Master Thesis

Navigating the Stroke Rehabilitation System:

A Family Caregiver's Perspective

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MSc. Degree in Health Systems

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University of Ottawa

December 2012

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ABSTRACT

Introduction/ Objectives: Stroke, the third leading cause of death in Canada, is projected to rise in the next 20 years as the population ages and obesity rates increase. Family caregivers fulfill pertinent roles in providing support for family members who have survived a stroke, from onset to re-integration into the community. However, the transition from rehabilitation to home is a crucial transition for both the stroke survivor and family caregiver. As the stroke survivor transitions home from a rehabilitation facility, family caregivers provide different types of support, including assistance with navigating the stroke rehabilitation system. They also are a constant source of support for the stroke survivor providing them with continuity during the transition. In this exploratory study we examined family caregivers' perceptions and experiences navigating the stroke rehabilitation system. The theories of continuity care and complex adaptive systems were used to examine the transition home from hospital or stroke rehabilitation facility, and in some cases back to hospital.

Methodology: Family caregivers (n=14) who provide care for a stroke survivor were recruited 4-12 weeks following the patient's discharge from a stroke rehabilitation facility. Interviews were conducted with family caregivers to examine their perceptions and experiences navigating the stroke rehabilitation system. Directed content analysis was used to explore the perceptions of family caregivers as they reflected on the transitions home. The theories of continuity of care and complex adaptive systems were used to interpret their experiences.

Results/Conclusions: During the transition home from a rehabilitation facility, family caregivers are a constant source of support, providing the stroke survivor with continuity. Emergent themes highlight the importance of the caregiving role, and barriers and facilitators that impact the role, and influence continuity of care. Also, supports and services in the community were limited or

did not meet the specific needs of the family caregiver. The acknowledgment of the unique attributes of each case will ensure supports and services are tailored to the family caregiver's needs. Mitigation of systemic barriers would also decrease complexity experienced at the micro-level in the stroke rehabilitation system, and better support the family caregiver during the transition home from a stroke rehabilitation facility.

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ACKNOWLEDGMENTS

First, I would like to thank my supervisors Dr. Craig Kuziemsky and Dr. Tracey O'Sullivan for their continued support, mentorship and guidance over the last 2 years. It has been such a pleasure to work with you and learn from you. Your love for research is a true inspiration. Thank you for everything!

Thank you to Bruyère Continuing Care, in particular Ms. Beverly Donovan and Dr. Hillel Finestone for all of their support.

Thank you also to Mallory Watson for her assistance with analysis, and the family caregivers who participated in the study and shared their stories with me.

I would like to thank my mom Ms. Lorri Taller who I could never have done this without. You are my rock, my heart, and my lifelong role model and friend. Your strength, drive, and determination are a true inspiration. I will never forget all that you have done for me over the last 26 years. I love you so much!

I would also like to thank Dr. Miriam Levitt for her friendship and mentorship over the years. Your outlook on life, and strength are much to look up to.

I would also like to thank Guy Lanzman for his love, support, and patience. You always know how to bring a smile to my face, even during the most difficult of times. Love ya!

Finally, I acknowledge financial support from Telfer School of Management (Excellence Award, and Student Graduate Research Fund), and the Ontario Government (Ontario Graduate Scholarship)

DEDICATION

I dedicate my thesis to my Bubby and Zaidie who I love from the bottom of my heart and will never forget. You were my drive, and my motivation. I wish you were here to celebrate this with me, but I know you are looking down from above. You will always be in my thoughts. Love you always!

I would also like to dedicate my thesis to Mr. Peter Burns whose love for knowledge and life, and determination for equality and justice was admirable and continues to be inspiring. You taught me to remain determined and strive to be the best, despite roadblocks along the way or challenges in life. You will remain in our thoughts and never be forgotten.

Finally, I would like to dedicate my thesis to Chris Kennaway who was a friend and brother to me. I know how proud you would be and wish you were here to celebrate this accomplishment with me.

CHAPTER 1: INTRODUCTION

1.1 Background

The increasing number of components within the Canadian health care system and the interactions between each component makes the system more complex (Kannampallil, Schauer, Cohen, & Patel, 2011). Complex adaptive systems provides a means for understanding health care from a systems perspective including the non-linear, and dynamic nature of complex systems. As the system becomes more complex, some processes evolve while others become extinct (Coiera, 2011). With the increasing complexity, policy-makers, health professionals and the public are becoming more concerned with the fragmentation of care delivery. Fragmentation impacts continuity of care, the extent to which patients receive consistent and coherent care across multiple health care settings, and has been identified as an essential element in quality service provision (Jones et al., 2009; Cree, Bell, Johnson & Carrier, 2006; Guillford, Naithani & Morgan, 2006). Three identified types of continuity of care are informational, relational, and management continuity (Haggerty et al. 2003). Stroke management is one area where continuity of care is important as many stroke survivors receive care from a variety of health professionals, across multiple health care settings over a prolonged period of time.

Stroke is a growing public health concern given it is the leading cause of disease and disability worldwide, and the third leading cause of death in Canada (Aziz, 2010; Public Health Agency of Canada [PHAC], 2009; Laver, Halbert, Stewart, & Crotty, 2010). The incidence of stroke in Canada is projected to rise as life expectancy and rates of obesity and diabetes increase (PHAC). Today, more than 300,000 Canadians are living with the effects of stroke (Smith, Gignac, Richardson, & Cameron, 2008), and it is considered to be a disabling disease, as more

than 70% of stroke survivors experience some form of moderate or severe disability (Smith et al.) Depending on the type and severity of stroke, the individual may experience complications such as aphasia, and other changes in functional ability, such as mobility, visual or cognitive limitations (Pulvermüller et al. 2001; Visser-Meily et al. 2006).

Stroke not only affects the individual, but also has significant impacts on the family (Visser-Meily et al., 2006). Family caregivers fulfill a vital role throughout the stroke trajectory, providing the stroke survivor with instrumental, emotional, appraisal and informational supports (Bourgeault, Dingwall, & de Vries, 2010) which include personal care, assistance with activities of daily living, and navigating the complexity of different parts of the health care system (Cameron & Gignac, 2008; Cameron, Tsoi & Marsella, 2008; Lutz & Young, 2010).

With the increasing complexity of the stroke rehabilitation system, family caregivers and stroke survivors experience a greater number of transitions across the continuum of care from emergency to acute care, rehabilitation and community care, and sometimes back to the acute or rehabilitation facility (Cameron et al., 2008). As patients transition across care settings, their family caregiver is often the only aspect that remains consistent (Coleman, Mahoney, & Parry, 2005). During these transitions, continuity of care is essential, to ensure the care recipient receives consistent and comprehensive care (Haggerty et al. 2003; Coleman et al.).

Upon discharge from emergency and acute care, many stroke survivors transition to stroke rehabilitation care, a key component in the continuum of stroke care. Stroke rehabilitation supports improved quality of life for the stroke survivor, and includes physical interventions as well as assistance with preparations for re-integration into the community and adjustment to acquired disabilities (Talbot et al, 2004; Aziz, 2010). The transition from a rehabilitation facility to home is a key transition for both the stroke survivor and the family caregiver, as they adjust to

many physical and psychosocial changes during re-integration home and into the community setting (Rittman, Boylstein, Hinojosa, Hinojosa, & Haun, 2007). A key element of this transition is trying to maintain continuity of care. As the stroke survivor transitions home the family caregiver provides them with consistency across the transition, in addition to fulfilling the role of support provider and system navigator (Turner, Fleming, Ownsworth, & Cornwell, 2008)

The Ontario Stroke Strategy was established to improve access to medical services along the continuum of care (Stroke Evaluation Advisory Committee, 2005). However, there are a number of deficiencies in the stroke rehabilitation system that continue to have an impact on continuity in stroke care, such as access to services and supports, which have not been addressed by the Ontario Stroke Strategy (Teasell, Foley, Slater, & Jutai, 2008). Following the transition home from a stroke rehabilitation facility, for some stroke survivors, formal rehabilitation services continue but there is often an interruption in rehabilitation and/or homecare services impacting continuity of care (Cott, Wiles, & Devitt, 2007).

By studying continuity of care through a complex adaptive systems lens, this qualitative research study enabled us to explore gaps in the literature, with particular emphasis on family caregivers' experiences navigating the stroke rehabilitation system during the transition home from a rehabilitation facility. During this transition, family caregivers are a constant source of support, providing the stroke survivor with continuity across health care settings. However, the complex and dynamic nature of the stroke rehabilitation system influences continuity of care during this transition, and the family caregiver's role as system navigator. This study provides an understanding of what is needed to evaluate and reshape processes in the system, to better support complex activities like stroke rehabilitation.

1.2 Research Questions

The overarching research question being explored in this study is: How can complex adaptive systems be used to understand continuity of care in the context of the family caregivers' experiences with the transition home from the stroke rehabilitation facility? The overarching question was answered through three supplementary questions: 1) What are the family caregivers' micro level needs as they navigate the stroke rehabilitation system during the transition home from a stroke rehabilitation facility? 2) How do complex adaptive systems depict the barriers and facilitators of continuity of care that impact family caregivers' abilities to navigate the stroke rehabilitation system? 3) How do we use complex adaptive systems to restructure macro processes to better support micro aspects of the stroke rehabilitation system?

1.3 Organization of the Thesis

In Chapter 2, I provide an overview of current literature and existing gaps. In Chapter 3, the methodological aspects of the study are discussed: the research design, the methods of data collection, sampling techniques, and analysis. In Chapter 4, I present the results of the study including barriers and facilitators to continuity of care. In Chapter 5, I present the theoretical framework, and discuss the results and the limitations of the study, and possible areas of future research. Finally, in Chapter 6 concluding remarks are provided.

CHAPTER 2: LITERATURE REVIEW

This chapter begins with a discussion of the methods used to conduct the literature review, followed by a description of the extant literature. To explore the research questions described in chapter one, a literature review was conducted using academic databases such as Scopus, Medline, Web of Science, CINAHL and Scholars Portal. Sample keywords included continuity of care, emotional support, transitions, caregiver, navigating, advocacy, stroke, and support. Additional keywords are shown in Appendix A.

The search was conducted by combining key words using AND and OR in the advanced search screen of each database (see Table 1 for examples). Data and language limits were placed on each of these searches. An individual key word search was also conducted for terms such as 'continuity of care' and 'complex adaptive systems,' because they are specific concepts or methodologies. A manual search of peer-reviewed journals, such as Qualitative Health Research, was also conducted. An additional search strategy was to review the reference lists from retrieved articles. Based on the journal articles retrieved during my literature search, I divided my literature review into the following sections: 1) Complex adaptive systems 2) continuity in health care 3) stroke in Canada, 4) family caregiving role, 5) social support, 6) stroke rehabilitation system, 7) transitions in the continuum of care, and 8) gaps in literature.

Table 1. Examples of key word searches

1. continuity of care AND stroke AND informal caregiving
2. (continuity of care OR coordination of care) AND information AND communication
3. social support AND (family caregiving OR informal caregiving) AND stroke
4. stroke rehabilitation AND stroke AND Canada
5. complex adaptive systems AND health care system AND stroke

2.1 Complex Adaptive Systems

Complexity is defined as the "interrelatedness of components of a system." (Kannampallil, Schauer, Cohen, & Patel, 2011, p.944). As a system becomes more complex, the number of components and interactions between each component increases (Kannampallil et al.). The theoretical foundation for complex adaptive systems provides a means for examining the complexity and dynamic nature of organizations and networks at the system levels (macro, meso, micro) (Ellis & Herbert, 2011). Edgren & Barnard (2012) compare complex adaptive systems to living organisms, because in both cases, the free flow of information, and relationships between agents are pertinent to overall functioning. Tenets common to complex adaptive systems include, feedback, emergent behaviours, and non-linear processes (Edgren & Barnard; Benham-Hutchins & Clancy, 2010; Ellis & Herbert). Complex adaptive systems may also exhibit tenets such as, co-evolution, requisite variety, connectivity, simple rules, self-organization, and non-discrete boundaries (see Table 2 for definitions) (Cowan, Pines, & Meltzer, 1999; Burns, 2001; Lansing, 2003).

Complex adaptive systems acknowledges the complexity of organizations and networks, and has thus been adopted by health researchers, leaders and managers, in the health care and management sectors, in order to understand multilevel organizational behaviour (Strumburg, 2003; Griffiths, 2007; Clancy, Eftken, & Pesut, 2008; Liu, 2008; Benham-Hutchins & Clancy, 2010; Kannampallil et al., 2011). This theory provides a means for understanding the health care system, due its non-linear and dynamic nature as well as its increasing complexity over time (Sturmberg; Coiera, 2011). Non-linearity or increasingly complex systems tend to be less predictable in nature, whereas linearity is characterized by predictability (Kannampallil et al., 2011). Complex adaptive systems has been used in health information systems research, and has been used to illustrate continuity of care (Sturmberg; Benham-Hutchins & Clancy; Diment, Yu, & Garrety, 2010; Edgren & Barnard, 2012). However, to my knowledge, research has not yet empirically examined continuity of care, using the complex adaptive systems approach.

Table 2. Tenets of complex adaptive systems

Tenets of Complex Adaptive Systems	**Definition**
Non-linear processes	Non-linear processes are changes made to a system that can impact other areas of the system in direct and indirect patterns.
Emergent behaviour	Behaviours that emerge as a result of the dynamic and complex nature of the system.
Feedback loops	The transfer of information or knowledge in the system, which is fed back through the system.
Co-evolution	The actors evolve as an adaptive response to the complexity of the system.
Requisite variety	The unique characteristics of the case, or actors in the system. Examples include, personality, beliefs or experiences.
Connectivity	The relationships between actors in the system. Communication plays an important role in these relationships.

Simple rules Non-discrete boundaries	The rules and boundaries in the system that impact the actors, and overall complexity. These rules and boundaries may be flexible or firm.
Self-organization	The actors' abilities to adapt to the complex nature of the system.

Sources: Burns, J. P. (2001). Complexity science and leadership in healthcare. *Journal of Nursing Administration, 31*(10), 474-482.
Cowan, G., Pines, D., Meltzer, D. (1994). *Complexity: metaphors, models, and reality in SFI studies in the science of complexity*. Addison-Wesley.
Lansing, J. S. (2003). Complex adaptive systems. *Annual Reviews of Anthropology, 32,* 183-204.

2.2 Continuity in Health Care

Continuity of care has been identified as an essential element in the provision of quality health services (Cree, Bell, Johnson & Carrier, 2006; Guillford, Naithani, & Morgan, 2006; Jones et al., 2009). The benefits of continuity of care identified in literature include increased patient satisfaction (Boutlon, Tarrant, Windridge, Baker, & Freeman, 2006; Guillford, Naithani, & Morgan, 2007; Jones et al., 2009), fewer hospitalizations and fewer emergency department visits (Cree et al., 2006; Ionescu et al., 2007; Cheng, Hou, & Chen, 2011). However, with the ageing population and the growing complexity of the health care system, health professionals, patients and policy-makers are increasingly concerned about fragmentation of care in the Canadian health care system (Reid, Haggerty & McKendry, 2002).

Continuity of care has been identified by the Canadian Health Services Research Foundation, along with other national bodies and key stakeholders, as a priority for research in Canada (Reid et al., 2002). Research has examined continuity of care in a number of areas, such as primary care and mental health services (Boulton et al., 2006; Weinberg, Lusenhop, Gittell, & Kautz, 2007; Adler, Vasiliadis, & Bickell, 2010; Worrall & Knight, 2011). Due to its conceptual nature, continuity of care has also been combined in research studies using additional models and measures (King et al., 2008; Jones et al., 2009; Liss et al., 2011). However, few studies have

examined continuity of care in a public health care setting, in the context of the stroke care trajectory and through the complex adaptive systems lens.

With no common definition or method of measurement, the term continuity of care remains unclear (Gulliford et al., 2006; Jones et al. 2009; Adler et al., 2010). In an attempt to develop a common understanding of the term, Haggerty, Reid, Freeman, Starfield, Adair, & McKendry (2003) conducted a literature review identifying three elements of continuity in the provision of health care services: 1) Informational, 2) relational and 3) management continuity; each are discussed in detail below.

2.2.1 Informational Continuity.

Informational continuity is defined as the information that links both providers and health care events. This information may be communicated verbally between health professionals or in electronic or paper-based documents (Reid et al., 2002). The information is patient-focused and outlines patient medical conditions, values, and/or preferences (Haggerty et al., 2003). Informational continuity has been widely examined in nursing literature, with specific studies focused on communication of information between nurses during handoffs (Reid et al.; Alvarado et al., 2006; Street et al., 2011). Guidelines were developed and implemented, in one study, to improve the transfer of patient information between nurses. The guidelines were found to be effective and to improve the continuity of patient care (Alvarado et al.). Similarly, in one study, the transfer of information between clinicians during patient handoffs in hospital was examined using a client-centered approach. Information breakdowns during patient handoffs illustrates the importance of guidelines or interventions in order to ensure the seamless transfer of patient information (Abraham, Kannampallil, & Patel, 2012). The transfer of information in the mental health, and primary care setting has also been examined in literature, in a systematic review

focused on "continuity of care" (Reid et al.). For informational continuity, emphasis was placed on seeing the same provider over time, impacting not only the transfer of information, but also the coordination of care in these health care settings. The quality of the information being transferred is also important as it could impact the care the stroke survivor receives, as well as the family caregiving role. Family caregivers may be required to inform the health care providers of the stroke survivors' health status, in the absence of quality information. Few studies have examined the quality of the information being transferred by the health care providers to the family caregivers in health care settings.

2.2.2 Relational Continuity.

Relational continuity connects past and current health care with future care, ensuring a continuous relationship between health care providers and their patients across care settings (Haggerty et al., 2003). This might include settings such as acute care and rehabilitation, providing the patient with predictable consistent care across health care settings (Haggerty et al.). Relational continuity has been widely examined in primary care using both quantitative and qualitative methods of measurement (Reid et al., 2002; Boutlon et al., 2006; Adler et al., 2010) and refers to the relationship between a single patient and provider over time (Reid et al.). Many benefits are associated with a continuous patient-provider relationship that includes trust, a sense of commitment, and patient satisfaction (Reid et al.; Boutlon et al., 2006; Guillford et al., 2007; Jones et al., 2009). It also fosters informational continuity, as the exchange of information is between the patient and the same provider over time. However, for chronic health conditions, such as stroke, the patient receives care from multiple health care professionals and may be

required to transition across multiple care settings such as acute care to rehabilitation, potentially impacting patient care and safety (Reid et al.).

2.2.3 Management Continuity.

Management continuity, unlike informational and relational continuity, focuses on the overall vision of treating a specific health problem or chronic condition. Management continuity examines the provision and organization of health care services over time in order to enhance quality of life (Reid et al., 2002; Haggerty et al., 2003). Consistency of care is a recurring theme in continuity of care and stroke literature. Stroke survivors receive care from several health professionals in multiple health care settings (Arora & Farnan, 2008). As the health care system becomes more complex, patients experience a greater number of transitions across care settings (Cameron et al., 2008). The presence of management continuity supports smooth transitions and ensures the patient's changing needs are met to align with the overall vision of treatment for a particular condition, which may include multiple intervention methods from different facets of a multidisciplinary team. However, the transition from one health care setting to another has been identified as the point where management continuity is commonly interrupted, impacting the provision of quality, continuous care (Reid et al.). This lack of continuity may impact the flow of treatment, the patient's progress towards improved health, and the family caregiving role. Further research is needed to examine the impact management continuity has on the caregiving role in the stroke care system.

2.3 Stroke in Canada

With increasing life expectancy, an ageing population, and rising rates of obesity and diabetes, the incidence of stroke is projected to rise (PHAC, 2009). In Canada, four out of five people over 20 years of age have at least one or more risk factors for stroke (PHAC). Stroke is currently the third leading cause of death, and the leading cause of disability in Canada (PHAC). The incidence and prevalence of stroke remains unknown, however hospitalization data provides some indication of its impact on the Canadian population (PHAC). With nearly 300,000 Canadians living with the effects of stroke and an estimated 50,000 new cases each year (Smith et al., 2008), stroke costs the Canadian health care system $2.7 billion in direct costs and $4 billion in indirect costs annually (Teasell et al., 2008).

The death rate due to stroke has decreased over the past decade due to technological advances resulting in improved medical care. As a result, more Canadians who have had a stroke are living with its effects (PHAC, 2009). Research indicates that more than 40% of stroke survivors experience a moderate level of disability and another 15 to 30% experience severe disability (Smith et al. 2008). The type and extent of disability varies, but may include difficulty communicating, performing activities of daily living and personal care, as well as depression (Smith et al.). Stroke also affects the survivors' family and is therefore considered a 'family disease.' Family caregivers play an instrumental role throughout the stroke trajectory as provide a consistent source of support for the stroke survivor across health care settings (Visser-Meily et al. 2006; Kang, Kim, Sohn, Cohen & Paik, 2011).

2.4 Family Caregiving Role

Nearly one in four Canadians is currently providing care for a family member with a chronic illness (Canadian Healthcare Association, 2009). An estimated one in eight Canadian adults provide care to family members with chronic health conditions residing in the community (Cameron et al. 2008). With limited supports and services available in the community, family caregivers are expected to provide more than 80% of the care necessary to ensure their family member's health and well-being (Canadian Caregiver Coalition, 2008; PHAC, 2009). Family caregivers across all conditions, contribute an estimated $5 billion to the Canadian health care system annually by providing more than 21 hours of care per week (Gibson & Houser, 2007; Canadian Caregivers Coalition, 2008)

Family caregivers play an instrumental role throughout the stroke trajectory from the onset of stroke to recovery, by providing social support to the stroke survivor (see section 2.4), and as part of their role, they often feel required to act as system navigators as the current stroke care system in Canada lacks a 'common coordinating system' (Cameron et al., 2008). For many caregivers, navigating the stroke care system is a new and challenging experience. Since stroke is typically sudden in onset, its effects are unpredictable and diverse. As such, patients and caregivers are often unprepared for the outcomes (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Lutz & Young, 2010). As the system navigator, family caregivers obtain supports and services for the care recipient.

In addition to fulfilling their caregiving responsibilities, family caregivers also balance employment demands (Canadian Healthcare Association, 2009). The 2004 National Alliance for Caregiving survey found that most family caregivers were employed full-time in addition to providing care for an aging family member (Wagner, 2006). Fulfilling both their caregiving and

work-related demands comes at a price, as more than 25% of family caregivers reported experiencing challenges balancing both demands (Canadian Caregivers Coalition, 2008). Some family caregivers were required to modify their work hours or leave work altogether, to allow them the ability to meet their caregiving demands (Wagner; Rajnovich, Keefe, & Fast, 2005). This places family caregivers at increased risk of loss of income or job related costs, such as the loss of advancement (Fast, Niehaus, Eales, & Keating, 2002). It is estimated that caregivers caring for a chronically ill family member experience a financial loss of $1,034,117 over a lifetime (Fast et al.). In an attempt to balance the multiple demands, family caregivers may also be required to put their personal lives on hold, engaging in less social or leisure activities (Greenwood, & Mackenzie, 2010; Wagner).

2.5 Social Support

The provision of social support by family caregivers' has been widely examined in the stroke literature (Coombs, 2007; Silva-Smith, 2007; Gaugler, 2010; Le Dorze & Signori, 2010; Lutz & Young, 2010). However, the provision of social support in a formal health care setting such as the stroke rehabilitation system in Ontario has not been examined. House (1981) defines social support as the "functional content of relationships" (Bourgeault et al., 2010, p.186) and has categorized the concept into four types of support: Informational, appraisal, emotional and instrumental.

Informational support is defined as the information that is provided in advance of or during times of need or stress. This might include advice, suggestions or other forms of information that will help the care recipient during times where decision-making is necessary (Bowsher, Maloney, Lillis, 1997; Bourgeault et al., 2010). Information is generally provided to

the family caregiver and may be in the form of information pamphlets, booklets, or provided verbally and helps the family caregiver to navigate the healthcare system. Appraisal support is similar to informational support; however, it involves the communication of information for self-evaluation (Langford, Bowsher, Maloney, & Lillis, 1997). Other forms of appraisal support include the provision of feedback, or social comparison (Bourgeault et al.).

Emotional support is thought to be the most important category of social support as the family caregiver shows feelings of love and compassion to the care recipient which may help the care recipient cope with stressful situations (Langford et al., 1997). Other forms of emotional support provided by the family caregiver might include trust and empathy (Bourgeault et al., 2010). Although the family caregiver providing the support may show feelings of love or admiration, instrumental support is distinct from emotional support as it includes providing concrete aid or assistance to the person in need (Langford et al., 1997). This might include assistance with personal care or activities of daily living such as scheduling and attending medical appointments, providing transportation, providing financial management, and/or going grocery shopping (Cameron & Gignac, 2008). The family caregiver may provide the stroke survivor with a number of these activities along the continuum of stroke care.

2.6 Costs of Caregiving

Caregiving for a family member with a chronic illness can have both negative and positive outcomes for the family caregiver. In addition to employment related costs, some family caregivers experience physical health consequences. A survey conducted on the physical well-being of caregivers revealed that caregiving had adverse effects on the caregivers' overall health (Fast et al., 2002). Compared to family caregivers who were not employed, the employed family

caregivers were more likely to report changes in sleep patterns and adverse physical health effects. Women were also twice as likely to report that their health was adversely affected (Fast et al.). Other health consequences identified in literature include depression, feeling overwhelmed, terrified, and stressed, as well as an increased risk of coronary heart disease and other chronic illnesses (Alexander & Wilz, 2010; Greenwood & Mackenzie, 2010; King, Ainsworth, Ponen, & Hartke, 2010; King, Hartke, & Houle, 2010; Levine, Harper, Peist, & Gould, 2010; Saban, Sherwood, DeVon, & Hynes, 2010).

Caregiving for a family member also comes with positive outcomes. The need to expand research to examine the positive aspects of caregiving has been acknowledged in literature (Cohen, Colantonio, &Vernich, 2002; Peacock et al., 2010). In at least three studies, family caregivers felt that fulfilling the role as caregiver strengthened their relationship with their loved one, and provided them with the opportunity to give back (Fast et al., 2002; Gaugler, 2010; Peacock et al., 2010). Other positive outcomes associated with caregiving are the feelings of companionship and fulfillment (Cohen et al.). However, the caregiving role is dynamic and the environment in which the caregiver provides care may impact the outcomes associated with caregiving.

2.7 The Stroke Rehabilitation System

The stroke rehabilitation system is a key component in the continuum of stroke care. According to the World Health Organization, rehabilitation is defined as “the combination and collaboration of medical, social, educational and vocational resources aimed at optimizing a person’s functional independence” (Talbot et al., 2004, p.54). Rehabilitation is intended to reduce the stroke survivor’s level of disability supporting improved quality of life (Talbot et al .;

Aziz, 2010). In Canada, health care is to a large degree publically funded, however since the provinces are responsible for ensuring the delivery of medical care, delivery may vary depending on resource availability and the population's needs (Teasell, Meyer, Foley, Slater, & Willems, 2009). Stroke rehabilitation services are also primarily publically funded; however, private programs are available once the stroke survivor returns home (Cott, 2004).

Publically funded programs include inpatient, ambulatory and home-care services (Cott, 2004). Inpatient rehabilitation occurs when the patient resides in the hospital or facility (Duncan et al. 2005). Patients with mild strokes are less likely to be admitted as an inpatient, as it is typically geared for those who have had severe strokes (Teasell et al., 2009). Ambulatory care is delivered on an outpatient basis where patients attend day programs at rehabilitation facilities. Home rehabilitation care, on the other hand, is rehabilitation that is provided in the patient's home (Duncan et al. 2005). The need for these services depends on the severity of stroke, the patient's stage of recovery, as well as personal finance resources. Ambulatory care and home-care programs are also available as private programs, should the stroke survivor require additional care (Cott).

In the late 1990's stroke was described as "Canada's forgotten disease" (Black, Lewis, Monaghan, & Trypuc, 2003, p. 44). It was regarded as a hopeless condition, which had life-altering effects, but little could be done to mitigate its impact (Black et al.). With advances in technology and new drug treatments, the overall outlook on stroke evolved. Rehabilitation services, in particular, were traditionally focused on inpatient programs. However, with a shift from hospital to community care, a greater number of rehabilitation programs emerged in the community setting, placing a greater importance on family caregivers (Ontario Ministry of Health and Long-Term Care [OMHLTC], 2000).

Despite these important developments, like many provinces in Canada, Ontario has experienced challenges in the delivery of stroke rehabilitation (Teasell et al., 2009). In 2000, the Ontario Ministry of Health and Long-Term Care released a report identifying gaps in the stroke continuum of care. The gaps that were identified in the stroke rehabilitation system included delays in care, inadequate duration of care, lack of coordination across the rehabilitation continuum of care, lack of informational and educational supports and uneven distribution of specialized services across communities (OMHLTC, 2000). In an attempt to address these gaps as well as other gaps in the stroke care system, the *Ontario Stroke Strategy*, an "integrated service delivery model," was established to "enhance stroke care across the care continuum" (Cameron et al., 2008, p. 2638). The Ontario Stroke Strategy is based on the following four principles: Comprehensive, integrated, evidence-based, and province-wide system (Stroke Evaluation Advisory Committee, 2005). A comprehensive and integrated stroke care system is a system that aims to improve access and delivery of services, and link service providers across the continuum of care. A system that is evidence-based ensures empirical evidence is used in the provision of care. Finally a system that is province-wide ensures all Ontarians will benefit from the Ontario Stroke Strategy's initiatives. These principles guided the implementation of the strategy and led to the development of infrastructure, improved educational initiatives, and funding among others (Stroke Evaluation Advisory Committee, 2005).

The Ontario stroke rehabilitation system has improved since the establishment of the *Ontario Stroke Strategy*. Teasell et al. (2008) identified deficiencies in the current system that, if improved, could result in an optimal stroke rehabilitation system. Firstly, interdisciplinary stroke rehabilitation units have been associated with improved health outcomes, however patient access is limited. With the establishment of a greater number of interdisciplinary stroke rehabilitation

units, rehabilitation services will be better geared to the patient's needs improving health outcomes, and reducing the length of hospital stays. Secondly, patients experience delayed access to inpatient rehabilitation services due to a shortage of beds. Evidence shows that early access to rehabilitation services maximize recovery (Gregory, Edwards, Faurot, Williams, & Felix, 2010; Hwang et al., 2009; Teasell et al.; Wallin, Talvitie, Cattan, & Karppi, 2007; Black et al. 2003). Thirdly, patients receive limited amounts of dedicated rehabilitation time, as the majority of the time is spent completing assessments or other documentation. Finally, outpatient therapy is essential for patients who have transitioned home from hospital. Outpatient programs are typically eight weeks in length, for two hours a day, three times a week. Unfortunately, outpatient hours are usually reduced or eliminated due to shortages impacting patient recovery (Teasell et al.). Although these deficiencies were identified, the authors of this study do not define the term 'deficiency' in the article. However, an improved understanding about how 'deficiencies' or gaps in the stroke rehabilitation system impact family caregivers' abilities to fulfill the role of system navigator and support provider as the stroke survivor transitions across care settings is needed.

2.8 Transitions in the Continuum of Care

Transitional care is defined as a set of actions that are intended to ensure patients experience continuity of care; continuous and coherent care between health care settings (Byrne, Orange, & Ward-Griffin, 2011; Coleman et al., 2005; Haggerty et al., 2003). Continuity of care in the stroke rehabilitation system has been impacted by the increased complexity of the health care system resulting in a greater number of transitions between health care settings (Teasell et al., 2008).

An understanding of family caregivers' experiences navigating the stroke rehabilitation system, in the context of continuity of care, is necessary in order to improve the current system and inform future interventions and policies. Research has examined family caregivers' experiences caregiving for a stroke survivor as they transition across the stroke trajectory (Cameron & Gignac, 2008; Burnman, 2001). A literature review conducted by Cameron and Gignac, examined the experiences of family caregivers of stroke survivors across the continuum of stroke care. The authors of this study developed a model depicting the caregivers' experience and needs over time as the stroke survivor transitions across care settings. The phases include event/diagnosis, stabilization, preparation, implementation and adaptation.

The event/diagnosis and stabilization phases include the hospitalization, treatment and stabilization of the patient. During this time, family caregivers focus on the impacts the stroke has had on their family member, often looking to health care professionals for information and guidance (Cameron & Gignac, 2008). The preparation phase occurs when the stroke survivor is receiving rehabilitation, just prior to returning home. As discharge approaches, family caregivers become increasingly worried about their new role as caregiver and often turn to health professionals for informational support and training (Cameron & Gignac). However, family caregivers report receiving insufficient information, a lack of support from health professionals and difficulty accessing resources (King et al., 2010; King & Semik, 2006). The caregivers' desire for training and support during this phase aligns with the findings of Silva-Smith (2007) who modeled the process by which family caregivers restructure their life following their family member's stroke. The family caregiver's desire for training and support is also reflected under informational support in House's (1981) Theory of Social Support.

The final two phases, implementation and adaptation, occur when the stroke survivor returns home. The implementation phase is a time of adjustment as the care shifts from the health professionals to the family caregiver. This is a time of learning for the family caregiver, as they try to apply any skills learned while the stroke survivor was at the rehabilitation facility (Cameron & Gignac, 2008). Grant et al. (2004) identifies safety as the most frequent challenge experienced by family caregivers during this time. In contrast, King et al. (2010) found interpersonal disruptions the most stressful, due to communication problems, role reversal and intimacy issues. During the adaptation phase, the family caregiver becomes more comfortable with the caregiving routine, and more objective about their feelings as they adjust to their new role (King et al., 2010; Cameron & Gignac; Grant et al. 2004).

During these two phases, the family caregiver is also often responsible for scheduling medical appointments, and coordinating community services providing the stroke survivor with instrumental and emotional support (Cameron & Gignac, 2008). As the system navigator, the family caregiver locates, evaluates, and integrates knowledge and information (Byrne et al., 2011). However, coordinating services can be a complex process as there is often little or no continuity in homecare and/or rehabilitation services, resulting in feelings of abandonment and isolation (Cott et al., 2007; Ellis-Hill et al, 2009). This impacts the stroke survivor's momentum toward recovery, as rehabilitation is often seen by stroke survivors and their family caregivers as a passage in which the stroke survivor transitions away from disability (Cott et al.).

Although this framework illustrates the family caregivers' experiences and support needs along the continuum of care. Further research is needed to examine the factors that impact the caregiver's desire for social support. A better understanding of the balance between care provided by health professionals and family support in the community setting is also necessary.

This will help inform future interventions such as those to assist family caregivers with navigation along the continuum of care (Rittman et al., 2007).

A study conducted by Egan et al. (2010) described and evaluated the Community Stroke Navigation service developed by the Stroke Survivors Association of Ottawa. Following a pre-intervention assessment, a registered occupational therapist interviewed each participant (n=41) and care partner (n=32) to determine their concerns and develop a plan of action. The plan of action was developed using both the interview and questionnaire data and included a number of services such as coaching, case coordination and education. Four months after the intervention, the care dyads (stroke survivor n=35; care partner n=26) participated in an assessment of the navigation service. The Community Stroke Navigation service had no impact on community reintegration of the care partner but was shown to be effective for the stroke survivor.

2.9 Gaps in Literature

As there is a shortage of health professionals in the healthcare system, and a shift from hospital to home, the voluntary sector, more specifically, family caregivers, play a pertinent role in the healthcare system by providing their family member with support throughout the care trajectory. The current research study addresses a number of gaps in the literature by examining family caregivers' experiences providing social support to the stroke survivor, in addition to navigating the stroke rehabilitation system during the transition home from a rehabilitation facility. Based on the literature review, there is a lack of information on continuity of care in a public health care system and along the stroke care trajectory. More specifically, research studies have not yet examined all three components of continuity of care, as defined by Haggerty et al. (2003), in the stroke rehabilitation system in Ontario. Research studies have also yet to

empirically examine continuity of care using a complex adaptive systems approach. Another gap is the need to examine the quality of information being transferred by the health care providers to the family caregivers and how management continuity impacts the caregiving role. As the stroke survivor transitions across care settings, the family caregiver provides care and is the stroke survivor's advocate in the support of their health and wellbeing. However, attributes in the stroke rehabilitation system not only impact the care being provided to patients, but may also impact the family caregiver's ability to fulfill their role as system navigator and support provider. Further research is needed to examine the complexities of how continuity of care and social support interact to influence family caregivers' experiences navigating the stroke system.

Another gap in literature is the lack of research on the provision of social support by family caregivers in the formal health care setting such as the stroke rehabilitation system in Ontario. Further research is necessary to examine the balance between care provided by health professionals and family caregivers throughout the stroke trajectory; a focus on this balance in care in the community is also needed (Cameron & Gignac, 2008). Family caregivers are important contributors in both formal and informal health care settings. Should family caregivers be unable to provide care to the stroke survivor, the health care system would not be able to fill the void due to a lack of capacity. By gaining a better understanding of the family caregivers' experiences during different transitions, policies can be developed or revised to better support family caregivers as they provide care for their family member in the stroke healthcare system.

CHAPTER 3: METHODOLOGY

In this chapter, the methodological aspects of the study are discussed: the research design, methods of data collection, sampling techniques, and analysis.

3.1 Research Design

This exploratory study used a qualitative approach to gain an understanding of the family caregivers' perceptions and experiences navigating the stroke rehabilitation system. This approach was selected as it provides a means of viewing an event through the eyes of the population being studied, as they experience it (Taylor, 1998; Gibb, 2002). Detailed descriptions of the experience are used to further our understanding, and ability to analyze the experience (Gibb). In order to understand the caregiving experience, the theory of continuity care was applied, in combination with a complex adaptive systems lens, to examine the transition home from hospital or stroke rehabilitation facility, and in some cases back to hospital.

3.1.1 Research Objectives.

In this exploratory study, the family caregivers' micro level needs as they navigate the stroke rehabilitation system, during the transition home from a stroke rehabilitation facility were examined, using a complex adaptive systems lens. The perceived barriers and facilitators, in the context of continuity of care, that impact family caregivers' abilities to navigate the stroke rehabilitation system were also examined. Further, improvements to macro processes in the stroke rehabilitation system, in order to better support the micro aspects were identified. Additional outputs from this research include a new systems model to depict the family caregiving experience during the transition from rehabilitation to home.

3.2 Research Site

Data collection took place at a large in-patient stroke rehabilitation facility with 90 beds available to stroke patients at the facility.

3.3 Data Sources

Upon receiving ethics approval, convenience sampling was used as the method to recruit caregivers for this study. To be eligible for this study, the caregivers were required to be over the age of 18 and able to understand and speak English, and self-identify as the primary caregiver for the stroke survivor who is a family member. A family member could include a spouse, companion, child, or friend. The caregiver must also have been present while the stroke survivor was receiving rehabilitation and were providing care for the stroke survivor at home at the time of data collection. At the time the caregivers participated in the study, the stroke survivor must have been living at home for four to twelve weeks post-discharge from a rehabilitation facility.

The family caregivers were contacted within 48 hours of being approached by the social worker at the rehabilitation facility (see Appendix F and G for recruitment scripts). If the family caregivers met the inclusion criteria and decided to participate in the study, they were scheduled for an interview, during a time that was most convenient for them. The interviews were conducted four to twelve weeks after the stroke survivor was discharged home from the rehabilitation facility. Participants had the option of either having the interview by phone, or in person. Caregivers of stroke survivors who were no longer receiving inpatient rehabilitation and were residing in the community were also eligible to participate in the study as long as they met the inclusion criteria outlined above (see Appendix E for recruiting flyer). The participants who

agreed to participate in the study, were provided with a consent form, which they were asked to sign and send or provide at the time of the interview.

3.4 Data Collection

In order to gain an understanding of the caregivers' experiences providing care to the stroke survivor during the transition home from a rehabilitation facility, as well as navigating the stroke rehabilitation system, interviews were conducted four to twelve weeks after the stroke survivor was discharged home from the rehabilitation facility.

Qualitative interviewing, as a method of data collection, provides insight and an understanding of experiences, processes, or behaviours (Rowley, 2012). Interviews are either with individuals, or with groups (Rowley) however, for the purpose of this study, individual interviews were the focus. Individual interviews are "more than just an interesting conversation (Bolderston, p.67, 2012)." Discussions are often focused on a narrow range of topics, and grounded in the interviewees' first hand experiences, providing the interviewees the opportunity to express themselves in a private environment (Bolderston, Rubin & Rubin, 2005). The rapport developed between the researcher and interviewee also encourages conversation and supports further discussion (Bolderston).

Individual interviews are increasingly being used to examine the family caregiving role and experiences with the health care system, in health services research (Crooks, Williams, Stajduhar, Allan, & Cohen, 2007; Chappell & Dujela, 2009; Funk, Allan, & Stajduhar, 2009; Funk, Stajduhar, & Cloutier-Fisher, 2011; Stajduhar et al. 2011). Types of individual interviews used in research include face-to-face, telephone, or e-mail/internet interviews. Face-to-face interviews, a more traditional method of interviewing, occur in person between the researcher

and interviewee. However, telephone and e-mail/internet interviews are forms of remote interviewing, which are useful when collecting data from participants who are not local, or are at a distance (Bolderston, 2012). These methods of interviewing are often more cost and time effective, and can be as productive as the more traditional method of interviewing (Bolderston).

Interviews are also classified based on their level of structure: structured, semi-structured and unstructured. Structured interviews are similar to questionnaires, where the questions are asked in an orderly fashion providing specific answers, whereas unstructured interviews encourage the participant to speak about a theme or topic, and the questions are adapted accordingly (Rowley, 2012). Semi-structured interviews consist of a common set of questions, like structured interviews, but offer the flexibility to probe for more information or clarification (Barribal & While, 1994). This method of interviewing is commonly used in health research, as it allows for the exploration of participant opinions, and experiences, on sometimes very sensitive issues (Barribal & While; Crooks, Williams, Stajduhar, Allan, & Cohen, 2007; Rowley).

In this study, a total of 14 family caregivers were recruited to participate in a 30-45 minute interview. Interviews were conducted in person, or by telephone using a semi-structured interview guide (see Appendix C). A semi-structured interview guide was selected, as it supports the exploration of the family caregiver's experience and perceptions as they journey though the stroke rehabilitation system, and fulfill the role of system navigator and support provider for the stroke survivor. Prior to the interview, participants were provided with the consent form (see Appendix H) and a summary sheet defining the theory of continuity of care (see Appendix D).

3.4.1 Face-to-Face and Telephone Interviews.

Depending on the participant's preference, interviews were either conducted in-person or over the telephone. The in-person interviews were conducted in a location that was private, to

ensure the participants felt comfortable discussing their experiences openly. Locations included their house, or at the rehabilitation facility. When the family caregiver selected their house, the stroke survivor did not join the interview, to ensure open discussion of experiences. The telephone interviews were scheduled and conducted at times of the participants' choosing.

Prior to beginning each interview the consent form was reviewed with the participant. At this time, the participant had the opportunity to ask any questions before the interview. The participant was then asked to complete the demographics questionnaire (see Appendix I) and respond to semi-structured questions from the interview guide (see Appendix C). One question in the interview guide required the use of the summary sheet defining the theory of continuity of care (see Appendix C; see Appendix D). The participant had the opportunity to ask questions throughout the interview, and they had the option of not responding to questions they preferred not to answer.

I conducted all 14 interviews. With each participant's permission, the interviews were audio recorded. If the participant did not consent to be audio recorded, interview notes were taken during the interview. Further, all family caregivers were assigned participant numbers in order to ensure anonymity. In order to ensure participant confidentiality, all electronic files were password protected, and all paper documentation (consent form and demographic information) was kept in a locked cabinet.

3.5 Data Analysis

Saturation of interview data was reached after 14 interviews. It was decided through consensus that we had reached saturation, as we were no longer hearing new information from

the family caregivers. All interviews were transcribed verbatim. I transcribed 5 interviews, while the remaining 9 interviews were transcribed by a professional transcription service. All the interviews were double-checked for accuracy prior to coding.

Coding is the process of identifying and categorizing data (Gibbs, 2002). Interview notes and transcripts were coded using NVivo 9, a qualitative data management software. Direct coding was conducted using the elements of continuity of care. Additional codes (parent and child nodes) were developed inductively by the principal investigator and thesis supervisors by reading through each coding report and identifying more specific codes. Prior to coding interview data, all codes were agreed upon and definitions for each node were developed (see Appendix J for coding tree). Any text that could not be categorized was given a new node. In order to enhance rigour, the thesis supervisors reviewed two coded transcripts. I met with my thesis supervisors on numerous occasions to discuss the coding of interview data.

3.5.1 Content Analysis.

Content analysis is a qualitative method of analysis that focuses on the content and meaning of text (Hsieh & Shannon, 2005). The three types of content analysis include, directed, undirected (commonly called conventional), and summative.

Directed content analysis was used as the method of analysis, as it provides the opportunity "to validate or extend conceptually a theoretical framework or theory." (Hsieh & Shannon, p. 1281, 2005). This study extends the theory of continuity of care, by examining it through the complex adaptive systems lens. Once the narrative data was coded, directed content analysis was conducted to identify emergent themes related to continuity of care, during the transition from a rehabilitation facility to home. Directed content analysis was conducted with the assistance of a research assistant in the identification of preliminary themes. Frequencies and

supporting quotes were provided for each theme (Hsieh & Shannon). These themes were refined, and the complex adaptive systems lens was applied. The results from the study, and theories of continuity of care and complex adaptive systems informed the development of the theoretical framework presented in section 5.2. The demographic data collected during the interviews was also combined and provided context to the results of the study. Further, the ongoing discussions amongst the research team throughout the analysis process enhanced rigour.

CHAPTER 4: RESULTS

In this chapter, the family caregiving experiences of continuity of care are described using the complex adaptive systems lens. Complexity is discussed for the overarching theme and each emergent sub-theme. Further, the barriers and facilitators to continuity of care are presented. As shown in figure 1 the overarching theme focused on inter and intra-relatedness between the types of continuity. Each theme is discussed below (section 4.2) with complex adaptive systems used as a lens to articulate the complexity and interrelatedness of each theme.

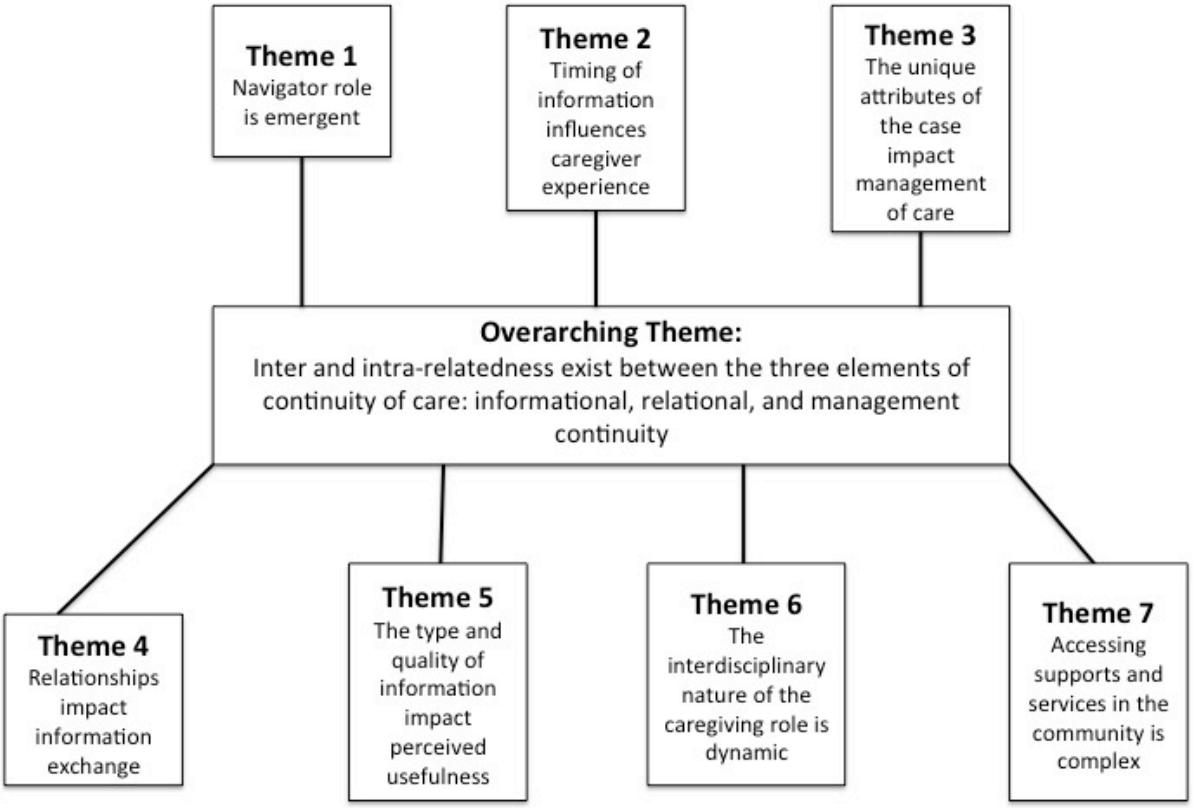

Figure 1. Emergent themes in the study

4.1 Mapping the Family Caregiving Experience using Complex Adaptive Systems

In this section, Table 3 maps the family caregivers' experiences navigating the stroke rehabilitation system during the transition home from a rehabilitation facility, using the complex adaptive systems lens. Each tenet of complex adaptive systems (see Table 2 for definitions of complex adaptive system tenets) was applied to the family caregiving experience of navigating the stroke rehabilitation system during the transition home from a rehabilitation facility, using macro and micro-levels of analysis. For the purpose of this study, the micro-level focused on the caregiver-patient dyad as the unit of analysis, whereas the macro-level examined anything (i.e. policies, procedures, information, services etc.) outside of the micro-level unit of analysis. The following examples in Table 3 below illustrate the interaction between complex adaptive systems and the family caregivers' experiences navigating the stroke rehabilitation system at the macro-level. Section 4.2 provides a micro-level analysis, and discusses the interacting complexities.

Table 3. A macro-level analysis of the family caregiving experience using complex adaptive systems

Tenets of Complex Adaptive Systems	**Application to the Caregiving Experience**
Non-linear processes	Changes to one area impact other areas in direct and indirect patterns. For example, early discharge from the stroke rehabilitation facility impacts the outpatient physiotherapy wait-list, and access to those services.
Self-organization	The actor's ability and tendency to adapt to the complex nature of the system. For example, professionals bending protocols or bringing in non-traditional resources.

Emergent behaviour	Behaviours that emerge as a result of the dynamic and complex nature of the system. For example the way an actor adapts to a specific event such missing information.
Feedback loops	Transfer of knowledge or information in response to an experience. For example information and knowledge was fed back into the system from the caregivers, contributing to management of care.
Co-evolution	The role of each actor changes according to the unique needs and attributes of the case. For example, the development of increased awareness of procedures and protocols at the facility and during transitions.
Requisite variety	The unique characteristics of the case, or actors involved, influence the changing context in continuity of care. For example, unique attributes such as past experiences, beliefs, medical knowledge, and social networks, influenced case management.
Connectivity	The relationships between actors in the system. For example, the relationships between actors involved in the case impact communication and information exchange.
Simple rules Non-discrete boundaries	The discovery of rules and boundaries within the system. Examples of rules and boundaries include, facility policies, procedures, and protocols, such as discharge procedures.

4.2 Emergent Themes

In this section I present the overarching theme and sub-themes that emerged from the study. Complex adaptive systems was used at the micro-level to analyze and articulate the details of each sub-theme.

4.2.1 Overarching Theme

- **Inter and intra-relatedness exist between the three elements of continuity of care: informational, relational, and management continuity**

Inter-relatedness is the relationship between the elements of continuity (i.e. management and informational continuity), whereas intra-relatedness exists within an element of continuity of care (i.e. informational continuity) (see Figure 2). Because all elements of continuity interact and relate to one another, individual elements of continuity should not be studied in isolation. In this study, relational continuity functioned as the back drop to informational and management continuity.

Relationships were described by the family caregivers in the study as providing a safety net; it was important to have someone to turn to for help and support. The quality of communication and family caregiver's expectations influenced the various relationships. Information was discussed in the context of the family caregiver's ability to coordinate tasks, such as pulling and pushing information to and from the health professionals and stroke survivor. Management was described by the family caregivers as how well the system operates in its ability to provide the stroke survivor with the necessary care, such as follow-up care post-discharge, and access to supports and services (i.e. outpatient physiotherapy). Throughout the

discussions on continuity of care, relationships were identified as having a key role in informational and management continuity.

Relationships, specifically the ones between the family caregiver and health professionals, impacted the exchange of information. This was also a main theme in the study. The relationship between the stroke survivor and health professionals, and the one between the stroke survivor and family caregiver also emerged as types of relationships in the study. However, the relationships between the family caregiver and health professionals will be used to illustrate the inter-relatedness that exists between informational, management and relational continuity.

During the transition home from a rehabilitation facility, the relationships between the family caregiver and health professionals influenced the family caregiver's ability to provide care to the stroke survivor, and navigate the stroke rehabilitation system. Health professionals were an informational resource for the family caregivers in the study. Many family caregivers pulled information from and pushed information to the health professionals about the stroke survivor's health, facility procedures and protocols such as discharge procedures, and supports and services in the community such as supports groups and exercise programs. The type and amount of information exchanged was impacted by the family caregiver's perceived comfort with the health professionals.

Family caregivers reported both positive and challenging experiences when interacting with health professionals who were involved in the stroke survivor's care. Communication styles, such as the use of layman terms or body language, impacted the family caregiver's perceptions of comfort, and either constricted or supported the flow of information. This also impacted their perceptions of continuity of care in the stroke rehabilitation system during the

transition home from a rehabilitation facility. Many family caregivers felt comfortable and found the interaction positive, whereas others found the interaction more challenging and relied on other sources such as the Internet or social support networks (i.e. friends, family, and work colleagues) for information. As described by one caregiver who did not feel comfortable with one of the health professionals, *"Just so it was like okay--you took the piece of paper and just body language said thanks very much I'm not even going to bother asking you any questions. [The health professional] just gave that perception." (P1).* Another caregiver described positive relationships with a health professional, which facilitated good communication:

> *"So I was really concerned when I came home and then I – the afternoon I came home and I emailed (the nurse) and I said we're home, but I'm really upset about his blood sugar I don't know how I'm going to manage this you know… That evening it was a Friday evening I think and she phoned me. So she's there I mean I could email her on the weekend and she'll call me, now who else would do that you know I mean it's really great." (P14)*

It is important to acknowledge the importance of relationships in information exchange as it has a direct impact on the family caregiver's ability to navigate the stroke rehabilitation system, more specifically to coordinate and access supports and services for the stroke survivor. This ultimately impacts the management of the stroke survivor's care during the transition home from a rehabilitation facility. The family caregiver's perceived comfort impacted their relationship with the health professionals involved in the stroke survivor's care and influenced information exchange and management of care. This example illustrates the inter-relatedness that exists between informational, relational, and management continuity. The sub-themes below further detail this overarching theme.

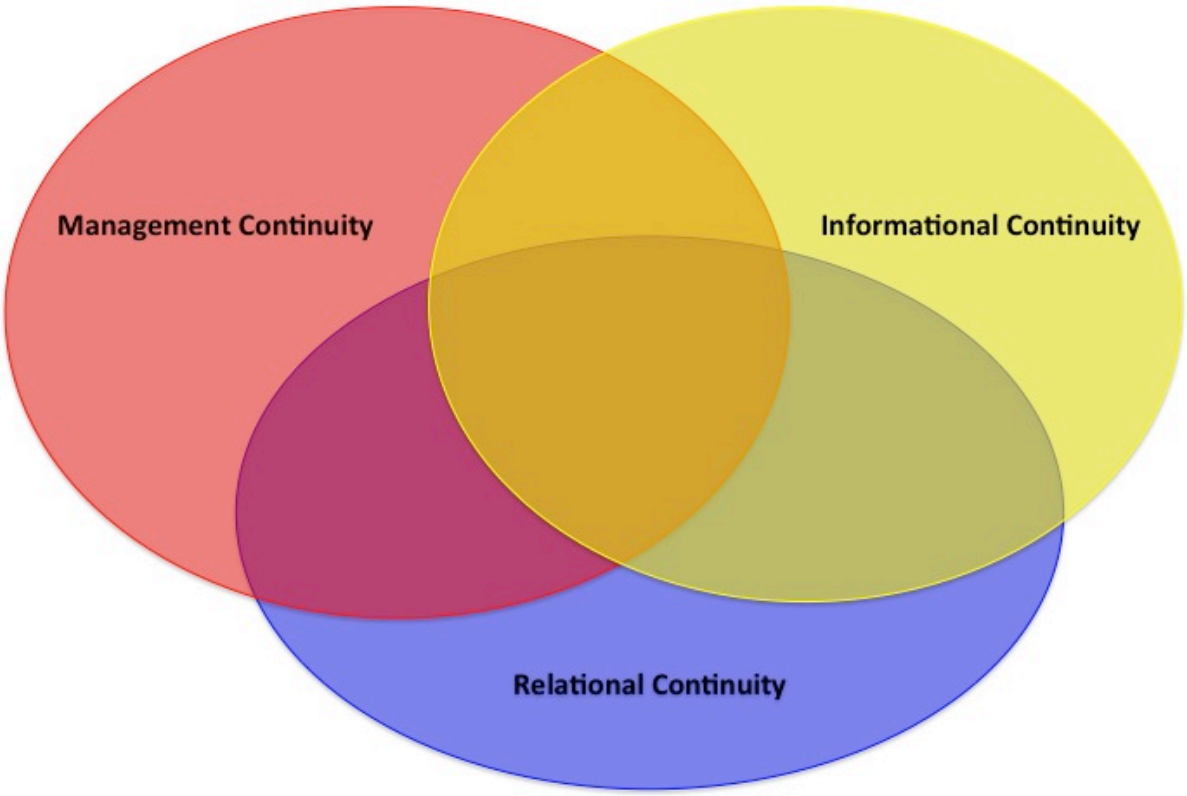

Figure 2: The inter and intra-relatedness between the three elements of continuity of care

4.2.2 Sub- Themes.

1. The navigator role is emergent

Family caregivers in the study described their role as system navigator during the transition from rehabilitation to home. This role emerged according to the gaps in the provision of care and support in the system. As the context changed, the family caregivers identified dysfunctions in the system, making the navigator role more apparent and clear. This emergent role is dynamic. Once the stroke survivor returned home, the family caregiver was responsible for coordinating supports and services in the community setting, in addition to providing care.

As part of the navigator role, the family caregivers were an informational link for the health professionals involved in the stroke survivor's care. They described pushing information to and pulling information about the stroke survivor's health status or care, and/or services and supports, from the health professionals. However, some lost their desire … *"So I kind of lost my desire to ask more questions at that point I felt tired of pulling the information out versus the information being offered." (P7)* Many family caregivers also advocated for the stroke survivor at the rehabilitation facility, and fulfilled administrative roles and responsibilities such as scheduling medical appointments, or filing and organizing paperwork.

> *"So yeah so you have to keep—you have to be on top of things and say "Well look is that still on or is that still off?" and I had to cancel one appointment and so— you have to keep tabs to make sure that you know everything's going according to plan because sometimes someone might forget to call so and so..." (P3)*

The complex nature of the stroke rehabilitation system influences the family caregiver's role as system navigator. Non-linear processes, such as the timing of information, affect the family caregiver's ability to push or pull information, schedule appointments, and advocate for the stroke survivor. Non-linear processes also create emergent behaviours, as the information needs are not always known or defined requiring the family caregiver to adapt to the information they receive, impacting their role as system navigator. Formal processes, such as facility procedures and protocols, govern when information is provided, and often increase complexity at the micro-level. Several family caregivers in the study used their social support networks as a source of informational support, and drew from their past experiences and/or medical background in order to manage this complexity. The family caregiver's relationship with the stroke survivor, and health professionals involved in the case, also impacted the exchange of information. For

example, family caregivers who experienced poor relationships with the health professionals lost their desire for information, and relied on other informational sources such as the Internet.

2. Timing of information influences caregiver experience

Family caregivers described receiving information from the health professionals upon the stroke survivor's admission to the health care facility and/or at discharge. However, these are both times of great adjustment for both the family caregiver and stroke survivor. The types of information provided to the family caregiver include information about stroke, supports and services in the community, the stroke survivor's health and progress, as well as information about the facility and rehabilitation program. Some family caregivers found this information to be useful, but many found the deluge of information overwhelming and did not have the time to review it all, or found it difficult to absorb all at once.

> *"When a person has a stroke, within the first week, you are given a ton of printed material and you are talked to, but you are going through a big drama, right. You don't know if your wife is going to live or die, you don't know if she is going to walk, so there is a lot going on that way. And yes you are given information, they give you tons of information. The only problem is by the time everything has settled down you find out, hey I could have used them." (P2)*

The complexity at the macro-level influences the timing of information and the degree of complexity experienced by the family caregiver at the micro-level. Formal processes such as facility procedures and protocols, which govern when information is provided to the family caregiver, impact continuity of care. However, this information is often not provided at the specific time of need, influencing the family caregiver's ability to self-organize and adapt to their role as system navigator. Connectivity, specifically the relationships between the health professionals and family caregiver, also impacts when information is provided. For example,

relationships that were perceived as positive helped to decrease the negative impacts of system complexity at the micro-level, supported timely flow of information, and supported the navigator role. This highlights the inter-relatedness between the timing of information and the family caregiver's emergent role as system navigator.

3. The unique attributes of the case impact management of care

Attributes specific to each case, such as the stroke survivors' mental, physical (functional), and emotional needs, and the family caregiver's own health and well-being, impact the provision and management of care. The family caregiver's previous caregiving experience and/or medical background also influence the caregiving role. *"Well you know I think maybe my situation was a little bit different because I did have a nursing background. And I was able to handle a lot of things that I could see though for a lot of people it would just be too traumatic for them even to entertain." (P14)*

Further, social networks such as friends, family, neighbours, and co-workers provided the family caregiver with social support. One family caregiver described receiving assistance with the navigation of the stroke rehabilitation system:

> *"The girl I work with was my information source because she had gone through it and she has I won't call it fully recovered you know still has her issues and she was at Bruyère. I went to her for my first source I would say how did you find this, where did you find that, what did they do here." (P7)*

The unique attributes of the case influence the family caregiving role during the transition home from a rehabilitation facility. For many family caregivers in the study, unique attributes such as past experiences, medical knowledge or caregiver health influenced the provision of care by the family caregiver, decreasing or increasing the complexity experienced at the micro-level.

These attributes illustrate requisite variety in the system, and interact with system components at the macro-level, such as policies and protocols, influencing complexity. Further, requisite variety of the case cross cuts the other emergent themes, to influence the family caregiving role and experience navigating the stroke rehabilitation system, during the transition home from a rehabilitation facility.

4. Relationships impact information exchange

The relationships between the family caregiver and health professionals involved in the stroke survivor's care, influenced each caregiver's experience, and were influenced by the family caregiver's comfort levels communicating with the health professionals. Family caregivers had mixed experiences providing the health professionals with feedback, as well as their ability to retrieve information. As described by one family caregiver, *"And the hardest part for me was getting information, I felt that I was inconveniencing [the health care professional] … [it] was extremely negative." (P1)*

The patient's ability to adapt to the culture and expectations at the facility also impacted the communication of information and relationship with the family caregiver and health professionals involved in their care. This emergent theme illustrates the strong inter-relatedness between informational continuity and relational continuity. Specifically, the impact relationships have on the transfer and exchange of information.

> *"Every time I saw the nurse she would report to me his progression and her comment was that (name) was an excellent student. He learned very early, if you do it their way they are happy. So he chose the easier route by doing what they asked of him. His philosophy was, keep the peace and do what they want because it will benefit me in the long run. So he took that philosophy and it worked well for him. So the nurse was very happy with him, he didn't disagree with her all the time and he just basically did what they wanted." (P7)*

Connectivity is affected by the degree of complexity that exists at the macro-level between the components of the stroke rehabilitation system. The relationships or connectivity between the family caregiver, health professional and stroke survivor influenced complexity at the micro-level, as it was a barrier or facilitator to communication. For example, a positive relationship between the family caregiver and health professional involved in the stroke survivor's care facilitated information exchange, impacting management of care and the family caregiver's ability to navigate the system. These relationships were dynamic and are often influenced by non-linear processes, such as procedures and protocols. Simple rules and boundaries in the system also governed the formality of these relationships, specifically between the health professionals, the stroke survivor and the family caregiver. However, the dynamic nature of these relationships, and the unique attributes of the actors, such as personalities, beliefs and previous experiences, impacted the exchange of information.

> *"Trying to get him into the right areas - it's been hard, but the hardest thing I find is getting information about his medical conditions, because I'm not power of attorney, so there is that confidentiality issue and just trying to navigate through getting his prescriptions set up for him and I can't get any information" (P1)*

5. The type and quality of information impact perceived usefulness

The type and quality of the information (print or verbal) provided to the family caregiver, influenced whether or not the information was perceived to be useful. Many family caregivers found the information to be useful, if it met their specific needs, if it was accessible, or was easy to understand (in lay terms). However, other family caregivers found information to be less useful when it was not patient or caregiver centered to meet their specific needs, (i.e. poor print quality or awkward layout). Information was a key navigational tool for many family caregivers,

however; having the information was simply not enough. This highlights the importance of the type and quality of information being provided to the family caregiver. As described by one caregiver, *"Well yes I've gone through them but the services that are listed are mainly for people residing in the city. It was not helpful as far as the services are concerned." (P12).* Another caregiver highlighted the ease with which some information was provided, *"I don't think he was a cardiologist, maybe it was a neurologist, who was there, was fantastic and just explained things in easy to understand terms to me." (P9)*

Complexity at the macro-level exerts an influence on the type and quality of information provided by the health professionals in the stroke rehabilitation system. Information that is perceived as useful by the family caregiver supports the family caregiving role as they are better able to access supports and services, decreasing the complexity experienced at the micro-level. However, information that is perceived as useless increases the complexity experienced by the family caregiver, as the information does not meet their specific needs and they must take additional steps to find information to assist them with coordinating care for the stroke survivor. Information that is perceived as useless forces the caregiver to self-organize, and become resourceful. Many family caregivers used their social support networks as an informational resource, whereas others used the Internet.

6. The interdisciplinary nature of the caregiving role is dynamic

For many of the family caregivers, the caregiving role was dynamic and shifted as the stroke survivor transitioned home from the rehabilitation facility. Several family caregivers described being a "gatekeeper" between the stroke survivor and friends/other family members, while the stroke survivor was at the facility. *"He had probably 20 friends who emailed me regularly asking for his status." (P7)* The family caregivers also provided the stroke survivor with

instrumental and emotional support, both at home and at the facility, however for many caregivers, the extent of instrumental support provided increased once the stroke survivor returned home. At home, some family caregivers felt the need to monitor the stroke survivor, and that they are *"really constantly on call for everything." (P14)*

Requisite variety, specifically the unique attributes of the case such as the stroke survivors' mental, physical (functional), and emotional needs, or the family caregiver's own health and well-being impacted the provision of care, and degree of complexity at the micro-level. For example, the family caregivers in the study who had serious health conditions, found providing care for the stroke survivor more complex, and relied on supports and services in the community for assistance. However, the availability and functioning of these services is pertinent, and impacted the degree of complexity experienced by the family caregiver, at the micro-level. For several family caregivers, this complexity resulted in financial constraints, and increased the coordination of supports and services during the transition home, impacting family caregiver satisfaction with the stroke rehabilitation system. Some family caregivers in the study also relied on their social support networks for assistance with the caregiving role. Friends, family and neighbours provided the family caregiver with respite, easing the caregiving role and decreasing complexity at the micro-level.

Non-linear processes, and simple rules and boundaries, also contributed to the complexity at the micro-level and the caregiving role, especially while the stroke survivor was at the rehabilitation facility. The rules change drastically between the in-patient care and outpatient services once the stroke survivor transitions home, therefore the caregivers must be aware of different protocols and procedures, at the same time as they are assuming more of a coordination role.

7. Accessing supports and services in the community is complex

Family caregivers had mixed experiences with the supports and services in the community. Many family caregivers discussed waiting, some for extended periods of time for services (i.e. outpatient physiotherapy), particularly during the holiday season. Other family caregivers found the transition between services smooth, with little waiting involved. Due to increased wait-times, many families were required to decide whether or not to pay for private services (especially for outpatient physiotherapy). However, in some cases the families decided the cost outweighed the benefit. The winter weather was also identified as a barrier to accessing supports and services, especially for the few families living outside the city limits.

> *"I could have gotten a physio to come in once a week, but you are talking, I think $100 a visit, and I think my plan only pays $400 so I didn't see the benefit of that […] I could have done it for 4 visits I guess, but what is 4 visits going to do when we knew we were going to get to out patient… you know what I mean, I weighed the two." (P2)*

The degree of complexity at the macro-level, such as the availability of financial resources or human resources in the system, impacts the family caregiver's ability to access supports and services in the community. Requisite variety in each case, such as the family's proximity to services, weather, or the family's financial situation impacted access to services, and the degree of complexity at the micro-level. For example, the family caregivers in the study who lived outside the city limits found accessing services more complex, especially during the winter months. The complexity of accessing services was then compounded by wait-times, which is a macro-level attribute of the system. As a result of these extended wait-times, many family caregivers were required to decide whether or not to pay for private services. However,

the cost of these services and the family's financial situation, for several family caregivers, was the determining factor.

4.3 Barriers and Facilitators to Continuity of Care

Figure 3 illustrates the inter and intra-relatedness between management, informational and relational continuity, and lists perceived factors from the experiences of the family caregivers, that act as barriers or facilitators to continuity of care. Macro-level complexity in the stroke rehabilitation system impacts whether these factors act as barriers or facilitators. This complexity exerts an influence on the micro-level experience as the family caregiver navigates the stroke rehabilitation system. These factors also demonstrate the relevance of requisite variety in the health care system, as they are influenced by the unique attributes of each case. Some of these factors impact one type of continuity of care, whereas other factors impact multiple types. Further, as illustrated in this figure, relational continuity functions as a back drop for informational and management continuity, and in the context of this study relational continuity does not function alone.

Poorly timed information exchange, a central theme in the study, was a barrier to all 3 types of continuity of care for many family caregivers. Information was often provided too early or too late, impacting the family caregiver's ability to navigate the stroke rehabilitation system. Timing of information can also either impact, or be impacted by the relationship between the family caregiver and health professionals. Type and quality of information also emerged as a barrier, impacting informational continuity. The information provided to many family caregivers did not meet their needs, as it was either difficult to read or not specific enough. Procedures and protocols at the macro-level determine the timing and types of information being provided to the

family caregiver. To overcome these barriers, many family caregivers utilized social support networks as a source of information, decreasing complexity at the micro-level, and supporting informational, relational, and management continuity in the stroke rehabilitation system. The elements in this figure are discussed in further detail in section 5.2.

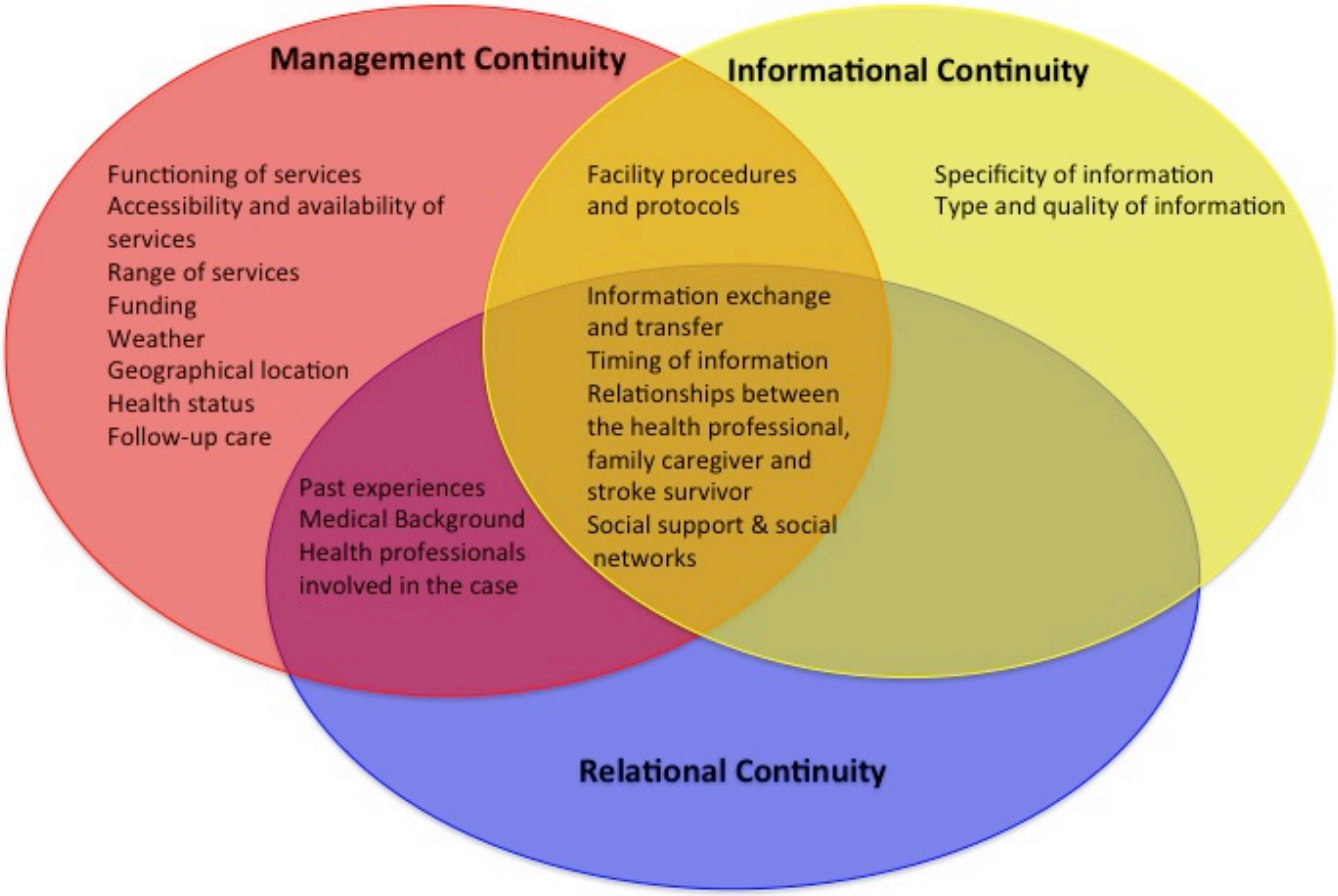

Figure 3. Barrier and facilitators to continuity of care, and relationship between each type of continuity

CHAPTER 5: DISCUSSION

In this thesis I set out to answer the following question: How can complex adaptive systems be used to understand continuity of care in the context of the family caregivers' experiences with the transition home from the stroke rehabilitation facility? The overarching question was answered through three supplementary questions:

- What are the family caregivers' micro level needs as they navigate the stroke rehabilitation system during the transition home from a stroke rehabilitation facility?
- How do complex adaptive systems depict the barriers and facilitators of continuity of care that impact family caregivers' abilities to navigate the stroke rehabilitation system?
- How do we use complex adaptive systems to restructure macro processes to better support micro aspects of the stroke rehabilitation system?

These research questions were answered in the results section (Chapter 4), and were used to develop the theoretical framework and identify the implications of the study. In this chapter I present the theoretical framework, discuss the research results in the context of the family caregiving experience, contributions to the literature and provide recommendations. I also discuss limitations of the study and suggest areas for future research.

5.1 Theoretical Framework Based on the Results

Figure 4 provides a macro system model of the stroke rehabilitation system as a complex adaptive system. The components of the model (i.e. supports and services, information etc.) emerged from the results of the study. The results were categorized into the components presented in this model, and are consistent with continuity of care literature (Reid et al., 2002; Haggerty et al., 2003; Weinberg, Lusenhop, Gittell, & Kautz, 2007; Adler, Vasiliadis, & Bickell,

2010). The categories of the model, which include inputs, care context, and outputs, were informed by the systems approach. The inputs, such as information, actors and physical resources, act on the system impacting the care context, specifically management of care, and the degree of continuity is influenced by the ability to adapt to the inputs or demands placed on it. This adaptation impacts the outputs at the system and individual levels. The arrows illustrate the flow of time and a feedback loop, which are characteristics of non-linear systems. The arrows also illustrate continuity, or continuous movement of the family caregiver and stroke survivor though the system, as well as the intra and inter-relatedness that exists between informational, management and relational continuity.

Continuity may be interrupted by the system's inability to adapt to its changing environment. As described in section 4.1 and 4.2, complexity at the macro and micro levels interact to influence the family caregivers' experiences navigating the stroke rehabilitation system, and system outputs. Complexity acts on continuity of care, to influence the intra and inter-relatedness between management, relational and informational continuity, and the perceived barriers and facilitators experienced by the family caregivers, as described in section 4.3.

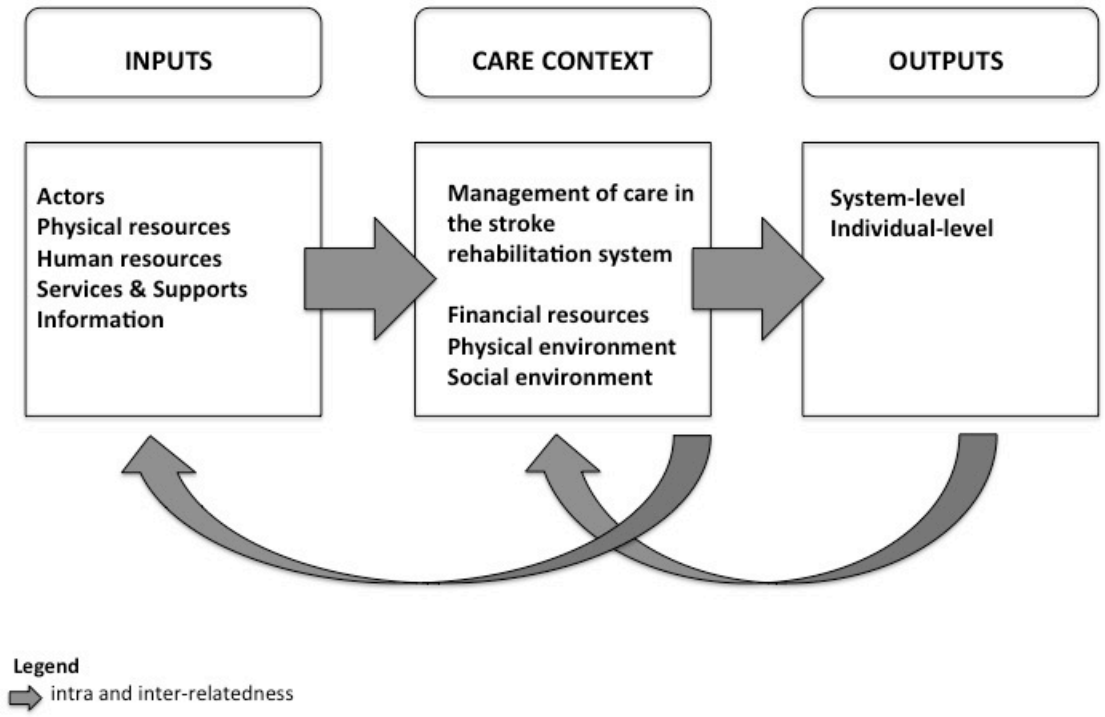

Figure 4. Macro systems model of the stroke rehabilitation system during the transition home from a rehabilitation facility from the family caregiver's perspective

The next figure (Figure 5) illustrates this complex adaptive system from a micro systems perspective, providing a more detailed perspective of the components that make-up the system, and operationalize those shown in Figure 4. These models were informed by the emerging themes from the study, specifically the perceived experiences of the family caregivers navigating the stroke rehabilitation system, from a formal to an informal setting, and are presented as an empirically-derived means of unpacking the complexity illustrated in the previous chapter.

The inputs in the system, such as supports and services or information shown in Figures 4 and 5, are constant as they are a standard type of input in each case, even if the attributes vary. Inputs may also vary depending on the degree to which they are present or available. The care

context, more specifically health care delivery in the stroke rehabilitation system, is dynamic and impacts the intra and inter-relatedness that exists between informational, management and relational continuity, influencing the degree of patient centered care in the system, and the family caregiver's satisfaction with the care being provided to the stroke survivor.

As described earlier, the timing of information was described as a prominent barrier to navigation if information was not provided at the appropriate time of need. This issue of timing, which is determined in part by procedures and protocols at the macro level, impacts continuity of care and complexity at the micro-level. The family caregiver's need for information (an input) is constantly changing as the stroke survivor transitions between health care settings and care demands change, placing changing demands on the system over time. The inherent complexity at the macro-level, and the system's ability to adapt to this demand, influence the inter and intra-relatedness between informational, relational and management continuity, and the complexity experienced at the micro-level by the family caregivers. The interacting elements from the macro and micro levels, and the degree of continuity of care in the system influence the delivery of health services and caregiver support.

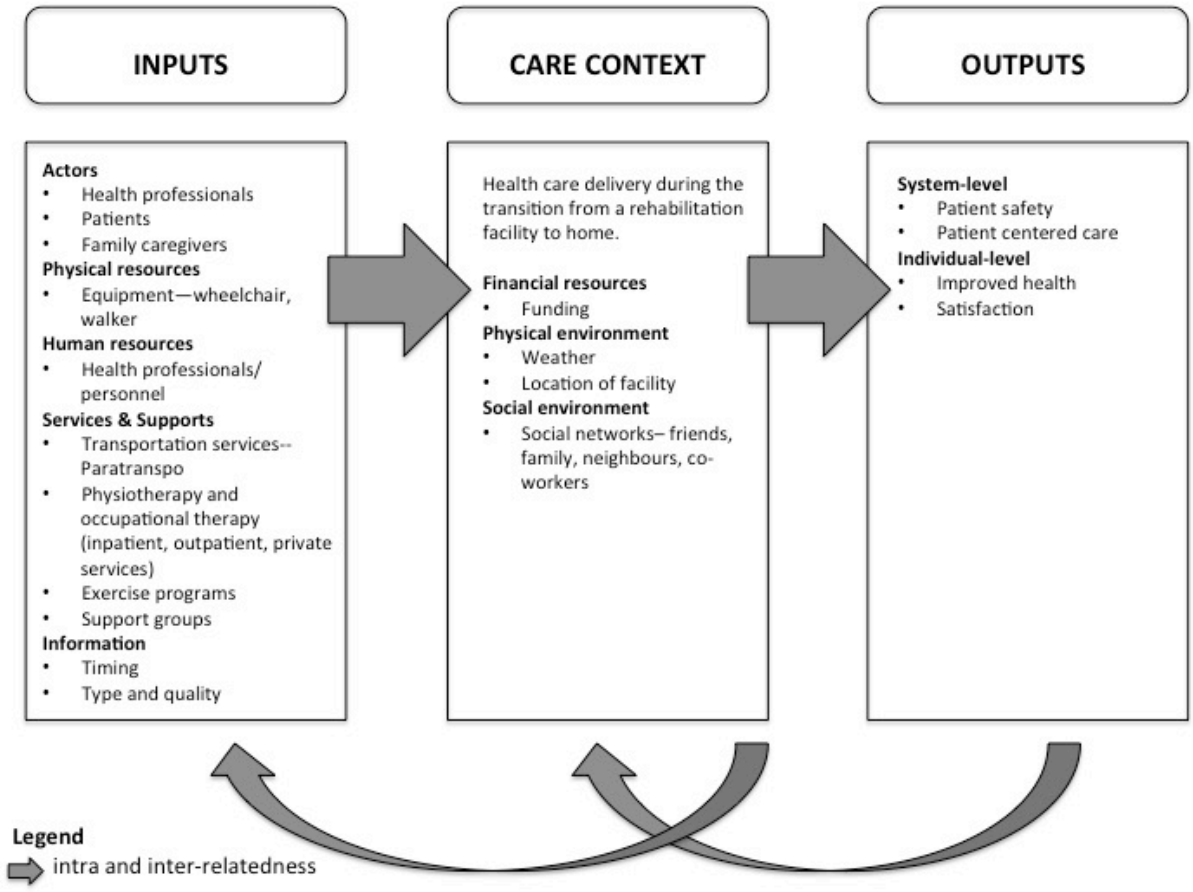

Figure 5. Micro systems model of the stroke rehabilitation system during the transition home from a rehabilitation facility from the family caregiver's perspective

5.2 Discussion of Results

The results from this study illustrate how complex adaptive systems lens can be used to understand continuity of care in the context of the family caregivers' experiences during the transition home from a stroke rehabilitation facility. Guided by the theoretical frameworks in section 5.1, this following discussion focuses on how the stroke rehabilitation system acts on the family caregiver as they navigate the stroke rehabilitation system, and the inherent complexity across levels of the system.

5.2.1 Roles

The family caregiver is a constant source of support for the stroke survivor throughout the stroke trajectory, but more specifically during the transition home from a rehabilitation facility. As part of the family caregiving role, the family caregiver also fulfills the role of system navigator. These roles are discussed in further detail in the sections below.

5.2.1.1 Caregiving.

Family caregivers play an instrumental role throughout the stroke trajectory from the onset of stroke to recovery. However, the caregiving role during the transition from a rehabilitation facility to home is particularly important, as it is a time of adjustment where the care shifts from the health professionals to the family caregiver (Cameron & Gignac, 2008). The family caregivers in the study described their caregiving role to be interdisciplinary in nature. They described themselves as the gatekeepers between the stroke survivors and friends/family, and provided instrumental and emotional support for the stroke survivor both at home and at the facility. However for many caregivers the amount of instrumental support they required once the stroke survivor returned home increased. The degree of support provided was case specific, and varied depending on the health status of the caregiver and stroke survivor, the amount of formal care received and competing demands such as work, or family. The relationship between the patient and the caregiver also impacted the degree of support provided and was influenced by expectations, need for autonomy, and emotions (such as fear, guilt, frustration).

These unique attributes illustrate requisite variety in the system and its role as either a barrier or facilitator to continuity of care. The provision of social support by family caregivers' has been widely examined in the stroke literature (Gaugler, 2010; Le Dorze & Signori, 2010; Lutz & Young, 2010, Cameron & Gignac, 2008; Coombs, 2007; Silva-Smith, 2007). The

relationship between the patient and family caregiver, the caregiver and stroke survivor's health status, and caregiver stress and strain have been identified in the literature as barriers to social support (Gaugler, Silva-Smith, Cameron & Gignac, Coombs), and align with the findings of the current study. However, despite these barriers, family caregivers continue to remain hopefully and optimistic for the future (Coombs). Findings from the current study extend our understanding of the caregiving role and the interrelationship with continuity of care during the transition from a formal to an informal health care setting and underscores the importance of recognizing requisite variety across cases which flow through the system.

5.2.1.2 Navigation.

Family caregivers fulfill the role of system navigator, as part of the family caregiving role. For many of the family caregivers in this study, navigating the stroke rehabilitation system was a new and challenging experience. The current stroke care system in Canada lacks a 'common coordinating system' (Cameron et al., 2008), and as a result the family caregivers become an informational resource and coordinator for the stroke survivor, as part of their navigational role. The family caregivers in the study provided the stroke survivor with informational continuity, by acting as a hub of information and an informational link for the health professionals involved in the stroke survivor's care. They described coordinating tasks, such as scheduling medical appointments, and pushing information to and pulling information from the health professionals about the stroke survivor's health status or care, and/or services and supports. This became embedded in the caregiving role. The family caregiver's role coordinating tasks for the stroke survivor align with the findings of Cameron & Gignac (2008). However, facility rules impact coordination and the accessibility of information (Eames, Hoffmann, Worrall, & Read, 2010). The caregivers in this study were faced with simple rules,

specifically administrative protocols and procedures at the macro level of the system regarding the sharing of information. The experiences with information exchange varied depending on the health provider and the type of information requested, and some rules were not as rigid as the family caregivers originally thought.

To work within the simple rules in the system, the family caregivers derived creative solutions to obtain the information they needed, including attending the stroke survivor's medical appointments, speaking to health professionals involved in the case who were available at the time, and pressuring health professionals to provide more information. However, as discharge approached, many of the family caregivers became increasingly concerned about their caregiving role at home (Cameron & Gignac, 2008) and had an increased need for information from the health professionals involved in management of the stroke survivor's care. Despite this need, many family caregivers reported receiving insufficient information; a finding which aligns with findings from previous studies (King, Ainsworth, Ronen, & Hartke, 2010; King & Semik 2006). When family caregivers are not provided with sufficient information, they use their social support networks as an informational resource, whereas others develop research skills to self-organize, and utilize the Internet as a source of information.

The findings from this study parallel the findings of Nagler et al. (2010), who found that cancer patients use the Internet and social support networks as an informational resource to fulfill their unmet informational needs. However, the Internet is not always a reliable source of information, and could impact the quality of information the family caregiver retrieves. This is an important consideration as the family caregivers transfer the knowledge back to the stroke survivor, or health care professionals involved in the case, as a feedback loop. The family caregiver's role as an informational link and hub of information illustrates the inter-relationship

between management and informational continuity, as well as their role as a constant source of support providing the stroke survivor with continuity across health care settings.

5.2.2 Supports and services

Supports and services throughout the stroke trajectory are pertinent for the family caregiver and stroke survivor as they ease the transition across health care settings. The family caregiver's desire for supports and services increases as the stroke survivor transitions home from a stroke rehabilitation facility (Cameron & Gignac, 2008; Silva-Smith, 2007). However, coordinating services is a complex process, as there is often little or no continuity in community services (Ellis-Hill; Robison et al., 2009; Cott et al., 2007). This discontinuity has a direct impact on accessibility, and the family caregiver's experience of providing care to the stroke survivor (Eames et al., 2010). The family caregivers in this study had mixed experiences accessing services and supports in the community; many of them described waiting long periods of time for services, while others found the transition between services smooth. Limited access to services and supports in the community has also been reported in the literature on spinal cord injuries (Silver, Ljungberg, Libin, & Groah, 2012). While many improvements may have been implemented with the Ontario Stroke Strategy, delays continue to be an issue in the stroke rehabilitation system (OMHLTC, 2000; Cameron et al., 2008)

Despite the discontinuity in the system, the family caregivers in the current study continued to navigate the system by learning as they went, and devising creative solutions to ensure the stroke survivor's continued progress towards improved health. Some family caregivers in the study used their social networks as a source of support to cope with the dynamic and non-linear nature of the system. Social support networks were identified in the

literature as an essential form of support while navigating the health care system (Nagler et al., 2010). Learning the rules and boundaries also assisted with this adaptation as family caregiver's were able to self-organize and develop new strategies for their next challenge or encounter with the system (Silva-Smith, 2007). Family caregivers play a pertinent role in providing continuity in the stroke rehabilitation system by being a constant source of support for the stroke survivor during the transition home from a rehabilitation facility.

5.2.3 Information

Information exchange and sharing is a complex process, as it requires effective coordination and communication (Janssen, Lee & Bharosa, 2010). Coordination and communication of information are particularly important during transitions between health care settings (Cameron & Gignac, 2008), and emerged as an important finding in this study. Relationships, timing of information and, type and quality of information were identified as factors influencing information exchange during the transition from a rehabilitation facility to home.

5.2.3.1 Relationships.

Relationships impact information exchange (Eames et al., 2010); they can be a barrier or facilitator to continuity of care. The relationships between the family caregiver and health professionals involved in the stroke survivor's case were discussed in depth by the family caregivers in the study because of their role in communication and their impact on the caregiving role. The family caregivers had mixed experiences providing feedback, and pulling information from the health professionals. Many family caregivers had positive experiences, whereas others found communicating with the health professionals involved in the stroke survivor's care

challenging. These experiences were influenced by the family caregiver's perception of feeling comfortable with the health professional and feelings of connectivity. Extant literature identifies the quality of the interaction, and perception of feeling comfortable as a barrier or facilitator to information exchange (Eames et al., 2010; Silva-Smith, 2007). Positive experiences in this study were linked with comfortable interactions, as a result of open dialogue between the family caregiver and health professional, and the family caregiver's ability to ask questions. The quality of the connection resulted in the exchange of useful information and acted as a stimulus for obtaining the necessary supports and services, easing the transition home from the rehabilitation facility.

In contrast, other family caregivers in the study found their relationship with the health professionals involved in the stroke survivor's care to be more challenging. This was a result of differences in communication styles, illustrating requisite variety in each case. However, these differences impacted the family caregiver's desire to ask for additional information or feedback. Additional barriers to information exchange identified in the literature include the family caregiver feeling intimidated by the hospital environment or feeling overwhelmed, and the perception that no one is an expert (Eames et al., 2010). The family caregiver's role in information exchange is also especially important when the stroke survivor has communication limitations and difficulty vocalizing his/her needs. In this instance, the family caregiver becomes the mediator between the stroke survivor and health professional. This emphasizes the importance of the relationship between the family caregiver and health professionals, as relationships influence the flow of information, and impact the management of the stroke survivor's care and health outcomes (Silva-Smith, 2007).

Communication styles can either constrict or enhance the flow of information (Eames et al., 2010). This impacts the functioning of the system, and influences connectivity between the actors in the system, the family caregiving role, and ultimately the management of the stroke survivor's care during the transition home from a rehabilitation facility. Requisite variety in each case, such as personalities, the family caregiver's past experiences or knowledge of the health care system, and the health professionals involved in the case, can either be barriers or facilitators to continuity of care. This impacts complexity at the micro-level, and is experienced by the patient-caregiver dyad. This theme illustrates the inter-relatedness between the three elements of continuity of care and enhances our understanding of the role of relationships during information exchange, in the context of the stroke rehabilitation system.

5.2.3.2 Timing of Information.

The timing of information is one important factor impacting this process (Janssen et al., 2010, Eames et al., 2010), and was a central theme in this study. The family caregivers described receiving information from the health professionals when the stroke survivor was admitted to the rehabilition facility and/or during discharge home. These times were described as periods of extensive adjustment for the family caregiver and the stroke survivor. Discharge home from a rehabiliation facility is identified in literature as a critical time of adjustment, as it requires learning and adaptation for the family caregiver and stroke survivor (Greenwood & Mackenzie, 2010; King, Ainsworth, Ronen & Hartke, 2010; Cameron & Gignac, 2008; Grant et al. 2004). However, high volumes of information and poor timing of when that information is shared resulted in a deluge of information which many caregivers found to be overwhelming. This rendered the information useless for many family caregivers and impacted their role as system navigator. The findings from this study align with the findings of Janssen, Lee & Bharosa (2010)

which were specific to disaster management, however, timing of information is pertinent both during disasters as well as in supporting the family caregiving role. In both instances, the need for information is continuously changing and influenced by the dynamic and complex nature of the system (Janssen, Lee & Bharosa).

Formalized procedures and protocols in the system, such as discharge procedures at the facility, determine when the information is provided to the caregiver-patient dyad. In Figure 6 below, timing of information is depicted in the context of the stroke rehabilitation system. The arrows in the figure illustrate the positive or negative interactions. However, the relationship between the family caregiver and health professionals can either impact, or be impacted by the timing of information. This influences the navigational role, specifically the family caregiver's ability to schedule services (i.e. physiotherapy services) for the stroke survivor upon their return home. Due to the timing of information, the family caregivers may be required to self-organize in order to adapt to the overload or gap in information. Ultimately, as was evident in this study, the family caregiver's ability to coordinate care for the stroke survivor, and his/her feelings toward the system are impacted. Timing of information illustrates the inter-relatedness between the three elements of contunity of care, and the interconnectedness between the components in the system (Sturmberg, 2003). Each of the themes in this study could be articulated using this type of diagram. However, this theme was selected as it is a central theme in the study.

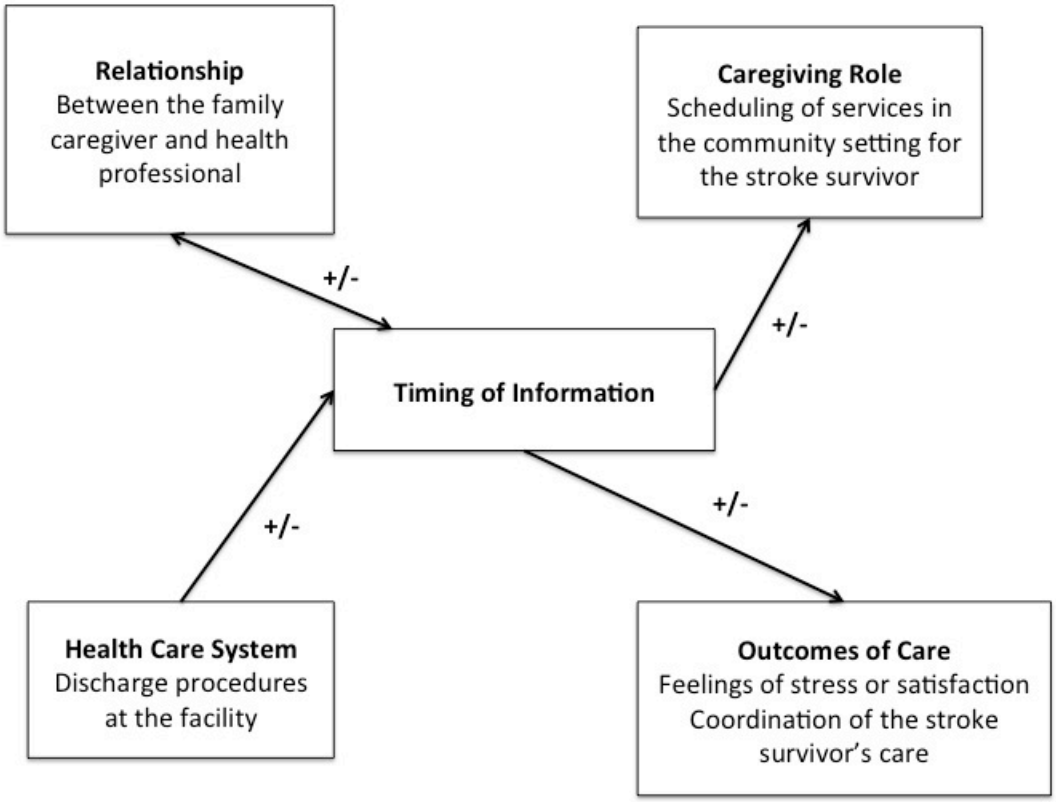

Figure 6. Timing of information as a barrier or facilitator to continuity of care

5.2.3.3 Type and Quality of Information.

Type and quality of information are determining factors impacting perceived usefulness of informational support provided to caregivers (Eames et al., 2010). In the current study, there were mixed opinions among the family caregivers as to whether the information provided to them was useful or helpful. The information provided to them was mainly in print format in the form of pamphlets, flyers and booklets. Factors impacting perceived usefulness included the specificity and readability of the information being provided. Readability is pertinent when communicating health information to the consumer (Miller, Leroy, Chatterjee, Fan & Thoms, 2007) and was of great importance to the family caregivers in the study. However, information

perceived as poor quality was considered to be inadequate. Although the informational support was present, the information was perceived as useless, impacting the family caregiver's ability to navigate the stroke rehabilitation system. This finding aligns with extant literature, as family caregivers receive insufficient information from the health professionals involved in the stroke survivor's care (King & Semik, 2006; King et al., 2010; Eames et al., 2010). In contrast, some family caregivers in this study perceived the information to be useful and informative, meeting their informational needs.

The specificity of the information was also an important factor. Many family caregivers described having to go through pages and pages of information that did not meet their specific needs, however most did not provide the health professionals with feedback on the quality of the information provided to them. This theme illustrates the intra-relatedness of informational continuity and requisite variety, as information is individual specific. Provision of information aligns with the family caregiver's expectations or needs, and influences their experience and satisfaction with the informational support being provided (Eames et al., 2010). The type and quality, and timing of information can act as either barriers or facilitators to continuity of care and may be contributing factors to the lack of informational supports in the stroke rehabilitation system, impacting the family caregiver's navigational role (OMHLTC, 2000). Findings from the current study highlight the importance of the type and quality of information being provided to the family caregivers by the health professionals, during the transitions home from a rehabilitation facility.

5.3 Contributions to Knowledge

The caregiving role is adaptive to the context of care and dysfunctions in the stroke rehabilitation system. This role during the transition home from a rehabilitation facility supports continuity of care across health care settings. This study illustrates the family caregiver as a constant source of support and continuity for the stroke survivor during the transition from a rehabilitation facility to home. Due to the non-linearity, and dynamic nature of the system, the family caregivers were required to adapt to the changing environment, by shifting their role as the stroke survivor transitioned from a formal to an informal health care setting.

By examining all three components of continuity of care, as defined by Haggerty et al. (2003), in the stroke rehabilitation system in Ontario, the current study enhances our understanding of the family caregiver's perceived experiences during the transition home from a rehabilitation facility. As research has not yet empirically examined continuity of care using the complex adaptive systems lens, the findings enhance our understanding of family caregiving experience from a macro and micro perspective. Specifically, the family caregivers' micro level needs, as they navigate the stroke rehabilitation system, were identified using the complex adaptive systems lens. The perceived barriers and facilitators, in the context of continuity of care, were also identified, and illustrate inter and intra-relatedness between the elements of continuity of care. This study also provides an understanding of what is needed to evaluate and reshape processes in the system, to better support complex activities like stroke rehabilitation, and the family caregiver's role as system navigator during the transition home from a rehabilitation system.

5.4 Recommendations

In this section I outline adaptations that could be made to the stroke rehabilitation system in order to better support family caregivers, during the transition home from a rehabilitation facility. The recommendations below are refinements that could be made to the current system, in particular adaptive case management, and are not another added layer on top of the current system. These recommendations are also based on the results presented earlier, and consistent with the categories: roles, supports and services, and information.

1. **Tailoring the timing of information.**

The recommendation that the timing of information be tailored to the caregiver and the case is consistent with the discussion on information in section 5.2.3 and the central themes of the study. Most of the family caregivers described receiving information during the stroke survivor's entry to the facility or at discharge. The timing of information is established at the macro-level influencing complexity at the micro-level, as experienced by the family caregiver. By tailoring the timing of information to the needs of the family caregivers, it would ensure that information is not provided too early or too late, but at the time of greatest need. This will support the family caregiver's role as system navigator and mitigate timing of information as a barrier discussed in section 4.2.2 and 4.3, supporting continuity of care, specifically informational, management, and relational continuity across health care settings. Tailoring the timing of information will also reduce the deluge of information improving the family caregivers' perceived experiences navigating the stroke rehabilitation system.

2. **Adapting the information being provided in order to meet specific needs.**

The recommendation that information be adapted is also consistent with the discussion on information in section 5.2.3. Many family caregivers in the study described receiving a variety of

information, however most of it was not specific to their needs. Although some found the information informative, others found it to be overwhelming and did not bother going through it all. Providing family caregivers with information specific to their needs could improve the utilization of supports and services in the community, and reduce complexity experienced at the micro-level by the family caregivers. Some family caregivers were not aware of the available supports and services because of the general nature of the information, its specificity to a certain city or the amount provided at one time. By adapting the information to meet the family caregiver's needs, type and quality of information discussed in section 4.2.2 and 4.3 as a barrier to continuity of care would be mitigated and accessibility to supports and services would be improved better supporting the family caregiving role.

3. **Fostering relationships in order to support information exchange.**

The recommendation to foster relationships in the stroke rehabilitation system is consistent with the discussion on information in section 5.2.3. As discussed, the relationship between the family caregiver and health professionals involved in the stroke survivor's case either constricted or supported the flow of information. Several family caregivers had positive experiences, however many found communicating with the health professionals more challenging. These experiences were influenced by the family caregiver's perception of feeling comfortable with the health professional and feelings of connectivity. In order to enhance connectivity, training programs and materials could be provided to the health professionals in order to help develop their skills in the area of relationships and communication with family caregivers. This would mitigate relationships as a barrier to continuity of care, specifically informational, relational and management continuity discussed in section 4.2.2, decreasing the complexity experienced by the family caregivers at the micro-level and better supporting the family caregiving role.

4. **De-centralize community services.**

The recommendation to de-centralize community services is consistent with the discussion on supports and services in section 5.2.2. The family caregivers in this study found it challenging to access services in the community setting. For example, many family caregivers described having to wait extended periods of time to access outpatient physiotherapy for the stroke survivor. By de-centralizing outpatient physiotherapy services, clinics would be able to offer this service, reducing wait-times, as the demand would no longer be localized to one area. This also applies to other community services, such as exercise programs, and support groups. The recommendation to de-centralize community services would reduce the degree of complexity at the micro-level, and enhance the family caregiver's ability to access these community services, as barriers such as weather and geographical location discussed in section 4.2.2, would be mitigated.

5.5 Limitations of the Study

There are several limitations in this study that need to be acknowledged. The first limitation is participant recruitment. Participant recruitment was conducted at a rehabilitation facility, using convenience sampling. This method of sampling limits the generalizability of this study's research findings. The second limitation is the sample, as the majority of participants (n=11) in this study self-identified as Caucasian. Thus, the results cannot be generalized to the experiences of family caregivers from other ethnic backgrounds. Most of the family caregivers (n=11) classified themselves in the middle to upper annual family income level (> $46,000). Finances may impact the family's ability to access private or additional supports and services, as well as buy any necessary equipment or make changes to their home. These limitations identified

in the sample may impact the family caregiver's experience navigating the stroke rehabilitation system during the transition from rehabilitation to home.

5.6 Future Research

Future research could examine the perceived experiences of health professionals in the stroke rehabilitation system, using institutional ethnography, in order to provide context to the family caregiving experience. Future research should also test and validate the systems model in other health care settings. A longitudinal study could be conducted to explore the family caregiving role once the stroke survivor has transitioned home, and the availability and functioning of supports and services in the community setting. Moreover, future research could compare the perceived experiences of the family caregiver and stroke survivor during the transition home from a rehabilitation facility. This would enhance our understanding of the patient-caregiver relationship and its impact on the navigational role. Finally, a pilot study could be conducted to explore the appropriateness, feasibility and effectiveness of integrating a case manager into the stroke rehabilitation team, in order to better support the caregiver-patient dyad during the transition home.

CHAPTER 6: CONCLUSION

This study enhances our understanding of the family caregiving role during the transition home from a rehabilitation facility. During this transition, the family caregiver is a constant source of support for the stroke survivor, and not only provides support to the care recipient, but also fulfills the role of system navigator. However, the non-linear and dynamic nature of the stroke rehabilitation system, and barriers and facilitators to continuity of care impact the complexity experienced by the family caregiver at the micro-level. The emergent themes from this study illustrate the importance of mitigating system barriers, and enhancing the facilitators to ensure continuity of care and better support for the family caregiver across health care settings.

The emergent themes also highlight the importance of supports and services to assist with the family caregiving role and navigation of the stroke rehabilitation system, during the transition home from a rehabilitation facility. However, the availability of these services is often limited, or does not meet the specific needs of the family caregiver or stroke survivor. Acknowledging the unique attributes of each case, and its role in management of care, is essential to ensure supports and services are tailored to the individual case. Tailoring these services would better support the family caregiver and stroke survivor, as it would ease the caregiving role and enhance the intra and inter-relatedness between management, relational and informational continuity. This would also decrease the degree of complexity experienced by the family caregiver and stroke survivor during this critical time of adjustment.

The results from this study should be considered in the design of future interventions, and implementation of existing programs targeting family caregivers of stroke survivors. They also provide a resource for future policy development, with the goal of enhancing the family caregiver experience in the stroke rehabilitation system.

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Appendix A

Keywords used in Literature Review

The following key words were used in the literature search:

- Continuity of care
- Emotional support
- Navigator
- Navigating
- Health care system
- Caregiver
- Caregiving
- Informal/family caregiver
- Stroke
- Family
- Quality of life
- Continuum of care
- Information
- Support
- Transitions
- Rehabilitation
- Complex adaptive systems
- Complexity theory
- Handoffs
- Ontario Stroke Strategy
- Stroke rehabilitation system
- Health outcome
- Burden
- Care coordination
- Advocacy
- Photolanguage
- Photo-elicitation
- Photography
- Focus groups
- Narrative
- Informational, management, and relational continuity
- Communication
- Qualitative

Appendix B

Summary Table of Current Literature

Themes	**Summary of Existing Literature**	**Gaps in Literature**
The increasing complexity of the health care system	The health care system is becoming more complex, resulting in an increased number of components and interactions between each component (Kannampallil, Schauer, Cohen, & Patel, 2011). Complex adaptive systems acknowledges the complexity of organizations and networks, thus provides a means for understanding the dynamic and non-linear nature of the health care system (Sturmberg, 2003; Coiera, 2011).	1. No studies were found that empirically examine continuity of care, using the complex adaptive systems approach. 2. Few studies have examined continuity of care in a public health care system 3. No studies were found that examined all three components of continuity of care, as defined by Haggerty et al. (2003), in the stroke rehabilitation system in Ontario. 4. Few studies have examined the provision of social support by family caregivers in a formal health care setting such as the stroke rehabilitation system. 5. The impact of the deficiencies in the stroke rehabilitation system on the family caregiver's ability to fulfill the role as support provider and system navigator. 6. Few studies have studied the stroke rehabilitation system in Ontario
The relationship between continuity of care and patient satisfaction is inconclusive	Research studies have highlighted the positive relationship between patient satisfaction and continuity of care in the primary care system (Adler et al., 2010; Boutlon et al., 2006). However, a systematic review conducted by Adler et al. (2010) found the relationship to be variable in the quantitative studies due to the lack of a common definition. The qualitative studies showed positive relationships	
High continuity of care results in fewer hospital/emergency department visits	High continuity of care has been associated with reduced hospital stays and emergency department visits (Cheng et al., 2011; Ionescu et al., 2007; Cree et al., 2006). One study found that low continuity was related to an increase in hospital and emergency department admissions (Cheng et al. 2011).	

Effective communication between health professionals positively impacts informational continuity	Effective communication of patient information between health professionals in the health care system is essential for high continuity of care. Studies have examined the role of communication in various hospital settings during nurse handoffs as well as in the mental health and primary care settings and highlight the importance of communication and its impact on patient health and safety (Street et al., 2011; Alvarado et al., 2006; Gandara et al., 2009; Reid et al., 2002).	
Continuity of care impacts consistency of care in the healthcare system	Consistency of care is a reoccurring theme in the literature. Continuity of care is essential to ensure the care recipient receives consistent and coherent care (Coleman et al., 2005; Haggerty et al. 2003). However, deficiencies in the rehabilitation system are impacting the consistency of care across care settings (Teasell et al., 2008).	
Caregiving demands can negatively impact employment	Some family caregivers may be required to modify their work hours, take a leave of absence or leave work altogether (Wagner, 2006; Rajnovich, Keefe, & Fast, 2005).	
Deficiencies in the stroke rehabilitation system in Ontario	The Ontario Stroke Strategy was established to improve access to stroke care. Teasell et al. 2008 identified a number of deficiencies in the system including 1) access to interdisciplinary stroke rehabilitation units is limited 2) delayed access to inpatient rehabilitation services 3) patients are receiving limited amounts of dedicated rehabilitation time 4) outpatient hours are usually reduced or eliminated	

Negative consequences of caregiving	Compared to family caregivers who are not employed, employed family caregivers were more likely to report changes in sleep patterns and adverse health consequences including depression, feeling overwhelmed, terrified, and stressed, as well as an increased risk of coronary heart disease and other chronic illnesses (King, Hartke, & Houle, 2010; Greenwood & Mackenzie, 2010; Levine, Harper, Peist, & Gould, 2010).	
Positive consequences of caregiving	Positive outcomes identified in literature include feelings of companionship and fulfillment, opportunity to give back, and an improved relationship (Gaugler, 2010; Fast et al., 2002; Peacock et al., 2010; Cohen et al., 2002)	
The transition from rehabilitation to home is a critical point in the stroke care trajectory	The transition from rehabilitation to home is a key transition for many stroke survivors and their family caregivers (Ellis-Hill, Robison, Wiles, McPherson, Hyndman, & Ashburn, 2009; Rittman et al., 2007; Cott, 2004). It has been identified as a time of adjustment for both the stroke survivor and family caregiver.	
Family caregivers provide the stroke survivor with continuity of care.	Family caregivers are often the only aspect that remains consistent across transitions (Coleman, Mahoney, & Parry, 2005). Family caregivers provide the stroke survivor with continuity by providing social support in the form of instrumental, emotional, appraisal and informational support in addition to fulfilling the role as system navigator (Le Dorze & Signori, 2010; Gaugler, 2010; Lutz & Young, 2010; Coombs, 2007; Silva-Smith, 2007; (Cameron & Gignac, 2008).	

Appendix C

Interview Questions

1. To start with, perhaps you could give me an overview of your caregiving experience during the past 2 months?

2. Based on the definitions on this sheet, please identify specific examples from your experience which relate to each type of continuity of care (management, relational and informational continuity) that symbolize your experience providing care for the stroke survivor during the transition home from a rehabilitation facility.

3. When you think back to your experience as a caregiver navigating the stroke rehabilitation system…
    a. What specific challenges did you notice in terms of continuity of care between the rehabilitation setting and when you were providing support at home?
    b. What barriers did you experience during the transition home? How did these barriers impact the caregiving role?
    c. What supports and services were available to assist you during this transition? Did you find them helpful/useful?
    d. What information were you provided with? Did you find this information helpful/useful?

4. How would you describe your role as primary caregiver while your family member was residing at the rehabilitation facility compared to now? Please describe any changes to your caregiving role, if there were any.

5. What do you think would have been helpful to know prior to starting your journey in the stroke rehabilitation system?

6. If you could make any changes to the health care system to improve continuity of care for stroke patients when they transition home, what would you do?

7. What specific supports or services would you include for the caregivers?

Appendix D

Caregiver Summary Sheet

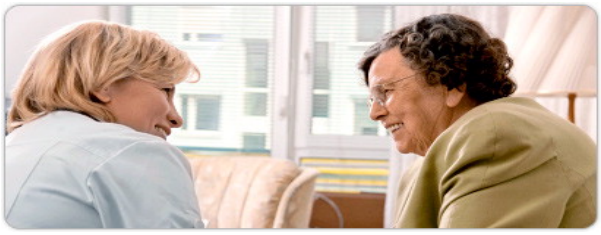
Continuity of Care

- **Management continuity:** The overall management of a patient's condition, including the vision of how different aspects of treatment work together as the patient's needs change across multiple settings.
- **Informational continuity:** The use and transfer of patient information (i.e.: medical information) to guide health care delivery across the various health care settings.
- **Relational continuity:** The ongoing relationships between the patient/family caregiver and the health care professionals involved in providing care for the stroke patient.

Appendix E

Volunteers Needed For a Research Study

Family Caregivers who are the Primary Caregiver for a Stroke Survivor during the Transition from Rehabilitation to Home



A research team from the University of Ottawa is conducting a research study on the family caregivers' experience navigating the stroke rehabilitation system as the stroke survivor transitions home from a rehabilitation facility. This study will specifically examine the supports and services available to family caregivers during this transition.

We are asking participants to participate in a short interview by phone or in-person (approximately 30-45 minutes in length).

If you are interested in participating in this study, or would like more information, please contact
Andrea Ghazzawi, MSc. (Candidate), Telfer School of Management, University of Ottawa.

uOttawa

SOINS CONTINUS Bruyère CONTINUING CARE

Appendix F

Script for Social Worker

Hello (name),

A research team from the University of Ottawa is conducting a research study on the family caregivers' experiences in providing support to a family member who survived a stroke, during their transition home from a rehabilitation facility. The study will specifically examine the supports and services available to family caregivers during this transition. You are eligible to participate. Would you be interested in finding out more information about the study?

(If no) Thank you for your time.

(If yes, the social worker will provide the family caregiver with the recruiting flyer) Would it be ok, if I provide the researcher with your contact information?

(If yes, the social work will document the verbal consent) They will be in touch with you in the next couple of days. Thank you for your interest in the study.

(If no) Thank you for your time.

Thank you again.

Goodbye.

Appendix G

Principal Investigator Telephone Script

Hello (name),

My name is Andrea Ghazzawi, and I am a Master's student at the University of Ottawa. For my thesis, I am studying the family caregivers experience navigating the stoke rehabilitation system.

I was provided your contact information by (name social worker) at Bruyère Continuing Care.

Thank you very much for your interest in our study.

We are recruiting primary family caregivers who live with their family member who has recently survived a stroke and is in a rehabilitation facility, or has been home for less than 8 weeks.

Has one of your family member's recently experienced a stroke?

(If yes) – I'm very sorry you and your family are going through this. Is this person home from a rehabilitation facility yet?

(If yes) - how long has he/she been home?

(If no) – have the doctors indicated when this person will be discharged?

Are you the primary caregiver for this person?

(If yes) – do you provide care for this person in your home?

If you would like, I can provide you with some information about our research study…

(If yes) – As I mentioned, we are recruiting primary caregivers, like yourself, who are providing (or will be providing) in-home care for a family member who has recently experienced a stroke and has been home for less than 8 weeks. We will be conducting interviews with family caregivers, in order to gain an understanding of the experience providing care for a family member who has survived a stroke, during the transition home from a rehabilitation facility. The interview takes approximately 30-45 minutes and can be done by phone or in-person.

If you choose to participate in this study, your confidentiality and anonymity are our priority. We take this very seriously and ensure that all information you provide is kept in a secure location, and is only available to our research team. Also – when we report this research, we do not use your name or any identifying information in any of our reports. We also emphasize that all participants have the right to withdraw from the study at any time. Participation is completely voluntary.

Do you have any questions that I can help clarify for you?

(If yes) – answer questions.

Are you still interested in participating in the study?

(If yes)- Could I please mail you the consent form?

(If yes)- Could you please provide me with your mailing address?

Should you have any questions please do not hesitate to contact me by phone at (number) or by e-mail at (e-mail address).

Once again, thank you for your interest in this study!

Good-bye!

Appendix H

Navigating the Stroke Rehabilitation System After Stroke: A Family Caregiver's Perspective

Research Project Title:
Navigating the Stroke Rehabilitation System After Stroke: A Family Caregiver's Perspective

Investigators:
Andrea Ghazzawi, University of Ottawa, Principal Investigator
Tracey O'Sullivan, University of Ottawa, Thesis Supervisor
Craig Kuziemsky, University of Ottawa, Thesis Supervisor
Hillel Finestone, Bruyère Continuing Care, Co-Investigator

PURPOSE

Family caregivers play an important role in providing support for family members who have survived a stroke. As the stroke survivor moves from rehabilitation to home, family caregivers often take on the role as care provider in addition to navigating the stroke rehabilitation system. This research study will explore the family caregivers' experiences navigating the stroke rehabilitation system as the stroke survivor transitions home from a stroke rehabilitation facility.

This research study is particularly interested in the factors (barriers, supports etc.) that impacted your experience caregiving for the stroke survivor during the transition home from a rehabilitation facility. We are very interested in learning about your experience in order to inform future policies and programs for family caregivers of stroke survivors.

YOUR PARTICIPATION

You are being invited to participate in this study because of your role as a primary caregiver for a family member who has had a stroke. Your participation in this study will include one interview (about 30-45 minutes in length). The interviews will be conducted in a location, which is private, to ensure you feel comfortable discussing your experiences openly. The interview could also be conducted over the phone, if you choose.

During the interview, you will be asked to discuss your experience caring for your family member during the transition home from a rehabilitation facility. You will be asked to discuss your experience caregiving for a stroke survivor during the transition home from a rehabilitation facility. For the purposes of the study, we will also be asking you some background questions (for example, your age, how you are related to the family member who has had the stroke, your employment outside the house, and the level of care that you are providing). All information gathered is completely confidential and your identity will be kept completely anonymous in all publications/ reports arising from this study.

The interview will be audio-recorded with your permission, and all audio recordings will be transcribed (typewritten) and analyzed.

BENEFITS

While it is not likely that you will notice immediate direct benefits of your participation in this study, the future benefit is the contribution of your shared experience to our society's knowledge about caregiving for a stroke survivor during the transition home from a rehabilitation facility, and how programming and policies can be improved to support caregivers and their families during this transition. We will be distributing a summary of the findings of this study to all caregivers who participate. It is possible that you may benefit by learning about other family caregivers' experience in this study.

RISKS

While participating in this study, it is possible that you may experience stress, and/or psychological or emotional discomfort. Please note that you may refuse to answer any questions that you do not wish to answer, and that you have the right to end the interview at any time. At any time, should you feel the need for follow-up or counsel, the principal investigator of this study (Andrea Ghazzawi) will be available to provide you with supports and services (resources) in the Ottawa Region. In the event that you wish to end your participation in the study, the information collected will be removed from the analyses.

ANONYMITY AND CONFIDENTIALITY

To protect your identity, your name will not be used on stored recordings and documents. Your anonymity and the anonymity of your family member who has had a stroke will be protected. This anonymity will be maintained by entering a false name (a pseudonym) instead of your actual names. There will be no use of personal identifiers in the study's research reports, and quotations will not contain identifying information. In addition, to ensure confidentiality, the list of participants will be kept in a secure area, separate from the interview material and will be accessible only to the research team (Ms. Andrea Ghazzawi, Dr. Tracey O'Sullivan, Dr. Craig Kuziemsky, Dr. Hillel Finestone).

All paper data will be kept in a locked filing cabinet in the research lab of Dr. Tracey O'Sullivan at the University of Ottawa. Electronic data files will be kept in a password-protected directory and only members of the research team will have access to the data. Information gathered for this study will be stored for 15 years after which time all paper and electronic materials, including the list of participants and contact details, will be destroyed.

QUOTATIONS

Participants may be quoted in the research study reports, but none of the quotations will contain names or any identifying information. You have the right to refuse to be quoted. Please indicate your preference by choosing the sentence below that you agree with most:

- *I agree to be quoted but all personally identifying information shall be removed or altered and contents of the quote shall not be revelatory of my identity.* _____.

- *I do not wish to be quoted at all. _____.*

As noted above, you will be asked for permission to audio-record your interview. You have the right to refuse to have your responses audio-recorded. Please indicate your preference by choosing the sentence below that you agree with most.

- *I agree and allow my interview and responses to be audio-recorded._____.*
- *I do not agree to allow my interview and responses to be audio-recorded._____.*

COMPENSATION

Compensation will not be provided to study participants.

SIGNATURES

Your participation is voluntary and you are free to withdraw from the study at any time. Your signature on this form indicates you understand the information regarding your participation in the research project and agree to participate as a subject.

Please note, we ask that you return your signed consent form by mail, email or fax before the interview. If you choose to send us your signed consent form by fax, all efforts will be made to ensure confidentiality and anonymity, however, please note that the fax machine is kept in a shared location and thus, is not secure.

If you have further questions concerning matters related to this research study, please contact Andrea Ghazzawi at 613-406-3700. If you have any questions concerning your rights as a participant in this research, please contact Ms. Dorothy Kessler, REB Chair, at 613-562-6262 extension 1420.

Participant name (please print): _____

Participant signature: _____

Date: _____

Investigator signature (please print): _____

Investigator signature: _____ Date: _____

A copy of this consent form has been given to you for your records and reference.

Appendix I

Demographic Information Questionnaire

Age: _____

Ethnicity: _____

Marital Status: _____

Do you have any other dependents?: _____

Highest level of education completed: _____

Household income level: (per year)

_____ <$45 000

_____ $46 000- 60 000

_____ $61 000- 80 000

_____ >$80 000

Occupation: _____

Number of hours employed work/week: _____

Do you have any serious health conditions? _____

Does the stroke survivor have any communication difficulties (i.e. aphasia) and/or cognitive impairment as a result of the stroke? _____

Does the stroke survivor have any serious health conditions? _____

Appendix J

Coding Tree

Informational Continuity

Process of Information Exchange

(*The process by which information is provided, transferred or received*)

- Pushing information
  (The family caregivers provide the health professionals with information (i.e. the stroke survivor's health), or the health professionals who provide the family caregiver with information.)

- Information retrieval (Pulling information)
  (The ability to get information from health professionals or other sources (i.e.: electronic, paper).

- Information Transfer
  (The transfer of information between health professionals, and/or health care settings.)

Attributes of Information

(*Attributes might include the quality and/or reliability of the information, or type of information provided*)

Impacts

(*This might include an improved quality of care, ability to navigate the system, information overload, and access and coordination of services.*)

Relational Continuity

Patient/caregiver relationship

- Interaction – attributes
  (The might include discussion about the positive or negative nature of the relationship, and the amount of contact received or provided)

Caregiver/Professional relationship

- Interaction – attributes
  (The might include discussion about the positive or negative nature of the relationship, and the amount of contact received or provided)

Patient/Professional relationship

- Interaction – attributes
  (The might include discussion about the positive or negative nature of the relationship, and the

amount of contact received or provided)

Management Continuity

Process

- Follow up
  (*Contact from health professional about the stroke survivors condition. This may be provided in the form of information, communication, services, assessment, check-in, or termination of services*)
- Timing
  (*This might include the timing of decisions and information, the provision of resources, and/or the notice of transfer or discharge*)
- Problem-solving
  (Process of solving problems or figuring it out as you go; self-organization based on the message that 'you're on your own'; coming up with creative solutions)
- Facility
  (*Discussion surrounding a specific facility (i.e.: Bruyère, St. Vincent's), the facility's rules / procedures for acute, rehab and outpatient services, and discussion about discharge, red tape, the availability of a case manager, and/or wait times for services at the facility*)
- Communication
  (*This might include the channels used for information exchange or transfer, the transfer of information across settings.*)

Attributes of the case

- Professionals involved and relationships (between professionals / caregivers / patient)
  (This includes discussion about the health professionals involved in the case, and the formation of any relationships between the health professionals, patient or caregivers.)
- Patient
  (This might include the stroke survivor's mental, physical, or emotional health; functional capabilities; overall health)
- Caregiver
  (This might include the family caregiver's health literacy or knowledge of the health care system; their mental or physical health, and energy levels)
- System
  (Discussion surrounding the health care system--this might include discussion about the availability of services; backlogs; caregivers taking up the slack when there are resource shortages)
- Resources / social capital / social networks
  (A network of social connections—this might include social interactions with friends, family, and/or colleagues)

  Physical Environment

(This refers to any mention of the physical environment; examples may include living in the country, changes that the families have to make to their homes to accommodate the care recipient, equipment needed in the house.)

- Financial situation
  (*Discussion about finances, and/or the impact the stroke has had on the family's financial portfolio.)*

Impacts

(This might include improved quality of care, improvements in the patient's condition, stress or satisfaction, caregiver education etc.)

Caregiving role

(*The family caregiver's role as support provider at the rehabilitation facility, during the transition from rehab to home, and at home. Types of support might include instrumental, information or emotional support. The family caregiver's inclusion or exclusion in the stroke survivors care; their role as first point of contact or system coordinator/navigator*)

Recommendations

(*Suggestions provided by the family caregiver in order to improve continuity of care in the stroke rehabilitation system, specifically during the transition home from a rehabilitation facility. Also, recommendations to ease the family caregiving role; recommendation for the facility etc.)*

Transitions/Handoffs

(The stroke survivor's movement between care settings or handoffs between health professionals.)