several meaningful contributions to the knowledge base on caregivers of community-based stroke survivors and their use of services. Study findings demonstrate that stroke caregivers who have been caring for stroke survivors for a prolonged period (> 6 months) in the community make limited use of formal health and social services, suggesting a misalignment between their needs and the services provided. They frequently wait until a point of crisis to access services but nevertheless they do benefit from those services that they use. Caregivers benefit from use of services such as respite, medical care, psychosocial care and opportunities for social engagement. Study findings also identified several important factors

that influenced caregivers' ability to access and use formal services. Key amongst them was how the losses caregivers experienced influenced their need to access services. Further influential factors were the presence of supportive social networks, the availability of finances and transportation, and caregivers' ability to trust in health providers and trust that the stroke survivor would be safe when left alone.

Even years after a loved ones' stroke, many stroke caregivers continue to experience the ramifications of the stroke as well as the effects of taking on a caregiving role. The current health system approach to service provision for stroke caregivers is not adequate to support many stroke caregivers. Improved inclusion of caregivers at all stages of the stroke caregiving trajectory beyond the post-acute care period is needed. Nurses are ideally positioned to support these caregivers but require more opportunities to do so. A greater onus must be placed on the health system to regularly assess caregivers' need for services and link them to these services. Increased funding is required for community programs that provide support to caregivers and stroke survivors.

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Appendix A

Literature Search Strategy

<i>MEDLINE (OVID) Search Strategy: January 2000 – November 2018</i>		
ID	Concept	Search
1.	Caregivers	caregivers/
2.		carer*.ti,ab.
3.		caregiver*.ti,ab.
4.		care giver*.ti,ab.
5.		1 or 2 or 3 or 4
6.	Stroke Survivors	survivors/
7.		surviv*.ti,ab.
8.		survivor*.ti,ab.
9.		6 or 7 or 8
10.	Stroke	exp stroke/
11.		stroke*.ti,ab.
12.		cerebrovascular accident*.ti,ab.
13.		brain infarction*.ti,ab.
14.		CVA.ti,ab.
15.		cerebrovascular event*.ti,ab.
16.		10 or 11 or 12 or 13 or 14 or 15
17.	Services	health services/
18.		exp community health
19.		health services for persons with disabilities/
20.		health services for the aged/
21.		exp rural health services/
22.		exp social work/
23.		exp suburban health services/
24.		exp urban health services/
25.		health service*.ti,ab.
26.		17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25
27.	Supports	community networks/ or social support/
28.		support*.ti,ab.
29.		social service*.ti,ab.

MEDLINE (OVID) Search Strategy: January 2000 – June 2016 Continued

ID	Concept	Search
30.		27 or 28 or 29
31.		26 or 30
32		5 or 9
33.		32 and 16 and 31
34.	Health Services	exp health services research/
35.	Use	utili?ation.ti,ab.
36.		usage.ti,ab.
37.		29 or 30 or 31
38.		33 and 37
39.		limit 38 to (english language and yr="2000 - Current")

Appendix B

Data Collection Forms

Caregiver Demographic Form.

The questions on this form are in reference to you, the caregiver.

1. What is your date of birth? _____
2. What are the first three alphanumeric symbols of your postal code? (to determine if rural or urban) _____
3. What is your gender? Male Female Transgendered
4. Marital Status: Single Married Widowed Divorced/separated
 Other (specify): _____
5. Ethnicity:
 Caucasian (white)
 South Asian
 Chinese
 Black
 Filipino
 Latin American
 Arab
 Southeast Asian
 West Asian
 Korean
 Japanese
 Other (specify): _____
6. Are you a: Canadian citizen Landed immigrant
 Other (specify): _____
7. How many years of education did you complete? _____

8. Are you employed? Yes No If yes, are you self-employed? Yes No
What of work do you do? _____
9. If employed outside of the home, do you work: Full-time Part-time Casual
 Other (specify) _____
10. What is your relationship to care receiver: Husband/wife/life partner Parent
 Parent-in-law Son/daughter Sister/brother Other (specify) _____
11. What is the approximate month and year that the caregiving began: ____/ ____ (mm/yyyy)
12. Do you get assistance with caregiving? Yes No
a. If yes from whom? _____
13. Do you have any medical conditions? Yes No
a. If yes what are they? _____
14. What is your religious preference: _____
Are you actively practicing? Yes No
15. What is your estimated annual household income before taxes:
 Less than \$10,000 \$10,000-\$19,999 \$20,000-\$29,999 \$30,000-\$39,999
 \$40,000-\$49,999 \$50,000-\$59,999 \$60,000-\$69,999 \$70,000 or more
 Prefer not to answer
16. Your finances meet your needs:
 Completely Very well Adequately
 With some difficulty Not very well Totally inadequately
- 17 a). Do you live with the person who has had a stroke for whom you provide care? **Yes / No**
- b). If yes, what type of residence do you and the person who has had a stroke live in?
 Own single dwelling home Own multiple dwelling (duplex/triplex)
 Rent single dwelling home Rent multiple dwelling (duplex/triplex)
 Own condominium/apartment Retirement / assisted living complex

Rent condominium/apartment

c). If no, where does the person who has had a stroke live?

Own single dwelling home

Own multiple dwelling (duplex/triplex)

Rent single dwelling home

Rent multiple dwelling (duplex/triplex)

Own condominium/apartment

Retirement / assisted living complex

Rent condominium/apartment

17. About the person you are caring for:

What is their date of birth? _____

What is their gender? Male Female Transgender

Health Professional Demographic Form.

These questions are about your background for statistical purposes only and will be used to describe the characteristics of the participants in this study.

1. Gender: ₁ Male ₂ Female
2. Age:
 - ₁ 18-20
 - ₂ 21-25
 - ₃ 26-30
 - ₄ 31-40
 - ₅ 41-50
 - ₆ 51-60
 - ₅ 61+
3. What is the highest level of education that you have completed? (*check one*)
 - ₁ College Diploma or Certificate ₃ Graduate Degree
 - ₂ Undergraduate Degree ₄ Other (*please specify*): _____
4. How many years have you been working in your field?
 - ₁ 0-3 ₂ 4-10 ₃ 11-5 ₄ 16-20 ₅ 21 +
5. How many years have you been working in your current position?
 - ₁ 0-3 ₂ 4-10 ₃ 11-5 ₄ 16-20 ₅ 21 +
6. Can you please define your role in your current position?

Number of Multiple Chronic Conditions.

*Number of MCC – to be administered to stroke caregiver **and** on behalf of the adult with stroke.

Stroke Caregiver

For each of the following conditions, please indicate “yes” or “no” if you have the condition.

* Check “yes” only for conditions being confirmed by a doctor or for which you are taking prescribed medicines.

No	Yes	
<input type="checkbox"/>	<input type="checkbox"/>	Hypertension (high blood pressure)
<input type="checkbox"/>	<input type="checkbox"/>	Depression or anxiety
<input type="checkbox"/>	<input type="checkbox"/>	Chronic musculoskeletal conditions causing pain or limitation
<input type="checkbox"/>	<input type="checkbox"/>	Arthritis or rheumatoid arthritis
<input type="checkbox"/>	<input type="checkbox"/>	Osteoporosis
<input type="checkbox"/>	<input type="checkbox"/>	Asthma, chronic obstructive pulmonary disease (COPD) or chronic bronchitis
<input type="checkbox"/>	<input type="checkbox"/>	Cardiovascular disease (angina, myocardial infarction, atrial fibrillation, poor circulation in the lower limbs)
<input type="checkbox"/>	<input type="checkbox"/>	Heart failure (including valve problems or replacement)
<input type="checkbox"/>	<input type="checkbox"/>	Stroke and transient ischemic attacks (TIA)
<input type="checkbox"/>	<input type="checkbox"/>	Stomach problem (reflux, ulcer or heartburn)
<input type="checkbox"/>	<input type="checkbox"/>	Colon problem (irritable bowel, Crohn’s disease, ulcerative colitis, diverticulosis)
<input type="checkbox"/>	<input type="checkbox"/>	Chronic hepatitis
<input type="checkbox"/>	<input type="checkbox"/>	Diabetes
<input type="checkbox"/>	<input type="checkbox"/>	Thyroid disorder
<input type="checkbox"/>	<input type="checkbox"/>	Any cancer in the previous 5 years (including melanoma but not other skin cancers)
<input type="checkbox"/>	<input type="checkbox"/>	Kidney disease or failure
<input type="checkbox"/>	<input type="checkbox"/>	Chronic urinary problem
<input type="checkbox"/>	<input type="checkbox"/>	Dementia or Alzheimer’s disease
<input type="checkbox"/>	<input type="checkbox"/>	Hyperlipidemia (high cholesterol)
<input type="checkbox"/>	<input type="checkbox"/>	HIV
<input type="checkbox"/>	<input type="checkbox"/>	Other: specify _____
<input type="checkbox"/>	<input type="checkbox"/>	Other: specify _____

(Fortin, 2014)

Adult with Stroke

For each of the following conditions, please indicate “yes” or “no” if you have the condition.

* Check “yes” only for conditions being confirmed by a doctor or for which you are taking prescribed medicines.

No	Yes	
<input type="checkbox"/>	<input type="checkbox"/>	Hypertension (high blood pressure)
<input type="checkbox"/>	<input type="checkbox"/>	Depression or anxiety
<input type="checkbox"/>	<input type="checkbox"/>	Chronic musculoskeletal conditions causing pain or limitation
<input type="checkbox"/>	<input type="checkbox"/>	Arthritis or rheumatoid arthritis
<input type="checkbox"/>	<input type="checkbox"/>	Osteoporosis
<input type="checkbox"/>	<input type="checkbox"/>	Asthma, chronic obstructive pulmonary disease (COPD) or chronic bronchitis
<input type="checkbox"/>	<input type="checkbox"/>	Cardiovascular disease (angina, myocardial infarction, atrial fibrillation, poor circulation in the lower limbs)
<input type="checkbox"/>	<input type="checkbox"/>	Heart failure (including valve problems or replacement)
<input type="checkbox"/>	<input type="checkbox"/>	Stroke and transient ischemic attacks (TIA)
<input type="checkbox"/>	<input type="checkbox"/>	Stomach problem (reflux, ulcer or heartburn)
<input type="checkbox"/>	<input type="checkbox"/>	Colon problem (irritable bowel, Crohn’s disease, ulcerative colitis, diverticulosis)
<input type="checkbox"/>	<input type="checkbox"/>	Chronic hepatitis
<input type="checkbox"/>	<input type="checkbox"/>	Diabetes
<input type="checkbox"/>	<input type="checkbox"/>	Thyroid disorder
<input type="checkbox"/>	<input type="checkbox"/>	Any cancer in the previous 5 years (including melanoma but not other skin cancers)
<input type="checkbox"/>	<input type="checkbox"/>	Kidney disease or failure
<input type="checkbox"/>	<input type="checkbox"/>	Chronic urinary problem
<input type="checkbox"/>	<input type="checkbox"/>	Dementia or Alzheimer’s disease
<input type="checkbox"/>	<input type="checkbox"/>	Hyperlipidemia (high cholesterol)
<input type="checkbox"/>	<input type="checkbox"/>	HIV
<input type="checkbox"/>	<input type="checkbox"/>	Other: specify _____
<input type="checkbox"/>	<input type="checkbox"/>	Other: specify _____

(Fortin, 2014)

Appendix C

Questions to guide in-depth interviews with stroke caregivers

Overarching Questions

- Can you tell me about your life as a caregiver?
- Can you tell me about a time when you felt supported in your role as a caregiver?
- Can you tell me about some of the challenges you have faced as a caregiver?
- Can you tell what has been helpful to you in managing these challenges?
- Can you tell me how being a caregiver has affected your life?
- Can you tell me what an average day looks like for you in your role as a caregiver?
- Can you tell me how being a caregiver of an adult with stroke has affected your health?
- Can you tell me how you would like to be supported in managing your own health and in your caregiving role?
- Can you tell me how your experience as a caregiver has changed over time?
- What is it like managing the complexity of MCC (in adult with stroke) as a caregiver?

Caregiving Role

- Can you tell me what qualities you bring to your caregiving? Prompt – Would you say you have specific skills or abilities?
- Can you tell me about what supports you provide?
- What are qualities that you bring to caregiving?
- How has caregiving changed you? What skills have you learned?
- What do you look forward to?

Social Support

- Can you explain what social supports you have in your life?
- How do these people make a difference in your life?
- Can you tell me about how being a caregiver has affected your social circle?

Adult with Stroke

- Can you explain how your relationship with your (stroke survivor /husband/wife/mother/father/other) has been affected by becoming a caregiver?

Health System/Community Resources

- Can you tell me about your experience in accessing and using services?
- Can you tell me about a time when you needed/wanted/used a service, either to support you in managing your own health or in your caregiving role?
- Have you accessed formal services to support you in your caregiving role?
- What makes it easy to use services?
- What makes it hard to use services?
- What recommendations do you have regarding services?
- What happened? How did you know about it? Why did you need it? What was going on in your life at the time?
- Can you explain what sort of health or social services you currently receive in your role as a caregiver?
- Can you tell me about the things you consider when choosing to use services?
- Can you summarize what services would help you as a caregiver?

Need-Services Gap

- Can you tell me about a time when you tried to access services?
- Can you tell me about what affects your decision to use services?
- Would you be willing to or are you currently paying for privately funded services?
- Are there services that are available to you but you do not use? For what reasons? (e.g. distance, cost of parking, work constraints)

Health

- Can you tell me about your health?
- Can you discuss how your health has been affected by your role as a stroke caregiver?
- Are there changes you would like to make to improve or maintain your health?
- Are there geographical constraints on your ability to seek/obtain services or respite?
- Can you tell me how you would feel supported to continue in your caregiving role?
- How would you like to see the health system assist you in your caregiving role?
- What services would you like to be able to use that are not currently available to you?

Contextual Factors – Economic/Social/Physical

- Can you tell me about something in your life that has had the most influence on your role as a caregiver?

Questions to guide in-depth interviews with health providers

Overarching Questions

- Tell me about a time when you felt you were able to provide support to a stroke caregiver(s).
- Can you tell me how you think being a stroke caregiver affects caregivers?
- Can you tell me what your day looks like in terms of the support you provide to stroke survivors and their caregivers?
- Can you tell me how you would ideally support stroke caregivers?
- Can you tell me how MCC in addition to being a stroke survivor affects the caregiving role?
- Can you tell me how having MCC as a caregiver affects their role?
- How do you perceive that being a stroke caregiver affects the caregiver's health?
- Can you tell me how you think caregivers' experience of being a caregiver changes over time?

Caregiving Role

- Can you tell about a time when you felt able to support a stroke caregiver?
- Can you tell me how you would like to support (or what you envision) stroke caregivers?
- Can you tell me what skills you have that can help stroke caregivers?

Social Support

- Can you tell me what people provide support to stroke caregivers?
- Can you tell me how you think these people affect the lives of stroke caregivers?

- Can you tell me how you think the social circles of stroke caregivers are affected by their caregiving role?

Stroke Survivor

- Can you tell how you think stroke caregivers' relationships with the stroke survivor change as a result of becoming a caregiver?

Health System/Community Resources

- Can you explain what sort of health or social services stroke caregivers receive?
- Can you explain an instance where you think health or social services have supported a stroke caregiver? How did they do this?
- Can you tell me about the things you consider when referring or connecting a stroke caregiver to services?

Need-Services Gap

- Can you provide examples of factors that make it challenging for stroke caregivers to access services?
- Can you tell me what you think affects stroke caregivers' choice to access services?
- Can you tell me what services available to stroke caregivers are not optimally accessed?

Health

- Can you tell me about a situation where you think a stroke caregiver's health has been affected by their caregiving role?
- Can you tell me how you think stroke caregivers could be supported in their caregiving role?

- Can you tell me how you think the health system could assist stroke caregivers in their caregiving role?

Contextual Factors – Economic/Social/Physical

- Can you tell me how the current health system is meeting the needs of stroke caregivers?