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Health Providers Perspectives on the Access and Use of Formal Health and Social Services by Stroke Caregivers

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Abstract

Informal stroke caregivers, comprised of family and friends, can experience prolonged stress that places them at risk of poor health and social outcomes. These caregivers may benefit from formal health and social services, but they are often underused and challenging to access. This qualitative interpretive description study sought to explore health providers' perspectives on the factors that impact stroke caregivers' access and use of formal health and social services. In addition, it sought to explore health providers' experiences and how they perceive their role in supporting stroke caregivers'. In-depth, semi-structured interviews were conducted with 18 health providers. Through inductive thematic analysis, resultant themes include: (a) a fragmented health system impacts the ability to provide continuity of care, (b) challenges in care provision and accessibility creates moral distress for health providers, (c) access to social support is pivotal for stroke caregivers' self-care, (d) stroke caregivers require individualized care, (e) providing a single access point for stroke caregiver support is essential for success, and (f) current services are not meeting people living with stroke and stroke caregivers' needs. Health providers are critical stakeholders due to their rich understanding of this issue, highlighting the importance of their involvement in caregiver initiatives.

Keywords: caregivers, health providers, stroke, health service delivery

Summary for Lay Audience

With improvements in healthcare, more individuals are surviving strokes, leading to an increased number of persons living with stroke (PLWS) recovering at home. This places a higher need for informal stroke caregivers. Informal caregivers are family and friends who provide essential and ongoing support for family members and friends. The stress they experience can lead to negative emotional, social, environmental, financial, and health-related consequences.

Formal health and social services can benefit stroke caregivers when they are available and used appropriately, providing relief, support, and opportunity for health promotion. However, evidence has shown many factors that influence stroke caregivers' ability to access services. Health providers are important individuals to consider when looking at this issue due to their knowledge and experience with PLWS, stroke caregivers, and community resources. However, there is limited research on this issue that includes the health provider perspective. This study aimed to explore the experiences of stroke caregivers in accessing formal health and social services from the perspective of health providers. Additionally, it sought to understand how health providers perceive their role in supporting stroke caregivers'.

This qualitative study examined interviews with 18 health providers across Southwestern Ontario. Interviews were analyzed to discover the following themes: a fragmented health system impacts the ability to provide continuity of care; challenges in care provision and accessibility creates moral distress for health providers; access to social support is pivotal for stroke caregivers' self-care; stroke caregivers require individualized care; providing a single access point for stroke caregiver support is essential for success; and current services are not meeting people living with stroke and stroke caregivers' needs.

By examining health providers' perspectives, we can better understand the challenges stroke caregivers face when accessing formal health and social services. In addition, we can understand the challenges health providers face when attempting to support stroke caregivers. With a clearer understanding of this issue, we can better support stroke caregivers so that they can successfully continue their vital role.

Co-Authorship Statement

Hannah Pollock completed the following work under the supervision of Dr. Anna Garnett and Dr. Yolanda Babenko-Mould, who will be listed as co-authors on any future publications. Dr. Jenny Ploeg, Dr. Maureen Markle-Reid, and Dr. Patricia Strachan were involved in the primary study which this secondary analysis developed from and will be listed as co-authors on any future publications.

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Chapter One

Introduction

Experiencing a stroke and living with the resulting effects can be a complicated and life-changing experience for persons living with stroke (PLWS) and their informal caregivers. Informal caregivers of PLWS, hereafter referred to as stroke caregivers, include family and friends "who provide essential and often ongoing personal, financial, social, psychological, and physical support, assistance and care, without pay, for family members and friends in needs" (Lantz & Freid, 2018, p. 2). With improvements in healthcare more individuals are surviving strokes, and the majority, approximately 57%, are being quickly discharged from an acute inpatient care unit without additional inpatient rehabilitation (Canadian Institute for Health Information, 2012; Public Health Agency of Canada, 2017). This has led to an increased number of PLWS living with chronic disabilities within the community, thus placing greater responsibility for care provision on stroke caregivers (Health Quality Ontario, 2016).

The lives of stroke caregivers are profoundly impacted, within a short period of time, as they must learn to meet the PLWS care needs, which are often extensive and can be complicated by conditions such as aphasia (Camak, 2015; O'Brien et al., 2014). Adjusting to changes in behaviour, physical limitations, communication challenges, and memory impairments, all while continuing to provide extensive care can be emotionally and physically taxing for stroke caregivers (Camak, 2015). The resultant stress associated with prolonged caregiving can lead stroke caregivers to experience adverse emotional, social, environmental, financial and health-related difficulties (Camak, 2015; Gbiri et al., 2015; Greenwood et al., 2009; Health Quality Ontario, 2016; Jaracz et al., 2015; Jaracz et al., 2014; Lou et al., 2017; Pucciarelli et al., 2018; Quinn et al., 2014; Smith et al., 2004; Watanabe et al., 2015). Therefore, stroke caregivers can

benefit from access to ongoing support throughout their caregiving journey to minimize the potential negative impacts of caregiving and optimize their health. Formal health and social services have the potential to benefit stroke caregivers when they are available and used appropriately by providing respite, support, and opportunity for engagement in health promotion activities. However, evidence has shown that there are many factors that impact stroke caregivers' ability to access services (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Shafer et al., 2019). Limited follow-up, not being recognized as individuals who need support, insufficient time with health providers, limited access to community services such as respite, income, transportation, and few education and training opportunities make it difficult for stroke caregivers to access resources that aid in their support (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Shafer et al., 2019).

Throughout the stroke trajectory, health providers are well-positioned to support both PLWS and stroke caregivers through the provision of education, assessment, treatment, referrals, and system navigation support. While we know stroke caregivers can benefit from these services, research suggests that not all stroke caregivers' are able to make use of services that are intended to support them (King & Semik, 2006; The Ontario Caregiver Organization, 2019). There is limited knowledge of the facilitators and barriers that impact stroke caregivers' access and use of formal health and social services. Furthermore, there is limited knowledge on how health providers perceive their role in supporting stroke caregivers' access and use formal health and social services. A better understanding of these factors can inform service delivery and policies that will optimize care delivery and uptake by PLWS and stroke caregivers. By exploring both stroke caregivers and health providers perspectives on service access and use, a comprehensive understanding of the issue can be attained.

Background

A stroke occurs when blood stops flowing to a part of the brain, damaging brain cells (Heart and Stroke Foundation, n.d.). There are various types of strokes, including ischemic, haemorrhagic, and transient ischemic attacks (Heart and Stroke Foundation, n.d.). Stroke is the third leading cause of death in Canada, predominantly impacting older adults, with approximately 80% of all strokes occurring in those over the age of 60 and with 10% of adults aged 65 years and older having experienced a stroke (Public Health Agency of Canada, 2017). The effects of a stroke depend on the part of the brain damaged and the extent of damage as well as any comorbidities experienced by the PLWS (Heart and Stroke Foundation, n.d.). A stroke may cause weakness, loss of sensation, confusion, difficulty speaking, vision problems, headaches, and loss of coordination and balance, for example (Public Health Agency of Canada, 2017). The effects can range from mild to severe, and many never fully recover (Public Health Agency of Canada, 2017). With a growing older population and improving medical treatments, more people live with the effects of stroke (Public Health Agency of Canada, 2017). In fact, in the age standardized mortality rate for stroke in 2017 was 80.5 per 100,000 population, representing a 13.6% decline since 2007 (Teasell et al., 2020). This is due to improvements in acute stroke care and rapid system responses (Teasell et al., 2020). In 2013, the number of PLWS living with a disability in Canada was approximately 405,000 (Krueger et al., 2015). This number is projected to increase to between 654,000 to 726,000 by 2038 (Krueger et al., 2015).

Recovery after a stroke is quite variable. A complete recovery following a minor stroke is expected six months after the acute event; however, recovery after more severe strokes may take years or may not be possible (Teasell et al., 2020). On average, 60% of PLWS are left with some disability and more than 40% are left with moderate to severe disability that requires more

support (Heart and Stroke Foundation, 2017). Governments and health systems are continually working to support PLWS' recovery in the community at home. With the understanding that there are a limited number of rehabilitation programs and long-term care beds, governments recognize the importance of PLWS remaining at home and the strain this removes from the health system (Health Quality Ontario, 2016). Approximately 93% of older adults also would prefer to stay at home if the proper supports were available (Home Care Ontario, 2020). The increase in community and home care reflects the growing need to improve care for people in their homes and support informal stroke caregivers (Health Quality Ontario, 2016).

Stroke caregivers often assume this role without warning and with limited knowledge of the demands associated with caregiving (Camak, 2015). In 2018, one in four Canadians aged 15 and older provided care to a family member or friend due to chronic health conditions (Statistics Canada, 2018). Still, many stroke caregivers are themselves older adults and often the spouse of the PLWS, with adult children being the second most common caregivers (Heart and Stroke Foundation, 2017; King & Semik, 2006; Watanabe et al., 2015). These stroke caregivers provide physical support such as bathing, dressing, feeding, ambulating, and toileting, in addition to the regular household tasks such as cleaning, cooking, handling finances, and more (Health Quality Ontario, 2016). A study conducted by Tooth et al. (2005) showed that stroke caregivers spent on average 4.6 hours per day providing care to a PLWS six months after the event. This time decreased to 3.6 hours 12 months after the event, showing that even over time, caregiving can be chronic, with stroke caregivers spending a considerable amount of time per day performing caregiving duties (Tooth et al., 2005). In addition, Statistics Canada reports that in 2018, most caregivers spent less than 10 hours a week caregiving, however, 15% of caregivers spent 10 to 19 hours, and 21% spent 20 hours or more (Statistics Canada, 2018)

The stress of such a role can lead to adverse emotional, social, environmental, financial, and health-related difficulties (Camak, 2015; Gbiri et al., 2015; Greenwood et al., 2009; Health Quality Ontario, 2016; Jaracz et al., 2015; Jaracz et al., 2014; Lou et al., 2017; Pucciarelli et al., 2018; Quinn et al., 2014; Smith et al., 2004; Watanabe et al., 2015). Stroke caregivers are often left feeling isolated, lonely, and exhausted because of lack of sleep or support (Camak, 2015). Stroke caregivers are at a higher risk of experiencing depression and anxiety due to the increased burden placed upon them, uncertainty about their loved ones' condition, fear for the future, and putting their own needs aside while suffering in silence (Camak, 2015; Greenwood et al., 2009; Jaracz et al., 2014; Lou et al., 2017; Quinn et al., 2014; Smith et al., 2004). In addition, because many stroke caregivers are themselves older adults, they often experience their own health issues, further complicating their role (Heart and Stroke Foundation, 2017).

In a nonexperimental study conducted by Jaracz et al. (2015), 44% of stroke caregivers felt considerable burden six months after the PLWS was discharged from hospital. The number of caregivers who felt significant burden decreased over time, with 30% five years after discharge; however, this is still a significant number of individuals who are suffering due to their role (Jaracz et al., 2015). In addition, those caregivers who spend more time caregiving experience higher levels of distress (Health Quality Ontario, 2016). The care recipient whose caregiver experienced distress received 31.5 hours per week of care from those caregivers, compared to 17.1 hours per week received by care recipients whose caregivers were not distressed (Health Quality Ontario, 2016). Furthermore, a quantitative study conducted by Watanabe et al. (2015) looked at changes in caregivers' sense of burden over a long-term period and found that 69.3% of caregivers have difficulty maintaining their own health, 66.7% had difficulty doing housework and coping at work, 68.8% had difficulty going out, 60% had

difficulty taking free time, and 60% had difficulty mentally relaxing. The consequences of this increased burden are significant and proper support and resources are crucial to support stroke caregivers in maintaining their own health to continue their critical role.

In summary, stroke has a significant impact not only on the PLWS, but also on their informal caregivers. Stroke caregivers spend a considerable amount of time caring for the PLWS overtime and are at risk of poor health and negative social outcomes because of their burden. Formal health and social services can provide the support required to improve their health and ease their burden; however, these have been shown to be challenging to access. Health provider are important stakeholders to consider with this issue due to their wealth of knowledge and experience with the health system, PLWS, and stroke caregivers. Examining this issue from their perspective can provide further understanding of this issue with the goal of informing improvements in practice and care provision to PLWS and their caregivers.

Literature Review

The following literature review provides an overview of the factors impacting stroke caregiver access and use of formal health and social services from the stroke caregiver perspective. There will then be a description of the various types of health providers who work in a variety of settings and their role in supporting stroke caregivers. Finally, there will be an exploration of the literature examining the health providers perspective on the barriers and facilitators stroke caregivers' experience when trying to access and use of formal health and social services as well as the various facilitators and barriers health providers experience when trying to support caregivers.

Stroke Caregiver Perspective

The literature outlines a number of challenges that stroke caregivers experience when accessing formal health and social services. Insufficient time with health providers, limited access to community services such as respite, and few education and training opportunities make it difficult for stroke caregivers to access resources that aid them (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Shafer et al., 2019).

Caregivers have expressed the need for education concerning stroke in general, their loved one's condition, their role, and resources available to support their loved ones as well as for themselves (Camak, 2015; Greenwood et al., 2011; Laparidou et al., 2019; Quinn et al., 2014). King and Semik (2006) discovered that only 40% of caregivers received information on stroke prevention, yet 63% rated it as important. A meta-synthesis of qualitative research conducted by Quinn et al. (2014) revealed when stroke caregivers received sufficient information from their health providers they felt better equipped to cope with changes and valued this communication from health providers. Receiving information about resources within the community, financial entitlements, and having help to fill out forms has been shown to be a considerable benefit to stroke caregivers' quality of life (Greenwood et al., 2009; Smith et al., 2004). When education and information are explicitly tailored to stroke caregivers and are administered at a specific time, it can promote beneficial behavioural changes (Cameron & Gignac, 2008). In addition, caregiver training in practical daily tasks is needed and seen as a benefit from stroke caregivers' point of view (Greenwood et al., 2011; Quinn et al., 2014; Smith et al., 2004). Often caregivers do not receive enough training and rely on trial and error when at home (Cameron & Gignac, 2008; Smith et al., 2004). Accessing services that provide additional training on advocacy skills, providing personal care, and looking after themselves are some ideas that can support caregivers

in their new role (Greenwood et al., 2009; Greenwood et al., 2011; Quinn et al., 2014; Smith et al., 2004).

Caregivers have expressed hesitancy in approaching health providers in consideration for their time, their disconnection from health providers, and their realization that their needs are often overlooked with the focus mainly on the PLWS (Hudson et al., 2004; Shafer et al., 2019; Smith et al., 2004). However, stroke caregivers recognize the need to address their own concerns and would appreciate more accessibility to a health provider to receive more information and support (Camak, 2015; Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Smith et al., 2004).

Access to community services such as respite care is essential in providing stroke caregivers with time away from their caregiving duties. Many caregivers express the need for time away to focus on themselves as being crucial to provide them the strength to continue with their caregiving role (Quinn et al., 2014). However, suitable respite is often unavailable or underutilized (Greenwood et al., 2009; Greenwood et al., 2011; Quinn et al., 2014). A cross-sectional mixed methods study by King and Semik (2006) discovered that services such as respite, were not used frequently despite being acknowledged as important. Many caregivers express their hesitancy in utilizing respite because they feel the need to be constantly present with the PLWS to ensure they are safe and well cared for (Quinn et al., 2014).

Health Providers Role in Supporting Stroke Caregivers

Caregivers typically receive the most support from health providers, family members, friends, and peers (Cameron et al., 2013). Health providers are in a unique position to support stroke caregivers, assess their needs, and help them access resources within the community due

to their education, experience, and relation to the stroke caregiver and PLWS (Greenwood et al., 2011; Parmar et al., 2020).

General practitioners can easily assess and provide support to stroke caregivers, as they are typically the first point of contact for stroke caregivers in the community (Aziz et al., 2016; Greenwood et al., 2010; Parmar et al., 2020). In one study conducted by Greenwood et al. (2010) where questionnaires were provided to general practitioners prior to an educational workshop, it was determined that while general practitioners are well positioned to support stroke caregivers, they often lack confidence, training, and knowledge concerning caregiver issues to properly support them.

Other health providers such as physiotherapists, nurses, and social workers, are also crucial in supporting stroke caregivers. In a study conducted by Ng (2009) surveys were used to discover the delivery of services to the caregivers of a variety of patients and opportunities for improvement. They found that physiotherapists and occupational therapists were involved in health and wellness services, caregiver assessments, and centre and home-based training (Ng, 2009). Social workers were involved in counselling, case management, leading support groups, and caregiver assessment (Ng, 2009). Nurses specifically, are well-positioned to provide support. Nurses were found to be involved in many resources to support caregivers such as case management, caregiver assessments, health and wellness services, as well as home-based and centre-based caregiver training (Ng, 2009). Utilizing psychoeducation, performing needs assessments, providing practical support, and peer support are useful approaches nurses can implement into their practice to positively impact caregivers (Becque et al., 2019).

Many of these practitioners' roles and ability to support stroke caregivers access services will vary depending on where they work and where the client and caregivers are in the stroke

recovery trajectory. Often there is a transfer of care from acute/specialist services to community health services and each has a different role in stroke care (Pindus et al., 2018). A common issue arises when many health providers view their role as primarily reactive and focus on the PLWS rather than stroke caregivers (Greenwood et al., 2011). For example, nurses working in an acute care setting are critical in the care of PLWS, however, they should also play an important role in discharge planning and education (Camak, 2015). These nurses are often pressed for time and can only focus on the acute needs of the PLWS, leaving little time to provide adequate education to stroke caregivers in preparation for the PLWS' discharge (Camak, 2015). Nurses in the community and in primary care settings are in a better position to offer support, advice, assessments, and education to both PLWS and stroke caregivers (Ng, 2009).

Despite health providers in a variety of settings having the capability to support stroke caregivers throughout their journey, a disconnect between service provision and service access remains (Cameron et al., 2013; Greenwood et al., 2011; O'Brien et al., 2014; Parmar et al., 2020).

Health Provider Perspective

A comprehensive search of the literature was done to identify research that addressed health providers' perspectives on the factors impacting stroke caregivers' access to and use of formal health and social services. Databases searched included: CINAHL, Scopus, and Embase. Search terms used include: caregiver, carer, support, social support, health services, service delivery, health providers, health professionals, and stroke, connected using the Boolean operators "and" and "or" depending on the database being searched. Articles were limited to peer-reviewed articles, written in English, and those published between January 2000 and April 2021. Ancestry searches were done as well by reviewing the references of applicable articles.

Nineteen articles met the inclusion criteria and were included in this review. While a broader selection of studies have examined health provider perspectives on caregiver service access and use across a variety of conditions, there is limited research focusing on the context of stroke caregivers specifically. Literature specific to stroke caregivers and additional literature concerning caregivers in general will be drawn upon to increase understanding of this phenomena. The following provides a compressive narrative review of the relevant studies identified.

Health providers are aware of caregiver burden and the difficulties many stroke caregivers face when trying to access services to support the PLWS and themselves. Health providers are also aware of many barriers they face when trying to properly support caregivers. They recognize a variety of barriers such as their heavy workloads and lack of time, their lack of knowledge and know-how to identify and support caregivers properly, situational and systemic level barriers such as income, transportation, a lack of resources available, difficulty navigating the system, and lastly, issues surrounding education and information sharing (Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Jansen et al., 2009; Laparidou et al., 2019; Ng, 2009; O'Brien et al., 2014; Parmar et al., 2020; Quinn et al., 2014; Shafer et al., 2019). Considering the challenges, health providers recognise the importance of supporting stroke caregivers and highlight familiar facilitators for stroke caregivers accessing formal health and social services. These include enhancing education and information sharing, implementing family centred and collaborative care, and having a designating care coordinator to support caregivers (Benton & Meyer, 2019; Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Jansen et al., 2009; Ng, 2009; O'Brien et al., 2014; Parmar et al., 2020).

These common barriers and facilitators health providers have identified that impact caregivers' access to and use of formal health and social services are complex in nature. The following section will explore these barriers in more detail, examining the resultant impacts on stroke caregivers.

Barriers

Time Constraints and Workloads of Health Providers.

The literature review suggests that health providers struggle to properly provide support to stroke caregivers due to time constraints which limit their ability to take stroke caregivers concerns into consideration. Health providers have hectic and heavy schedules making it difficult to identify and support caregivers (Greenwood et al., 2011; Hudson et al., 2004; O'Brien et al., 2014). Even when health providers recognized they were well-positioned to support caregivers, they felt constrained by their workload to properly support them (Greenwood et al., 2011; O'Brien et al., 2014). Often health providers focus solely on the PLWS due to time constraints and caregivers recognize this and follow suit, focusing solely on the needs of their loved ones (Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Parmar et al., 2020). Stroke caregivers often feel like they are burdening health providers thus, avoid discussions and seeking support, particularly if it concerns themselves (Hudson et al., 2004). This often leads to an increased caregiver burden, which is associated with anxiety, depression, and other poor health outcomes since the caregivers' own needs are overlooked (Cameron et al., 2013). When caregivers are not consulted regarding their ability to manage, cope, and their requirements for any support in their new role, their own health and well-being is impacted, leading to vulnerability and concerns for the future (Quinn et al., 2014; Smith et al., 2004).

Likewise, those health providers who specifically work in homecare are strained to provide support for caregivers. A descriptive interpretive qualitative study by Jansen et al. (2009) identified that home care providers often lacked time at the caregiver and patients' homes to accomplish their tasks for the day and provide much needed emotional and informational support to the caregiver. This lack of time stems from practice and system-level barriers, such as a lack of human and fiscal resources, that prevent them from providing anything beyond the client's basic medical needs.

Health providers need to have sufficient time to provide the appropriate care and support to stroke caregivers and the PLWS (Jansen et al., 2009). Caregivers recognize the significance of their role and are wanting to be part of the focus of care (Cameron et al., 2013). If health providers were more aware and had more time, this could promote beneficial results for all (Cameron et al., 2013).

Health Providers Insufficient Knowledge Pertaining to Stroke Caregiver Support.

Findings in the literature suggest that health providers have concerns about the adequacy of their knowledge and training pertaining to caregiver issues. The literature suggests that health providers' ability to support struggling caregivers is impacted by their difficulty to identify caregivers, lack of knowledge on caregiver burden, lack of resources available for caregivers, and an inability to implement interventions at appropriate times (Greenwood et al., 2011; Hudson et al., 2004; Ng, 2009). This impacts their confidence to properly identify, approach, and support caregivers.

A study conducted by Greenwood et al. (2010) showed that nine out of ten primary care providers felt that they had insufficient training to support caregivers and about half lack the

appropriate confidence required to meet caregivers' needs (Greenwood et al., 2010). This can be an individual issue or issue pertaining to a lack of family-focused education and caregiver education in the school curriculum (Greenwood et al., 2010).

When addressing caregivers, it is vital that health providers develop confidence and feel capable of supporting them throughout the caregiving journey (Hudson et al., 2004). They need more opportunity for ongoing education to increase their ability to identify, assess, and support caregivers (Parmar et al., 2020). Having the appropriate education and opportunity for ongoing education to attain the knowledge to properly address caregiver issues will significantly impact their ability to identify, assess, and support caregivers to guide them to further resources (Parmar et al., 2020).

Situational and Systemic Level Barriers.

Though health providers need and want to be more vigilant in identifying and supporting caregivers, they recognize that many individual and systemic level factors make it difficult for caregivers to access services and for health providers to provide support (Greenwood et al., 2011; Greenwood et al., 2010; Ing et al., 2014; Jansen et al., 2009; Ng, 2009; Parmar et al., 2020; Shafer et al., 2019; Smith et al., 2004; Syed et al., 2013) Within the literature, health providers identified various situational and systemic level barriers that impede caregivers' access to appropriate formal health and social services. A complex and fragmented health system, limited community services, difficulty navigating services, finances, and transportation are all factors that have the potential to impact caregivers' access and use of formal health and social services.

Currently, health systems are complex and fragmented with health providers lacking time, functioning in a reactive rather than proactive way, and facing difficulty referring to and receiving information from various organizations (Parmar et al., 2020). This leads to the risk of

declining health for caregivers due to the stress and difficulty coping without sufficient information and support provided by health providers and services (Smith et al., 2004).

Although primary care is well-situated to address caregiver needs, additional community-based services are sometimes available and even more suitable; however, these services are few in number and referring caregivers to these services can be difficult (Greenwood et al., 2011; Parmar et al., 2020). Findings in the literature suggest that primary care providers would like to refer caregivers to community services but these are often unavailable or difficult to access (Greenwood et al., 2010; Jansen et al., 2009; Parmar et al., 2020). Fewer resources lead to waitlists and a heavier burden on caregivers, leading to them accessing additional services such as emergency rooms, acute care, and long-term care, which are all costly to caregivers and the health system (Jansen et al., 2009).

Not only are there few resources available, but caregivers' navigation through the system to access those services that are available can be stressful on its own, and often require education and support to do so (Jansen et al., 2009). Having a disjointed system between acute and community care makes navigation and accessibility problematic (Parmar et al., 2020). Referrals to community services are important to many health providers; however, this can be difficult due to long wait times and services not meeting caregivers' needs (Greenwood et al., 2011; Parmar et al., 2020). Interdisciplinary collaboration, policy changes, and service bridging are required to make significant system-level changes that allow health providers to efficiently provide support to caregivers to access health and social services (Jansen et al., 2009; Parmar et al., 2020).

Financial support and stability are some of the most critical ways to support caregivers and promote their health. Caregivers often face an increased financial burden caring for a loved one and often struggle trying to maintain a job or having to leave one's job, as well as the

possibility of taking over management of the family finances (Ng, 2009; Smith et al., 2004). With proper education and support from health providers to discover and retain care allowances, tax deduction, and benefits, caregivers can experience relief from financial strains (Ng, 2009).

Transportation for PLWS and their caregivers is critical for attending appointments, receiving rehabilitation services, and accessing other vital resources. Without access to such resources this leads to rescheduled or missed appointments and delayed care for the PLWS; often resulting in more burden on caregivers having to deal with possible health consequences, reschedule appointments, and potentially missing work (Syed et al., 2013). Frequently, due to ongoing disability, PLWS rely on their informal caregivers for transportation support and other times they require formal community transportation services for support (Ing et al., 2014). However, having suitable and reliable transportation can be a challenge that PLWS and stroke caregivers face daily (Ing et al., 2014; Ng, 2009; Shafer et al., 2019; Syed et al., 2013). Formal community transportation services are not without their own challenges such as scheduling, availability, eligibility, and expenses (Ing et al., 2014). Ensuring PLWS and their caregivers have access to reliable transportation is crucial for attending appointments and fully utilizing additional services and support. When service providers arrange for transportation, this enables PLWS and caregivers to access services more comfortably (Ng, 2009).

The barriers identified by health providers are diverse and complex in nature, making it critical to address these issues to improve care for stroke caregivers. In the next section, facilitators will be examined, to shed some positivity on this issue by explaining some strategies that are extremely beneficial to stroke caregivers when trying to access health and social services.

Facilitators

Education and Information Sharing.

Several issues pertaining to education and information sharing between health providers and stroke caregivers were identified within the literature that directly impacts caregiver's ability to access and use health services. These include the benefits of the provision of sufficient education about services, the importance of having a variety of educational materials, and the importance of proper timing when providing information.

Education and information for stroke caregivers can significantly improve their ability to successfully care and access health services (Quinn et al., 2014). A meta-synthesis of qualitative research conducted by Quinn et al. (2014) revealed that when there is sufficient communication and information sharing between stroke caregivers and health providers, stroke caregivers felt better able to cope in their role and seek out help when required (Quinn et al., 2014) However, other literature shows that health providers have found that educational resources for stroke caregivers are often limited and that ensuring proper timing for information sharing is difficult for health providers.

Stroke caregivers have expressed the need for education concerning the PLWS condition, their role, and resources available to support the PLWS as well as for themselves (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Quinn et al., 2014). Caregivers should be offered a variety of educational tools to support themselves, including verbal, written, and videotaped resources; however, there are often only one of these formats available, which may not work for everyone (Hudson et al., 2004). Rather than providing verbal education and information, it is valuable to provide more concrete material, so that caregivers can refer to the information later if needed (Cameron et al., 2013; Hudson et al., 2004; O'Brien et al., 2014).

Caregivers benefit from a combination of educational materials suitable to address problem-solving strategies, how to care for their loved ones, how to monitor their health, and where to seek further support from health services if needed (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; O'Brien et al., 2014; Quinn et al., 2014).

In addition to receiving the right education tools, caregivers need to receive information at the right time (Cameron & Gignac, 2008; Cameron et al., 2013; Hudson et al., 2004). That is, the needs of caregivers change over time, and as Cameron et al. (2013) suggest, they change during specific phases, including event/diagnosis, stabilization, preparation, implementation, problem-solving, and adaption. Caregivers' needs for information are highest during the preparation phase when the PLWS arrives home and the stroke caregiver begins caring for them during the first few months (Cameron et al., 2013). They wish to receive information on providing care, community care services, secondary prevention, and navigating the healthcare system (Cameron et al., 2013).

Health providers recognize their responsibility to provide support, advice, and counselling to stroke caregivers, but view the timing of information provision as a challenge (Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; O'Brien et al., 2014). When health providers are able to provide stroke caregivers with proper information, training and support, this results in reduced anxiety and the lessened perception that the caregiver needs to take on more roles and responsibilities (Cameron et al., 2013; Jansen et al., 2009; Parmar et al., 2020; Shafer et al., 2019). Cameron and Gignac (2008) created the "Timing It Right Framework" which can help health providers get a better understanding of what information they should be providing at what time. For example, during the preparation phase, which is before the PLWs

goes home, this is an ideal time to share information about the availability and how to access

community resources (Cameron & Gignac, 2008).

Family-centered Care and Collaborative Care.

The literature suggests that the health system generally places emphasis on the care of the

PLWS' while the needs of stroke caregivers are often neglected. Despite this shortcoming in care

provision the literature describes increasing recognition of the benefits of family-centred care

and the need for collaborative care to better address caregivers' needs.

Caregivers often feel as though they are not included in the PLWS' care plan, while

health providers feel they are unable to address caregiver needs on top of the PLWS' needs

(Cameron et al., 2013; Greenwood et al., 2011; Parmar et al., 2020). Given that caregivers are

often the primary source of care for the PLWS, it is essential to support them so they can provide

safe and appropriate care. The concept of family-centred care and collaborative care is critical

for supporting caregivers. Family-centred care emphasizes the inclusion and assessment of

family members and encourages health providers to assist families to develop routines and

access services that will be critical for the long-term maintenance of the PLWS and caregivers

health (Creasy et al., 2015) There is a need to recognize that the patient and caregiver's needs

will change over time and a family-centred care approach can be utilized to address and adapt to

these changing needs (O'Brien et al., 2014). Collaborative care aligns well with this idea, where

all disciplines are involved within the care team and work together to provide care for the patient

and their family (Parmar et al., 2020). Involving the patient's family, most notably their

caregiver, and other health providers ensures that the best outcomes are possible for the PLWS

and the caregiver. Stroke caregivers are more likely to be identified and supported when they are

included in the care plan (Creasy et al., 2015). Being present and focusing on family-centered

care, where collaboration and partnerships between patients, families, and health providers is emphasized, while considering biopsychosocial factors impacting their individual needs, is important for lessening many of the negative experiences stroke caregivers face (Creasy et al., 2015).

Designated Care Coordinators for Stroke Caregivers.

The literature shows that having a designated person to provide information and coordinate care specifically for caregivers is a beneficial solution to address many of the disadvantage's caregivers face. Caregivers often feel as though there is a lack of continuity of care and that their needs are never properly addressed (Camak, 2015; Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Pindus et al., 2018; Quinn et al., 2014; Smith et al., 2004).With a designated health provider present to identify caregivers and coordinate access to resources and services, this can greatly improve caregivers' burden and overall health (Jansen et al., 2009; Parmar et al., 2020). This role can provide education and information, support navigation through the health system, and enhance the caregiver's overall capacity and confidence in their role (Jansen et al., 2009; Parmar et al., 2020). Individuals in these positions can provide adequate time to listen to caregivers, recognize their needs and difficulties, answer their questions, find resources, and follow up to ensure that caregivers feel supported (Greenwood et al., 2010; Jansen et al., 2009).

The literature on stroke caregivers documents their experience with caregiver burden and identifies some of the barriers and facilitators impacting their access and use of formal health and social services. However, there is limited literature on health providers' perspectives on stroke caregivers' ability to access and use formal health and social service. Furthermore, there is a lack of literature on health providers' role in supporting stroke caregivers. In order to optimize care

and support for stroke caregivers, it will be important to address this gap in knowledge and generate findings that can be used to better inform care and service delivery to stroke caregivers.

Problem Statement

The literature suggests that stroke caregivers face an extreme burden when tasked with caring for PLWS with chronic disabilities (Camak, 2015; O'Brien et al., 2014). They suffer from physical, social, and emotional issues that stem from this burden and face many challenges accessing formal health and social services (Camak, 2015; Cameron & Gignac, 2008; Cameron et al., 2013; Gbiri et al., 2015; Greenwood et al., 2009; Greenwood et al., 2011; Health Quality Ontario, 2016; Jaracz et al., 2015; Jaracz et al., 2014; Lou et al., 2017; Pucciarelli et al., 2018; Quinn et al., 2014; Shafer et al., 2019; Smith et al., 2004; Watanabe et al., 2015). Caregivers require increased support, and formal health and social services can help them; however, there are many factors that contribute to stroke caregivers successfully accessing these services. Health providers are ideally individuals who are well-positioned to support stroke caregivers and help them access services; however, this has been shown to be difficult to accomplish. There is limited research on health providers' perspectives on the barriers and facilitators stroke caregivers face when trying to access formal health and social services as well as their experiences and perceptions of their role in supporting stroke caregivers within their practice and communities (Cameron & Gignac, 2008; Cameron et al., 2013; Greenwood et al., 2011; Hudson et al., 2004; Jansen et al., 2009; Laparidou et al., 2019; Ng, 2009; O'Brien et al., 2014; Parmar et al., 2020). Currently, health providers are not fully engaging with stroke caregivers, nor are they able to focus their efforts on programs and initiatives that effectively support stroke caregivers. Furthermore, systemic challenges mean that in some instances services are simply not available to stroke caregivers despite recognition of their need by health providers. To help inform this

mismatch in service provision and uptake, it is important to elucidate the issue from both stroke caregivers and health providers perspectives. A more comprehensive understanding of health providers' perspectives on the factors that impact stroke caregivers' access to formal health and social services can help inform health service policy, the development of initiatives better tailored to meet stroke caregiver needs and improve care for both stroke caregivers and PLWS.

Purpose of the Study

The purpose of this secondary analysis study is to explore the experiences of stroke caregivers in accessing formal health and social services from the perspective of health providers.

1) From health providers' perspectives, what barriers and facilitators influence stroke caregivers' access and use of formal health and social services?

2) What are health providers' experiences and how do they perceive their role in supporting stroke caregivers' access and use of formal health and social services?

Significance

Health providers are well-positioned to support not only PLWS but also their caregivers due to their education, experience, and relation to the stroke caregiver and PLWS (Greenwood et al., 2011; Parmar et al., 2020). A more comprehensive understanding of the barriers and facilitators stroke caregivers face when attempting to access formal health and social services from health providers' perspectives is required. In addition, further understanding of health providers 'experiences and perceptions of their role in supporting stroke caregivers is needed. This understanding will enhance our knowledge and support the development of strategies and actions to promote practice change that will help health providers create supportive environments

to properly engage with stroke caregivers and foster utilization of the supportive formal health and social services within their communities.

Research suggests that when caregivers feel heard, appreciated, receive sufficient help, information, and can take time for themselves, they are often satisfied with their caregiving role and live more fulfilled lives (Greenwood et al., 2009; Quinn et al., 2014). When health providers can successfully provide support to stroke caregivers who require formal health and social services, the adverse effects of caregiving can be reduced or even mitigated. The resultant impact is that both PLWS and their caregivers have an increased opportunity to remain safely in their homes for extended periods, thereby potentially removing stress from the healthcare system.

Declaration of Self

As a nurse with current experience in medical-surgical nursing, I often see the struggle of patients, families, and staff with discharge planning, often having difficulty trying to set up appropriate resources at home and within the community. Not only is this a prevalent problem, but having patients admitted to hospital due to caregiver burnout is a common occurrence. The burden of caregiving is common knowledge within healthcare and hospitals often are a sanctuary for caregivers to bring their loved one when they have nowhere else to turn to get some relief from their stressful role.

While I have been educated to practice family-centred care, the realities of working in the hospital often mean that we have limited access and knowledge of community resources and limited time to properly support caregivers. I am aware of the common pattern to focus on the patients' needs rather than looking at other factors and the larger picture to visualize why the family may be struggling and what we as health providers in an acute care setting can do to support them better. Providing the appropriate support and helping them access resources seems

to be an ideal way to prevent caregiver burnt out, leading to patients remaining in their homes for as long as it is safe and possible. Family-centred care and supporting caregivers is an interesting practice that I have recognized is lacking within my practice. Thus, it makes me curious about how health providers in various roles can practice family-centred care and support caregivers more so that they can confidently continue their critical role.

While observing the struggles in the hospital environment when trying to coordinate care while considering family dynamics, it is important to acknowledge my subjectivity. There is a typical mentality within healthcare that the family is responsible for the care of their loved ones. I recognize the importance of having family support to care for individuals at home or else our health system would be overwhelmed; however, this transition is often done poorly. Caregivers often find themselves in situations they may not be prepared for. Recognizing that I have experienced working in an environment where care is thought as "the family's responsibility" is important when entering this study to understand some of my caregiving biases. Acknowledging that caregivers want to help their friends and family as much as possible but need support to access appropriate resources to do this to the best of their ability is crucial.

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Chapter 2

Introduction

This chapter provides insight into the philosophical underpinnings of this research study, the conceptual model used to situate study findings, the methods used, and how the researchers ensured study quality. Details about the overarching paradigm, ontology, epistemology, and the methodological approach (interpretive description) are discussed. This chapter then discusses the methods used for this secondary analysis, including details from the primary study such as the study setting, recruitment strategies, the study sample, and data collection methods. The approach used to guide data analysis for this secondary analysis is discussed followed by an examination of how study quality was assured.

Philosophical Underpinnings

Paradigm

Paradigms can be understood as a set of beliefs that represent a worldview (Guba & Lincoln, 1994). Describing a researchers beliefs about the world and their interpretation of reality, paradigms can be used to guide a study as well as inform it's ontology, epistemology, methodology, and methods (Singh, 2019).

This study's purpose was to investigate and create shared meaning around health providers knowledge of the facilitators and barriers stroke caregivers face when accessing formal health and social services, as well as health providers' perceptions of their role in supporting stroke caregivers. Due to this, this study aligns well with an interpretive paradigm (Guba & Lincoln, 1994; Weaver & Olsen, 2006). Within this paradigm, phenomena are studied through multiple people's eyes in their lived situation, in this case, health providers, working towards a collective meaning while still being open to new interpretations (Guba & Lincoln, 1994; Weaver

& Olsen, 2006). Remaining open to new meanings and recognizing that individuals have their subjectivity and unique interpretations allows new insights to come to light and inform study findings (Guba & Lincoln, 1994; Weaver & Olsen, 2006).

Ontology

Ontology refers to what is the nature of reality and what can be known about reality (Guba & Lincoln, 1994; Singh, 2019). Aligning with the interpretivist's paradigm, the ontological stance for this research study was that of relativism. This assumes that there are multiple realities, reality is subjective, and it is socially constructed with different ways to access it (Singh, 2019). Recognizing that knowledge development is transactional, with the researcher and participants co-creating meanings, while being influenced by social constructions and dynamic environments is essential to keep in mind when revisiting data previously collected, such is the case in a secondary analysis (Guba & Lincoln, 1994; Weaver & Olsen, 2006). This was important for this study since the interviews were conducted by another researcher in various environments with the current researcher bringing their own subjectivity to reanalyzing the data.

Epistemology

Epistemology refers to how knowledge can be created, acquired, and transferred (Singh, 2019). Within the interpretivist paradigm, it is understood that knowledge is transactional, meaning it is produced between the researcher and the participant in specific environments (Guba & Lincoln, 1994). The knowledge and meaning found for this study were dependent and created through the interactions between the interviewer and participants in their environment and through the analyzing researcher's subjectivity.

Methodology

An interpretive description methodological approach guided this study. Interpretive description has philosophical underpinnings relating to naturalistic inquiry and is grounded within the interpretivism paradigm with its belief that there are multiple subjective realities that are socially constructed (Guba & Lincoln, 1994; Hunt, 2009). This methodology, therefore, aligns well with the philosophical underpinnings guiding this research study. Interpretive description conducts research within a natural setting appropriate for participants, assumes absolute, objective knowledge is unattainable through empirical analysis and "assumes the existence of multiple realities, which are context-bound, experientially based, and intersubjectively constructed through social interaction" (Hunt, 2009; Lasiuk et al., 2013, p. 2; Thorne, 2016).

Interpretive description was developed as a means to conduct qualitative research capable of generating an understanding of complex clinical phenomena relevant and useful for the applied disciplines, specifically within nursing (Hunt, 2009; Thorne, 2016). While other methodologies from the social sciences are commonly practiced within applied health research, the aim of these methodologies often does not align with the goals of research within the applied health disciplines, which involves discovering and theorizing about practical solutions that will improve practice (Thorne, 2016). Interpretive description builds methods with guidance from disciplinary epistemological ideas, is informed by clinical expertise, adheres to systematic processes, and develops knowledge applicable to practice (Hunt, 2009; Thorne, 2016). The researcher can utilize the methods that will best address and which are most appropriate for the nature of the research question within an interpretive descriptive study (Thorne, 2016).

The current study's intent to inform practice and improve service delivery for stroke caregivers aligns well with the intent of the interpretive description methodology, which is to guide research studies in applied health disciplines (Hunt, 2009). The choice of this methodology enabled the researcher to utilize the most appropriate and beneficial techniques to develop an understanding of the factors that influence stroke caregivers ability to access formal health and social services as well as health providers' ability to properly support stroke caregivers in this endeavour (Thorne, 2016).

Conceptual Model

A conceptual model "provides a coherent, unified, and orderly way of envisioning related events or processes relevant to a discipline" (Mock et al., 2007, p. 2). Conceptual models can be used in three different ways: (1) to provide on organizing structure for a research design, (2) to guide the development and testing of interventions and hypothesis based on the model, or (3) to explain and situate study findings (Mock et al., 2007). This study will be using the *Logic Model: An Outcome Orientated Approach to Health Service Delivery*, hereafter referred to as the *Logic Model,* which provides health providers with a tool for planning activities to achieve desired outcomes for caregivers (Lantz & Freid, 2018). The *Logic Model* will be used to situate the study findings (Lantz & Freid, 2018).

In 2016, the Central Local Health Integration Network (LHIN) asked the Alzheimer Society of York Region to lead the process of developing a caregiver framework (Lantz & Freid, 2017). Through consultation with health providers and family caregivers from the York Region, they developed a document called *A Planning Framework for Improving Support to Caregivers: A Discussion Document* (Lantz & Freid, 2017). In 2017, they sought further input from a variety of health providers and informal caregivers from different regions across the Central LHIN, thus,

developing a second edition of the framework, which includes the *Logic Model* within the document (Lantz & Freid, 2018). The goal was to further investigate the caregiver experience with the health system and test the original models suitability to enhance the support available to informal caregivers in a wide variety of situations (Lantz & Freid, 2018). Surveys, focus groups, and interviews gathered information from a wide range of stakeholders and discovered impressive results leading to the new document and *Logic Model* (Lantz & Freid, 2018). For example, they found that only 37% of caregivers report that health providers ask how they are doing, feeling, managing, or if they have any questions (Lantz & Freid, 2018). However, health providers did show an interest in improving care for caregivers such as helping with health system navigation and planning, offering talk therapy, and identifying at-risk caregivers (Lantz & Freid, 2018). The group identified many barriers that prevent caregivers from accessing formal health and social services and barriers that health providers experience when trying to support caregivers. Such challenges included getting care at home, transportation issues, financial constraints, referral and navigational challenges, and a need for more integrated interprofessional teams (Lantz & Freid, 2018).

The *Logic Model* is a simple model that was developed to provide health providers with a tool for planning activities to achieve a desired outcome (Lantz & Freid, 2018). The model lays out five sections, vision, main components, implementation objectives, long-term outcomes, and system outcomes (Lantz & Freid, 2018). Its overall vision is "to improve the recognition, resiliency, and supportive resources for informal caregivers, in collaboration with health and community care providers, peers, and other organizations" (Lantz & Freid, 2018, p. 10). The model's main components include, identify and recognize, referral and navigation, caregiver assessment and care plan, caregiver education and supports, and monitor and re-evaluate

caregiver care plans (Lantz & Freid, 2018). Each of the main components is associated with specific implementation objectives (Lantz & Freid, 2018). For example, under referral and navigation, it recommends increasing caregiver self-referral and navigation tools and resources, expanding care provider adoption of referral and navigation best practices, and increasing care provider skills in referring and navigating caregivers to the right supports (Lantz & Freid, 2018). The model then addresses long term outcomes with two overall indicators of success. The first is early caregiver recognition with proactive referral, navigation and access to support for caregivers (Lantz & Freid, 2018). The second is caregiver assessment, care planning and coordination of supportive resources and services (Lantz & Freid, 2018). The model's final section, system outcome, aims for "continually improved quality of care and services in partnership with patients and caregivers" (Lantz & Freid, 2018, p. 10). The *Logic Model* is presented in Figure 1.

The *Logic Model* aligns well with this study by acknowledging the burden placed on informal caregivers regardless of their situation and the system-wide issues impeding caregivers from receiving proper support. The *Logic Model* provides recommendations for health providers to implement that will allow them to properly enhance support for caregivers (Lantz & Freid, 2018). The model will be helpful to inform and situate study results by providing an already established model that is relevant to the phenomena of interest in this study, allowing for improvements to be made to the model that can be of greater benefit to the population of interest, stroke caregivers and health providers. The model will help to support any solutions or recommendations found within the data, identify gaps, and clarify any future directions focusing on health service delivery specifically for stroke caregivers (Mock et al., 2007).

Figure 1

Logic Model: An Outcome-Orientated Approach to Health Service Delivery Planning

Logic Model: An Outcome-Oriented Approach to Health Service Delivery Planning
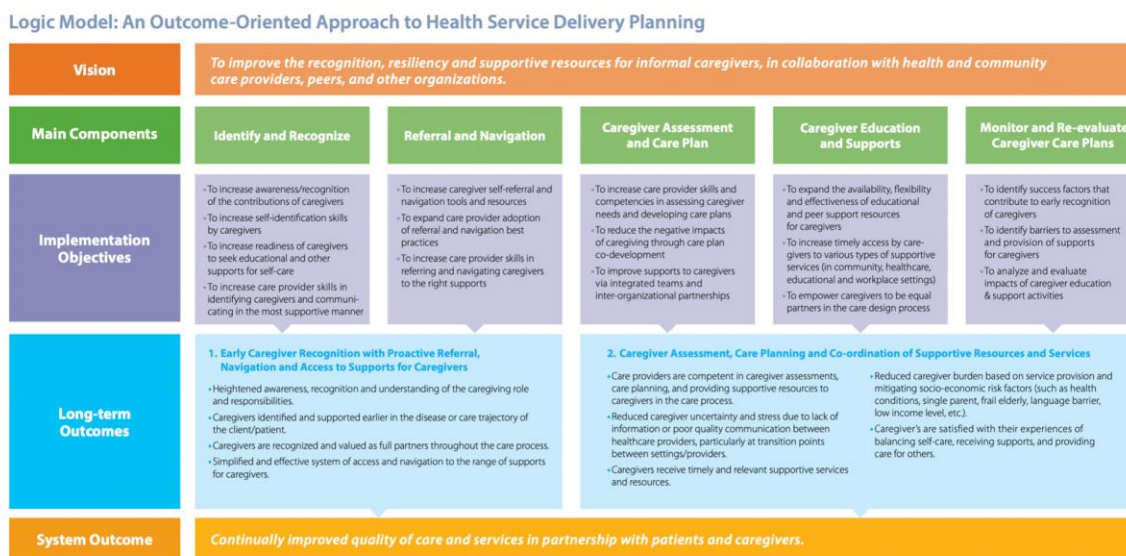
Methods

Study Design

This study is a qualitative secondary analysis, which involves analyzing data gathered from a previous research study (Heaton, 1998; Heaton, 2004; Heaton, 2008). This study used the in-depth qualitative interview data from a subsample from the primary study titled *Access and Use of Formal Health and Social Services by Caregivers of Stroke Survivors: An Interpretive Description Study*, conducted between 2017-2018 (Garnett, 2019). The primary study received ethics approval from the Hamilton Integrated Research Ethics Board in Hamilton, Ontario (Appendix A). The current study received ethics approval from the Health Sciences Research Ethics Board at Western University, London, Ontario (Appendix A).

According to the five types of secondary analysis outlined by Heaton (2008), this study is a supplementary analysis which involves "a more in-depth focus on an emergent issue or aspect of the data, which was not addressed, or was only partially addressed, by the primary research"

(p.53). In a qualitative secondary analysis, it is critical to assess the reusability of the data and ensure the quality of the work. According to Heaton (2008), this involves assessing the primary data's accessibility, quality, and suitability. For this qualitative secondary analysis, the primary investigator from the primary study was involved and agreed to share the data, making the data accessible. Having the primary investigator involved provided an in-depth knowledge of the data and the interviews' original contexts, which benefited this study (Heaton, 2008). The subsample of the data was complete, with interviews being transcribed verbatim. The current study's purpose was developed after seeing a gap in the primary study's original goals leading well to this study's purpose and research questions.

Sample and Setting

The primary study 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 (Garnett, 2019). The primary study determined that an adequate sample size for a qualitative interpretive description study ranged from eight to 18 with an average of 12 (Garnett, 2019). Participants were recruited using a combination of criteria, maximum variation, theoretical, and snowball sampling strategies, to promote diversity in profession, geographic location, and to explore ideas and findings later discovered in the data collection process (Garnett, 2019). Health providers were eligible to participate in the study if they met the following inclusion criteria: (a) provided direct or indirect care to the PLWS and/or stroke caregivers and (b) provided or were able to provide information and/or education regarding community-based services for a stroke caregiver (Garnett, 2019). The distribution of study information, posters, introducing the study at organizations, communication with caregiver liaisons, relationship building with health

providers, and the use of already established relationships, were recruitment approaches used to make contact with potential health provider participants (Garnett, 2019). Those who expressed interest in the research were invited to participate

Data Collection

Once participants were recruited and consented to participate in the study, a total of 18 health providers engaged in a one-time in-depth interview conducted via phone or in-person by a single interviewer (Garnett, 2019). Interviews were 45-60 minutes long and were audio-recorded then transcribed verbatim. Basic demographic information was collected in addition to the open-ended questions contained in the semi-structured interviews (Garnett, 2019). Questions revolved around the caregiving role, social support, the PLWS, health system and community resources, the need-services gap, caregivers health, and contextual factors. (Appendix B).

Data Analysis

According to Thorne (2016), researchers may make use of the most appropriate and beneficial techniques to analyze and interpret data. Thematic analysis was used to analyze this subsample of data by identifying, analyzing, and reporting patterns within data (Braun & Clark, 2006). Thematic analysis can be used to examine the experiences, meanings, and realities of participants, aligning well with the purpose of this study of exploring the experiences of stroke caregivers in accessing formal health and social services from the perspective of health providers (Braun & Clark, 2006). The steps include becoming familiar with the data, generating codes, searching for themes, reviewing the themes to ensure they work with the coded extracts and the entire data set, defining and naming themes, and producing the report (Braun & Clark, 2006).

The researcher began by reading the data and taking notes, looking for possible meanings and patterns (Braun & Clark, 2006). Coding than began by using NVivo 12 to generate initial

codes by organizing data into meaningful groups (QSR International, 2020). "Codes identify a

feature of the data that appears interesting to the analyst and refer to the most basic segment, or

element of the raw data or information that can be assessed in a meaningful way regarding the

phenomenon" (Braun & Clark, 2006, p. 88). Once this was complete, codes were sorted into

potential themes by analyzing the codes and considering the relationships between them and how

they may combine to develop overarching themes (Braun & Clark, 2006). At the end of this

stage, the researcher developed potential overarching themes and sub-themes which were

reviewed and refined by reviewing the coded data extracts ensuring they formed a coherent

pattern (Braun & Clark, 2006). These themes were also reviewed by and discussed with the

thesis supervisor and revisions were recommended. Through this process some themes were

reworked, new themes created, data moved to other themes, and some themes discarded from the

analysis (Braun & Clark, 2006). Next, the themes were reviewed to ensure they accurately

reflected the meanings evident in the data set as a whole and then themes were confirmed and

agreed upon between the novice researcher and thesis supervisor (Braun & Clark, 2006).

Flexibility was practiced throughout allowing for movement back and forth amongst steps.

Constant comparison was also used to compare coded segments from one transcript to others in

order to examine possible relations between various pieces of data (Thorne, 2000).

Study Quality

Thorne (2016) identifies eight criteria for enhancing credibility within interpretive

descriptive studies. These include epistemological integrity, representative credibility, analytic

logic, interpretive authority, moral defensibility, disciplinary relevance, pragmatic obligation,

contextual awareness, and probable truth (Thorne, 2016). Relevant criteria and how they were

accomplished in this study will be discussed in this section.

Epistemological Integrity

Epistemological integrity is expected within qualitative research, meaning that there is consistency amongst assumptions around the nature of knowledge and methodological rules throughout the research process (Thorne, 2016). The philosophical underpinnings and assumptions for this study, from the paradigm, ontology, epistemology, methodology to the methods used, all align and match the assumptions of the primary study. These assumptions were identified prior to data analysis and align with the research questions developed for this study. They were continuously reflected on throughout the study to ensure epistemological rigor and integrity.

Representative Credibility

Representative credibility is shown when theoretical claims are consistent with how the phenomenon was sampled (Thorne, 2016). The primary study utilized interpretive description and collected data using in-depth interviews with 18 health providers recruited using criteria, maximum variation, theoretical, and snowball sampling methods to increase the diversity and representability of the sample (Garnett, 2019). Through the recruitment of these participants, the sample included a diverse group of health providers who accurately represented individuals with experience and unique perspectives on supporting stroke caregivers access formal health and social services.

Analytic Logic

Within qualitative studies, analytic logic makes explicit the researchers' reasoning behind choices throughout the study (Thorne, 2016). Remaining transparent and showing a clear, logical flow of decision making throughout the study, especially regarding the analysis process, is vital for ensuring a rigorous and trustworthy study. By selecting thematic analysis, following the

analysis procedure, keeping an ongoing record of the process, having a supervisor oversee this process, and sharing this information, transparency and openness have been achieved by providing evidence which shows an audience how the study was conducted and that proper steps were taken to ensure rigour (Thorne, 2016; Tracy, 2010). Since this is a secondary analysis study, rigour was applied to the data analysis process. Using the original transcriptions and being systematic in reducing data into codes was practiced ensuring authenticity (Milne & Oberle, 2005). Initially, reading all the transcripts and taking notes, then frequently returning to the original transcripts, was essential to ensure proper meaning and perspectives to facts were maintained (Braun & Clark, 2006; Milne & Oberle, 2005).

Interpretive Authority

Interpretive authority is an essential aspect of a qualitative study's credibility and rigour to show interpretations are trustworthy and that they show some truth apart from the researcher's own bias or experience (Thorne, 2016). By practicing reflexivity, referring to the audit trail from the primary study, maintaining an additional audit trail for the proposed study, and using detailed descriptions and quotes from the data to support findings, interpretative authority was achieved (Thorne, 2016). Reflexivity was practiced throughout to ensure integrity within the study. The researcher reflected on biases, thoughts, opinions, and values throughout analysis and how these could impact findings (Milne & Oberle, 2005; Tracy, 2010). Being aware and acknowledging clinical experiences and how they influence assumptions was an essential aspect of reflexivity. Reflexivity occurred at all stages, including before, during and after analysis.

Disciplinary Relevance

As a central piece to interpretive description, the study must have disciplinary relevance, particularly to nursing practice (Thorne, 2016). This study explores the perspectives of health

providers, including nurses. The primary goal of the study was to identify factors that impact stroke caregivers' access to and use of formal health and social services. Nurses and many other allied health providers are involved in supporting stroke caregivers throughout various care stages and the findings of this study can be used to inform their future practice**.**

This chapter has provided insight into the philosophical underpinnings of this research study, the conceptual model used to situate study findings, the methods used and how the researchers ensured study quality. An interpretive description methodological approach was used to conduct this study, aligning with the overall philosophical underpinnings of this secondary analysis. Through rigorous planning and analysis, the study findings emerged from the analysis and were situated within the conceptual model, the *Logic Model*, which will be discussed in Chapter 4 of this document.

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Chapter 3: Results

Introduction

The following chapter presents the results of this interpretive description study. First the participant demographics will be presented, followed by the results of the analysis organized in six thematic categories supported by direct quotes from study participants. The following section presents the findings of the overall purpose of the study which was to explore the experiences of stroke caregivers in accessing formal health and social services from the perspective of health providers. Responses to the two research questions, from health providers' perspectives, what barriers and facilitators influence stroke caregivers' access and use of formal health and social services, and what are health providers' experiences and how do they perceive their role in supporting stroke caregivers' access and use of formal health and social services will also be presented.

Characteristics of Sample

A total of 18 health providers from various regions in Southern Ontario participated in this study. All demographic characteristics of the study participants are described in Table 1 which included five registered nurses (one clinical nurse specialists, one visiting nurse, and three stroke prevention clinic nurses), one occupational therapist, two speech-language pathologists, three social workers, one therapeutic recreationist, one kinesiologist, two personal support workers, one family physician, one geriatrician, and one neurologist. The majority of participants were female ($n=14$), between 31-40 years of age ($n=7$), have been employed in their field for equal to or greater than 21 years ($n=7$), hold a graduate degree ($n=10$), and have been in their current position for equal to or less than three years ($n=9$).

Table 1

Characteristics of Health Providers

Variables	n (%)
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	2 (11.1)
Social Worker	3 (16.7)
Therapeutic Recreationist	1 (5.6)
Kinesiologist	1 (5.6)
Personal Support Worker	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	
≤ 3	3 (16.7)
4-10	7 (38.8)
11-15	1 (5.6)
16-20	5 (27.8)
≥ 21	2 (11.1)
Level of Education	
Diploma or Certificate	5 (27.8)
Undergraduate Degree	3 (16.7)
Graduate Degree	10 (22.2)
Years in Current Position	
≤ 3	9 (50.0)
4-10	5 (27.8)
≥ 21	4 (22.2)

Note. N=18

Themes

Thorne's interpretive description approach encourages the researcher to draw upon other methods to describe and interpret data to best address the research question (Thorne, 2016).

Selecting specific methods allows the researcher to use those methods that best suit the research

questions and allow for more meaningful results to be discovered in health related research

(Thorne, 2016). For this study, thematic analysis was used to interpret various aspects of this

data to explore the experiences, meanings, and realities of the health providers in this study to

form a better understanding of the needs of stroke caregivers in accessing formal health and

social services (Braun & Clark, 2006). Constant comparison was used to compare coded

segments from one transcript to others in order to examine possible relations between various

pieces of data (Thorne, 2000). In addition, confirmation of themes was done through discussions

with the thesis supervisor. Through this process of data analysis, six main themes pertaining to

access and use of formal health and social services by stroke caregivers emerged: (a) a

fragmented health system impacts the ability to provide continuity of care, (b) challenges in care

provision and accessibility creates moral distress for health providers (c) access to social support

is pivotal for stroke caregivers' self-care, (d) stroke caregivers require individualized care, (e)

providing a single access point for stroke caregiver support is essential for success, and (f)

current services are not meeting PLWS and stroke caregivers' needs.

A Fragmented Health System Impacts the Ability to Provide Continuity of Care

Currently, stroke caregivers struggle to make use of and access the services available

within the health system. Health provider participants noticed that PLWS and their caregivers

moved through many different areas and stages in their recovery, and at times, were lacking

proper guidance. They were being sent home early, with little understanding of what to expect or

how to access support in the community, "Once you're not medically need to be in the hospital

anymore, you're released and go sort of like figure it out when you get home." (HP18) Though

health providers felt the hospital was seen as a safe place where the PLWS was well taken care

of, the limited time in a hospital setting does not seem to allow the PLWS and stroke caregivers adequate time to prepare thoroughly for home. Participants recognized that stroke caregivers would often begin their role without fully comprehending what their new reality would entail. Without support or adequate knowledge of resources in the community, health providers noted that stroke caregivers became overwhelmed and felt ill-prepared for their new role:

> I think it's very overwhelming. A lot of, we find a lot here, that when we're talking about discharge planning it can be very overwhelming for caregivers to think about transitioning home. After being in such a supported, safe environment, here right? With a full team of people. They know that their reality at home will be might different, right? And they worry about the gaps in the system and the gaps in support and how they'll manage. (HP03)

Participants noticed that prior to discharge, those health providers working in a hospital setting spend a lot of time and build relationships with the PLWS and stroke caregiver. However, upon discharge, health providers must relinquish their role in supporting the PLWS and stroke caregiver and pass on that role to community services. Health providers shared that they hope the needs of the PLWS and stroke caregivers are being met adequately in the community; however, there is variation when it comes to continuity of care from the hospital into the community:

> But that's the other part is that there's no um, community kind of transition from the hospital with our, with like me or, our team. Right. So, we, so, that's it. And that's sort of what families report as being really hard, is that, you know, up until the last minute we're having these conversations, we're counselling, we're supporting, or you know talking about all of these strategies and all these things and bringing all these people in. But then

someone goes home and it could be a week later it could be a very different reality.

(HP03)

Health providers appeared to be dependent on community services to follow through with referrals and support, however, coordinating with these services was seen as challenge. The separation between the hospital and community services seemed to impact those health providers in the hospitals' ability to create a seamless transition home for PLWS and stroke caregivers, "Exactly, completely separate system that we can say until we're blue in the face that this patient needs, this, and we have no control over it. CCAC makes the final decision." (HP03)

In addition, health providers working in hospital settings were not able to follow up with stroke caregivers due to the separation between hospital and community service provision. They wondered how clients were doing at home, and even though they wanted to check in with them, health providers were apprehensive of the answers. If a stroke caregiver was not managing well, these health providers were constrained in their ability to provide support because their role did not extend to community service provision:

> So everywhere I've worked in in-patient care at rehab at St. Peter's we always have this idea that we would like to call one month later. "How are you doing." But there's some resource attached to that. And then also I think we'd be a little bit afraid of the answer. "Oh you're not doing very well?" Well what am I going to do now? (HP02)

Multiple participants discussed their concerns regarding stroke caregivers' ability to navigate the health system without support. Health providers had a difficult time navigating the convoluted system themselves, leading to their difficulty in sharing valuable information with stroke caregivers and supporting them to access formal health and social services. As a result, health providers felt that stroke caregivers would be left feeling unsure about the services that

were available to them and how to access these services. Participants were concerned that this lack of knowledge and uncertainty experienced by stroke caregivers would result in feelings of loneliness and helplessness, "And sometimes, I know the system can be very hard to navigate, so they feel isolated." (HP06) Health providers acknowledged the struggle they faced when trying to navigate through the health system to advocate for their clients and that without proper guidance, this is an impossible task for stroke caregivers to do on their own:

> I think the thing… I guess the thing in my mind that could be improved upon is that um, navigation for patients and caregivers. Because that's as I said, it's challenging oftentimes for health care providers to navigate the system on behalf of patients and caregivers. So, you can only imagine how difficult it is for them to navigate. (HP09)

Health provider participants noticed that even when stroke caregivers would receive services and support in the community, specifically in their home, they faced issues. Inconsistent health providers within the home created a lot of confusion in the care of the PLWS and caused distress for stroke caregivers. Health provider participants noted that having one consistent health provider within the home would be a simple way to obtain continuity of care; however, they recognized that there were many barriers to achieve this. Systemic issues, such as staffing levels and time, impede home health providers ability to work with a consistent list of clients and their ability to spend time with the PLWS and their caregiver to assess their needs and provide much needed support:

> There's always continuity, it's always an issue, and I don't think that's going to ever change. Because it's a staffing thing, right? And it has nothing to do with the people. It has only to do with agencies that are managing them. You just can't seem to get even five

... We can't even get three or four people to regularly go see the same person. It's really

hard. (HP15)

The identification of a lack of continuity of care from the hospital into the community,

and the issues around provision of consistent care once at home, appears to be a source for

distress amongst stroke caregivers.

Challenges in Care Provision and Accessibility Creates Moral Distress for Health

Providers

Health providers discussed challenges they experienced that negatively impacted their

ability to be a knowledgeable and supportive resource for stroke caregivers. Their heavy

workloads, limited time, limited resources, and lack of awareness and experience caring for

stroke caregivers left them feeling ill-prepared to provide the necessary support stroke caregivers

required. Many wished they could better support stroke caregivers and find the services they may

need, but they were strained by time, resources, and a lack of knowledge of available resources.

The emotional strain and moral distress health providers seemed to experience was evident in the

interviews when they were not meeting their client's needs to the best of their abilities.

Within this study, health providers shared that on a typical day when they meet with the

PLWS and stroke caregivers, there is an abundance of topics to address, usually pertaining to the

PLWS. Participants felt that constraints on their role, such as limited time, impeded their ability

to inquire about and support stroke caregivers. The issue around time was applicable for health

providers across various settings. From those participants working in clinic settings to those

working in clients' homes. They expressed that they did not have the proper amount of time to

address their clients' emotional and social needs, "We're getting pulled out of homes as quickly

as possible, just a few tasks come in and sort out the fact that someone has moved home with a

stroke and set up their PEG feeds and that's it right?" (HP13) Health providers in this study felt

as though they were pressured to get tasks done and move onto the next client, not allowing them

to provide holistic health care and leaving them feeling as though they were not meeting their

client's needs. Within the interviews, many participants expressed moral distress since they

recognized the importance of supporting peoples social and emotional health needs, however,

this is something that they were not able to achieve due to time limitations and workload.

Not only was the concept of time a barrier for health providers, but participants shared

that they were limited by the resources available to them. They noted there were not enough

people or money to properly achieve what they felt their role should entail, "It's lack of money.

It's a lack of persons to do it. The resources in the hospital are just not enough." (HP04) Without

the system providing the proper resources required for health providers to practice to their full

scope, such as more staff and more money towards resources, health providers are being put at

risk for experiencing moral distress. The resultant effects of health providers feeling morally

distressed and burnt out in their role are detrimental to their clients.

One of the most significant barriers participants identified was the difficulty of knowing

what resources and services were available in the community for stroke caregivers to access at

any point in time. They discussed how there were various resources for a range of health issues

but that they are constantly changing within the community, "I have to say I probably don't

know enough about services available to stroke survivors, there's just so many diseases to go

around that you can't know everything about everything…" (HP13) Participants explained how

they would try their best to keep up and in touch with the community services; however, they felt

disconnected from the community and were constantly searching for resources to support stroke

caregivers, only adding to their workload:

I often, to be honest, it's hard to keep up with what's out there too. So, we have our

community stroke resource guide. Which I have in my clinic rooms I give that to patients

and caregivers. But I have to reference it on a regular basis too. (HP09)

Due to these many constraints inhibiting health providers from properly supporting stroke

caregivers and linking them to appropriate formal health and social services, participants

described their emotional and moral distress:

I would say inadequately in that for better or for worse we have a certain amount of time

to spend with patients in stroke problem clinics, and while I do my best to be sensitive to

caregiver issues there often really isn't enough, enough time. And so I feel badly about

that at times and try to do what I can in identifying problems and education but I don't

feel like I do it as well as I'd like. (HP14)

Health provider participants wanted to and felt that their role should enable them to

attend to caregivers' social and emotional needs and to provide the level of attention and care

they required. However, the limitations they discussed, such as heavy workloads, limited time,

limited resources, and lack of awareness of resources caused the participants to feel despondent

because they could not achieve the standard of care that they sought to provide.

Access to Social Support is Pivotal for Stroke Caregivers' Self-Care

Participants acknowledged the importance of respite care, day programs, family support,

and peer support groups as facilitators for promoting stroke caregivers' mental health. In turn,

this enabled stroke caregivers to continue their critical role. However, these support systems are

not always readily available or easily accessible.

Health providers shared that when the PLWS leaves the hospital setting, there is an

incredible burden placed on the stroke caregiver and the family. Participants observed that

having a solid social support system with family and friends to help relieve some of the burden on the stroke caregiver was critical for promoting the their health and enhancing their ability to engage in self-care, "So I, I think ... you know where I see things more successfully done is, is their family around that can pitch in and give the caregiver some help and sometimes just respite a few days away is important." (HP14)

Health providers recognized that though social supports were essential to stroke caregivers by providing them with some much-needed time away and relief from their caregiving role, these support systems could often be inconsistent. Participants explained how stroke caregivers' social circles often diminished over time, with support being more prominent during the early months after discharge and slowly dwindling thereafter. Participants described how that when caregivers had fewer people around and less consistent support, this resulted in the stroke caregivers feeling isolated and strained under the burden they take on:

> Yeah I almost feel it gets worse as times goes on for some of them. You know the more time that they're, the story that I hear at least is initially a lot of people are receiving supports but then as time goes on those numbers tend to dwindle more and more. (HP12)

The support provided to stroke caregivers by family and friends served as informal respite care. Participants described how this informal respite enabled stroke caregivers the ability to take some time away from their role and care for themselves while being reassured that someone trustworthy was caring for the PLWS. In addition, the provision of formal respite care through in-home or via the PLWS attending a formal healthcare setting also served as a potential opportunity for stroke caregivers to engage in self-care . Participants noted that they would often encourage stroke caregivers to take advantage of all available options for respite care. For example:

That's the one thing I tell everyone, is you need to get a respite or do something to get out

of the house just to have your, you know to be able to think, to breath. To you know just

be away for a little bit. (HP18)

Within this study, participants explained that though it is important for stroke caregivers

to understand the importance of respite care, it was often challenging for stroke caregivers to

access, "Sometimes to access respite beds, like overnight respite beds, there is a lot of challenges

around um, restrictions for getting somebody into that bed…" (HP01) Participants explained that

this was often due to the availability of beds, limited staff, and various restrictions. Health

providers discussed how accessibility is an issue, but also, when it is available, it does not always

meet the needs of the stroke caregiver. For example, one participant explained how if respite care

is available for only a short time during the day, the stroke caregiver felt pressed for time and

could not genuinely enjoy the time away, "No and the caregiver you know when they do get their

2 hours of respite they're running like the devil and their watching the clock, you know." (HP04)

Simply having respite to do errands and chores can be difficult when the stroke caregiver is

limited by the amount of time they have to accomplish their tasks. This may not be an enjoyable

experience for stroke caregivers, negating the purpose of respite care since the stroke caregiver is

unable to engage in self-care activities.

In addition, participants discussed the importance of having trust in respite care. They

shared that stroke caregivers needed to trust whoever provides respite care, whether it is informal

providers, such as family, or formal, such as a health provider. When the stroke caregiver was

away, if they did not trust whoever was providing respite care, they spent most of the time

worrying and concerned about the well-being of the PLWS, rendering their time away useless.

Participants understood that being certain that the PLWS was being cared for well, by a trusted

provider, allowed the stroke caregiver to have peace of mind and eased their conscious, therefore, promoting self-care:

> 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 PSW or whoever coming into their home and their still not 100% comfortable with that person, and they don't take that time to build that repour. 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. (HP06)

Participants spoke about the importance of peer support, and how it is an essential resource for stroke caregivers to access. They felt as though with peer support groups, stroke caregivers can learn and interact with individuals in similar situations to themselves. Being around like-minded people who share similar questions and concerns, promotes feelings of connectivity, and decrease feelings of loneliness. Bonding with others who understand what the stroke caregiver is going through helps to avoid stroke caregivers feeling isolated. Hearing other people's stories solidifies that they are not the only one going through this and that other people understand and are there to provide acceptance and support:

> I would say, I mean I think again drawing on that model of peer support. I think that's one really, a really great model that works where caregivers can be connected with other caregivers and persons with stroke connected with other persons with stroke so. I think that that's one sort of example that exists within the health system that's really great. (HP01)

Regardless of whether stroke caregivers have access to social support, health providers in this study discussed how they found themselves at times fulfilling this role. Participants noted that when they had the time and ability, they were able to listen, support, and advise stroke caregivers. Being an approachable and trusting ally for stroke caregivers meant that the health providers were well-positioned to support stroke caregivers and link them to suitable services:

> Ya, I mean the biggest thing in the experience I've had is mostly just being someone that they can communicate with, share their concerns with, and then if you're… most of the time you are able to link them or provide a suggestion. (HP09)

In addition, participants recognized how they may not always be providing formal health advice to stroke caregivers. Certain health providers found themselves simply socializing with stroke caregivers during therapy sessions because sometimes, that was one of the few opportunities stroke caregivers would have to socialize and interact with other people due to the isolation often involved in their role. For example, a kinesiologists spoke about their experience building relationships with stroke caregivers throughout various therapy sessions. The stroke caregivers would become interested in them and want to socialize. This participant shared how this could be difficult for health providers due to professional reasons and time constraints, but they recognized the benefits of providing these types of interactions:

> And sometimes it's… they're certain people you know are really, well its they are isolated or really chatty or really friendly. They take more of your time and it's not in a bad way. And it's not even a complaining or a venting way, just that social interaction. Or like, they learn things about you that they're interested in and it's just that interaction. It's somebody new to talk to. (HP06)

Overall, having social support, time away for themselves, and maintaining social connections is pivotal in stroke caregiver's ability to practice self-care. Health providers in this study shared that they have a role in enabling stroke caregivers' connections with services that can support them to engage in society and promote self-care.

Stroke Caregivers Require Individualized Care

PLWS and stroke caregivers' lives are often deeply interconnected. Study participants were aware of how PLWS are dependent on stroke caregivers for their daily lives. They also recognized that in turn, when the pair had a strong health provider team surrounding them, it benefited both the PLWS and stroke caregiver significantly. For example, when PLWS participated in day programs where health providers assumed responsibility for the PLWS, this provided respite for the stroke caregiver. This in turn enabled stroke caregivers to take time away from their caregiving responsibilities and engage in self-care. Participants discussed how these kinds of interactions inherently benefitted the stroke caregiver; however, they also recognized that stroke caregivers are individuals whose issues need to be addressed separately. Health providers were aware of the importance of addressing caregivers as individuals but note barriers to accomplishing this.

Participants recognized the importance of family centered care which includes both the PLWS and the stroke caregiver. However, it appeared that some participants recognized that prioritizing the stroke caregivers' needs and addressing them as individuals was widely unaccomplished, "I would say that those of us you know involved in in-patient/outpatient stroke care, physicians, and others, I think it's recognized and appreciated the importance of addressing caregiver issues and needs. I think it's widely appreciated but incompletely addressed." (HP14)

Health providers suggested that stroke caregivers were often not prioritized within the circle of care, "But we don't get into that level of detail with the caregiver. You know so, "how are you coping? What do you need?" (HP09) Participants identified the PLWS as their priority, "I guess the reality is the caregiver doesn't really figure in, it's the survivor that the health system recognizes. 100%." (HP07) Study participants discussed how they identified the stroke caregiver as not technically their patient, and that therefore their needs were not assessed nor addressed, leaving the focus solely on the PLWS.

Study participants explained that when they encountered stroke caregivers, they were most often with the PLWS for an appointment. Health providers recognized that these appointments were an excellent opportunity to touch base with the stroke caregiver and practice family-centered care. However, participants explained how they had multiple tasks to be accomplished which focused on the PLWS in such short amount of time that, unfortunately, the stroke caregiver did not figure in, "I think because of so much happening and they're so concerned about the patient and the stroke survivor that that's often the last thing on their mind right." (HP03)

Renumeration for their time caring for the stroke caregiver was also a concern for participants. Only so much money is allocated to care for the PLWS, and the stroke caregivers were not prioritized due to a lack of reimbursement for the time it would take health providers to provide the necessary support, "And I'm not sure why that is exactly, but um, part of it is these are patients that need care and we have "x" number of dollars and the caregivers aren't our patients." (HP02)

Unfortunately, interviews with health provider participants suggested that they would often wait for stroke caregivers to approach them to bring up their issues rather than proactively

addressing them, "Oftentimes, they just sort of bring up their own…Issues as well." (HP10)

Participants also discussed how stroke caregivers were often only acknowledged when there was

a crisis. Once the stroke caregiver verbalized a crisis or a health provider recognized one, then

the system would react and provide support and services. Participants acknowledged that

although stroke caregivers would receive support when they required it in these circumstances, it

is an unfortunate and counterproductive approach:

> So again it's like the entire focus is on the survivor, but the caregiver is playing a huge
>
> role and yet it's only until a crisis happens that suddenly there's this awareness that oh
>
> perhaps we need to look at that as well. (HP13)

Study participants suggested that the ideal approach would be to address the stroke

caregivers' needs directly and implement services in the community that would be beneficial

prior to the PLWS being discharged home from the hospital. Addressing their needs directly

prior to discharge can ease the stroke caregivers transition home, setting them up for success in

their new caregiving role:

> There should be a little more directed attention. And say ok, a little more conversation.
>
> You know in a month or 3 weeks, this person is coming home from the hospital, what do
>
> you need to get ready. Like what do you need to be prepared for this change? What kind
>
> of support do you think you need in place? What are you comfortable doing? How can
>
> we, how can the health care system, whoever the big "We" is, help you be prepared?
>
> (HP06)

The health providers in this study recognized that stroke caregivers needed to share their

frustrations and concerns to gain acceptance of their situation. They saw it as a priority to be able

to take the time to explore how the stroke caregiver was doing, what they were going through and what they needed:

> If health care providers took a little more time, especially initially, when everything is initially happening, especially in the hospital. Or when they are being discharged or whenever there is a big change, um, when they start coming to a day program, when they are going to an outreach group. If people actually sat down with the caregivers and took a little… just that extra 5 minutes to check in with them. "how are you doing today?" I think that would make a big difference and take an extra few minutes and provide them with a little more education. (HP06)

Identifying and acknowledging stroke caregivers as individuals who require care and support is an important step in the promotion of their health. Participants shared that by doing this early in the stroke trajectory, they can align stroke caregivers with health and social services that can better allow stroke caregivers to be successful in their role while ensuring they remain heathy.

Providing a Single Access Point for Stroke Caregiver Support is Essential for Success

Study participants discussed potential ways to improve support for stroke caregivers who are seeking access to formal health and social services. Several participants suggested that the community is lacking a centralized place for stroke caregivers to seek support and access services. They suggested the issue is that there are many services in the community, however, it is difficult for stroke caregivers to be aware of them and how to access them. From interviews with health providers, it appeared that some services in the community try to be responsible for coordinating care for caregivers, but even still, these services do not function perfectly and there

is nothing that is stroke focused, resulting in stroke caregivers not always receiving the kind of support that they require:

> I feel, I think the biggest problem is that there isn't sort of a, like central access point.
> Like there isn't…There's a lot of different services out there's VON and March of Dimes
> you know there is out patients and there's CCAC um, who try to be you know a central
> access point. But there really isn't one stroke specific person or entity that they can go to
> and have them be heard out basically. Who knows them and who can sort of help them
> through their situation and know and understand how the system works and how
> everything fits together. (HP01)

This led to several participants discussing the idea of having a single access point for follow-up, information, and navigation support. They shared that ideally, this would be one institution or person with the knowledge and ability to access services and provide information for stroke caregivers. Having a single access point where an individual is familiar with the PLWS, the stroke caregiver, and their current situation would ease confusion and promote continuity of care.

The participants recognized the confusion stroke caregivers encounter when trying to navigate the system. They discussed how stroke caregivers are tasked with speaking with different individuals from multiple areas and agencies. Therefore, many participants believed that having one central person to speak with and ask questions to would be an ideal approach to diminish confusion and improve system navigation, "That's the other challenge too, is that they feel like they are calling multiple people for different things. Yes. Ok. So, it would be nice if you could call one person to get those answers." (HP09)

In addition to this, several participants noted the benefits of having continuity in care by having a provider support both stroke caregivers and PLWS from hospital to community allowing for increased trust and stability in service provision:

Yeah I think in an ideal world you would have met this family in the hospital setting and then walked through with them into the home setting, visited their home with them and then continued that relationship. I think there's a lot of value in that in many different ways. (HP13)

Health providers shared that they believed this role would focus specifically on individuals and their families living with stroke in the community, therefore, family-centered care would be integral to their role. The individual in this role could provide follow-up, help coordinate services, and continually advocate for and support the PLWS and the stroke caregiver with service accessibility. They would be able to identify, assess, and support the PLWS and the stroke caregiver, relieving some of the confusion present in our current system:

But it would be great if that um, if there was a role that could sort of address, the role of the caregiver right away and help people understand that they also need to be looking out for these things within themselves. Helping them become oriented to the services that are in the community as well as the services being there when they need them right? (HP01)

Participants felt that this role would not only be beneficial for the PLWS and stroke caregivers, but this would help other health providers trying to navigate the system to support clients. If there were one access point, other health providers such as general practitioners would be able to easily access information, link clients to this resource, and navigate the system with ease:

But it's a great idea, because that's a prime example of there's all kinds of services all over the city and they're for ever changing and I would never be able to keep up with that one. But in theory I should be able to refer them to Contact Hamilton, there's a case worker that does the preliminary intake and then makes recommendations as far as where to go. Something like that would be amazing. (HP10)

Study findings suggest that a single access point to a broad variety of community services would be ideal to support stroke caregivers who currently struggle to access many formal health and social services within the community.

Current Services are not Meeting People Living with Stroke and Stroke Caregivers' Needs

Within this study, participants identified that the services currently being offered in the community were often not meeting the needs and requirements of the PLWS or their caregivers. The importance of the closely intertwined relationship between the PLWS and stroke caregivers is echoed and essential within this theme. When there was a lack of stroke-specific resources, resources for varying severities of strokes, and varying age groups, this in turn had an impact on the stroke caregiver.

A number of study participants explained that there were a variety of resources that are streamlined and geared towards individuals living with other kinds of diseases such as kidney disease, Parkinson's, and Alzheimer's, for example. However, PLWS and stroke caregivers did not always fit these groups, or these services did not meet their needs. Therefore, stroke caregivers were more limited in their ability to access and utilize some formal health and social services in the community, "I'm not sure there's that good a privation for stroke but, I should know more about that. I'm not aware of any. I just remember, I just know that I'm always impressed with the support that Alzheimer Society can give…" (HP08) Study participants

explained how a stroke was often a very sudden, and unexpected occurrence, that drastically changed one's life. The needs of these individuals were often quite different than families living with other diseases that progressed more slowly and allowed for the time to adjust. Stroke caregivers needed to adjust very quickly to their new reality and caregiving role, highlighting the importance of the intense support they required:

> Well yeah because you know what, it's kind of like Parkinson's and ALS, right? And there's a lot of support for those conditions which are very debilitating, right? But they're, they're a slow ... they're a slow going debilitating disease. People usually have time to prepare or get things in order, right? You have a stroke that's it. It's already gone. It's already happened. And there isn't a lot of support. (HP15)

In addition, participants discussed how some of the services offered to PLWS and stroke caregivers are tailored to certain disabilities associated with strokes, such as aphasia, which excluded many others who still might benefit from such a resource:

> I mean one of the like one of the hardest things for me is to know that like there's caregivers that want to join a group that there spouse doesn't have aphasia but that excludes them from our program unfortunately. (HP12)

Furthermore, study participants recognized that many services were not available to stroke caregivers and PLWS if their disability was not considered severe enough. Health providers felt that some PLWS who suffered from less debilitating strokes and their caregivers fell through the cracks as they were not seen as a priority in the health system compared to others who required more care. However, health providers shared that stroke caregivers who had been caring for the PLWS for a long period of time, regardless of the PLWS' disability, were greatly impacted by their role and needed formal health and social services for support:

I think there's definitely room for improvement when you're looking at those with -- or

when you're looking at the minor stroke and TIAs, I think they're sometimes lost. They

don't always receive, you know, lots of, you know, good information about what's out

there. I mean, I think they're lost because they are doing relatively well. (HP17)

Interviews with participants suggested that resources and services that were available to

PLWS and stroke caregivers were not always suitable for different age groups. Study participants

found that older adults who have had a stroke and their older caregivers may require different

services compared to younger PLWS and caregivers, and vice versa, "But let's say someone who

was, older, elderly you know, so in their 70's and 80's. What they're looking for is entirely

different than a much younger, 40 to 65 are looking for." (HP11) Many participants recognized

that age differences in groups made some people feel as though they could not relate or did not

belong, which acted as a deterrent to the program. Experiencing the feeling that they did not

belong and that they were not comfortable in a certain environment was associated with stroke

caregivers not utilizing the services available to them, further complicating the issue of service

accessibility for stroke caregivers:

Even though there are some young stroke survivor groups, some of our… even caregiver

groups, some of them don't want to be part of those groups as well. I'm just thinking of

one recently, a caregiver, she went to a support group, 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.

(HP09)

Health providers in this study suggested that without adequate resources to meet the

PLWS and the stroke caregivers' specific needs, stroke caregivers were left feeling unvalued and

at a loss for support. Study participants identified a need for more resources and services that directly accommodate stroke-specific individuals with various disabilities and of varying ages.

In summary, participants provided valuable insight into the experiences of stroke caregivers in accessing formal health and social services. The fragmented health system, health providers limitations in their ability to provide support, lack of direct attention to stroke caregiver needs, and unfit services all impede stroke caregivers from accessing suitable formal health and social services. Health providers shared the many barriers they face in their work such as a lack of time and heavy workloads that prevent them from working to their full potential which results them experiencing moral distress in their role. Finally, the health providers in this study provided a possible solution through the establishment of a central access point for stroke caregivers to access information and support. They recognized that there are currently services in the community who have this responsibility, but participants felt as though they are not currently meeting the needs of stroke caregivers. Through their perspective on these factors involved in stroke caregivers accessing services, their own experiences in supporting stroke caregivers, and their outlook on possible solutions, we have gained valuable knowledge concerning this phenomenon to consider when moving forward in addressing this issue.

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Chapter 4: Discussion

Introduction

The overall purpose of this interpretive description secondary analysis was to explore the experiences of stroke caregivers in accessing formal health and social services from the perspective of health providers. Question guiding this research were: (a) from the health providers' perspectives, what barriers and facilitators influence stroke caregivers' access and use of formal health and social services and (b) what are health providers' experiences and how do they perceive their role in supporting stroke caregivers' access and use of formal health and social service? The six themes described in this study include: (a) a fragmented health system impacts the ability to provide continuity of care, (b) challenges in care provision and accessibility creates moral distress for health providers (c) access to social support is pivotal for stroke caregivers' self-care, (d) stroke caregivers require individualized care, (e) providing a single access point for stroke caregiver support is essential for success, and (f) current services are not meeting people living with stroke and stroke caregivers needs.

Interpretive description emphasizes the importance of engaging in thoughtful examination, reflection, and reinterpretation of the study findings in relation to what else is known about the phenomena within the literature (Thorne, 2016). Consistent with interpretive description, this discussion will explore how the results are supported by current literature in addition to how this study expands on what is currently known (Thorne, 2016). The study results expand the literature on stroke caregivers by providing the perspective of health providers who care for PLWS and stroke caregivers. This stance can inform the current literature on stroke caregivers and be used to inform practice, policy, and education to better meet the needs of stroke caregivers. Since health providers are integral to the stroke management circle, having

their perspective is critical to make well-informed decisions on health service access and delivery improvements.

In addition, through the use of the conceptual model, the *Logic Model: An Outcome Orientated Approach to Health Service Delivery,* the study findings can be situated in and enhance this model which currently exists in practice to provide guidance for health providers trying to enhance support for informal caregivers (Lantz & Freid, 2018). By situating the findings within this model, we can observe what works well in the model, what could be improved upon, and if the model is a suitable resource for use when considering stroke caregivers specifically.

The current study has emphasized some barriers and facilitators associated with stroke caregivers' ability to access formal health and social services from the health providers perspective. For the purposes of this section, the following four key themes will be discussed in relation to the breadth of knowledge currently available: (a) a fragmented health system impacts the ability to provide continuity of care, (b) challenges in care provision and accessibility creates moral distress for health providers, (e) providing a single access point for stroke caregiver support is essential for success, and (f) current services are not meeting people living with stroke and stroke caregivers needs. This chapter will also include a discussion of the study findings in relation to the *Logic Model* and how the results can expand our knowledge and use of this model. Finally, the limitations and implications of this study will be discussed.

A Fragmented Health System Impacts the Ability to Provide Continuity of Care

The literature has shown that stroke caregivers are challenged to navigate the health system alone (Chen et al., 2020; Chen et al., 2021; Denham et al., 2020; Pindus et al., 2018; Quinn et al., 2014; Shafer et al., 2019; Zawawi et al., 2020). Caregivers have identified the

difficulty they face when trying to organize and coordinate with the healthcare team, with 56%

of caregivers finding the process difficult (The Ontario Caregiver Organization, 2019).

Participants noted the differences in how inpatient and community settings function, providing

one potential reason as to why stroke caregiver struggle to navigate and seek support from

community resources once at home.

The fragmentation between inpatient and community care often leaves families feeling

forgotten and impedes their overall goals for the future (Chen et al., 2021; Denham et al., 2020;

Pindus et al., 2018). Study findings suggest that health providers were concerned that once at

home, stroke caregivers experience great difficulty when trying to access services and navigate

the community health system, leading to feelings of helplessness and loneliness. A systematic

review conducted by Chen et al. (2021) noted that PLWS and stroke caregivers gained

confidence in navigating the complex community health system through the support of

competent health providers. When services were in place in the community and follow-up

services ensured continuity of care once home, this increased the PLWS and stroke caregivers'

sense of safety (Chen et al., 2021) However, without integrated and well-coordinated services in

the community in place prior to the PLWS being discharged home, the transition of care is

compromised, placing increased expectations and burden on stroke caregivers to support the

PLWS (Chen et al., 2020). Many participants within this study shared these concerns, with many

who work in inpatient settings stating that they often want to follow-up with stroke caregivers

once they are home but are afraid of the response. These health providers recognize that once the

PLWS and stroke caregiver are discharged, they are unable to provide support since they do not

work within the community setting. These key findings highlight the need for improved

continuity of care and support with navigation through the different systems over a longer period

post stroke to ensure families can properly access and utilize formal health and social services in the community.

Extending our knowledge, health providers in the current study noted that they themselves also struggle to navigate the system and stay up to date with the current services available within the community. Ultimately, the difficulty they face navigating the system impedes their ability to effectively guide and support stroke caregivers. Current literature suggests that health providers become easily frustrated when trying to locate and refer clients to services that extend beyond their clinical context because of their time constraints and the paucity of suitable services (Parmar et al., 2020). Conversely, when health providers have a thorough knowledge of available services and are well-positioned to share this information with caregivers, this greatly increases the competence and confidence of stroke caregivers (Chen et al., 2021).

The existence of siloed services within the health system, also created obstacles for health providers. Participants in the current study were challenged to provide current information to clients on available programs and services for stroke caregivers in the community. Current literature echoes these concerns with health providers who work in community settings struggling to provide their clients with adequate information and supports (Parmar et al., 2020). For example, collaborative, integrated care is recommended, but community health providers, such as general practitioners struggle to refer to and receive information from community organizations (Parmar et al., 2020). These findings highlight the need for transitional bridging of services and the need for health system navigators in the community to ensure that caregivers and PLWS are connected to appropriate services and receive ongoing care and support.

Providing a Single Access Point for Stroke Caregiver Support is Essential for Success

Citing the challenges of navigating a fragmented health system, participants in this study discussed the potential for a single, central access point for follow-up and navigation support to provide a solution to many of the issues surrounding service accessibility for stroke caregivers. Participants acknowledged the presence of current services that seek to fill this role but recognized that there could be improvements and enhancements to the functioning of such services.

A recent report from The Ontario Caregiver Organization (2019) shares that most caregivers identified a need for a single point of access for information and support. Within the literature, stroke caregivers agreed that it would be beneficial to have a central point of contact throughout the stroke trajectory (Chen et al., 2021). In particular, having the same person support them in the hospital with discharge planning and following them through the transition home and beyond is an ideal approach (Chen et al., 2021).

Participants in this study discussed that ideally, having a member of the health team initiate a relationship with the PLWS and stroke caregiver in hospital and continue to support them within the community would be an ideal way to enhance current services and promote continuity of care. Current literature supports this by suggesting that having a single person, such as a caregiver champion, advanced practice nurse, or navigator, could streamline the process of accessing formal health and social services (Parmar et al., 2020). These roles have been shown to greatly benefit caregivers in particular by helping caregivers to problem solve, provide emotional support, navigate resources, provide education about a disease, and provide guidance to help prepare for the future (Bernstein et al., 2019; Hudson et al., 2019). In a qualitative study by Hudson et al. (2019), participants described very positive experiences working with nurse navigators. Patients and caregivers alike shared how the nurse navigator helped to improve their

transition home by supporting the attainment of training, equipment, and helping the family to understand what their reality might look like (Hudson et al., 2019). The support navigating the health system provided by the nurse navigators was critical for enhancing the families confidence (Hudson et al., 2019)

In addition, the findings from the current study suggest that having a central point of contact would not only benefit the PLWS and stroke caregiver, but also other health providers. They shared the difficulty they experienced trying to stay up to date with current services, impeding their ability to sufficiently support stroke caregivers. If there was a central organization or person to access information when health providers needed it, this would in turn benefit stroke caregivers.

Challenges in Care Provision and Accessibility Creates Moral Distress for Health Providers

Participants discussed the many barriers they experience in their role impeding them from properly supporting stroke caregivers, such as heavy workloads and a lack of time. These findings confirm current literature, highlighting that the heavy workloads, limited time, limited resources, and lack of experience health providers experience leaves them feeling ill-prepared to provide the necessary support stroke caregivers require (Chen et al., 2020; Greenwood et al., 2011; Greenwood et al., 2010; Magwood et al., 2019; O'Brien et al., 2014; Parmar et al., 2020). Current literature explains how health providers recognize they are well-placed to provide support, advice, and information to stroke caregivers due to their position within the health system; however, due to their workload, time constraints, and the health systems inherent focus solely on PLWS, health providers are unable to properly assess and support stroke caregivers, leading to them functioning in a reactive rather than proactive way (Greenwood et al., 2011;

Greenwood et al., 2010; O'Brien et al., 2014; Parmar et al., 2020; Pindus et al., 2018). Health providers also do not feel overly confident in their role and feel insufficiently trained in supporting caregivers (Greenwood et al., 2010; Parmar et al., 2020). The current study findings extend the current literature through the finding that without the confidence and ability to fully engage with stroke caregiver's, health providers are unable to practice family-centered care and consequently experience moral distress. Moreover, study results suggest that health providers feel constrained in their ability to practice at the full scope of their intended role. These results are of particular concern because if health providers are feeling moral distress or job dissatisfaction, this could potentially cause issues around job retention and further limit support available to PLWS and stroke caregivers (Halcomb et al., 2018; Lamiani et al., 2017). Research shows that in nursing, moral distress resulting from not being able to do what one believes is right due to internal or external constraints is associated with decreased job satisfaction (Lamiani et al., 2017). Moral distress experienced by health providers is closely related with negative feelings such as anger or guilt and is linked to the intention to resign from ones position (Halcomb et al., 2018; Lamiani et al., 2017). When health providers experience this moral distress, this has a great impact on service delivery and the quality of care provided to others (Halcomb et al., 2018; Lamiani et al., 2017).

Current Services are not Meeting People Living with Stroke and Stroke Caregivers Needs

In addition to the challenge's health providers have identified in supporting stroke caregivers, study findings also suggest that services available within the community were not meeting PLWS and stroke caregivers needs. Participants explained that a lack of stroke-specific resources, and limited resources tailored for severity and age of PLWS and stroke caregivers led to increased caregiver workload and hindered their ability to engage in self-care.

There are many services in the community that are generic and pay little attention to the specific needs of PLWS or stroke caregivers (Hickey et al., 2012). In addition, some diseases receive more attention than others, such as Alzheimer's, Parkinson's, and kidney disease, which have strong organizational and government support to establish community services and resources. However, these disease's often progress slowly and allow caregivers the time to adjust and become accustomed to seeking out formal health and social services. Stroke caregivers face a very different reality with their lives changing drastically in a short period of time. Stroke caregivers require much more specific support and education in a short amount of time. These findings support the *Timing It Right Framework* by Cameron and Gignac (2008), which explains how stroke caregivers needs change drastically over time, but if they receive the proper interventions and support at the right time, this will likely enhance their well-being.

In addition to a general lack of stroke-specific services, study findings suggest that there is a lack of services for PLWS who have varying disabilities. Many services may not be available to PLWS and stroke caregivers if the PLWS' disabilities are not severe enough or do not meet certain criteria, even though they might benefit from them. For example, health providers in this study shared that there are many aphasia groups that provide a lot of support that would benefit many stroke caregivers. However, if the PLWS does not have aphasia the caregiver is not able to access this service, limiting their ability to gain support. A cross-sectional study in Ireland echoes these concerns and found that there were many issues surrounding patient access to services (Hickey et al., 2012). For example, ongoing referral from physiotherapy was dependent on the severity of the PLWS' disability and any potential for improvement (Hickey et al., 2012). Even though this service may be of great benefit to the PLWS and stroke caregiver, they may not be eligible to receive the level of care and support they require (Hickey et al.,

2012). Many stroke caregivers' roles are chronic and regardless of the PLWS' disability, the stroke caregivers will be greatly impacted and require support from services. When support from a variety of community services are offered, these are generally appreciated by stroke caregivers and result in feelings of confidence, reassurance, and encouraged positive coping behaviours (Pindus et al., 2018).

Study results also identified that health providers are concerned that current services are not meeting the PLWS and stroke caregivers needs due to age discrepancies. The current study shows that services available are not always suitable for different age groups. For example, having support from other caregivers in support groups is seen as important. Support groups help caregivers by making them feel less alone, providing opportunities to talk and learn from others, and creates a sense of community (Christensen et al., 2018; Greenwood et al., 2013; Hartford et al., 2019). However, there is sometimes a lack of support groups with caregivers of a similar age (Quinn et al., 2014). An intriguing finding from this study is that many peer support groups included mostly younger PLWS and stroke caregivers, and older adults do not feel that they fit in. It is not clear within the literature why there is a lack of peer support for older age groups or if older adults are simply not utilizing these services, and if so, why this is. This study emphasizes the potential need for more peer support groups for older age groups and for further research into this phenomenon. Having suitable resources and services that cater to a variety of age groups is important to ensure everyone has access to beneficial support.

The *Logic Model* in Relation to Study Findings

The Alzheimer's Society of York Region on behalf of the Central LHIN investigated the caregiver experience with the healthcare system (Lantz & Freid, 2018). Through consultation with various stakeholders, they developed a framework called the *Caregiver Support*

Framework: A Planning Tool for Healthcare Providers which includes the *Logic Model* (Lantz & Freid, 2018). This model was developed to provide health providers with a tool for planning activities to achieve a desired outcome when supporting caregivers (Lantz & Freid, 2018). The model refers to "care providers", so within this section, "care providers" and "health providers" will be used interchangeably.

The *Logic Model's* overall vision is "to improve the recognition, resiliency, and supportive resources for informal caregivers, in collaboration with health and community care providers, peers, and other organizations" (Lantz & Freid, 2018, p. 10). This model has many applicable and beneficial components relevant to stroke caregivers. Findings from this study were mapped onto the specific components of the *Logic Model* and as a result, highlighted further enhancements of the model. Additions to this model include: the optimization of a central access point for caregivers, encouraging family-centred care, developing more services and strong organizational support for various diseases including stroke, creating more tools to support health providers in the assessment of caregivers, emphasizing the education of health providers, caregivers, and the general public on the role and significance of informal caregivers, and enhancing the system outcome statement in the model to include the importance of accessibility and suitability of services.

Identify and Recognize

The main component of "identify and recognize" includes many implementation objectives that are sound and applicable to stroke caregivers (Lantz & Freid, 2018). To further enhance these objectives, it is important to emphasize the need to increase health providers knowledge in addition to their skills in identifying caregivers and communicating in the most supportive manners through education opportunities. The current study and literature show that

health providers feel as though they are lacking the knowledge and skills to adequately support

caregivers and refer them to services in the community. Bolstering health providers' education

and enhancing their knowledge of other available services, can improve professional resilience,

and increase the quality-of-care provision to stroke caregivers and PLWS.

Referral and Navigation

Under the main component "referral and navigation" there are many important

implementation objectives that refer to the improvement of the current fragmented system, which

was identified as a barrier to accessing services by the health providers within the current study

(Lantz & Freid, 2018). As has been shown, making the system easier to navigate is a priority for

health providers. They recognize that the current fragmented system impacts continuity of care,

and for stroke caregivers and health providers to successfully work together, the system needs to

be easier to maneuver and both parties need to be more knowledgeable of the services available.

One additional implementation objective that would be beneficial in this model would be to

optimize current community systems in place to create a central access point for caregiver

follow-up and support. Ideally a stroke navigator would work with the families consistently and

provide ongoing support to caregivers as they navigate through the system over time.

Caregiver Assessment and Care Plan

The model's main component "caregiver assessment and care plan" includes many

implementation objectives that are applicable and beneficial to stroke caregivers (Lantz & Freid,

2018). Study findings suggest that the model could be enhanced by inclusion of the benefits of

encouraging and practicing family-centred care. The model already includes the idea of co-

developing a care plan which is an important aspect of family-centred care (Lantz & Freid,

2018). However, specifically mentioning the importance of family-centred care in practice is

critical for trying to identify, assess, and treat stroke caregivers as a member of the health team and as an individual whose health should be prioritized. Study findings also indicate the benefits of developing more disease specific organizations and forging collaborative relationships across organizations in order to optimize care delivery to a broader population of caregivers.

Caregiver Education and Supports

"Caregiver education and supports" emphasizes the importance of caregiver opportunities for education and support within the community and the significance of timely access (Lantz & Freid, 2018). As findings from this research have shown, social support is pivotal for caregiver well-being. Expanding the opportunities for social support through the implementation of more resources, such as peer support groups and respite care, is an important consideration and critical piece to this model. Increasing timely access to various supportive services is a key piece to this objective, however it should state more concrete examples of how this can be done (Lantz & Freid, 2018). For example, creating more day programs for PLWS and caregiver peer support groups would be one way to expand the availability, flexibility, and effectiveness of resources that would greatly benefit stroke caregivers. However, study findings highlight the need for caregiver involvement in such initiatives to ensure that the services are offered in a manner and time that they can benefit from.

Monitor and Re-evaluate Caregiver Care Plans

"Monitor and re-evaluate caregiver care plans" includes critical aspects to recognize, assess, and monitor caregiver success (Lantz & Freid, 2018). Caregiver burden develops over time making it important to have ongoing and recurrent opportunities within the system of care to follow-up with caregivers. Study findings suggest that health providers lack the time and ability to properly identify and engage with stroke caregivers. Going forward, it will be

important to situate community health providers so that they have the knowledge, time, and capacity to properly assess and support stroke caregivers over protracted periods of time if necessary. Having policies and procedures to explicitly include caregivers in the circle of care can help ensure that caregivers' needs are addressed. Furthermore, creating more assessment tools to support health providers in the ongoing assessment of caregiver health can be used to identify and negate the potential impacts of caregiver burnout.

Long-Term Outcomes

The *Logic Model* outlines two long-term outcomes. The first aims for "early caregiver recognition with proactive referral, navigation, and access to supports for caregivers" (Lantz & Freid, 2018, p. 10). The goal is to increase awareness, recognition, and understanding of the caregiving role and responsibilities (Lantz & Freid, 2018). Adding emphasis that this should include health providers, informal caregivers, and the general population is critical. Another outcome that should be added into the model is to highlight the importance of health providers being knowledgeable, confident, and able to identify and spend the appropriate amount of time with caregivers to properly provide support. Findings from the current study suggest a health system that is fragmented and difficult for both stroke caregivers and health providers to navigate. A solution health providers mentioned within this study was the idea of improving current community services to allow for a central access point for caregiver as well as health providers to access information and services. Identifying this as a long-term outcome encourages work towards and the improvement of a central access point to support caregiver follow-up and system navigation.

The second long-term outcome includes "caregiver assessment, care planning, and co-ordination of supportive resources and services" (Lantz & Freid, 2018). One aspect of this

outcome is to ensure that caregivers receive timely and relevant supportive services and resources (Lantz & Freid, 2018). Enhancing this by emphasizing continuity of care from a hospital setting into the community and ensuring there are services that are suitable for everyone, not just those with a certain disability or of a certain age range, are critical ways to achieve this outcome. By doing so, this enhances the availability and suitability of supportive services available for all caregivers, including stroke caregivers.

System Outcome

The *Logic Model* finally outlines a broad system outcome which states: "continually improved quality of care and services in partnership with patients and caregiver" (Lantz & Freid, 2018, p. 10). This is a sound goal, with the idea of listening to what caregivers require and continually improving the system to properly support them (Lantz & Freid, 2018). It would be beneficial to incorporate the idea of improving accessibility and suitability of services. Accessibility was highlighted as a major issue by health providers due to the fragmented system. Trying to enhance this should be a priority for systemic change. In addition, health providers highlighted that many services were not meeting the needs of stroke caregivers. Ensuring that the services that are available are suitable and that there are a variety of options available is critical for moving forward. Changing the final system outcome to state: "continually improved quality of care, accessibility, and suitability of services in partnership with patients and caregivers" would enhance this statement within the model.

In summary, to be inclusive of stroke caregivers within this model it would be beneficial to add some key points throughout. These include: the optimization of a central access point for caregivers, encourage family-centred care, develop more services and strong organizations for various diseases including stroke, create more tools to support health providers in the assessment

of caregivers, emphasize the education of health providers, caregivers, and the general public on

the role and significance of informal caregivers, and enhance the system outcome statement to

include the importance of accessibility and suitability of services. The model has been adapted,

with copyright permission, to include some additional components that will be beneficial for

enhancing health system delivery and for health providers to be aware of when utilizing this tool

(see Figure 2). Overall, *the Logic Model* appears to effectively reflect many important steps

necessary to improve caring for caregivers and enhancing their ability to access formal health

and social services.

Figure 2

Logic Model: An Outcome-Orientated Approach to Health Service Delivery Planning- Adapted with Study Findings.

Logic Model: An Outcome-Oriented Approach to Health Service Delivery Planning

Vision	To improve the recognition, resiliency, and supportive resources for informal caregivers, in collaboration with health and community care providers, peers, and other organizations.				
Main components	**Identify and Recognize**	**Referral and Navigation**	**Caregiver Assessment and Care Plan**	**Caregiver Education and Supports**	**Monitor and Re-evaluate Caregiver Care Plans**
Implementation Objectives	• To increase awareness/recognition of the contributions of caregivers • To increase self-identification skills caregivers • To increase readiness of caregivers to seek educational and other supports for self-care • To increase care provider *knowledge* and skills in identifying caregivers and communicating in the most supportive manner *through education opportunities*	• To increase caregiver self-referral and navigation tools and resources • To expand care provider adoption of referral and navigation best practices • To increase care provider skills in referring and navigating caregivers to the right supports • *Optimize current community services and organizations in place to create a central access point or create caregiver coordinator positions to better support caregivers*	• To increase care provider competencies in assessing caregiver needs and developing care plans • To reduce the negative impacts of caregiving through care plan co-development • To improve supports to caregivers via integrated teams and inter-organizational partnerships • *Implement family-centred care in practice to encourage the identification and active involvement of family members and caregivers within the health team* • *Develop more disease-specific services and organizations to offer more options for a variety of caregivers*	• To expand the availability, flexibility, and effectiveness of educational and peer support resources for caregivers • To increase timely access by caregivers to various types of supportive services (in community, healthcare, educational, and workplace settings) • To empower caregivers to be equal partners in the care design process • *Increasing services within the community such as peer support groups or respire care to offer more opportunities for caregivers to access support and take time for themselves*	• To identify success factors that contribute to early recognition of caregivers • To identify barriers to assessment and provision of supports for caregivers • To analyze and evaluate impacts of caregiver education & support activities • *Create more assessment tools to support health providers in the ongoing assessment of caregiver health and need for services*
Long-term Outcomes	1. **Early Caregiver Recognition with Proactive Referral, Navigation, and Access to Supports for Caregivers** • Heightened awareness, recognition, and understanding of the caregiving role and responsibilities *for care providers, caregivers, and the public.* • Caregivers identified and supported earlier in the disease or care trajectory of the client/patient. • *Care providers are knowledgeable, confident, and able to efficiently identify and support caregivers.* • Caregivers are recognized and valued as full partners throughout the care process. • Simplified and effective system of access and navigation to the range of supports for caregivers. • *Enhancement of a central access point or caregiver coordinators for caregivers and care providers to access support when navigating the health system*		2. **Caregiver Assessment, Care Planning, and Co-ordination of Supportive Resources and Services** • Care providers are competent in caregiver assessments, care planning, and providing supportive resources to caregivers in the care process. • Reduced caregiver uncertainty and stress due to lack of information or poor-quality communication between healthcare providers, particularly at transition points between settings/providers. • Caregivers receive timely and relevant supportive services and resources, *with a variety of services available for different disease, disabilities, and age ranges to meet specific needs.* • Reduced caregiver burden based on service provision and mitigating socio-economic risk factors (such as health conditions, single parent, frail elderly, language barrier, low-income level etc.). • Caregivers are satisfied with their experiences of balancing self-care, receiving supports, and providing care for others.		
System Outcome	*Continually improved quality of care,* **accessibility, and suitability** *of services in partnership with patients and caregivers.*				

Note. Adapted with permission from Loren Fried and Sue Lantz of the Alzheimer's Society of York Region and Collaborative Aging.

[a] Black writing indicates the imbedded study findings.

Strengths and Limitations

A limitation associated with secondary analysis is what Heaton (2004) describes as "the problem of not having 'been there'". Without being involved in the original data collection within the primary study, and being removed from the contexts of the original interviews, this does limit the researcher's ability to fully engage in the data analysis (Heaton, 2004). However, working closely with the researcher of the primary study is considered a strength, with this helping to enrich engagement with the study data.

In addition, another limitation associated with secondary analyses is that the data was not collected to answer this study's specific research questions. Rather the research questions were developed as a result of the initial data analysis in the primary study. However, with the questions stemming from an identified need for further analysis, to provide a more in-depth focus on issues that were not fully addressed in the primary study, this can be considered a strength by furthering our knowledge on a phenomenon of importance to nursing practice (Heaton, 2008).

Another limitation of this study is that the sample included health providers, but no social service providers such as those working at the YMCA with day programs or in financial aid organizations. For future research purposes, including this group would be beneficial to obtain a fuller sense of community-based formal health and social services and the barriers and facilitators they witness stroke caregivers endure.

Implications

Interpretive description is a qualitative research methodology that was developed for the applied health disciplines, such as nursing (Thorne, 2016). Using this approach, researchers seek to explore topics of relevance to individuals engaged in practice settings. Findings determined

using interpretive description can support clinicians to potentially be more sensitive, better informed, and increasingly thoughtful in their clinical roles (Thorne, 2016). The findings of this study inform a more comprehensive understanding of the barriers and facilitators stroke caregivers face when attempting to access formal health and social services through attainment of health providers' perspectives. In addition, study findings represent health providers' experiences and perceptions of their role in supporting stroke caregivers.

Practice Implications

Health providers in the current study highlighted some important findings that need to be considered when supporting stroke caregivers to access formal health and social services. For example, a fragmented health system hindered both health providers' and stroke caregivers' ability to connect with services particularly when bridging between in-patient and community service sectors. The culmination of stroke caregivers' and health providers' difficulties in system navigation was resultant in stress for both parties.

In addition to this, health providers gaps in knowledge of services, inexperience with caregivers, and their heavy workloads made it extremely difficult for health providers to engage and support stroke caregivers. Health providers struggled to stay up to date on community services and support stroke caregivers in the manner they wished to. These experiences contributed to the development of feelings akin to moral distress for these health providers which could have significant practice implications such as leading to staff burnout and decreased job retention (Halcomb et al., 2018; Lamiani et al., 2017).

Participants commonly spoke about a potential solution to enhance the support for stroke caregivers, navigate the health system, and promote continuity of care by having a central access point for follow-up, information, and navigation support. Though there is currently an

organization in the community, the Community Care Access Centre (CCAC), whose aim is to be this central access point, participants acknowledged that current services do not always meet the demands of stroke caregivers. Going forwards, it will be important to try to streamline and centralize community services for PLWS and caregivers. As part of this process, it would be important to enhance or implement a stroke navigator role to assist PLWS, stroke caregivers, and health providers in connecting with suitable services and supports. Navigation roles have been shown to greatly improve caregiver's confidence by supporting them to problem solve, navigate the system, obtain supportive resources, and promote a smooth transition home (Bernstein et al., 2019; Hudson et al., 2019)

Finally, a key finding of this study suggests that many services are not meeting PLWS' and stroke caregivers' needs. Health providers noted that both stroke caregivers and PLWS did not attend community support groups if they felt the age or disability level of most participants did not match their own. This knowledge is critical for moving forward to improve access to appropriate services for this group. Next steps could include engagement of stroke caregivers and PLWS in the planning and development of community service programs to ensure that their needs and concerns are addressed.

Policy and Education Implications

With health providers feeling the strain of their workload and lacking the knowledge of services and experience working with caregivers, they are limited in their ability to properly support stroke caregivers. A study finding that was used to enhance the *Logic Model* was the proposition to create more tools to enhance health providers' ability to properly identify and assess caregivers within a healthcare setting. Enhancing or creating tools which help health providers to assess stroke caregivers quickly and effectively during daily encounters is critical

for improving practice. Policies and guidelines are required to promote family-centered care across a range of clinical settings to ensure health providers are well-positioned to support caregivers during their interactions.

In addition, study findings suggest that some health providers required more education and increased access to resources to comprehensively address caregiver issues within their own practice. Going forward, the development of virtual education programs could facilitate health provider education and include opportunities to engage with professional partners across a range of interdisciplinary community settings.

Research Implications

The findings of the current study inform many opportunities for further research. Further research needs to be done to examine the issue of a fragmented health system to determine the breaking points in service delivery between in-patient and community settings and to develop solutions to improve continuity of care for PLWS and stroke caregivers.

New and already developed policies or tools that support health providers in assessing caregivers within their practice require further research. Future research could be developed to examine the effectiveness, feasibility, and validity of any current tools or to develop and test new tools that health providers could use in their daily practice to assess caregivers for burnout efficiently. This research would be an important step to implementing these tools as a standardized approach to caring for caregivers and assessing potential burnout.

In addition, future research should seek to develop ideas to optimize current services or to build other services or roles that act as a central access point for stroke caregivers and PLWS. The idea of having a stroke navigator, or caregiver coordinator nurse, was mentioned in this study and within current literature. These navigational roles have been shown to greatly benefit

caregivers by supporting them throughout their transition into their caregiving role and promoting confidence when navigating the health system (Bernstein et al., 2019; Hudson et al., 2019). An intervention study where these roles are introduced into the community would be beneficial to explore the effectiveness and efficacy of implementing such roles into the community health system.

Further research should also explore whether other platforms such as virtual peer support groups would be well-received and feasible for this population. Virtual support groups have been shown to be beneficial to caregivers by reducing their perceived pressure, feelings of helplessness and depression, and improving their self-efficacy (Armstrong & Alliance, 2019; Han et al., 2020; Wallace et al., 2021). Developing a mixed-methods study that implements a virtual peer support group for stroke caregivers and then engages in in-depth qualitative interviews with participants would be beneficial to explore this idea further. This would allow for exploring the benefits, challenges, and areas for improvements associated with such a program.

Conclusion

Informal stroke caregivers face extreme burden and stress when tasked with caring for PLWS, placing them at risk of poor health and social outcomes. They may benefit from formal health and social services, but these are often underused and inaccessible. Valuable insight from health providers have been described concerning the facilitators and barriers stroke caregivers face when attempting to access such services. In addition, health providers shared their experiences and perceptions of their role in supporting stroke caregivers, furthering our understanding of this phenomenon. Findings suggest that a fragmented system impacts the ability to provide continuity of care; challenges in care provision and accessibility creates moral

distress for health providers; access to social support is pivotal for stroke caregivers' self-care; stroke caregivers require individualized care; providing a single access point for stroke caregiver support is essential for success; and current services are not meeting people living stroke and stroke caregivers' needs.

The findings from the current study suggest that health providers can provide an important contribution to the knowledge base regarding the challenges that stroke caregivers experience when accessing and using formal health and social services. Interviews with providers revealed some of the structural challenges that impede their ability to provide ongoing support to caregivers. Going forward, it will be important to engage health providers and stroke caregivers in conversations about health policy reform to better recognize and support caregivers within the PLSW circle of care. Further funding and research are required to inform the improvement of service access and navigation among caregivers based in community settings. Moreover, there is need to explore blended models of care and their role in optimizing support provision for caregivers.

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Zawawi, N. S. M., Aziz, N. A., Fisher, R., Ahmad, K., & Walker, M. F. (2020, Aug). The Unmet

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https://doi.org/10.1016/j.jstrokecerebrovasdis.2020.104875

Appendix A

Ethical Approval

The following provides evidence of ethical approval from the primary study and the current secondary analysis from the Hamilton Integrated Research Ethics Board and the Western University Health Science Research Ethics Board.

Figure A1. Primary study ethical approval from the Hamilton Integrated Research Ethics Board.

Project Title: Use of Formal Health and Social Services by Stroke Caregivers: An Interpretive Description

Principal Investigator: ██████████

This will acknowledge receipt of your letter dated March 31-2017 which enclosed revised copies of the Application, Information Consent Form, and the Telephone/Email Scripts along with a response to the additional queries of the Board for the above-named study. These issues were raised by the Hamilton Integrated Research Ethics Board at their meeting held on March 21-2017. Based on this additional information, we wish to advise your study had been given *final* approval from the full HiREB.

The following documents have been approved on both ethical and scientific grounds:

Document Name	Document Date	Document Version
Caregiver Demographics - SCSUse - Version 1 - 26-01-17	Jan-26-2017	1
Confidentiality - SCSUse - Version 1 - 26-01-17	Jan-26-2017	1
Health Prof Demographics - SCSUse - Version 1 - 26-01-17	Jan-26-2017	1
Info & Consent Form - CG - SCSUse - Version 2 - 31-03-17	Mar-31-2017	2
Info & Consent Form - Hlth Prof - SCSUse - Version 2 - 31-03-17	Mar-31-2017	2
Interview Guide - SCSUse - Version 1 - 26-01-17	Jan-26-2017	1
Number MCC - Caregiver & Stroke Survivor - SCSUse - Version 1 - 24-01-17	Jan-24-2017	1
PhD Proposal - SCSUse - Version 4 - 26-01-17	Jan-26-2017	4
Recruitment Poster - SCSUse - Version 1 - 26-01-17	Jan-26-2017	1
Telephone & email contact script - CG - SCSUse - Version 2 - 31-03-17	Mar-31-2017	2
Telephone & email contact script - Hlt Prof - SCSUse - Version 2 - 31-03-17	Mar-31-2017	2

The following documents have been acknowledged:

Document Name	Document Date	Document Version
CITI - REB ████ 11-01-17	Jan-11-2017	1

Please Note: All consent forms and recruitment materials used in this study must be copies of the above referenced documents.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the HiREB meeting on March 31-2017. Continuation beyond that date will require further review and renewal of HiREB approval. Any changes or revisions to the original submission must be submitted on a HiREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

PLEASE QUOTE THE ABOVE REFERENCED PROJECT NUMBER ON ALL FUTURE CORRESPONDENCE

Sincerely,

██████████████

Chair, Hamilton Integrated Research Ethics Board

Figure A2. Current study's ethical approval from the Western University Health Science
Research Ethics Board.

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Research Protocol-verson 1	Protocol	26/Oct/2020	1
Interview Guide - SCSUse - Version 1 - 26-01-17	Interview Guide	26/Jan/2017	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB , except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Ethics Officer on behalf of

Appendix B

Semi-Structured Interview Guide

The following provides the semi-structure interview guide used in the primary study during interview with the health provider participants.

Figure B. Health Provider Semi-structured interview guide.

Health System/Community Resources

Can you explain what sort of health or social supports caregivers of stroke survivors receive?

Can you explain an instance where you think health or social services have supported a caregiver of a stroke survivor? How did they do this?

Can you tell me about the things you consider when referring or connecting a caregiver of a stroke survivor to services?

Need-Services Gap

Can you provide examples of factors that make it challenging for caregivers of stroke survivors to access services?

Can you tell me what you think affects caregivers' choice to access services?

Can you tell me what services available to caregivers are not optimally accessed?

Health

Can you tell me about a situation where you think a caregiver's health has been affected by their caregiving role?

Can you tell me how you think caregivers could be supported in their caregiving role?

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

Contextual Factors – Economic/Social/Physical

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

Curriculum Vitae

Hannah Pollock

Education:

- Bachelor of Science in Nursing with Advanced Major | May 7, 2017.

Awards:

- Ontario Graduate Scholarship- Western University, London, Ontario | April 2020.

- Arthur Labatt Family Graduate Scholarship in Nursing- Arthur Labatt Family School of Nursing, Western University, London, Ontario | September 2019.

- Athletic Director's Award for Academic Achievement- St. Francis Xavier University, Antigonish, Nova Scotia | 2018.

- Gold Medal for Outstanding Academic Achievement- St. Francis Xavier University, Antigonish, Nova Scotia | May 2017.

- Advanced Major Award- Rankin School of Nursing, St. Francis Xavier University, Antigonish, Nova Scotia | May 2017.

- First class distinction- St. Francis Xavier University, Antigonish, Nova Scotia | May 2017.

- Dean's List- St. Francis Xavier University, Antigonish, Nova Scotia | May 2014-2017.

- Academic All Canadian- U-Sports | January 2014-2016.

Work Experience:

- Registered Nurse- Intensive Care Unit- Bluewater Health, Sarnia, Ontario | October 2021- current time.

- Registered Nurse- Acute Medicine Unit- Charlotte Eleanor Englehart Hospital, Bluewater Health, Petrolia, Ontario | April 2019- October 2021.

- Western Graduate Fellowship- Western University, London, Ontario | August 2020- October 2021.

- Registered Nurse- COVID-19 Unit- Bluewater Health, Sarnia, Ontario | March 2020- April 2020.

- Teaching Assistant- Western University, London, Ontario | September 2019- December 2019.

- Registered Nurse- Inpatient Surgical Unit- Bluewater Health, Sarnia, Ontario | April 2018- April 2019.

- Registered Nurse- Medical/Surgical-Stroke Unit- St. Martha's Regional Hospital, Antigonish, Nova Scotia | June 5, 2017- September 23, 2017.

Conferences, Presentations and Publications

- Garnett, A., Pollock, H., Floriancic, N., Donelle, L., Babenko-Mould, Y., Oudshoorn, A., Hand, C., Forchuk, C. (2021, November). Social connectivity in the context of COVID-19 and long-term care. [Oral Presentation]. Presented at Gerontological Society of America Annual Scientific Meeting: Disruption to transformation: Aging in the "New Normal", Phoenix, Arizona.

- Pollock, H., Garnett, A., Floriancic, N., Donelle, L., Babenko-Mould, Y., Oudshoorn, A., Hand, C., Forchuk, C. (2021, October). Social Connectivity Between Family Caregivers and Older Adults Living in Long-Term Care Homes in the Context of COVID-19. [Oral presentation]. Presented at Lawson Joint Mental Health Research and Innovation Day, London, Ontario, Canada.

- Pollock, H., Garnett, A., Ploeg, J., Markle-Reid, M., & Strachan, P. (2021, October). *Healthcare providers perspectives on the access and use of health and social services by stroke caregivers.* [Poster presentation]. Presented at Hindsight 20/20: Looking back for a

vision forward in gerontology, Canadian Association on Gerontology 50th Annual Scientific and Educational Meeting, Toronto, Ontario, Canada.

- Pollock, H. (2021, September). *Health Providers Perspectives on the Access and Use of Formal Health and Social Services by Stroke Caregivers.* Inspiring Minds- Showcasing Western's Graduate Research, Scholarship and Creative Activity. 128. https://ir.lib.uwo.ca/inspiringminds/128/.

- Pollock, H., & Garnett, A. (2021). Effectiveness of Home-Based Cardiac Rehabilitation and Its Importance During COVID-19. *McGill Journal of Medicine, 19*(1). https://doi.org/10.26443/mjm.v19i1.857.

- Attendee at the Legacy Research Conference- Honoring our Past, Creating our Future: Transforming Education, Services, Systems, and Policies that Impact Health. Arthur Labatt Family School of Nursing, Western University, London, Ontario | May 3, 10, 25, 31, 2021

- Pollock, H., & Garnett, A. (2021, May). Effectiveness of Home-Based Cardiac Rehabilitation and Its Importance During COVID-19. [Oral Paper Presentation]. Presented at Legacy Research Conference- Honoring our Past, Creating our Future: Transforming Education, Services, Systems, and Policies that Impact Health, Arthur Labatt Family School of Nursing, London, Ontario, Canada.

- Garnett, A., Pollock, H., Ploeg, J., Markle-Reid, M., & Strachan, P. (2021, May). Access and Use of Formal Health and Social Services by Caregivers of Stroke Survivors: An Interpretive Description Study. [Oral Paper Presentation]. Presented at Legacy Research Conference- Honoring our Past, Creating our Future: Transforming Education, Services, Systems, and Policies that Impact Health, Arthur Labatt Family School of Nursing, London, Ontario, Canada.