Caring for Caregivers: Establishing Resilience through Social Capital

by

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Abstract

There is growing agreement in the research literature that informal caregivers play a crucial role in supporting high needs populations as well as contributing to the sustainability of formal healthcare systems. This dissertation uses a convergent parallel design consisting of three main research phases: analysis of secondary qualitative data from two case studies providing supports to informal caregivers of community-dwelling high-needs persons, including both seniors and children with complex medical needs; collection and analysis of primary qualitative interview data from providers involved with the case studies; and qualitative interviews with informal caregivers and care providers from across Ontario. The dissertation applies social capital theory as a conceptual framework to analyze how care providers and informal caregivers perceive different formal approaches to supporting informal caregivers as contributing to caregiver resilience.

Within the policy and academic literature, there has been increased recognition for supporting people and their informal caregivers. Yet, this focus remains largely at the individual level, and caregiver burden and burnout continues to be assessed solely as a byproduct of the complex (mainly medical) needs of the care recipient. The findings from this dissertation suggest the importance of cultivating broader understandings of the ‘caregiver problem’ in order to identify,
support, and assess networks of support (both formal and informal). Applying social capital theory and the concept of resilience, this dissertation identifies the importance of the healthcare system and connecting people to it and within it. This dissertation provides evidence for supporting the development of formal and informal ties, particularly at the bridging and linking levels to improve a care network’s access to resources and produce longer-term capacity and resilience.

The use of social capital presents a novel conceptual advance in research on caregiver resilience, the relationship between caregiver and system sustainability, and the benefits that can derive from the multidimensional aspects of social capital.
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Chapter 1
Introduction

1 Introduction

This dissertation aims to apply social capital theory as a conceptual framework to analyze how different approaches to providing formal interventions to informal caregivers—mostly unpaid spouses, parents, family, friends, and neighbours—of community-dwelling high-needs persons (including both seniors and children with complex medical needs) can contribute to caregiver resilience through building resource rich support networks.

This dissertation argues that policy interventions that promote the development of social capital will lead to strengthening resilience—having the ability to overcome adverse events and function at a level greater than expected. That is, initiatives that promote flexible supports to encourage the strengthening of networks (at multiple levels) will improve access to resources (that are commonly associated with building resilience) thereby resulting in long-term resiliency for individuals, families, communities, and broader healthcare systems. This dissertation argues that the academic literature on resilience provides necessary insight into the individual needs of informal caregivers to continue in their role, yet how resilience is construed and applied often fails to conceptualize how caregiver resilience can be impacted and supported by broader societal level constructs. This dissertation relies on the theory of social capital to bridge this gap within the resilience literature by considering the roles of networks at various levels as a means to improve access to personal, social, and societal resources. For the purpose of this dissertation, social capital is used to explore the extent to which different policy interventions, or combinations of interventions (self-directed community care, psychosocial supports, financial supports, alternative therapies, skill development), may strengthen bonds between individuals (care recipients, informal caregivers, and front-line providers) and their communities (organizations, community agencies) thereby improving access to all levels of resources resulting in benefits for caregivers, families, and formal health systems.
1.1 Changing Demographics and Needs

Due to improved living conditions and medical advancements, adults and children across all developed nations are living longer, often with multiple chronic health and social needs. These needs are predominantly met by informal caregivers (Kemp et al., 2013; Reinhard et al., 2012; Tadema and Valskamp, 2010). Indeed, these two populations reflect a seismic shift in healthcare demographics from a historical predominance of patients suffering from acute illnesses to one of chronically ill individuals who require ongoing care and management over the course of a lifetime (National Alliance for Caregiving, 2009; Reinhard et al., 2012). Out of every five Canadians, aged 20 years or older, three have a chronic disease, and four are at risk of developing a chronic condition. Additionally, care recipients who have chronic conditions may require intermittent care that entails regular trips to specialists, medication management, and adjustments to household and personal procedures (Betancourt et al., 2014).

These demographic (demand-side) trends have garnered the interest of policy makers and researchers alike, as they stand to impact both formal and informal care. The changes in population health, combined with various policy shifts (which move the nexus of care back into the home), place increased reliance on informal caregivers for health and social care (Hermus, Stronebridge, Thériault, & Bounajm, 2012). Increasingly, researchers and policy makers are expressing concern about the availability and capacity of families given structural changes such as divorce, geographic distance, and increased labour force participation (Fast, 2015; OECD, 2010). As a result of these structural changes, reports have declared the informal caregiving pool as decreasing (Fast, 2015; Keefe et al., 2007; Keefe, 2011; Keating et al., 2013; OECD, 2010). In addition, availability of informal caregivers will continue to be eroded by falling birth rates, and, particularly in rural and remote areas, children are leaving to follow education and jobs in urban areas (Keefe et al., 2007; Williams et al., 2014; Williams et al., 2015).

1.2 Health System Changes

Other factors affecting the ‘responsibilities’ and capacity of the informal caregiver are system-related (or supply-side driven), where acute care--focused healthcare systems were not built to support and respond to the changing demographic shifts and the rise of chronic health and social needs. Moreover, since the 1990s, there has been an increased focus on in-patient length of stay, and initiatives began to center on reducing the number of hospital beds and lengths of inpatient
hospital stays, which subsequently increased the demand for outpatient and community-based care (Penning et al., 2006; Williams, 2009a; Williams, 2009b). As pressures have mounted to discharge hospital patients ‘quicker and sicker,’ greater proportions of available home-care resources have been directed towards post-acute care patients, with consequently fewer resources available for prevention and maintenance in the home and community (Keefe et al., 2007; Williams et al., 2014; Williams et al., 2015). These trends are likely resulting in a greater burden of care and increased pressure on informal caregivers. From a system perspective, these shifts create an increased reliance on informal caregivers to ‘fill the gap’ and provide health and social care. These shifts were often based on cost-effectiveness where home care was seen as a ‘cheaper’ substitute for care in hospitals and people did desire care that was ‘closer to home.’ However, effecting this shift requires resources. As Ontario’s Health Services Restructuring Commission cautioned in the late 1990s, the push-out of hospitals assumed that needed resources would be made available within community-based care, including proactive primary and preventative care. However, in Ontario, home and community care budgets remained flat-lined with new investments predominately directed towards residential long-term care (LTC) (Canadian Home Care Association, 2003; Canadian Home Care Association, 2008; Stabile et al., 2006).

Both the demand- and supply-side trends point not only to an increasing burden of care for informal caregivers, but to a substantive shift in the type of care they provide. Care that would have been provided in institutional settings by trained professional staff is now being provided by untrained, unpaid, and often poorly--resourced informal caregivers (Cohen et al., 2008; Cohen et al., 2012; Expert Group on Home & Community Care [Donner Report], 2015; OECD, 2011; Rosenbaum, 2008). This is particularly evident among children with complex medical needs whose parents now, in addition to normal parenting, perform medicalized tasks such as suctioning and administering medications. For people of all ages who cannot manage on their own, a lack of informal caregiving can mean loss of independence. For already stretched formal healthcare systems, a decline in informal caregiving could increase formal system costs, eroding sustainability (CIHI, 2010; Keefe et al., 2007; OECD, 2010; Williams et al., 2014).
1.3 Policy Approaches to Sustain Caregivers

In a bid to sustain current informal caregivers and encourage others not to shy away from a caregiving role, industrialized countries have implemented a range of caregiver supports. These supports include direct services such as respite, counseling, peer support, and economic benefits such as pension credits and payments to help preserve income, work prospects, and wellbeing (Fast, 2015; Keefe & Rajnovich, 2007; Keefe at al., 2007; Karp et al., 2010).

The outcomes of such interventions appear inconsistent. Some of the variability in outcomes has to do with the challenges inherent in evaluating a suite of initiatives with varying elements and designs (Craig et al., 2008; Fast, 2015). Indeed, the delivery of caregiver initiatives varies extensively across jurisdictions. For example, care-leave arrangements, available in several OECD countries, differ in length, amount of compensation, and allocation interventions (e.g., care allowances, tax exemptions, or contributions to pension schemes) (Williams et al., 2014). Eligibility also varies; criteria may involve combinations of income and needs tests, co-residency with care recipients, or minimum hours of caring (Change-Ability Inc., 2009; Fast, 2015; OECD, 2010; Williams et al., 2014). While consensus may be growing in principle around the need to support caregivers, there is little consistency across, and even within, jurisdictions about how this should manifest in practice. The variability that is observed may also reflect the complex nature of the interface between formal and informal care; this is reflected in the international literature on the balance between formal and informal care (Hollander & Chappell, 2002; Hollander et al., 2009; Stabile et al., 2006; Ward-Griffin & Marshall, 2003). Research has highlighted the association between various formal approaches to care, for example home care and facility-based long-term care, and the cost of hospital-based care (Hollander & Chappell, 2002; Hollander et al., 2009). Within these studies, informal caregivers are commonly recognized as playing a role in determining the costs associated with various formal care options. However, the existing work does not offer a consistent or comprehensive understanding of the intersection between formal and informal care, or of factors influencing outcomes for care recipients and caregivers.

A number of conceptual approaches have emerged in an attempt to address the intricacies of the relationship between formal and informal care. One line of argument suggests a supplementation effect or complementary model, whereby providing formal supports to caregivers can result in greater informal care capacity and reduced reliance on costly formal care (Kemp et al., 2013;
Ward-Griffin & Marshall, 2003). However, another argument points towards a substitution effect, whereby formal care ‘fills the gap’ created when informal caregivers do not provide needed care (Denton, 1997; Peckham et al., 2014b; Ward-Griffin & Marshall, 2003), or where the provision of more than minimal formal supports itself contributes to a decline in informal caregiving (Denton, 1997; Edelman & Hughes, 1990; Stabile, Laporte & Coyte, 2006; Ward-Griffin & Marshall, 2003). These approaches suggest completely different outcomes, where the former argues that supportive policies can pay strong dividends for both the individual family and formal systems, and the latter suggests increased formal supports might simply cost the formal system more.

Two additional perspectives are worth noting. The first suggests a task-specificity model where there is a division of labor between formal and informal caregivers (Penning, 1990). While informal caregivers are best equipped to perform non-technical tasks related to normal activities of daily living (ADLs) such as eating, personal hygiene, locomotion, and toilet use, more technical clinical tasks are best performed by trained professionals such as nurses (Denton, 1997). The second perspective, referred to as a hierarchical compensatory model, suggests that individuals prefer care to be provided first by partners and children, then by other relatives, friends, and neighbors, with formal services filling a residual role. Here, informal caregivers are seen as the first option, with the formal system a last resort (Kemp et al., 2013; Peckham et al., 2014b; Penning, 1990). Both perspectives acknowledge that formal and informal care are necessarily related and suggest that when designing supports and interventions they should be co-considered, yet they continue to be considered separately.

This dissertation suggests that the failure to find consistent outcomes of caregiver support initiatives is related to an ongoing failure to adequately consider two key issues:

1. The nature of the relationship between formal and informal care must be considered. For example, while caregiver burden and resiliency is usually addressed as an individual phenomenon, it is heavily impacted by macro-system issues. Caregiver burden, resiliency, and willingness/unwillingness to continue to care are not simply individual level problems related to the needs of the cared-for persons or the internal resilience and capacity of the caregivers. Rather, these factors, combined with the efforts necessary to navigate fragmented formal care systems, all interact to affect a caregiver's ability to remain
resilient. This suggests that interventions that neglect system-level challenges cannot be successful in building caregiver capacity over the long term.

2. Policy makers often focus on interventions aimed at individual short-term fixes rather than those that support longer-term capacity building. Interventions, which aim to address individual immediate crises will have limited ongoing benefits if they fail to address the factors that precipitated the crisis.

1.4 Impact on Informal Caregivers

The demand-side factors combined with the supply-side factors put increased pressure on the informal caregiver. While caregiving can be a rewarding role for some (Heywood et al, 2009), caring for individuals for extended periods of time can lead to long-term burdens on informal caregivers, resulting in negative effects on their psychological, emotional, and/or social wellbeing.

Changing demographics are affecting the demands placed on informal caregivers, and such negative impacts can be magnified by formal care systems (Conference Board of Canada, 2012; Keefe, 2011; Kemp et al., 2013; Rajnovich et al., 2005). Public policies may have an impact on caregiver stress and burnout that could lead to ‘default’ use of hospital and institutional care (Dybwik et al., 2003; Paraponaris et al., 2012). Fragmented formal “non-systems” of care, which are not well-equipped to serve children or older adults who require services from multiple formal providers in different sectors, contribute to this negative cycle of caregiver stress (Donner Report, 2015). Informal caregivers experience stress and frustrations as they grapple with multiple points of access, different assessments, inconsistent eligibility, and variable out-of-pocket expenses (Chou, 2000; Dybwik et al., 2003; Paraponaris et al., 2012). As such, policy makers across the industrialized world are debating what exactly should be done to support the role of the informal caregiver (Brown & Seeman, 2015; Donner Report, 2015; OECD, 2011).

1.4.1 A Focus on Resilience

The informal-caregiver literature focuses on the key outcome of caregiver resilience—the ability to overcome adverse events and function at a level greater than expected—and other related concepts such as caregiver distress and burden. Much of the academic literature focuses on stress, distress, and depression as signs of declining resilience (Lavretsky, Siddarth & Irwin, 2010; Scott, 2013). While there is clarity in the literature around both the positive benefits and negative
consequences associated with the informal caregiver role, there is less clarity as to why some individuals cope well in the face of adversity, and others do not (Cherry et al., 2013).

The application of resilience remains theoretically disjointed and, within the literature, often overlaps with other constructs (mainly stress, distress, burden, and burnout). Burden, burnout, stress, and distress are often associated with and assessed as a result of the care recipient’s medical needs or the specific informal caregiving ‘tasks’ associated with the role. The concept of resilience has begun to push the classification of caregiver “burden” and “burn-out” beyond the medical needs of the care recipient, yet it lacks a theoretical foundation. Informal caregiver resilience is a multifaceted concept that is affected by the needs of the care recipient, the caregiver’s own capacity, and the fragmented formal system.

Windle (2011) outlines various “protective factors” to maintain resilience referring to resources which have been argued to influence health and emotional wellbeing. Access to these resources are thought to buffer the negative impacts of stressful situations, thus supporting one’s ability to maintain resilience. These resources include personal characteristics, as well as external or environmental conditions. It is argued that, through their interplay, they enable one to respond positively in stressful situations (Coon, 2012, Cherry et al., 2013, Walsh, 2013; Windle, 2011). Windle (2011) identifies the following factors across three protective levels of functioning necessary to support increased resilience:

1. Personal (psychological, neurobiological)
2. Social (family cohesion, parental support)
3. Societal (support systems generated through social and political capital)

While academics acknowledge that resilience is related to factors at many levels, which extend beyond the individual’s personal resources to include access to social- and societal-level resources, often the application of the concept remains clinical and individualistic. The focus on resilience pushes the conceptualization of the ‘caregiver problem’ forward by acknowledging that resilience can be affected by personal, social, and societal factors. However, much of the research on resilience fails to bridge the external factors and broader context in which resilience emerges and is sustained (Coon, 2012; Walsh, 2013).
While research suggests there are multiple levels of protective factors supporting resilience, much of the applied research focuses on personal factors (see Chapter Two for examples). There is a general lack of understanding of how supports or interventions can leverage social and societal factors to produce longer-term resilience and capacity. This dissertation draws on the theory of social capital to bridge this gap within the applied resilience literature by considering how the development of networks at various levels can improve access to personal, social, and societal resources.

1.5 Establishing Resilience through Social Capital

Conceptually, there is a need to think beyond the needs of the care recipient and end-user. Social capital, theorists conceptualize or define social capital as having access to resources (personal, social, and societal) within one’s networks that allow individuals to “get ahead”. As such, an individual with limited access to resource rich networks at any or all of the personal-, social-, or societal-levels will have less social capital and, therefore, reduced ability to get ahead or become resilient (Finsveen and VanOorschot, 2008; Lin, 2001; Windle, 2011).

Kemp et al. (2013) attempt to further this thinking and suggest that, thus far, the literature surrounding the interface between formal and informal care has kept formal and informal care separate, rather than addressing the possible overlap between the two worlds. As an alternative, they outline the “convoys of care” model, which suggests that individuals are “embedded in convoys, which are dynamic networks of close personal relationships that serve as vehicles through which social support is distributed or exchanged” (p. 17). The “convoy of care” model argues that relationships should be conceptualized at the centre of care and proposes that improving outcomes for care recipients, informal caregivers, and formal providers is about building relationships and improving connections (Kemp et al., 2013). Conventionally, when developing policies, the focus is on targeting individual end-users (Donner Report, 2015), thus neglecting the importance of building networks (Kemp et al., 2013).

Social capital theory builds on the resilience literature as both recognize the benefits of developing relationships to ‘get ahead’ or ‘cope’. Social capital theorists have argued that the development of social capital can contribute to both individual and community resilience (Boeck et al., 2008; Heenan 2010). The construct of social capital offers the broader contextual piece, which the applied resiliency literature often lacks. Further, social capital focuses not only on the
resources embedded within one’s networks but how networks can improve access to and use of said resources (Lin, 2001). Social capital is not about one’s possessed goods, but rather about one’s access to resources through direct and indirect network ties (Lin, 2001). The theory of social capital proposes that the more easily and efficiently social capital is accessed and used, the better the outcome (Chapter 2 provides additional details).

This dissertation draws on social capital as a theoretical construct to help us understand and explain how to develop and improve access to resources, to improve resilience, through the development of network ties. While there are many different approaches to defining and measuring social capital, this dissertation uses a networks approach to social capital, focusing on elements that situate individuals within broader social networks. Social capital theory suggests these networks can be strengthened or weakened by policies which encourage linkages between an individual’s informal network and formal resources (Health Canada, 2006).

Social capital theory proposes that social capital may be generated through the development of three types of networks: bonding ties—capture the essence of the connectivity between individuals, reinforcing exclusive and homogenous groups (DiCicco-Bloom et al., 2007); bridging ties—heterogeneous groups with different positions and functions (Derose & Varda, 2009); and linking ties—heterogeneous networks that contain formal vertical relations (Health Canada, 2006). Social capital theorists argue that both the quantity and quality of social and societal resources far outweigh an individual caregiver’s personal resources in terms of potential usefulness to the caregiver. While these resources are not completely independent of one another, the extent to which resources are available and accessible to support caregivers has been tied to one’s network relations at the social and societal levels, subsequently boosting one’s personal resources. Social capital theory also points to the importance of strengthening networks at multiple levels (bonding, bridging, and linking) to improve one’s personal resources and affect community benefits.

This dissertation argues that policies aimed at supporting informal caregivers and their networks that recognize the importance of building and supporting these three pathways to social capital will be more likely to produce access to personal, social, and societal resources and lead to greater caregiver resilience (see Chapter 2) (Briggs, 2004; Health Canada, 2006). Based on this theory, this dissertation argues that, if we fail to develop policies that consider people embedded in
networks that encourage or reinforce the development of resources, the benefits of such policies will be short-lived. This dissertation suggests that policies that target caregiver capacity and system-level concerns will be more effective in producing collective benefits and caregiver resilience over the long term.

The resilience literature provides insight into the characteristics that allow caregivers to manage better and improve their ability to continue to care. There remains a lack of understanding regarding how to leverage an individual’s access to resources. This dissertation draws on the theory of social capital to fill this gap. Social capital focuses on the role of networks and considers the effects of policies on these networks in improving access to resources. This dissertation argues that, where social capital is strong, access to personal, social, and societal resources will be improved, thus leading to improved resilience.

1.6 Research Questions

This multi-stage, convergent parallel design dissertation was grounded by the following question:

Do policy interventions that consider an informal caregiver’s broader context and work to support the building of social capital (bonding, bridging, and linking ties) lead to increased access to personal, social, and societal resources and therefore improved caregiver resilience?

Sub-questions for this dissertation are:

1. What policy interventions appear to influence the development of bonding, bridging, and linking ties?
2. How does the development of bonding, bridging, and linking ties influence access to personal-, social-, and societal-level resources?
3. What do formal service providers and informal caregivers perceive as priorities to consider when developing policies to support familial, formal, and social networks in the community?

The proposition for this dissertation is:

Policy interventions that consider caregivers within their broader context, and work to support the building of social capital (bonding, bridging, and linking), will lead to enhanced access to personal, social, and societal resources, and improved caregiver resilience.
1.7 Data and Methodology

As detailed below, this dissertation aims to explore whether different approaches to providing formal supports to informal caregivers of community-dwelling persons can build social capital (ties at the bonding-, bridging-, and linking-levels) and improve access to resources (personal, social, and societal) and therefore lead to improved caregiver resilience. To do this, the research uses a mix of qualitative and quantitative methods.

This dissertation used a convergent parallel design, according to which the analysis of each phase was done concurrently but independently and the data sets were brought together only at the point of interpretation (Creswell and Clark, 2011). There are three main phases: Phase 1 employed an analysis of secondary data for two evaluations of caregiver-support initiatives to address questions 1 and 2; phase 2 involved qualitative interviews of providers involved with the two caregiver-support initiatives to address questions 1 through 3; and phase 3 utilized qualitative interviews of providers and caregivers from across Ontario to address questions 1 through 3.

**Phase 1** involved analysis of secondary data collected for two evaluations of caregiver-support initiatives implemented in the Toronto Central LHIN. The first initiative was a Caregiver Support Program (CSP) that supports informal caregivers of high-needs older adults at risk of hospitalization or residential long-term care as a result of chronic illnesses and conditions including dementia. These older adults require high levels of ongoing personal, instrumental, and emotional care. The second initiative was the Caregiver Framework (CF) for Children with Medical Complexities (CMC), which supports caregivers of children discharged from hospital with high levels of medical needs (e.g., ventilators, G-tubes, lifts) often as a result of life-threatening illnesses such as cancer, coronary heart disease, muscular dystrophy, and cystic fibrosis. These data were reviewed to determine if there is evidence to suggest that certain supports produce bonding, bridging and linking ties and if these ties improve access to personal-, social-, and societal-level resources. These two cases add value to the applied and theoretical literature as they look past providing a single approach (e.g., money) to interventions that offered at-risk caregivers of high-needs individuals combinations of cash, in-kind services, education, and case management. These initiatives focused on two different populations, yet both aim to support informal caregivers who are at risk of burning out. Including both of these initiatives in the analysis was valuable in order to determine if building networks of supports can benefit two
seemingly different populations using more or less similar interventions of support. As demonstrated in the case study analysis, while cash is helpful in dealing with immediate changes, the long-lasting benefits can be attributed to a process of problem identification and problem solving facilitated by a trained formal case manager (bridging networks of support).

**Phase Two** consisted of semi-structured key informant interviews to gain insight into designing effective interventions to support informal caregivers and their networks over the longer term. Interviews were conducted with case managers and project administrators who worked directly and on a regular basis with hundreds of informal caregivers during the course of the two support initiatives. The qualitative interviews assisted with understanding, from their perspective, the impact of the support initiatives on caregivers, and particularly the extent to which they encouraged the development of ongoing support networks. The purpose of this phase was to better comprehend shared meaning and understanding around the extent to which some caregiver supports might be one-off interventions with short-term outcomes and others might produce longer-term resilience building.

The participants were asked to consider how a caregiver’s involvement in the CF or the CSP might have impacted their overall wellbeing and resilience (i.e., their ability to continue to care). Specifically, participants were asked to address the possible outcomes experienced by caregivers and families as a result of the CF or CSP and whether or not they assess these outcomes to be longer-term sustainable outcomes or shorter-term one-off benefits and why.

**Phase Three** involved semi-structured qualitative interviews aimed at identifying what support interventions caregivers and services providers from across Ontario perceive to best improve and support caregiver resilience. Specifically, these interviews aimed to identify whether or not access to personal, social, and societal resources are seen as crucial to sustaining a caregiver in his or her role and whether or not developing and strengthening networks at the bonding, bridging, and linking levels were seen to improve access to these resources.

Participants were broadly asked about what they perceive as working most effectively to build stronger connections among families, social networks, and formal providers and whether or not these connections were important to sustain informal caregivers in their roles. These interviews were used as a follow-up method to inform and validate the findings identified through the initial round of qualitative semi-structured interviews.
Please refer to Chapter 3: Methods for detailed description of the data collection and analysis process.

### 1.8 Organization of Dissertation

This dissertation is divided into seven chapters (including this introductory chapter). Chapter Two describes the results of the literature review and conceptual framework used to guide and inform the findings of this dissertation. Chapter Three outlines the methodology used to collect and analyze the data. Chapter Four reports the results of the analysis of the secondary data collected for the two caregiver-support initiatives. Chapter Five reports the results from the qualitative interviews of providers involved with the two caregiver initiatives. Chapter Six presents the findings from the qualitative interviews conducted with providers and caregivers from across Ontario, and Chapter Seven contains a review of the dissertation, a review of the findings, the theoretical and applied conclusions and implications, data limitations, and recommendations for future research.

### 1.9 Chapter Summary

The academic and policy literature offers inconclusive evidence to guide how informal caregivers should be supported to ensure their continued involvement and overall resilience. The resilience literature provides insight into the characteristics that allow caregivers to manage and improve their ability to care. However, there remains a lack of understanding regarding how to leverage an individual’s access to resources. This dissertation draws on the theory of social capital to help understand the role of networks and the effects of policies on these networks in improving access to resources. This dissertation provides valuable insight for policy makers as it discusses the importance of targeting various levels of supports to informal caregivers that will produce longer-term impacts at both the individual and system levels.
Chapter 2
Literature Review and Conceptual Framework

2 Introduction

This chapter examines the academic literature that addresses the role of the informal caregiver to identify and address the key issues related to this dissertation.

This chapter will begin by outlining the methods used to conduct a literature review of both the academic and gray informal caregiver literature, as well as social capital literature. The chapter will then synthesize the results of both the gray and academic literature reviews.

The second section begins by asking “who cares?” both in the sense of understanding the characteristics of caregivers and the type of care they provide and in the sense of analyzing why sustaining caregivers has emerged as a top issue for policy makers and academic researchers in Canada and other industrialized countries. This section will then go on to highlight federal-, provincial-, and organizational-level policies/programs available to support informal caregivers. This chapter acknowledges that there has been progress—in that there has been an increased focus on developing interventions aimed at supporting informal caregivers across Canada. Unfortunately, availability of and access to these services remains a critical issue—as the home and community care sector falls outside of the boundaries of the Canada Health Act, and, what’s more, caregivers fall outside the boundaries of eligibility criteria for standard home and community care.

The remainder of the chapter is structured around the three main concepts identified within the conceptual model (see figure 2): “policy interventions”, “social capital”, and “improved access to resources”.

There follows discussion of the current policy interventions offered more broadly, which argues that policy makers are implementing a variety of supports within and across jurisdictions, albeit without any clear understanding of what works best for which caregivers under what conditions.
The fourth section discusses the more theoretical social capital literature, noting the benefits of building, improving upon, and leveraging resources through the strengthening of ties at the bonding, bridging, and linking levels. This theory looks beyond individual assets and circumstances to the broader social and formal context in which groups are located.

Both the fifth and sixth sections highlight a review of the academic caregiving literature, which identifies the concept of resilience as a primary focus. Resilience is defined variously but broadly refers to one’s ability to cope through adverse circumstances. While the concept of resilience is used throughout the caregiving literature, it is often applied at the clinical level around the efficacy of particular services and supports for individual caregivers. This dissertation argues that, while the concept of resilience provides necessary insight into the individual needs of informal caregivers, it often fails to conceptualize caregiver capacity as more than an individual construct. This dissertation argues that focusing on ties at multiple levels (social capital) will lead to increased access to resources and thereby, as the resilience literature suggests, support improved resilience.

The chapter concludes by outlining the conceptual model used for this dissertation. The conceptual model highlights the main propositions of this dissertation suggesting that policy intervention(s) aimed at encouraging the development of bonding, bridging, and linking ties will improve access to personal, social, and societal resources and thereby support the desired output of resilience.

2.1 Literature Review Methodology

The literature review was conducted to accomplish two goals:

1. To highlight and synthesize the informal caregiver literature and review evaluations of informal caregiver-support programs to ascertain the factors associated with caregiver resiliency.
2. To review and synthesize the social capital literature to identify the key principles of social capital and to review the networks approach to social capital to explore what policy interventions might be more capable of strengthening bonds between individuals and their communities.
In order to understand these inquiries, a literature review was undertaken to search for articles published in English on:

- characteristics of informal caregivers;
- programs supporting the role of the informal caregiver;
- caregiver resiliency, coping, and the interface of the formal and informal care systems;
- the key principles and dimensions of social capital; and
- the application of social capital to supporting informal caregivers.

The review was conducted using the following databases: PubMED, AgeLine, PsychINFO, Health Sciences: A SAGE full-text collection, JSTOR, Proquest, MEDLINE, OECDiLibrary, Cochrane Library, and the Health Systems and Policy Monitor Network. The following key words and phrases were used and combined in various groupings to ensure key articles and initiatives were identified:

- “informal caregiver*” or “unpaid caregiver*” or caregiver* and
- “older adult*” or elderly or aged or ageing and
- “children with medical complexity” or “children with complex health needs” and
- “support program*” or initiative* or program* or intervention* or support and
- evaluation* or intervention* or initiative* and
- policy* and
- “social capital” or “social network*” or “social trust” or “social connection*” or “social structure*” or “social relation*” or “bonding” or “bridging” or “linking” and
- “OECD” or “organization for economic co-operation and development”

The literature that focused on initiatives and approaches to support informal caregivers were included if published between 2002 and 2013. The search was updated to identify recent articles and initiatives identified between 2014 and 2015. This time frame is considered relevant, as the Romanow (2002) commission on the future of healthcare in Canada brought informal caregivers into the spotlight by highlighting the importance of supporting their increasingly crucial role. The purpose of this review was not to undertake a historical analysis but rather identify more recent initiatives and understandings of possible effective long-term solutions to support informal
caregivers. Articles on social capital were included if they were published from 1985 onward, to allow for more classic works to be included as well as more recent research and advancements.

Literature was excluded from review if the article was not population-specific, did not address individuals in the home and community care setting, did not address caregiver coping or resilience, was not related to support programs for informal caregivers, and/or was not related to social capital.

2.2 Who Cares?

2.2.1 Informal Caregiver Characteristics

Research consistently estimates that informal caregivers provide 70-80% of the care given in the community setting to older adults (CIHI, 2010; Hermus et al., 2012; OECD, 2010;). Nearly half of Canadians at some point in their lives will provide some form of care to a family member or a loved one with a long-term health condition (Sinha, 2013). A report highlighting the results of the 2012 General Social Survey (GSS) documented that 8.1 million Canadians aged 15 years of age and older provided care to a chronically ill loved one within the 12 months preceding the survey (Sinha, 2013). Caring for an older relative (parent or parent-in-law) remained the most common caring relationship (Keefe, 2011; Sinha, 2013), with 48% of caregivers providing care to their parent or parent-in-law and 28% of caregivers providing care to an individual with aging-related needs. The second most common caring relationship, at 16%, was close friends, colleagues, or neighbours (Sinha, 2013), highlighting that care is also being provided by people outside of the immediate family structure (Rajnovich et al., 2005). Providing care to spouses accounted for 8% of the GSS respondents. Overall, spouses and children were among the least common categories of care recipients. Analysts suggest this might be a result of spousal caregivers not identifying as informal caregivers (Cranswick & Dosman, 2008). However, when spousal and parental caregivers are identified they tend to provide more hours of care and they provide more personal support (i.e. bathing and dressing) than other caregivers (Keefe, 2011; Sinha, 2012).

While much of the information on informal caregivers focuses on those who provide care to older adults, caregiving is located within a broader context of increasing chronic health and social needs which need to be managed over the course of a lifetime. The GSS identified that problems with
mental health, such as depression, bipolar disorder and schizophrenia were the most common reasons for parents providing care to a child (Sinha, 2012).

Caregivers are most often between the ages of 45-54 years (24%) and 55 to 64 years (20%). Informal caregivers provide a range of supports to individuals living in the home and community setting. The type of support provided has most commonly been categorized into four overlapping classifications (Keefe, 2011): advice and emotional support; instrumental activities of daily living (IADL), which include transportation, medication management, meal preparation; system management, and navigation of formal supports; and activities of daily living (ADL), which include more personal care like bathing and toileting (Keefe, 2011; Sinha, 2012; Williams et al., 2010). While spousal caregivers will provide personal care, informal caregivers are generally more likely to provide IADL care over ADL care, with transportation being the most common form of support provided (Sinha, 2012).

Despite personal care (ADL support) and medical care being the least common categories of care provided, when informal caregivers provided these forms of care, they were provided more regularly. Of the caregivers who provided personal care, 66% did so at least once a week (Sinha, 2013). Caregiving is not generally associated with one specific task. In fact, 71% of caregivers providing regular support provided support for two or more tasks (Sinha, 2013).

While the gender gap is narrowing, women (54%) are still more likely to provide informal support than men (Keefe, 2011; Sinha, 2013). Women are also more likely to spend 20 or more hours per week on caregiving tasks than men (Sinha, 2013). The increased intensity of caregiving among women is in large part due to the type of tasks commonly performed—providing support for activities that must be completed on a regular basis, such as personal care or medical treatments (Keefe, 2011; Sinha, 2013). Men are more likely to perform house maintenance or outdoor work, which can often wait until the caregiver has time to complete the tasks (Sinha, 2013). It has been noted that time-specific tasks are likely to add burden and stress to caregivers (Cranswick & Dosman, 2008).

2.2.2 Informal Caregiving Can Come at a Cost

While caregiving can be a rewarding role for some (Greenwood et al., 2009), caring for individuals for extended periods of time can lead to long-term burdens on informal caregivers,
resulting in negative effects on their psychological, emotional, and/or social well-being. Most persons living with disabilities or chronic conditions receive support from their informal networks (Carrière et al., 2007; Fast et al., 2010; Keefe, 2011). It has been estimated that 16% of informal caregivers who provide care to a senior receiving home care experience distress related to their role, and the rate increased to 52% for those caring for a loved one who exhibits aggressive behaviours (CIHI, 2010; Sinha, 2013). Providing unpaid care to a loved one with complex health- and social-care needs increases the risk of psychological co-morbidity, such as anxiety and depression (Perkins et al., 2013).

While informal caregivers do prefer to provide care, and often feel positive value as a product of their role (Toljamo et al., 2011), they can experience negative consequences as a result (Keefe, 2011; OECD, 2011). The responsibilities of caring often constrain social participation and necessitate withdrawal from the work force impacting on caregivers’ economical, physical and/or emotional well-being (Keefe, 2011; OECD, 2011; Turcotte, 2013).

In addition to the personal costs, economic costs include direct expenditures for such things as services or equipment as well as loss of income or benefits from employment (Keating et al., 2013). For example, caregivers might take days off work in order to attend medical appointments or, as the intensity of caregiving increases, a caregiver might be required to replace full-time employment with part-time employment (Fast et al., 2010; Keefe, 2011; Turcotte, 2013).

2.2.3 Informal Caregivers: Policy Salience

The Canadian healthcare system relies heavily on the role that informal caregivers play. Informal, and mostly unpaid, caregivers—spouses, parents, family, friends, and neighbours—play a crucial role in supporting the health, wellbeing, functional independence, and quality of life of growing numbers of individuals of all ages who cannot manage on their own (Keating et al., 2013; Neuman et al., 2007; OECD, 2010).

There has been significant discussion surrounding the complications that might develop as a result of the increasing age of the population and other formal and demographic shifts that will affect the availability of informal support (Hermus et al., 2012; Keefe, 2011; OECD, 2010). Not only do informal caregivers provide an estimated 70-80% of all home care services to older adults; but a possible and expected decline in informal caregiving due to factors such as declining birth rates
and the increasing participation of women in the paid labour force, (Fast, 2015; Hermus et al., 2012; Kemp et al., 2013), could increase system costs by 5-35% (OECD, 2010).

The informal caregiver role is becoming increasingly important as individuals live longer with increased multiple complex conditions (Sadler & McKevitt, 2013; Cohen, 2012). Not only do informal caregivers support the independence and quality of life of complex needs populations, but they are also seen to contribute to the sustainability of formal care systems (Hoffman & Rodrigues, 2010; Hollander et al., 2009; Jacobs et al., 2013; Keefe, 2011). As more people are living longer, often with multiple chronic health and social needs, healthcare utilization and expenditures are expected to rise, putting additional strain on already stretched healthcare systems and threatening system sustainability. Caregivers are essential in filling the needs not addressed by formal care services, supplementing them, and ensuring that care is provided during critical junctures through the care continuum (e.g., discharge from hospital to home). Informal caregivers are often the only fallback option when formal services are not available or lack the adequate supports necessary to transition individuals safely (Hoffman & Rodrigues, 2010; Paraponaris et al., 2012). Informal caregivers are increasingly responsible for coordinating care across multiple points of access with inconsistent eligibility criteria and ease of access to services. This navigation role is complex, as disparities do exist in terms of access to services based on income, geography, and health condition (Dawson et al., 2015; Juliano & Yunes, 2014). A recent study outlined that a senior who lived with a partner or family member used significantly fewer home care services overall (Mery et al., 2012). Other studies point to the importance of IADL service needs in driving long-term care admissions (Williams et al., 2009a; Williams et al., 2009b).

There is growing emphasis placed on the value of transitioning individuals from institutional settings to the home (Walker, 2011). As such, individuals are less likely to be cared for in institutional settings, particularly given the increased policy emphasis on quicker hospital discharges and home as the desired site of care. Certain strategies (i.e., Aging at Home) respond to individuals’ desire to live at home. Home is also seen as the appropriate environment for childhood development. However, in order for the transition from institutions to the home to succeed, supports and services need to “follow” these individuals home. Home is further represented as a cost-effective substitute for care in hospitals and institutional settings (Hollander & Chappell, 2002), often on the assumption that unpaid informal caregivers will take up a greater burden of the care that would have otherwise been provided by paid specialized professionals.
Health Council of Canada, 2012; Keefe et al., 2007). A recent report by the Conference Board of Canada (Hermus et al., 2012, p. 28) further illustrates this point:

Defined in its broadest sense, most home and community care is provided by family, friends and volunteers. Our estimate of the contribution of this care is substantial – 1.5 billion hours of unpaid home care support per year. This is between 8 and 11 times larger than the number of paid hours of care offered for home health, home support, and community care (estimated between 140 million and 182 million hours). A further shift toward care in the home and out of institutions means an even greater reliance on unpaid caregivers.

To recapitulate, changing demographics and shifts in policies are affecting the demands placed on informal caregivers (Hermus et al., 2012; Keefe, 2011; Kemp et al., 2013; Rajnovich et al., 2005;). Public policies may have an impact on caregiver stress and burnout that could lead to “default” use of hospitalization and institutional care. Fragmented formal “non-systems” of care that are not well-equipped to serve children or older adults who require multiple providers in different sectors can contribute to a negative cycle of caregiver stress. Informal caregivers experience stress and frustrations as they grapple with multiple points of access, different assessments, multiple professionals, inconsistent eligibility, and variable out-of-pocket expenses (Chou, 2000; Dybwik et al., 2003; Paraponaris et al., 2012). As such, policy makers across the industrialized world are debating what exactly should be done to support the role of the informal caregiver and improve caregiver resilience.

2.3 Policy Interventions

Although Canada has neither a national caregiver strategy, nor a national strategy on aging, there is a range of caregiver policies at the federal, provincial, and local levels. Over the last several years there has been an increase in policies aimed at supporting the role of the informal caregiver across Canada (Rajnovich & Keefe, 2005). Many of the policies used to support informal caregivers focus on respite, self-managed care, direct compensation, indirect compensation, and labour policies (Keefe, 2011; Rajnovich & Keefe, 2005). Many of the supports offered are provincial- or local-level strategies (i.e. respite, self-managed care), although there are other programs that are driven by federal jurisdiction (i.e. tax credit, compassionate care benefit). Respite includes direct services (e.g., home care) delivered to the recipient; “self-managed care” refers to funds provided directly to the caregiver for the sole purpose of purchasing healthcare services for the care recipient; and “direct compensation” refers to funds provided directly to the caregiver to be used at their discretion. “Indirect compensation” programs are non-direct cash.
payments such as tax relief or pension security. Lastly, “labour policies” provide leave from work to provide care, either through paid leave or an assurance of job security. However, there has been little evidence to suggest which supports or combinations of supports work best, for which caregivers, and under what circumstances.

Federal-level strategies to support informal caregivers focus mostly on providing families with indirect compensation or work-leave support:

- Compassionate-care benefit is an employment insurance provided for up to six weeks when care is provided to a family member who is at risk of death. Caregivers receive from 55% of their average income up to a maximum of $514.00 per week.
- Paid parental leave is provided for a maximum of 52 weeks, and this cannot be received for any other type of caring relationship.
- The family caregiver tax credit is a non-refundable credit in the amount of $2,040. This benefit is for caregivers who are providing care to a dependent who is living with either a physical or mental impairment.
- The disability tax or medical expenses tax credits are available to cover out-of-pocket expenses for disability-related costs.

(Canadian Association for Retired Persons, 2014)

Provinces, as a result of the home and community care sector falling outside the boundaries of the Canada Health Act, have jurisdiction over the provision of home care services. As such, the organization and delivery of home and community care varies extensively from province to province.

Ontario, under the leadership of the Harris Government in 1996, introduced 43 Community Care Access Centers (CCACs), which are regionally based not-for-profit community agencies responsible for the assessment, care planning, coordination, and quality assurance of publicly-funded home and community care services in Ontario (Baranek et al., 2014). In 2003 the McGuinty government introduced the Local Health System Integration Act, which created 14 regional NFP organizations called Local Health Integration Networks (LHINs). The Ministry of Health and Long-term Care continued to have responsibility over strategic directions and provincial priorities. The LHINs were introduced to focus on the local level to determine the
strategic directions for their geographic regions, including planning, integrating, and funding of the local health services. It was with the introduction of the LHINs that the CCACs were realigned to merge with the boundaries of the 14 LHINs. CCACs often serve as the access points for many of the community support services offered within Ontario namely, adult day programs, complex continuing care, convalescent care, supportive and assisted living programs. While many community support services within Ontario require co-payments, the CCAC does not and directly purchases an array of in-home services including, speech language pathology, nursing, occupational therapy, physio-therapy, social work, dietetic services, and personal support (Baranek et al., 2014). Currently, caregivers are not considered clients in their own right for traditional home and community care services, although there are some community service agencies specializing in respite (e.g., Wesway) and caregiver counseling (e.g., Alzheimer’s Society).

Nova Scotia has an income-tested caregiver allowance which gives $400 per month to caregivers providing care to an individual who is 19 years or older. Couples with net incomes of less than $37,209 and singles of net incomes of less than $22,125 are eligible for the allowance. Both Nova Scotia and British Columbia use a “self-managed” care model, which is aimed at providing funds to care recipients to purchase additional support. In British Columbia, the individual cannot be a family member (British Columbia Law Institute & The Canadian Centre for Elder Law, 2010). Manitoba offers a refundable credit of up to $1,275 a year to people who are providing ongoing voluntary care to a family member, friend, or neighbour.

Beyond income supports and self-management models, respite is a common support used to address the needs of informal caregivers. Respite is a form of support offered to a caregiver so they are able to receive a period of rest or relief. Respite can be offered for a few hours, a few days, or even a week. Respite can be provided using services and providers who can substitute for the caregiver and is provided in the care recipient’s home. Short-stay programs are also available through various long-term care homes, retirement homes, or alternative community organizations that offer short-stay and over-night respite. Respite can be offered using a multitude of interventions including in-home support, adult day programs, or alternative living arrangements to provide a longer period of relief.
As highlighted in Figure 1 below, current policy interventions are ultimately targeting individual informal caregivers, more or less directly, in the hope that they will result in some form of informal caregiver resilience (or improved willingness/ability to continue to care).

Figure 1: Conventional Wisdom Targeting Individual Caregivers

The role of the informal caregiver has received attention from the Government of Ontario. Recently, Ontario has introduced a family-caregiver leave, which provides employees unpaid, job-protected leave for up to eight weeks a year. The Ministry of Labour passed the Employment Standards Amendment Act, 2014 which builds on the previous Family Medical Leave policy (Bill 21 Legislative Assembly of Ontario, 2014). While there have been improvements, there remains no provincial caregiver strategy or program. Therefore, the supports offered to caregivers remain sparse and vary by region. These initiatives are all targeted at the individual level aiming to improve access to personal resources in hopes to reduce burden and improving resiliency (See Figure 1). With a lack of an overarching framework or caregiver strategy, supports and interventions that are offered across Ontario offer a variety of services and approaches to support as identified by the local and provincial examples identified in Appendix 1.

Current supports often focus on the individual as a way to assess both eligibility and outcomes, focusing on either individual caregiver characteristics or “caregiving responsibility” associated with the care needs of the care recipient. Additionally, objective burden is most often assessed as a construct of hours spent on care and type of caring tasks conducted (Janse et al., 2014). This is not to argue that care needs of the care recipient do not impact caregiver wellbeing, ability to cope, or overall resilience, but rather this dissertation suggests it is not the sole variable impacting on a caregiver’s ability to maintain resilience. Caregivers are most often not explicitly addressed,
and, when they are, they are often acknowledged as a separate unit from the care recipient and their social and political contexts. A recent OECD (2015a; 2015b) report highlights the importance and benefits of developing integrated social services for vulnerable populations, arguing vulnerable populations often have multiple underlying issues, which require attention and support if any form of long-term benefits are to be achieved.

Many regional and community agencies have developed a variety of initiatives or programs aimed at supporting the role of the informal caregiver, beyond the supports identified within this dissertation. There has been progress towards an increased focus on supporting informal caregivers across Canada. Unfortunately, availability of and access to these services remains a critical issue. Informal caregivers still remain relatively invisible in the provincial health and social service systems.

2.3.1 Evaluated Interventions

Evaluations of various caregiver-support programs often target and measure individual (personal and sometimes social) level outcomes. While most studies to date have focused on the immediate physical or psychosocial outcomes associated with resilience (Sadler & McKeivitt, 2013), it is suggested that a next step should involve the effective integration of psychosocial and community support interventions that bridge the individual or interpersonal-levels with system-, organizational-, and community-levels that have previously been unexplored (Coon, 2012; Hendrix et al., 2011). One study assessed the value of a psycho-educational course as a model to improve longer-term preventive benefits. Above and beyond improving personal resources (education and knowledge), the model offered access to psychologists and added a crucial social dimension (societal and social resources), and offered extended benefits (Milne et al., 2013).

Two studies highlighted the importance of improving the quality of social resources for caregivers encouraging caregiver resilience. Roth, et al. (2005) measured whether an enhanced support intervention improved caregivers’ social resources, focusing primarily on mobilizing pre-existing support networks rather than leveraging and developing broader heterogeneous social networks. He found the quality of the social interaction was more important for the determinants of caregiver satisfaction than the actual amount of assistance received. Mittleman et al. (2007) also measured satisfaction with social support as a possible outcome to a counselling and support intervention. As a result of the family counselling sessions, the intervention group demonstrated
improved satisfaction with caregiver social support during the first four months. The results of this research do suggest that social support appears to alter appraisals and wellbeing even in the face of sustained stressors (Roth et al., 2005; Mittleman et al., 2007).

Another study by Hautsalo et al. (2012) focused on both the personal and social level resources that have been argued to impact caregiver resilience and ability to cope. This research identified personal resources, such as education, age, and gender, impacted the social support received. Hautsalo et al. (2012) also found that the needs of caregivers and family members vary, and, therefore, the assessment of needs, care planning, and on-going updating are crucial to ensure continuous benefits. Other studies have similarly argued that taking a flexible approach to each family is essential if supports are to be effective at meeting their needs (Al-Gamal & Long, 2012; Brandon, 2013; Toljamo et al., 2011). Research is also beginning to reveal that complex multicomponent interventions are likely to be more effective in supporting families and strengthening their ability to cope and to be resilient (Brandon, 2013).

2.4 Social Capital

As outlined below in Figure 2, this dissertation argues that caregiver-support initiatives that promote the development of social capital will lead to strengthening resilience. Initiatives that provide individualized supports aimed at encouraging the development and strengthening of all levels of “resources” (personal, social, and societal) will be most successful in producing familial and caregiver benefits over the longer term and similarly will build benefits beyond the family unit to broader social networks and healthcare systems as a whole. This dissertation draws on the concept of resiliency and the theory of social capital to further the argument that a caregiver-support initiative that leverages networks supporting access to resources at all levels will result in long-term resiliency for individuals, families, communities, and healthcare systems.

While caregiver-supports are often addressed as individual interventions, such as promoting caregiver resiliency or decreasing caregiver burden, questions around supporting informal caregivers have important conceptual and theoretical dimensions that are often overlooked. Using the theory of social capital to explore caregiver-support interventions beyond the individual level may help us understand and discover which interventions could potentially generate longer-term collective benefits for informal caregivers, cared-for persons, broader social networks, and health and social care systems.
This dissertation uses the theory of social capital to consider the impact of policies on strengthening bonds between individuals (care recipients, informal caregivers, formal care providers and organizations) and their communities over the longer-term, thus providing benefits for caregivers, families, and formal health systems. Using social capital theory builds on the concept of caregiver resilience to identify the possible benefits of implementing caregiver-supports, which build longer-term capacity through developing networks at multiple levels, thereby improving access to personal, social, and societal resources.

The following section provides a synopsis of social capital theory—a theory that considers the role of bonding, bridging, and linking ties—on personal, social, and societal outcomes. This dissertation argues that components of caregiver initiatives that encourage bonding (intragroup of homogenous social networks, family, or kin), bridging (heterogeneous social networks, composed of cross-cutting ties), and/or linking (vertical connections, linking to formal community/institutional agencies) ties will be more likely to support informal caregivers over the long term by improving their access to personal, social, and societal resources.

2.4.1 Origins and Definitions of Social Capital

The concept of social capital dates back to the work of sociologists Marx and Weber (Light, 2004; Lin, 1999). Experts differ in the treatment of the concept. Social capital was popularized by neo-capital theorists who focus on specific forms of capital such as: human capital, cultural capital, and social capital. Human capital conceives of capital as an investment with expected returns, with the “capital” being in the owner’s person, not in the owner’s bank account (Light, 2004; Lin, 1999). Education and training have been described as the most essential investment to gain human capital (Light, 2004). For example, human capital can also be classified as an investment (education) with expected returns (earnings) (Lin, 1999). A similar concept of cultural capital originated from the work of Bourdieu. Cultural capital can be defined as cultural knowledge, which leads to returns in socioeconomic advantages (Light, 2004). Cultural capital is essentially having access to knowledge where one can reproduce symbols and meanings that are internalized by the dominant class (Lin, 1999; Light, 2004).

In contrast to the other two forms of capital, social capital refers to the characteristics of social order such as “networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit” (Putnam, 1995, p. 67). The social capital theorists most commonly cited by health
Researchers are Bourdieu, Coleman, and Putnam (Derose & Varda, 2009). Table 1 presents definitions, in chronological order, of social capital by theorists from various disciplines, including public health, sociology, and social sciences.

Table 1: Definitions of Social Capital

<table>
<thead>
<tr>
<th>Author (Year)</th>
<th>Discipline</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bourdieu (1986)</td>
<td>Sociology</td>
<td>“Social capital is the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition” (p. 248).</td>
</tr>
<tr>
<td>Coleman (1988)</td>
<td>Sociology</td>
<td>“Like other forms of capital, social capital is productive, making possible the achievement of certain ends that in its absence would not be possible….Unlike other forms of capital, social capital inheres in the structure of relations between actors and among actors. It is not lodged either in the actors themselves or in physical implements of production” (p. 98).</td>
</tr>
<tr>
<td>Putnam (1995)</td>
<td>Sociology/Political Science</td>
<td>Social capital refers to the features of social networks, such as trust, norms, reciprocity, that can improve the efficiency of societies.</td>
</tr>
<tr>
<td>Portes (1998)</td>
<td>Sociology</td>
<td>Social capital refers to one’s ability to secure benefits through membership in networks and other social structures.</td>
</tr>
<tr>
<td>Lin (1999; 2001)</td>
<td>Sociology</td>
<td>Social capital focuses on the resources embedded in one’s social network, and access to these resources benefit the individual’s actions.</td>
</tr>
</tbody>
</table>

Coleman introduced the notion of social capital to American sociologists (Ports, 1998). Coleman, like Bourdieu, saw social capital as being imbedded in social structures. Unlike Bourdieu, Coleman saw social capital as a product of interactions and he argued that strong communities are produced as a result of strong ties among members. Lin and Coleman focus the concept at the individual level and stress the value of accessing and using resources embedded in social networks, while Bourdieu, Putnam, and Coleman express the importance of solidarity and reproduction of a group, stressing the importance of investment in mutual recognition and acknowledgement (Lin, 1999). Even with the disparities in definitions (see Table 1), there are overlapping attributes of social capital. Overall, the concept has been used to explain access to, and acquisition of, resources. Additionally, it has been utilized as a determinate for quality of life,
health, and wellness (Health Canada, 2006). While social capital has a wide application, there seems to be a common understanding that social capital has to do with social relationships between people and among groups (De Silva, McKenzie, Harpham, & Huttly, 2005). For example, older adults who raised their children to believe in filial piety trust that the time and effort they spent providing care to their children will be reciprocated when they require assistance as they age.

The benefits of social capital are vast and can be social, psychological, emotional, as well as economical (Lin, 1989). For example, building social capital can facilitate the flow of information and reinforce one’s identity. By bringing people together in formal and informal networks, social capital builds confidence and leads to increased awareness, knowledge, and trust. It enables people to build communities, to commit themselves to each other, to feel a greater sense of belonging, and to tie social knots (Health Canada, 2006; Lin, 1999).

While there are ongoing debates regarding social capital as either an attribute of individuals or collectives, many scholars argue that it can be both (Ferlander, 2007; Griffiths et al., Jun 2009). At the individual level, social capital is measured through social connections, where an individual gains returns through access to social networks. Social capital has also been conceptualized to include elements at a more collective level, where level of generalized trust is assessed to explore how trust is vital to the creation of the collective asset. Social relations can be beneficial (or harmful) to both an individual and the collective, and accumulation of individual returns can also benefit the collective (Kawachi, Kim, Coutts & Subramanian, 2004; Lin, 2001).

Individuals have three types of resources they can access: 1) personal resources, 2) social resources, and 3) societal resources. Personal resources are those that are possessed by an individual and can be material possessions (e.g., a car) or symbolic and psychological possessions (e.g., education, language). Social resources refer to an individual’s social connections; depending on one’s diversity and extensity of social connections, individuals will have differing social resources. Societal resources are those available to an individual and community based on the support system generated through political supports. Social capital theorists often argue that both quantity and quality of social and societal resources far outweigh one’s personal resources in their potential usefulness to individuals (Finsveen and Van Oorschot, 2008; Lin, 2001).
Social capital can be seen as an individual’s access to resources within his or her networks. Therefore, people with no network relationships, or with relationships that do not avail the resources necessary to achieve one’s goal, have no social capital (Finsveen and Van Oorschot, 2008; Lin, 2001). An individual who lacks a social structure—be it social resources or societal resources—to facilitate the achievement of a goal is an individual without social capital.

Using social capital to conceptualize caregiver-supports highlights the possible benefits that can come from supporting access to personal, social, and societal resources through the development of bonding, bridging, and linking ties. Using the concept of social capital encourages us to consider how policy interventions can build and support access to these resources.

2.4.2 Importance of Social Capital

Social capital is a multidimensional concept and refers to the connections and relationships between individuals and social networks as well as the norms, reciprocity and trust that can evolve from them (Boehm, Eisenberg, and Lampel, 2011).

Social capital is argued to be a result of the interactions between networks at three main levels.

**Bonding** captures the essence of the connectivity between individuals, reinforcing exclusive and homogenous groups (DiCicco-Bloom et al., 2007; Warburton, Cowan, & Bathgate, 2013). Bonding ties refer to intragroup homogenous social networks (e.g., family-to-family or nurses-to-nurses). Bonding may be exclusionary and may not act to produce broader community benefits (Baum & Ziersch, 2003).

**Bridging** is a more complex and dynamic attribute, incorporating actions among groups with different knowledge. Bridging networks are heterogeneous with different positions and functions, such as nurses and clients, and this form of connection is often described as good for “getting ahead” in life. Bridging ties are seen to create the opportunity to facilitate information more broadly, resulting in improved access when intragroup norms or knowledge might not be adequate to achieve this goal (Derose & Varda, 2009; Warburton et al., 2013).

**Linking** social capital emerges when heterogeneous networks that contain more vertical and formal relations are created. This form of social capital has networks of trusting relationships between people who are interacting across explicit, formal, or institutionalized gradients in
society. For example, providers and informal networks of care accessing community agencies or formal institutions (Derose and Varda, 2009; Heenan, 2010).

It has been argued that linking and bridging social capital are particularly relevant in terms of producing larger community benefits as they encourage individuals to feel a sense of responsibility beyond those in their immediate bonded group (Baum & Ziersch, 2003). Having access to all forms of social capital can provide differing levels of support to address stress, crisis, or illness. These relational dimensions of social capital describe the type of personal relations people have built up between them through a number of interactions.

Over the last decade, there has been an increase in the evidence that highlights the benefits of social capital and outlines the influence of social factors on the health of individuals and communities (Health Canada, 2006). Research has established positive connections between social capital and health; additionally social capital is promoted as having the potential to improve and inform the development of public policy (Lin, 1989; Rohe, 2004; Health Canada, 2006). The concept of social capital can be useful for policy fields that aim to support vulnerable populations, health, and community development (Heenan, 2010). Social capital theory proposes that building and sustaining relationships at various levels (bonding, bridging, and linking) can promote information sharing, improve access to necessary resources, and address urgent social needs (Briggs, 2004). Therefore, initiatives that contribute to the development of bonding ties providing networks the necessary resources to accomplish everyday activities; bridging ties that connect internal networks to external networks; and linking ties that foster the connections across formal and vertical gradients will produce longer-term capacity building for individual networks and formal health systems (Health Canada, 2006).

There are two theoretical approaches that describe the process of how social capital can produce returns (Lin, 1999). One process is defined as “accessed social capital” and is conceived in terms of the network’s capacity—the resources embedded in one’s network. The other process is termed “mobilized social capital” and is defined in terms of the actual use of one’s social ties and related resources (Lin, 1999). Much research on measuring social capital has focused on horizontal links (bonding ties) that occur within a relatively homogenous community (family, majority groupings). However, there is an argument that vertical links (linking ties) is equally as important to consider (McKenzie, Whitley, & Weich, 2002).
2.5 Improved Access to Resources: Informal Caregiver Resilience

While there has been much discussion around the negative impact that the informal caregiving role can have, there is less known about why some individuals cope well in the face of adversity while others cope less well (Cherry et al., 2013). Within the academic literature, there has been a shift towards identifying and clarifying resources that empower people to cope and become resilient. Resilience is often referred to as the process whereby caregivers maintain normal or enhanced functioning in the face of adverse events (Coon, 2012; Cherry et al., 2013; Windle, 2011).

Resilience, or coping, has been defined and explored in a variety of ways in both academic and policy literatures (Cherry et al., 2013; CIHI, 2010; The Conference Board of Canada, 2012; Coon, 2012; OECD, 2011). Resilience can be defined as adapting successfully or positively in the face of a stressful experience.

Caregivers often hold multiple roles and face several stressors (e.g. job loss, barriers to services, and stressful familial environments) and thus the caregiver role often extends past individual needs of the caregiver to other people and their environment, ranging from care recipients and family members to work settings and neighbourhoods (Cherry et al., 2013; Coon, 2012; Kemp et al., 2013). Resilience in caregiving situations would encompass the caregivers’ broader sociocultural context. Windle (2011) conducted a systematic review to operationalize a definition of adult resilience, which incorporates one’s ability to manage or adapt to significant sources of stress and identifies resources within the individual and his or her environment that facilitate one’s ability to adapt and manage.

The caregiving literature expanded the concept of resilience by highlighting the protective factors associated with resiliency. These protective factors have been argued to influence health and emotional well-being, and buffer the negative impacts of stressful situations (Windle, 2011; Coon, 2012). In order for resilience to be achieved, there is a need for “protective factors” (which are also characterized as “assets” or “resources”) to be present, protective factors that encompass personal characteristics, as well as external or environmental conditions, and that, through their dynamic interplay, enable one’s ability to respond positively to stressful circumstances (Cherry et al., 2013; Coon, 2012; Walsh, 2013; Windle, 2011).
Windle (2011) outlined the protective factors involved with achieving resilience. These factors have been identified across three levels of functioning:

1) Personal (psychological, neurobiological, material)
2) Social (family cohesion, parental support, social connections)
3) Societal (support systems generated through social and political capital).

Resilience is a complex concept that involves layers of resources and assets that can either facilitate or hinder one’s ability to be resilient. The review by Windle (2011) identified various levels of protective factors that, when present, can strengthen and facilitate resiliency. This framework suggests that an individual with protective factors and resources at each of the personal-, social-, and societal-levels has a greater likelihood of building resiliency during challenging and demanding circumstances. Yet this concept has not been based within a theoretical construct and offers no assumptions around how to build or improve access to these resources at these levels for informal caregivers. This dissertation will re-conceptualize the concept of resilience more explicitly within the social capital literature to identify if building social capital can develop networks (bonding, bridging, and linking) that support access to personal, social, and societal resources.

2.5.1 State of the Evidence: Informal Caregiver Resilience

Caregiver resilience, within the academic literature, shares intellectual overlap with other constructs commonly referred to in the literature, including self-mastery, self-efficacy, acceptance, stress-resistance, hopefulness, and coping (Coon, 2012; Windle, 2011). The academic literature focuses heavily on stress, distress, and depression as signs of declining resilience (Lavretsky et al., 2010). Resilience is the antidissertation of stress and burnout. The application of resilience remains theoretically disjointed and is often overlapping with various other constructs (mainly burden and burnout) within the literature. The idea of resilience has begun to consider caregiver “burden” and “burn-out” beyond the medical needs of the care recipient, yet still fails to establish a theoretical foundation.

Informal caregiver resilience is a multifaceted concept and is affected by the needs of the care recipient, the caregiver’s own capacity, and the fragmented formal system. Many studies evaluating the needs of caregivers focus on personal and social resources yet fail to highlight the challenges and opportunities of societal-level resources. There has been movement towards
intellectualizing what assists caregivers to cope or reduce burden. However, much of the literature reviewed remains focused on personal (and at times social) resources and does not bridge the external factors in which resilience emerges and is sustained.

While few studies on caregiving specifically identify resilience as the primary construct within their research, they all focus on one or more of the resources (personal, social or societal) described as necessary to achieve resilience, continue caregiving, or maintain independence. Most studies focus on social resources that can contribute to successful coping and resilience (Al Gamal, 2013; Al-Gamal & Long, 2013; Amakali & Small, 2013; Bambara et al., 2014; Buys et al., 2015; Cecil et al., 2013; Nabor et al., 2013). For example, Bambara et al (2014) associate perceived social support with an informal caregiver’s depressive symptoms, after controlling for the care recipient’s disease severity. While less research discusses personal resources that can contribute to effective coping, several studies observe that individual factors such as education and a caregiver’s own competency do indeed affect one’s ability to build resiliency and access social and societal resources (Amakali & Small, 2013; Cecil et al., 2013; Greenwood & Smith, 2015; McKenzie et al., 2015; Yu et al., 2013). Even fewer studies discuss community- or societal-protective factors or resources as they relate to a caregiver’s ability to cope or build resiliency. This is not to suggest that community and societal resources are any less crucial in sustaining an individual’s ability to manage. Coping requires access to community supports and resources like instrumental support (Amakali & Small, 2013; Hendrix et al., 2011; Nichols et al., 2013; Quinn et al., 2012).

Research suggests that social resources do impact personal resources, acknowledging how resources can interact, rely on, and build upon each other (Al-Gamal & Long, 2012). Additionally, research that did not measure the societal resources still highlighted that societal resources can impact social and personal resources (Amakali & Small, 2013; Lageman et al., 2015). The studies also identified that quality over quantity of interaction played a large role in contributing to a caregiver’s ability to cope (Roth et al., 2005; Mittleman et al., 2007; Bambara et al., 2014). Evidence is beginning to acknowledge the benefit that can come from formal providers (nurses) collectively working with families and individuals with family health needs which occur within a broader social context (Capezuti, 2014; Lu et al., 2015). Additionally, research stresses that access to social resources can be impacted by and improved through societal resources where communities offer support for school, community, and work environments (Juliano & Yunes,
2014). Another study out of Australia found that a caregiver’s ability to access care would require personal (knowledge) and societal resources (access to formal workers and involvement in care planning) (Dawson et al., 2015). The empirical research is identifying the crucial role formal providers (nurses, therapists, care teams) have in identifying supports and assisting families in efforts to develop and build social resources (Al-Gamel and Long, 2012; Amakali and Small, 2013; Capezuti; 2014; et al., 2015; Duca, 2015).

Much of the evidence highlighting the needs of the informal caregiver continues to focus on personal resources with some focus on social resources, neglecting the extenuating factors that can impact a caregiver’s ability to cope and build resiliency (Coon, 2012; Walsh, 2013). This chapter goes on to discuss the role that social capital can play in supporting resilience.

2.6 Supporting Resilience through Social Capital

Social capital theory builds on the resilience literature and both recognize the benefits of developing relationships to “get ahead” or cope. The academic literature has brought these concepts together, suggesting social capital can contribute to (individual and community) resilience (Boeck et al., 2008; Heenan 2010; Pinkerton & Dolan, 2007; Warburton et al., 2013; Windle, 2011). However, the resilience literature—while helpful in identifying individual needs of informal caregivers—lacks the broader contextual piece that the theory of social capital encompasses. Similar to the overarching concept of resilience as identified by Windle (2011), social capital theory suggests that there are resources (personal, social, and societal) enmeshed in social connections at multiple levels (bonding, bridging, linking) that can facilitate individual- and community-level benefits.

Resilience research, in the context of informal caregivers, stresses the importance of strengthening and developing networks at multiple levels as “protective factors’ to ensure an individual is able to cope over the long term (Evans & Plumridge, 2007; Griffiths et al., 2009). Community initiatives that are aimed at improving the social factors that influence the health of individuals and communities increasingly include strategies to develop resilience through the building of networks and social capital (Griffiths et al., 2009; Kemp, 2015). This dissertation argues that caregivers who have more social capital (through well-resourced networks at the bonding, bridging, and linking levels) are better able to be resilient and cope through adverse circumstances.
Most academic research, that is conducted to assess the benefits of social capital or social networks on one’s ability to overcome adversity, focus more on the effects of bonding ties (close knit networks i.e., families) (Brown et al., 2007; Cheng et al., 2013; Evans & Plumridge, 2007; Griffiths et al., 2009; Pickard, Inoue, Chadiha, & Johnson, 2011; Warburton, Cowan, & Bathgate, 2013) than they do on the effects of bridging ties (weaker networks, i.e. nurses-to-families) (Brown et al., 2007; Evans & Plumridge, 2007; Griffiths et al., 2009; Maidment & Macfarlane, 2011; Pickard et al., 2011; Warburton et al., 2013). Very few studies focus on the effects of linking ties (vertical formal relations) (Galaskiewicz, Hobor, Duckles, & Mayorova, 2012; Maidment & Macfarlane, 2011). Many studies found a positive correlation between social capital and individual level outcomes (i.e., overall wellbeing). Similarly, many evaluations and studies identified positive social level outcomes (i.e., improved quality and access to family- and friend-time) (Al-Gamal & Long, 2012; Amakali & Small, 2013; Cecil et al., 2013; Nabors et al., 2013). There is also evidence to suggest community/societal level outcomes, such as improved access to information or services and/or improved individual well-being (Brown et al., 2007; Galaskiewicz et al., 2012; Griffiths et al., 2009; Maidment & Macfarlane, 2011; Pickard et al., 2011; Warburton et al., 2013). Other studies found that, while there were individual and social benefits, there was no tangible evidence to suggest social capital impacted the community or societal level as it relates to access to services (Evans & Plumridge, 2007; Garcia, Simoni, Alegria, & Takeuchi, 2012).

2.7 Conceptual Model: Establishing Resilience through Social Capital

The conceptual model presented in Figure 2 below was informed by the literature. As presented below, the conceptual model for this dissertation suggests that initiatives that consider people within their broader context and work to support and build all forms of social capital (boning, bridging, and linking) will lead to improved access to personal, social, and societal resources for both formal and informal support networks, thereby improving resilience.
The conceptual model was used to identify that developing social capital among vulnerable informal caregivers and their families begins with developing sound social policy (interventions) and improved connections between formal and informal avenues of care. As such, social capital building—focusing on improving connections and networks at the bonding-, bridging-, and linking-levels and encouraging access to resources (at the personal-, social-, and societal-levels)—is critical for caregiver-support interventions to be effective in producing caregiver resilience over the longer term. In essence, highly resilient informal caregivers and families are those who can cope with not only everyday life stressors but also with longer-term stressors. High levels of resilience are likely amongst individuals who are well-supported by immediate social networks, as well as other informal and formal social networks—or in other words where social capital is strong at the bonding, bridging, and linking levels.

This conceptual model outlines the proposition that policy interventions that work to build connections at all levels will lead to improved access to resources and caregiver resilience.
Linking ties\(^1\) refer to a network’s connection to people in positions of power, for example, connections to institutions or community agencies. Bridging ties\(^2\) refer to a connection between networks that are different. Often bridging ties are characterized by weaker and cross-cutting ties. For example, being connected to acquaintances or front-line health professionals. Bonding ties\(^3\) refer to within-group networks consisting of homogenous close-knit relationships. For example, connections among family, close friends, or like groups.

Personal resources\(^4\) refer to resources possessed by an individual and can be both material (e.g. vehicles, home, finances) and psychosocial (e.g. education, knowledge, language) in nature. Social resources\(^5\) refer to access to resources (e.g. material and/or psychosocial) through social connections, as well as the quality of social interactions. Societal resources\(^6\) refer to the resources available as a result of various formal and political developments, for example, having access to societal resources through systems of support, where individuals and communities have access to supports and services.

### 2.8 Summary

As people are living longer with multiple chronic conditions and are less likely to be supported in the hospital or institutional settings, the role of the informal caregiver within the home and community care sector is becoming increasingly important. However, supports available to informal caregivers are most often implemented at the provincial or local level and focus mainly on direct or indirect supports. While there are some economic supports offered at the Federal level, there remains an overall inconsistency between provinces. As such, initiatives that are offered at the local and provincial levels have little consistency in approach and produce minimal evidence to suggest what might be working as a result of jurisdictional differences (i.e. geography).

Conceptually speaking, we are similarly making progress, the concept of resilience is providing insight into the characteristics that allow caregivers to manage better and improve their ability to care. Unfortunately, much of the literature or evidence remains at the personal and social levels. There remains a general lack of understanding around how supports or interventions can leverage social and political factors to produce longer-term outcomes. This dissertation draws on the theory of social capital as a means to fill this gap.
A social capital framework offers a broader conceptualization, which focuses on the role of social relations and considers the effects of policies on these social relations. People have three types of resources to draw from—personal resources, social resources, and societal resources. Social capital theorists argue that both quantity and quality of social and societal resources far outweigh one’s personal resources in their potential usefulness to individuals. This dissertation aims to apply social capital theory as a conceptual framework to analyze how providers and caregivers perceive different approaches to providing formal interventions to informal caregivers—mostly unpaid spouses, parents, family, friends, and neighbours—of community-dwelling high-needs persons (including both seniors and children with complex medical needs) can contribute to caregiver resilience through building resource-rich support networks (social capital).
Chapter 3
Methodology

3 Introduction

As described below, this dissertation aims to explore whether different approaches to providing formal supports to informal unpaid caregivers of community-dwelling persons can build social capital (bonding, bridging, and linking ties) and improve access to resources (personal, social, and societal) and therefore lead to improved caregiver resilience.

The chapter details the methodological steps used and the aims of each of the three study phases: 1) Analyze the secondary data collected for the formative evaluations of the caregiver-support program for older adults and the caregiver framework for children with medical complexity; 2) Collect primary qualitative data and analyze in-depth, semi-structured interviews conducted with providers, who were directly involved with either of the two case study initiatives; and 3) Collect primary qualitative data and analyze semi-structured interviews conducted with informal caregivers and providers from across Ontario. Table 2 below details the phases, data sources, and aims of all three phases.

This dissertation used a convergent parallel design. Data collection and analysis for each of the phases was collected and analyzed independently (Cresswell, 2009). While data was collected and analyzed independently, the final inferences of the research were based on the analysis of all phases. The research was implemented in multiple phases including both concurrent and sequential timing over the course of the research. This chapter will be divided into three main sections as they relate to the phases of the research (Cresswell & Clark, 2011).

Table 2: Timing, Purpose and Tasks Associated with Research Phases

<table>
<thead>
<tr>
<th>Phase</th>
<th>Timing</th>
<th>Data Source</th>
<th>Aims</th>
<th>Tasks</th>
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<tbody>
<tr>
<td>Phase One Analysis of Secondary Data: Case Studies</td>
<td>Concurrent</td>
<td>1. Review and analysis of administrative data, including client characteristics and qualitative and quantitative results from &quot;one-minute</td>
<td>1. To determine if there is evidence to suggest that certain supports produce bonding, bridging, and linking ties and how these ties might improve access to personal-, social-, and societal-level resources.</td>
<td>Analysis of secondary data involving multiple data sources.</td>
</tr>
</tbody>
</table>
## Phase Two

**Qualitative Semi-Structured Interviews: Case Studies**

1. Interview transcripts.

1. To identify what supports might be more likely to produce the development of bonding, bridging, and linking ties.

2. To understand how/if the development of bonding, bridging, and linking ties improves a network’s access to personal, social, and societal resources.

3. To determine what providers and caregivers see as crucial priorities to consider when developing policies to support familial, formal, and social networks in the community.

Conduct semi-structured interviews with informal caregivers, project management staff involved with the two Toronto-central LHIN caregiver initiatives.

## Phase Three

**Qualitative Semi-Structured Interviews: Caregivers and Providers from Across Ontario**

1. Interview transcripts

1. To identify what supports might be more likely to produce the development of bonding, bridging, and linking ties.

2. To understand how/whether the development of bonding, bridging, and linking ties improves a network’s access to personal, social, and societal resources.

3. To determine what providers and caregivers see as crucial priorities to consider when developing policies to support familial, formal, and social networks in the community.

Conduct interviews with informal caregivers and providers from across Ontario who are familiar with the caregiving experience and the caregiver policy landscape.
Ethics clearance was originally received from the University of Toronto Ethics Review Board on September 18, 2013. Please see Appendix 2 for the amended approval letter received March 11, 2015.

3.1 Phase One Analysis of Secondary Data: Case Studies

This phase of the dissertation entailed secondary analysis of data that was collected for two multi-year (2011 – 2013) formative evaluations conducted on caregiver-support initiatives implemented in the Toronto Central Local Health Integration Network (TC LHIN). Paralleling the findings in the literature, both the CSP and CF further exemplify the important role that informal caregivers play. The CSP and the CF are examples of the policy world attempting to provide necessary supports in an effort to sustain caregivers in their role. This dissertation reviewed the case studies to determine the extent to which the initiatives developed bonding, bridging, and linking ties and whether there was evidence to suggest if these ties improved access to personal-, social-, and societal-level resources. The results of the formative evaluation of the caregiver-support project (CSP) and the caregiver framework (CF) for children with medical complexity (CMC) were informed by multiple data sets that are discussed in further detail below.

The CSP was funded by the TC LHIN and delivered by the Alzheimer Society of Toronto (AST) in collaboration with the Toronto Central Community Care Access Centre (TC CCAC). The CSP supports informal caregivers of high-needs older adults at risk of hospitalization or residential long-term care as a result of chronic illnesses and conditions. These older persons require high levels of ongoing personal, instrumental and emotional care. The CF for CMC is led by the Hospital for Sick Children, in partnership with the TC CCAC. The CF for CMC is an initiative that supports caregivers of children discharged from hospital with high levels of medical needs (e.g., ventilators, G-tubes, lifts), often as a result of life-threatening illnesses such as cancer, coronary heart disease, muscular dystrophy, and cystic fibrosis.

These support initiatives recognized caregivers of older persons and children as “clients” in their own right; as such, they may receive supports ranging from cash benefits to formal support services to education, counseling, and peer support. Neither the CF for CMC nor the CSP offer fixed services or benefits; rather, they establish a platform for negotiating flexible support packages with the aim of meeting the needs of caregivers and cared-for persons. There is no one set intervention because negotiated support packages vary extensively in content and cost. These
interventions were not unitary, which allowed the opportunity to explore what supports or approaches to support might work best for individual families within their circumstances—for example, providing resources and supports for social care, additional hours of care, and/or medical supplies.

What is not yet well understood is how, and to what extent, supports within these packages may serve as a short-term fix for individual “crises”, with few lasting benefits, or whether some may better equip caregivers to build resilience by improving their networks of support (bonding, bridging, and linking ties) and access to resources (personal, social, and societal).

The secondary analysis of this data provided the opportunity to bring a new perspective to the pre-existing data as well as form a base for comparison with the qualitative interview data (Lewis & Nicholls, 2014). The original evaluation focused heavily on the administrative aspects of the initiatives. This research went beyond the original evaluations to determine whether evidence exists to suggest that certain supports or approaches to support might strengthen and develop skills and/or ties at multiple levels resulting in bridging, bonding, and linking networks and improving the personal, social, and societal resources available to these networks.

The formative evaluations conducted on both interventions drew on a number of quantitative and qualitative data sources. For the purposes of this research, the following data was analyzed further:

- Administrative data generated as part of the CSP and CF describing key characteristics of participating caregivers (age, language, and ethnicity); the type and amount of services received; and qualitative and quantitative results from “one-minute evaluations” and “caregiver surveys” completed by informal caregivers involved in both initiatives.
- Qualitative field notes of semi-structured debriefing sessions with the TC CCAC case managers participating in the CSP and semi-structured interviews conducted with the key workers and project management staff of the CF.

Heaton (2008) suggests that secondary analysis of qualitative data is an effective methodological approach when the data is being used to investigate new research questions. This dissertation took a more in-depth look at the data to identify whether any evidence suggests these initiatives supported the development of bonding, bridging, and linking ties and if so, how these ties may or
may not have benefited caregivers, cared-for persons, and formal systems over the long term by improving access to personal, social, and societal resources. All of these data sets were reviewed using a deductive approach to content analysis as outlined in Figure 3. This approach is used when the analysis is based on previous knowledge, theory testing, or when using a previous construct or model (Elo & Kyngäs, 2007; Hinds et al., 1997). A similar approach is described by Gibbs (2007) when discussing the process of “concept-driven coding” and suggests that a template could be generated with concepts, categories, and codes taken from the literature. The process of analysis followed the three-tiered approach identified by Elo & Kyngäs (2007). Elo & Kyngäs (2007) argue that the analysis process has three main phases: preparation, organization, and reporting. Beyond this, there is no systematic analysis process; the key piece of content analysis is that the data is classified into many smaller categories (Elo & Kyngäs, 2007; Fereday & Muir-Cochrane, 2006).

The preparation phase involved highlighting the unit of analysis. This dissertation used the complete field notes and administrative assessments as the unit of analysis. In this way, the data can be considered whole and would provide appropriate context and meaning during analysis (Spencer, et al., 2014).
The second phase of the analysis involved developing a categorization matrix. For the secondary analysis of the case studies, this dissertation used a more structured matrix, allowing for a thorough and detailed analysis of the secondary data (Elo & Kyngäs, 2007; Gibbs, 2007). A more structured matrix was deemed appropriate for the secondary analysis as a way to narrow the focus and ensure the emphasis remained on determining whether particular supports produced bonding, bridging, and linking ties and whether these ties might improve access to personal-, social-, and societal-level resources. The analysis did not specifically code for instances of resilience, there
was a built in assumption, as the resilience literature suggests, that if there was evidence to support improved access to resources resilience is a likely outcome. An example of the categorization matrix used for the secondary data analysis is detailed in Table 3 below:

Table 3: Secondary Data Analysis Categorization Matrix

<table>
<thead>
<tr>
<th>Resources</th>
<th>Personal Resources</th>
<th>Social Resources</th>
<th>Societal Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forms</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Bonding Ties</td>
<td></td>
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<tr>
<td>Bridging Ties</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linking Ties</td>
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</table>

Review of the secondary data aimed to determine whether any evidence suggests if certain types of supports contribute to the development of bonding ties that support internal network relationships; bridging ties that connects internal networks to external networks; and linking ties that will foster the connections across networks. Additionally, evidence was sought to determine whether the caregiver-support initiatives influenced access to personal, social, and societal resources through the networks/ties fostered by the initiatives.

3.1.1 Matrix Index:

Forms of Social Capital:

- **Bonding ties**: Based on connections between individuals with similar positions and functions. They are good for “getting by” in life (e.g., Family-to-family or nurses-to-nurses).
- **Bridging ties**: Networks are linkages among people with different positions and functions. Connections between people are characterized by weaker, but more cross-cutting ties. They are good for “getting ahead” in life (e.g., nurses and clients, clients and clients-acquaintances, inter-professional collaboration).
- **Linking ties**: Emerge from heterogeneous networks that contain more vertical and formal relations. Norms of respect and networks or trusting relationships between people who are interacting across explicit, formal, or institutionalized power or authority gradients in
society (e.g., organization-to-organization, community and local government structure, client interactions with social service agencies).

Types of Resources:

- **Personal resources** are reserves possessed by an individual and may include both material items (finances) as well as symbolic goods (education). Personal resources can also include physical health and intelligence.

- **Social resources** are accessed through social connections (being able to rely on a neighbour to watch a loved one). Like personal resources (borrowing a vehicle), these can include material goods, but are embedded in the ties of one’s social networks. Such things as marital status and access to friends, neighbours, peers, and relatives can influence social resources.

- **Societal resources** are resources developed and produced through political and formal avenues. Societal resources include formal avenues of support like clinical care, economic opportunities, and social services (housing, educational systems).

3.1.2 Review and Analysis of Administrative Data:

**Review of the Caregiver Support Project for Seniors Administrative Data:**

The administrative data were collected by the Alzheimer Society of Toronto as part of the Caregiver Support Project. The data were derived from the case managers’ assessment, care plans, and a short, “one-minute evaluation” open-ended written questionnaire completed by caregivers who participated in the CSP upon intake. Data were collected at the end of the first funding period (March 2012) and again at the end of the second funding period (March 2013). The evaluation aimed to assess change over time based on the CSP in the following areas:

- Caregiver descriptives
- Mix and volume of supports provided through CSP
- How well the initiative has met caregiver needs

The administrative data highlighted nicely the components of the CSP that were likely, from the perspectives of caregivers, to meet the needs of caregivers.
Review of the Caregiver Framework for CMC Administrative Data:

Key workers conducted a detailed risk assessment that provided characteristics (language, age, ethnicity), information about home care supports, functional status, and medical needs of the child, caregiver risk factors, and family functioning. Care plan details were also included within the assessments.

The key workers involved in the CF distributed caregiver surveys that once completed were returned directly to SickKids. The caregiver surveys asked about the services received and their overall experience.

After the data from multiple sources were separately coded using the categorization matrix (Table 3), the results of the separate analyses were compiled to identify common trends and themes across the three data phases (refer to chapter 7).

3.1.3 Review and Analysis of Qualitative Field Notes: Focus Groups and Key-Informant Interviews:

Review of the Caregiver Support Project for Seniors Focus Groups:

As part of the evaluation, semi-structured “debriefing sessions” were conducted with the CCAC case managers participating in the CSP at strategic points in time. The field notes from the debriefing sessions were analyzed in a directed content analysis approach to identify whether the case managers provided any insight into understanding if particular supports produced bonding, bridging, and linking ties and if these ties might improve access to personal, social, and societal level resources (Leech & Onwuegbuziw, 2011; Hsieh & Shannon, 2005).

A total of six debriefing sessions provided detailed information on how CCAC case managers perceived the effectiveness of the CSP. The debriefing session field notes were analyzed using the matrix as outlined above using a deductive approach to analysis to allow for a better understanding of what types of supports and interventions were thought to be associated with developing networks of support and improving access to resources.

Review of the Caregiver Framework for CMC Key-Informant Interviews:
Similarly, the Key Workers involved in the CF engaged in semi-structured key informant interviews at three points in time. Three interviews were conducted at time 1, three interviews were conducted at time two and two interviews were conducted at time 3. A total of eight interviews were completed with the front-line key workers. An additional 15 interviews were conducted with administrative project management staff involved with the CF. Five interviews were conducted at time 1, eight interviews were conducted at time two, and two interviews were conducted at time 3. The field notes from the interviews were analyzed to determine whether the key workers identified any particular features of the CF as being predominantly helpful in producing bonding, bridging, or linking relationships and whether the initiatives provide caregivers with increased access to personal, social, and community level resources.

3.2 Phase Two and Three: Qualitative Semi-Structured Interviews

3.2.1 Phase Two Qualitative Semi-Structured Interviews: Case Studies

The qualitative interviews with the CSP and CMC project managers and staff aimed to identify specific supports that might lead to bonding, bridging, and linking ties and the extent to which these ties would support the development of caregiver resilience. Therefore, for the purpose of this dissertation, qualitative in-depth, semi-structured interviews were conducted with providers who were directly involved with either of the two case study initiatives (see Appendix 7 for the interview guide).

The researcher originally planned to interview up to 20 informal caregivers participating in either of the two caregiver-support initiatives. To preserve confidentiality, the two administering organizations (Hospital for Sick Children and the Alzheimer Society of Toronto) agreed to inform caregivers about this research, along with an invitation to contact the researcher if they wished to participate (see Appendix 4). In fact, four informal caregivers did contact the researcher and participated in interviews. However, it soon became clear that few others were likely to do so, in part because of the considerable stress and burden they experienced as caregivers of high-needs persons, and because they themselves faced a range of health, mobility, and literacy issues which limited their ability and willingness to participate. In addition, in the case of caregivers of older persons, a substantial number of cared-for older persons had passed away, with the result that their caregivers had withdrawn and contact had been lost; even where contact had been
maintained, it was judged that those experiencing bereavement should not be approached to conduct an interview.

In response to the low informal caregiver participation rate, the qualitative in-depth, semi-structured interviews were expanded to include case managers and project administrators of the two caregiver-support initiatives. This convenience sampling technique improved the sample size and included additional participants who had similar experiences and understanding to inform the exploration of the central themes and questions of this research. Interviews were conducted with a total of nine case managers and project administrators involved in the CSP and CF for CMC.

The case managers and administrators of the CF and CSP were invited, by e-mail, to participate in an interview. The invitation to participate was sent by the project management staff of both the CSP and the CF (Appendices 3 and 4). The letter specified that the interview was voluntary and choosing to participate or not participate would not affect their employment. The participants were asked to connect with the researcher by telephone or by e-mail if they were interested in participating to schedule a time at their convenience.

While the sample size was selected for reasons of convenience and feasibility, the purpose of expanding the sample was to insure sufficient data was collected to complete the conceptual matrix and clearly ascertain the experiences being presented by participants. The participants had variation in their personal experiences and characteristics, yet were homogenous enough to ensure comparison and validation of findings was appropriate. The aim of the in-depth interviews was to better comprehend shared meaning and understandings of these particular groups (Ritchie & Ormston, 2014; Ritchie et al., 2014).

Each participant was fully informed of the purpose and aim of the interview and was given an informed consent form to sign prior to the interview taking place (see Appendices 5 and 6). Each participant was asked if the interview could be audio-recorded to allow for ease of analysis. The length of the interviews ranged anywhere from thirty minutes to one hour. The interviews were conducted between December 2014 and January 2015.

The participants were asked to consider how a caregiver’s involvement in the CF or CSP might have impacted their overall well-being and resilience. Specifically, participants were asked to consider the possible outcomes for caregivers and whether or not they saw these outcomes as
being a result of improved access to resources through the development of various formal and informal networks (see Appendix 7).

3.2.2 Phase Three Qualitative Semi-Structured Interviews: Ontario Provider and Caregiver Population

In order to achieve a broad perspective and understanding around supports necessary to build and sustain networks of supports for informal caregivers, invitations to participate (Appendix 8) were e-mailed to members of the Ontario Caregiver Coalition, which includes informal caregivers as well as formal service providers from across Ontario. The invitations specified that, if they chose to participate, they were to contact the researcher by telephone or e-mail to schedule a time and place of their convenience.

A stratified purposive sampling approach was selected to further inform and validate the findings identified through the initial round of interviews conducted with caregivers and providers immersed in the two Toronto Central Initiatives (Ritchie et al., 2014). Extending the invitation to participate through the Ontario Caregiver Coalition would ensure additional participants who were particularly knowledgeable about the experiences involved with informal caregiving. Additional interviews were conducted with seven informal caregivers and six formal service providers.

The interviews elaborated the extent to which some caregiver supports might produce longer-term resilience building, paying particular attention to strategies suggested to support caregivers and their networks which would avoid crises and dissolution. The ultimate goal was to understand how/whether the development of bonding, bridging, and linking ties improves a network’s access to personal, social, and societal resources and thereby improve resilience.

Each participant was fully informed of the purpose and aim of the interview and was given an informed consent form to sign prior to the interview taking place (see Appendix 9). Each participant was asked if the interview could be audio-recorded to allow for ease of analysis and was reassured that no identifying information would be used. The length of the interviews ranged anywhere from thirty minutes to one hour. The interviews were conducted between February 2015 and March 2015.
Participants were asked broadly about what they perceive would work best to build stronger connections (and enhanced social capital) among families, social networks, and formal providers and whether these connections were important or crucial to consider to build resilience to sustain informal caregivers in their role (see Appendix 10).

3.2.3 Qualitative Data Analysis

The qualitative data analysis, described below, was similar for both the qualitative semi-structured interviews conducted with providers involved with the CSP and CMC and the qualitative semi-structured interviews conducted with providers and caregivers from across Ontario.

The literature review identified a myriad of available caregiver-support options, yet there remains no clear evidence to inform how caregiver supports can improve access to resources that are necessary to produce caregiver resilience. The literature also tends to address the role of the informal caregiver separately from their external (social and societal) contexts. This dissertation draws on the theory of social capital to bridge the personal factors with the broader context to determine if certain interventions are more likely to develop ties at multiple levels and determine how this might produce caregiver resilience. The analysis of the interviews was specifically set out to address:

- “How does the development of bonding, bridging, and linking ties influence access to personal-, social-, and societal-level resources?”
- “What do formal service providers and informal caregivers perceive as priorities to consider when developing policies to support familial, formal and social networks in the community?”

The interviews were audio-recorded and transcribed verbatim to ensure the content was accurately retained. The transcript process was content-focused and speech-focused (did not include latent content), and all questions and answers were transcribed fully. The analysis focused on the experiences, understandings, and opinions of the participants as it related to supports that would contribute to resilience.

The development of main dimensions for categorization was informed from the literature review. A deductive approach to content analysis is used when the analysis is based on previous knowledge and theory testing. As highlighted above (Figure 3), the transcripts were also analyzed using the three-tiered approach (Elo & Kyngäs, 2007). Elo & Kyngäs (2007) argue that the
Analysis process has three main phases: preparation, organization and reporting. Beyond this, there is no systematic analysis process; the key piece of content analysis is that the data is classified into many smaller categories (Elo & Kyngäs, 2007; Fereday & Muir-Cochrane, 2006).

A directed content analysis approach was taken as the research was structured with particular theories and hypotheses in mind, with the aim to better understand how these theories can apply to and/or inform the development of appropriate sustainable caregiver interventions (as identified by research participants) (Elo & Kyngäs, 2007; Hsieh & Shannon, 2005). A similar method to conducting applied qualitative research to address policy-relevant research was developed in Britain and termed the “framework approach” (Pope, 2000). This approach is considered beneficial when the research can be used to directly inform an understanding of a contemporary issue (Ritchie & Ormston, 2014). This dissertation uses the theory of social capital to inform the collection of data, as well as to interpret the findings. This dissertation aims to further the way we conceptualize informal caregiver interventions to consider caregivers within their broader context and work to support and build all forms of social capital leading to improved access to resources and resilience.

The preparation phase involved highlighting the unit of analysis. This dissertation uses the complete interview as the unit of analysis to ensure it was large enough to consider as a whole yet small enough to provide context and meaning during analysis. For the purpose of this analysis, only manifest context was used (verbal data), meaning no particular attention was paid to latent (behavioural data) context (silence, laughs, sighs).

The second phase of the analysis involved developing a categorization matrix (Table 4). For the qualitative interview analysis, a more unconstrained matrix was used, allowing categories to be created within the matrix during analysis. As noted above, the analysis of this data also did not explicitly identify resilience as a coding construct, there was a built in assumption, as identified through the resilience literature that with improved access to resources at the personal, social, and societal levels resilience can be deduced.
Table 4: Qualitative Interviews Categorization Matrix

<table>
<thead>
<tr>
<th>Bonding</th>
<th>Bridging</th>
<th>Linking</th>
</tr>
</thead>
<tbody>
<tr>
<td>What interventions appear to encourage</td>
<td>Does the development of bonding, bridging, and linking ties improve access to personal, social, and societal resources?</td>
<td>What policy interventions are needed to sustain informal networks of care and formal systems?</td>
</tr>
</tbody>
</table>

The data was reviewed for content and coded for correspondence with representation of the categories. Analysis at this stage was guided by the categorization matrix but not confined. From this, codes were compared and connected to discover patterns and themes within the data. The data for both qualitative interview phases were coded into three main categories specifically relating to the three network levels (bonding, bridging, and linking) and the impact of these networks on access to resources (personal, social, societal) (see findings in Chapters 5 and 6 for examples of coding).

From this, the final inferences made as a result of the analysis from all three phases are highlighted in the discussion chapter, and particular note was made of three broad themes and four sub-themes (see discussion chapter for examples of theme development).

3.3 Chapter Summary

In summary, this dissertation employed a convergent parallel design. A literature review was conducted to assess the relevant informal caregiver literature and factors that impact informal caregiver resilience. A review of administrative data and semi-structured qualitative interviews with case managers from two caregiver-support initiatives was completed to ascertain the extent to which various approaches of support may encourage the development of bonding, bridging, and linking ties, thus improving access to resources leading to improved caregiver resilience.
The interviews with caregivers and providers from across Ontario similarly focused on identifying whether participants believed certain caregiver supports are associated with developing ties at the bonding, bridging, and linking levels, thereby improving access to personal, social, and societal resources and leading to increased resilience.
Chapter 4
Results: Review of Case Studies

4 Introduction

As highlighted in earlier chapters, there is growing agreement in the research literature that informal caregivers play a crucial role in supporting high-needs populations (of all ages) as well as contributing to the sustainability of formal health systems. This role is all the more crucial as more people live longer with multiple health and social needs, and as governments attempt to constrain healthcare spending.

As such, policy makers across the industrialized countries are experimenting with a range of measures aimed at supporting informal caregivers and encouraging them to continue to care. However, for a variety of reasons identified in earlier chapters, there remains insufficient evidence to suggest how supports can leverage social and political factors to produce caregiver resilience.

Analysis of secondary data for two caregiver-support initiatives implemented in the Toronto Central Local Health Integration Network (TC LHIN) in 2011 was conducted to determine whether evidence suggested that certain supports might be likely to produce bonding, bridging, and linking ties and how these ties may or may not improve access to personal-, social-, and societal-level resources. These two initiatives provide a natural experiment since, while each targets a different population (informal caregivers of older adults and caregivers of children with medical complexity respectively), both take place in a common policy environment, and both are designed to provide continuing support to highly burdened “at risk” caregivers. Both initiatives also offer an extensive suite of caregiver supports including education, counselling, in-kind services, and cash. This provided an opportunity to identify whether service providers saw different supports and approaches to work best and why. As such, these initiatives offer an opportunity to examine how differences and similarities in the design and delivery of these two initiatives impact caregivers over a three-year period.

Using social capital theory to consider broader contexts, this chapter aims to explore these two initiatives to identify if the caregivers involved in the initiatives identified experiencing access to personal, social, and societal resources as a result of participating within these initiatives. Furthermore, it aims to identify if the initiatives can build, support, and provide access to these
resources, thereby supporting these caregivers and families in “getting ahead” and sustaining resiliency. While access to networks at the bridging-, bonding-, and linking-levels is necessary, it is not sufficient. This dissertation argues that it is the degree to which providers, caregivers, and families have access to relevant resources within these networks to achieve their goals and support their ongoing needs.

The first section of this chapter describes the two caregiver-support initiatives, presented as separate case studies. As noted in earlier chapters, while serving different populations, both employ a case manager to work closely with caregivers to identify problems, co-create solutions and look ahead to anticipate what is needed to support caregivers and cared-for persons as a unit over the long term.

The second and third sections present results from the secondary analysis of administrative data from the two caregiver-support initiatives, the caregiver-support project (CSP), and the caregiver framework for children with medical complexity (CF for CMC) respectively. For both initiatives, findings describe the characteristics of participants, the “menu” of supports accessed, and the key elements of this initiative identified by caregivers as being crucial to support continued caregiving.

The final section examines findings from the focus groups with formal service providers involved in the CSP and CF. These findings suggest that although the “target” populations were different, caregivers expressed similar needs, and service providers experienced similar challenges. They also suggest the importance of utilizing approaches that go beyond service-by-service thinking to ensure caregivers are connected to broader systems of social supports. Service providers articulated that focusing on personal-level characteristics and resources are important but insufficient on their own. It was clear that providers believed benefits stemmed mostly from developing networks beyond the bonding level and improving caregiver access to social and societal resources.

4.1 Description of the Interventions

This section reports on the analysis of secondary data from two initiatives funded by the TC LHIN, the regional health authority. The caregiver supports provided through these two initiatives are in addition to care that was normally received by cared-for persons through Community Care
Access Centre (CCAC) and other community agencies. Since caregivers are not considered clients, they would not normally receive such supports.

4.1.1 Description of Caregiver Support Project (CSP)

The CSP was funded by the TC LHIN and delivered by the Alzheimer Society of Toronto (AST) in collaboration with the Toronto Central Community Care Access Centre (TC CCAC). In addition to the home care services the TC CCAC case managers normally provide to clients, this initiative allowed the case managers to offer additional supports to informal caregivers in the form of cash (e.g., to purchase medical supplies) or additional in-kind services (e.g., housekeeping, respite, counselling, education). From a current client roster, the case managers recruited caregivers who were living in the TC LHIN catchment area, provided at least 10 hours per week of direct care and were considered “at risk, or on the cusp of being at risk, because of caregiving burden” to participate in the CSP (Warrick et al., 2014).

Case managers attended a one-day workshop at the Reitman Centre where they were given special training in a technique called “problem-solving therapy” (PST). The Reitman Centre, based out of Mount Sinai Hospital in Toronto, provides several education and support programs to both professionals and informal caregivers who are providing care to high-needs older adults, particularly those living with a form of dementia. The case managers involved with the CSP were taught how to work with caregivers to approach problems methodically, exploring and finding solutions without directly focusing on the emotions often inherent in these complex circumstances (Chiu et al., 2013). This training provided case managers with the skills necessary to engage caregivers in a thorough conversation in a manner substantially different from their “normal” practice. Training case managers in PST provided them with practical and applicable tools to engage caregivers in meaningful and solution-focused conversations. Case managers developed skills to support caregivers through a highly focused conversation regarding identifying problems and agreeing on achievable goals to rectify the problems. Case managers working within the CCAC often have a background in nursing, physiotherapy, occupational therapy, speech language pathology, or social work and have at least two years of work experience. Beyond that, case managers do not receive PST as a regular component to their career.

Case managers used budgets averaging $1,450/caregiver/year to engage with caregivers in the PST approach. With the budget as a platform and training as a tool kit, the case managers were
able to engage caregivers and co-create flexible care packages tailored to individual circumstances, needs, and preferences.

Initiated in October 2011 as a time-limited initiative, the CSP did receive extended funding by the TC LHIN under its 2011-2014 strategic plan to ensure high-quality care oriented around people and communities (Warrick et al., 2014). This dissertation reviews and analyzes data from October 2011 to March 2013.

During this time frame the CSP:

- Provided support to a total of 258 “at risk” caregivers, 41 of whom received care packages in both its first and second years;
- Grew to include eight community providers;
- Encompassed a range of health and social supports including personal care, respite, education, counselling, peer support, transportation, medical supplies and equipment, health promotion, and wellness care.

4.1.2 Description of Caregiver Framework (CF) for Children with Medical Complexity (CMC)

The premise behind the caregiver framework (CF) for children with medical complexity (CMC) was very similar to that of the caregiver-support project for older adults. The CF for CMC was also initiated in 2011, funded by the TC LHIN and run by the Hospital for Sick Children in partnership with the TC CCAC and Holland Bloorview Kids Rehabilitation Hospital. The key workers (equivalent to case managers within the CSP) identified “at risk” caregivers who were considered “under stress” due to “the degree and/or intensity of caregiver effort in meeting the health needs of the child; or the collateral physical, emotional, social, or financial impact on the family as a whole” from the current client roster (Peckham et al., 2014a).

The key workers did not receive the formal one-day problem-solving therapy workshop that was delivered to the case managers involved with the CSP. However, unlike case managers who work with the older adult population, key workers within the paediatric field are more familiar with engaging families and working with families and draw upon a broader network of care to develop care plans. Key workers were similarly using a budget of about $3,500 per caregiver/per year to engage caregivers in a dynamic process of problem identification and problem solving, leading to
the co-creation of flexible and individualized care packages aimed at establishing short- and
longer-term goals; these goals were reviewed by an administrative team prior to the authorization
of packages.

The CF for CMC was initiated in October 2011. This dissertation reviews and analyzes data from
October 2011 to March 2013.

Within this time frame the CF:

• Provided support to a total of 52 “at risk” caregivers, 18 of whom received support in both
  the first and second years of the project; and
• Encompassed a wide range of health and social supports including (but not limited to)
  family care, household expenses, recreational programming, and medical supplies and
equipment.

4.2 CSP Administrative Findings

Two forms of CSP administrative data were analyzed for the purpose of this dissertation:

• CSP assessment and care plans completed by case managers; and
• “One-minute evaluations” brief questionnaires completed by caregivers and returned to
  the Alzheimer Society of Toronto.

The administrative data consisted of assessments and care plans that recorded descriptive
information about caregivers as well as the mix and volume of services/supports provided through
the CSP. A total of 216 caregivers responded to the one-minute evaluation at Time 1 (December
2011), and 144 caregivers responded to the one-minute evaluation at Time 2 (January 2013).
However, these evaluations were not always completed in their entirety.
4.2.1 CSP Caregiver Characteristics

Table 5: CSP Caregiver Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Label</th>
<th>N</th>
<th>% (mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td>258</td>
<td>(65.8 years)</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>59</td>
<td>22.9%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>199</td>
<td>77.1%</td>
</tr>
<tr>
<td>Language</td>
<td>English</td>
<td>182</td>
<td>70.5%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>76</td>
<td>29.5%</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>137</td>
<td>53.1%</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>121</td>
<td>46.9%</td>
</tr>
<tr>
<td>Observed Financial Need</td>
<td>Yes</td>
<td>249</td>
<td>96.5%</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>9</td>
<td>3.5%</td>
</tr>
<tr>
<td>N of Cases</td>
<td></td>
<td>258</td>
<td></td>
</tr>
</tbody>
</table>

As highlighted in Table 5, the data for “all caregivers” show that the majority faced, or were likely to face, challenges related to age, sex, language, ethnicity, and financial capacity.

• Caregivers were often older persons themselves, averaging 65.8 years of age.
• Over three quarters (77.1%) were female.
• About a third (29.5%) spoke a language other than English.
• Almost half (46.9%) identified with minority communities.
• Nearly all (96.5%) were identified by TC CCAC care managers to be in financial need.

From these characteristics, we can conclude that the caregivers and families involved within this initiative were not “rich” in personal-level resources (primarily financial resources). While social capital does not categorize personal resources as the most crucial for benefiting individuals, this
resource is still useful for individuals in allowing them to “get ahead”. Additionally, an individual who has deficits in personal resources would also likely experience difficulty in accessing and developing resources at the social level. Personal resources (access to finances to support outings and/or knowledge of additional support) were seen to be helpful in supporting social engagement. As highlighted in section 4.4.3, the providers involved with the CSP and CF for CMC believed that the caregivers who were involved in the two initiatives were provided with opportunities to expand their personal-level resources.

4.2.2 Mix and Volume of Supports Provided Through the CSP

Phase 1 funding spanned October 2011 to March 2012. Funding for Phase 2 spanned April 2012 to March 2013. A descriptive analysis of the administrative data highlighting budgets and services purchased reveals that, on average, each caregiver in Phase 1 (n=257) received $1,451.70; in Phase 2, they averaged (n=41 Missing value 218) $1,363.18. The funding provided to families remained consistent over the first two years of the initiative. The missing value is a result of both incomplete data as well as timing of receiving the data, where not all care plans had been fully implemented to accurately assess the total value to the care package.

As illustrated in the figure below (Figure 4), caregivers and case managers used this funding to access supports from four broad categories:

- **Social care** where money was spent on things like private caregivers, transportation, and attending social activities;
- **Direct support** where money was spent on personal support worker hours, adult day programs, or short stay respite;
- **Caregiver well-being** where money was spent on services directed specifically for caregiver wellbeing namely massage, gym memberships, physical therapy; and
- “**Supplementary services**”, which were not well-labeled but where the money was spent on things such as the purchase of medical equipment.
As the data in Figure 4 show, out of the four broad categories of support, non-medical “social care” was accessed most often. The majority of the participants received support for social care, which included a variety of activities that extended beyond the individual caregiver and the care recipient to include broader social networks. For example, support was arranged to ensure an adult child caregiver could attend an evening date night with her husband to support the marital relationship, which was strained as a result of the caregiving responsibilities. As another example, supports were arranged to support a caregiver’s engagement in community events, such as re-engaging in their spiritual community. Traditional formal supports are not typically arranged to allow caregivers to meet their extended social needs. Often “respite” is provided for an hour while the caregiver is able to accomplish chores or attend the grocery store. The flexibility and range of supports provided as a result of the CSP went beyond individualized medical concerns and provided caregivers opportunities to extend their networks above and beyond the “dyad”, thereby supporting caregivers to engage with and develop both their bonding and bridging networks, which would expand their social resources, a crucial component identified by social capital theorists.
4.2.3 Caregiver One-Minute Evaluations

There were a total of 360 one-minute evaluations available for analysis. A total of 216 evaluations were received for phase one and 144 evaluations were received for phase two; however, many evaluations had either brief or incomplete responses.

Responses to the one-minute evaluations suggest that caregiver concerns, challenges, and possible solutions to meet their needs were tied to their personal, social, and societal resources.

When caregivers were asked to identify their most important problem or frustration, 15 individuals responded that it was the personal challenges associated with maintaining a loved one at home, including financial concerns, personal health ailments, and lack of knowledge to provide adequate care. There were a total of 20 caregivers who specifically made note of an overall lack of social resources as their most prominent frustration, highlighting specifically the effects of not being able to participate in social activities, having no family support or experiencing an overall lack of emotional support, and impact of the care demands on marital and familial relations. For example, one caregiver stated: “The lack of time and energy to maintain any of my own interests and activities other than caregiving. Even when I do have time, I’m too tired and emotionally drained. Consequent isolation and its negative emotional consequences.”

When caregivers were asked to highlight what they needed in order to continue, many emphasized the importance of increased formal supports. It was evident that the societal-level resources (resources available as a result of various formal and political developments) were considered key for informal caregivers to continue to provide care. In fact, 60 caregivers specifically mentioned formal-level connections and supports as important to sustaining a caregiving role (i.e., “the security of having the same services and possibly access to additional supports if needed”). The societal-level resources were often discussed as a means for caregivers to fulfill both personal (i.e., maintaining their own health, n=23) and social (i.e., attending clubs or dinner with their spouse, n=20) needs. Caregivers did address various societal-level resources necessary beyond the need for “additional hours of support”. Here, caregivers identified the need for improved legislative employment benefits; better education and training for personal support workers; removal of red tape that limits a support worker’s ability to provide additional IADL care (e.g.,
changing a light bulb); support in identifying services that are available (i.e., a “service road map” identifying the various layers of agencies and the supports offered within each agency).

This stresses the importance of providing informal caregivers with access to societal-level resources, which can better support their caregiving role. Developing formal level supports for caregivers and improving their access to societal resources, as highlighted by social capital theorists, will likely outweigh the benefits of one’s personal resources in terms of potential usefulness to individuals and improve their capacity for adaptation and “bouncing back”. This is not to say personal level resources are irrelevant to ensuring a caregiver’s resilience but that only focusing on one’s personal resources would be insufficient to produce/sustain resilience. Additionally, while one might have access to networks, if these networks are built on weak ties with a lack of understanding and trust, social capital will be equally weak. Similarly, if access to resources within the network is low, an individual’s ability to “get ahead” will be limited. Additionally, as evidenced by the one-minute evaluations, it appears here that caregivers see societal-level resources as allowing them to develop and improve their social and personal resources. While much of the literature and caregiver specific programs tend to focus on the individual caregiver (which is an improvement from focusing on body parts or solely the cared-for person), these initiatives identify that there are other broader resource (social and societal) issues that come into play and need to be addressed to improve a caregivers ability to care and overall resiliency.

4.3 CF for CMC Administrative Findings

As part of the CMC framework, key workers conducted a detailed risk assessment. In total, 66 caregivers participated in the first three years of the framework. There were seven caregivers who participated only in phase one; 16 participated only in phase two; and 14 participated only in phase three. Two people participated in both the first and second phase. Two people also participated in both the second and third phase. Twenty-five caregivers were able to participate in all three phases.

A total of 66 administrative risk assessments were conducted for this group. Two of the assessments were excluded from the analysis because the files were corrupt. In total, 64 assessments were included in the analysis.
The administrative risk assessments asked about additional home care supports and services, functional status and medical status of the child, caregiver risk, and family functioning. Care plan details were also highlighted within the assessments, identifying needs and supports or services that could be used to meet those needs. Unfortunately, not all caregiver assessments were completed in their entirety, and caregivers who were a part of the initiative from the onset have more details in their administrative assessments than those who were brought on at a later date. Similarly, as the initiative progressed over the years, the risk assessments shifted as additional and different details were considered important to assess. For example, as time went on, to ensure an increasingly holistic approach to care planning, the assessments included a greater number of questions that asked about external circumstances.

4.3.1 Caregiver and CMC Characteristics

The table below identifies the characteristics of the caregivers who participated in the CF. Please note that not all assessments provided complete demographic information. The majority of the primary caregivers are female, speak English as a first language, and are the parent of the CMC.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Label</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>Male</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>54</td>
</tr>
<tr>
<td>Primary Language</td>
<td>English</td>
<td>38</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>3</td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>30</td>
</tr>
<tr>
<td>Relationship to Child</td>
<td>Mother and Father</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>5</td>
</tr>
<tr>
<td>Single Parent Household</td>
<td>Yes</td>
<td>14</td>
</tr>
<tr>
<td>Reported Financial Stress</td>
<td>Yes</td>
<td>64</td>
</tr>
<tr>
<td>Total N of Cases</td>
<td></td>
<td>64</td>
</tr>
</tbody>
</table>
Families reported diverse ethno-cultural backgrounds with the majority identifying with minority communities. After Caucasian (n=21), South Asian was the most prominent ethnicity identified (n=13). All primary caregivers were parents of the child with medical complexity.

Of the 64 families who participated in the CF, all coped with complex medical, health, and psychosocial needs. All the families reported some form of financial stress, most frequently related to not being able to afford extras (e.g., swimming lessons). Additionally, a total of 14 caregivers reported that they headed single-parent households. This demonstrates that families involved within the CF are likely experiencing low levels of personal resources.

The majority of CMC were under the age of 15 with only three over the age of 16. Children had on average over seven medical conditions ranging from three to fourteen. Even with the complex medical needs of the children, of the 36 who rated how much they agreed or disagreed with the following statement: “most of the time I feel my family is functioning and coping well ‘1 being ‘strongly disagree’ and 10 being ‘strongly agree’”, scores averaged 6.3, suggesting most families somewhat agree that they are coping and functioning well. Many caregivers reported that they experienced physical challenges; 22 caregivers expressed that they experienced pain; 20 expressed that they have chronic medical conditions themselves; and two noted that they suffered from an acute illness at the time of initial assessment.

4.3.2 Mix and Volume of Services Provided Through the CF for CMC

Phase 1 funding spanned October 2011 to March 2012. Funding for Phase 2 spanned April 2012 to March 2013. Not all of the case notes reported the cost per care package for each client. From the available data, the average cost per care package across the first two phases of the CF was $3599.55 per phase.

As illustrated in Figure 5 below, caregivers were able to use the funds to purchase a number of social, medical, personal, and formal supports. Similar to the supports that were acquired as a result of the CSP initiative, “social care” was the most popular form of support requested by these families.

- **Social Care** includes, but is not limited to, using resources to support family time; socializing or pursuing hobbies; or connecting families to community resources. Social care was the most common support purchased.
• **Direct supports** include extra formal support or in-home respite; additional healthcare or supports which are not currently offered; and additional clinical supports such as physical or behavioural therapy. Direct supports were the second most common category of supports purchased using the CF resources.

• **Caregiver wellbeing** includes supports relating to caregiver self-care, resources to attend medical appointments, receiving massages, purchasing a gym membership, and receiving support to attend the gym.

• **Supplementary services** include purchasing household items (hospital beds, generators) and making home modifications.

*Figure 5: Mix of Services; CF for CMC*

As identified in Figure 5, the supports that were most frequently accessed are the types of supports that extend beyond the medical needs of the CMC and extend beyond the dyad (the individual needs of the caregiver and the CMC) to include avenues for extended social and societal resources to develop.

4.3.3 Caregiver Surveys

In the caregiver survey, caregivers were asked to rank several statements highlighting the degree to which they believed that the CF improved their access to social and societal resources.
Caregivers were asked to rate how much they agree with the following statements, from strongly disagree (1) to strongly agree (10).

As a result of the caregiver framework:

- Their quality of life had improved (scores averaging 8.7)
- Their child’s quality of life had improved (scores averaging 8.8)
- Their ability to socialize had improved (scores averaging 6.6)
- Their ability to maintain relationships had improved (scores averaging 6.6)
-! Their relationship with family members has improved (scores averaging 7.1)
- They felt more confident knowing where to go for help when they need it (scores averaging 7.6)
- Their overall mood has improved (scores averaging 8.3)
- They are more able to take care of their child over the long-term (scores averaging 8.6)

The findings of the caregiver survey highlight that the CF had improved caregivers’ ability to engage in social activities, thus improving their social resources at both the bonding and bridging levels. It also identified that their access to societal-level resources was improved and gave caregivers confidence in knowing where to receive support when needed. As a result of improving personal, social, and societal resources at various levels, caregivers apparently believed they were better equipped to care for their child over the long term, alluding to increased capacity or resilience. This also suggests that caregivers perceived their challenges and concerns to extend above and beyond the needs of their children who live with medically complex needs.

Caregivers were asked to identify what it was that they liked most and least about the CF. Those who responded to these questions reported they wouldn’t change anything about the CF. Particularly, caregivers highlighted the benefits of improving personal and social resources: being able to increase the time spent as a family (n=4); having someone to call (n=4); and the financial support (n=5). Here caregivers had space to provide additional details and noted, “Mostly, I loved being supported” and “having someone else’s help to figure out what is the best way to handle the problem,” thereby recognizing the crucial role of the case managers.

Caregivers were asked “what would help most to support them over the long term”. Four stated that developing their social resources through bridging ties by connecting with other family and friends who experience similar circumstances would be beneficial. One caregiver advocated for the potential benefits that could come from having access to an online discussion board. Seven
caregivers suggested that having someone help them identify needed resources and supports would be crucially important to support them over the long term. A total of three caregivers mentioned that having access to flexible and additional formal supports, including PSW and nursing care, would be valuable. One caregiver specifically mentioned the importance of supporting the family unit holistically, writing: “I need my health to continue; support me emotionally, physically and financially [that] is a huge help”.

4.4 Qualitative Field Note Analysis

Field notes from 6 focus groups (CSP) and 25 interviews (CF) were analyzed for this dissertation. As highlighted in Chapter 3: Methodology, the purpose of this analysis was to determine if there was any evidence to suggest that certain supports or approaches to support produce bonding, bridging, and linking ties, and to identify if these linkages benefit an individual’s access to personal-, social-, and societal-level resources. While these focus groups and interviews focused on the design dimensions of the two initiatives (these findings have been highlighted in section 4.4.1 and 4.4.2), they also provide important insight into the extent to which both initiatives pushed beyond the logic of individual services for individual clients to broader conceptualizations of what it means to support an informal caregiver, recognizing caregivers and their families need to be considered within their social context (these findings have been highlighted in section 4.4.3).

4.4.1 CSP Service Provider Focus Groups

4.4.1.1 Eligibility Criteria: A Focus Beyond Personal Resources

The providers who participated in the focus groups highlighted that they were targeting (and saw value in targeting) families and informal caregivers who experience a lack of resources at the personal (finances), social (lack of familial support), and societal levels (challenges accessing supports). The providers acknowledged that there are likely system-level barriers that impact a family’s overall ability to cope, suggesting that eligibility criteria should consider all aspects that have the potential to affect families.

For example, providers noted that “adult children experience very different life stressors and this might really benefit younger caregivers”. It became clear that providers believed caregivers who have “limited family support”, “housing limitations”, and “stressful situations involving trouble
behaviour or low socio-economic status” all would benefit from a formal initiative like the CSP. For example one focus group member noted:

“Many pensioners with adult children who are still working, many are just coming back from the hospital, they have recent financial needs for equipment. Look for financial constraints, and if the caregivers say they are burnt out both physically and mentally. Look for individuals with system barriers, like paying for physio, and situations where the needs are above what CCAC can provide.” [Focus group 2]

The providers noted that the eligibility criteria should not be too narrow, but common factors related to an individual’s resources should be considered. As an example, the providers pointed out that families and caregivers with limited family support, unsafe housing, language barriers, and who had their own health concerns (both emotional and physical) would be ideal participants for the CSP (n=5 focus groups). One participant of a focus group exclaimed:

“Identify who is appropriate, it would include age, living conditions, socio-economic status, pensioner or working, feelings of burnout, are there system barriers from the medical system?” [Focus group 2]

Families who were experiencing complex circumstances were seen to be ideal participants for this initiative, as it allowed for creative and flexible solutions to be arranged addressing individually complex circumstances. These service providers, as a result of the flexibility and the problem-solving therapy, were able to address and enhance the personal resources of these families, which providers deemed as crucial to sustaining a caregiver’s overall wellbeing. These comments demonstrate that the providers’ ideas around resilience include and go well beyond the personal characteristics and personal resources of the caregivers.

4.4.1.2 Delivery and Supports: Building Bridging Ties

While some caregivers suggested that personal resources (finances) should be the sole determining factor for eligibility, many providers emphasized that, even if someone has the personal resources available (finances), they may lack the ties, resources, and capacity to connect to formal level supports. One case manager stated:
“Even if they can’t benefit financially [from the project], the counselling piece is important to help them to understand what the issues really are and allow them to understand how they can use the finances.” [Focus group 1]

This suggests that providers believed the financial (a form of personal resource) resources are helpful, but not sufficient on their own. Providers emphasized that, even if caregivers were financially well resourced, there are other factors that might limit their ability to adequately access needed supports, noting specifically the challenges of navigating the formal complex system. Participants pointed out that caregiver resilience is not just about personal needs and resources, suggesting that it extends beyond that to include formal and structural impediments. Additionally, an individual without financial resources may remain quite stable if provided with the appropriate ties and connections necessary to access formal-level supports.

The providers consistently put emphasis on the importance of case management—having “in-home” conversations where they are able to work with the families to identify underlying issues and identify solutions. The providers noted that being able to access creative solutions quickly was a huge benefit of being involved with the initiative. Knowing that support is available and could be accessed reduced stress for both the providers and caregivers. The providers indicated that this is typically not the case when working with families in the community sector. They went on to emphasize that eligibility requirements, user fees, and wait lists often impede access to services. Fortunately, having flexible funding allowed the providers to access services in different ways and/or access services that otherwise would have been inaccessible. This was identified by one case manager who stated:

“Caregiving is important because some people don’t just need extra hours, they need things more than hours, and if that was all you could do it would be a waste for some. Things that can’t be provided through OHIP or community programs. Use a combination of services, it’s good to have a combination.” [Focus group 2]

Providers suggested that this specific approach of service delivery is particularly interesting as it provides families with the opportunity to engage in a “supported self-management” model where the providers work closely with families to identify problems, develop goals, and locate interventions to support accomplishing those goals. The results of this analysis highlight how this particular model can provide a better understanding of how developing these networks at various
levels can be beneficial to sustaining caregivers and highlights the benefits of focusing beyond the individual needs of the cared-for person and the individual needs of the caregiver.

The providers involved in the focus groups felt that the relationship they were able to build with the families, as a result of this initiative, were unique from their typical experience. The providers highlighted that these relationships were built on trust. The providers emphasized that, while the funding intervention was helpful as a platform to engage families and access unique and flexible supports, the money alone would not do the job. The providers pointed out that often it was more complicated than individuals just needing money. The benefits of the initiative came from having support to identify the main source of concern, and then identifying resources to meet their needs. The providers recognized that, as time went on, a relationship developed between the families and themselves, suggesting the importance of ensuring there is consistency in care providers; being able to develop these relationships allowed families to feel more comfortable when discussing challenges, and providers argued that “developing that connection makes this process effective.”

As a result of the relationship that developed between the providers and the caregivers, caregivers were better equipped to provide care and navigate the formal system. The inability to navigate the formal system was seen to be a significant hindrance to a caregiver’s ability to maintain resiliency. This suggests the connection/relationship has a longer-term impact, as caregivers had more capacity and resources to access and navigate the system. However, this relationship remains only one piece of the puzzle, as other ties (bonding, linking) simultaneously affect a caregiver’s ability to access additional resources and maintain resiliency.

The service providers noted the benefits of being able to tailor care plans to meet the individual needs of families. This allowed providers to take a holistic perspective and engage supports, which typically would not be available, enabling them to meet the emotional, psychological, and physical needs of family members. Supports involved making it possible for caregivers and families to engage in meaningful social interactions like spending time with family (e.g. dinner with a spouse) and/or attending social and cultural outings. The care plans also involved making arrangements so caregivers could attend personal medical appointments. Providers believed that supporting caregivers in improving social and family circumstances, as well as encouraging healthy behaviours, was a proactive approach to maintaining informal caregivers and their loved ones in the community.
Providers reported that considerable benefit resulted when providers are able to work with families to tailor supports to meet unique needs. Providers emphasized that, while some families require respite or additional hours of support, other families require different supports. Providers noted that, if these initiatives were solely about increasing hours of support, that the initiatives would be a “waste”. These initiatives allowed the providers to work with families to tailor supports to individual needs and to access supports that are not typical of community programs. This process was particularly helpful to caregivers who were unsure of what supports might be needed or what supports are actually available.

4.4.1.3 Opportunities, Challenges and Benefits: A Focus on Societal Level Resources

Participants from three of the focus groups made particular note of the benefits that would likely stem from engaging caregivers and families in identifying problems and working through solutions together. Particularly, providers emphasized that working with families by connecting them with services, while also informing them of the types of supports available, was of significant benefit in terms of sustaining them in their role.

There was also discussion around the importance for the system to adapt in order to fully meet the needs of these families. Providers noted that the system plays a large role in caregiver experience and overall stress. They emphasized the importance of building in prevention by building up community resources, by paying attention to those individuals who do not access CCAC services, and by focusing on preventing deterioration rather than reacting to crises. As highlighted by one participant:

“There will never be a real benefit to the healthcare system unless we build in prevention, we need to build up community resources, lots of people do not access CCAC, and overall we do not prevent deterioration, for the most part, we are always just reacting to it.” [Focus group 3]

It was mentioned by participants in two focus groups that if, as a society and as a system, we want to continue to support people in the community, then we need to listen to what people need and support those needs flexibly. Allowing people to take control of their own lives and supporting their needs in a holistic and individualized manner is a necessary step in cultivating caregiver endurance.
4.4.2 CF Service Provider Interviews

4.4.2.1 Eligibility Criteria: A Focus Beyond Personal Resources

While two providers emphasized that this initiative should be means-tested, eight providers mentioned that a lack of financial resources should not be a specific eligibility requirement. However, they also suggested that, in targeting families who have a medically complex child, there would likely be some form of financial strain as the circumstance often results in a single-parent household and/or a single-earning household. These initiatives are unique in that they consider needs and supports above and beyond the individualized medical approach of the current system. Interestingly, in targeting families, providers mentioned that various personal factors like cultural or language barriers (e.g., English is not the first language) would likely impact a family’s ability to cope and should be considered when targeting families in need. However, providers mentioned that “overall need” should be considered (n=8). While finances do impact a family’s overall need, providers emphasized that, while some families, on paper, might appear to be able to afford services, their ability to locate and access them may be limited as a result of high levels of stress, difficulty coping, or the simple unavailability of services. Providers went on to suggest that the needs assessment should look beyond the caregivers to consider the familial unit. Here, providers were suggesting that the benefits for one family member often will positively impact other family members. Providers acknowledged that when targeting families “in need,” it is necessary to consider the emotional, psychological, and financial circumstances of families. Similarly, providers felt that the initiative should be targeting families with complex needs at the personal and social level.

“Ethically it is important to address all of the issues – not just funding caregivers, but supporting the whole family through the complex system.” [Interview 5]

Additionally, another provider stressed the need to acknowledge that, while some caregivers or families might appear resilient or appear to have access to resources on paper, they may be functioning with a high level of stress in a difficult system, limiting their ability to access resources:

“Criteria cannot be too stringent. More families who have financial resources, but have a family situation with several children – although on paper they might look like they could afford it – it is
actually that they are operating on high level of stress all the time. There is no real relief. If you do not consider a broad term of need – you might cancel out families that would truly benefit.” [Interview 3]

Providers also stressed that the medically complex child’s age should not be used as an eligibility criterion. Providers made note that often this population experiences a scarcity of resources to support ongoing needs as the child ages. It was suggested that this initiative might be able to support families through these transitions to allow for longer-term capacity planning. Within this context, providers also noted that it is essential to target families as early as possible, before burn out (n=6). Targeting people already “at risk” was thought to be counterintuitive.

“Other CCACs should see this and say ‘we have flexibility in funding we should do something like this too, I would like to see it provided on a regular basis and not just to ‘at risk’ families. Use a similar program to avoid people from being at risk. Learning from the flexibility, if it is truly flexible there are some important things we can learn from this. Something that is far more meaningful for caregivers – flexibility.” [Interview 4]

The eligibility criteria and targeting for this initiative needs to be proactive, looking to families not yet in crisis, but who, as a result of social, psychological, or emotional circumstances, are likely to become at risk. They related the need to be proactive to the challenges associated with re-building families’ resilience once it has already been depleted.

4.4.2.2 Delivery and Supports: Building Bridging and Linking Ties

There was consensus that the relationship between families and the service provider, who not only knew the family but was also well versed in the system, was essential for being able to adequately support the family’s medical and psychosocial needs (n=11). The relationship was seen as crucial particularly as parents tended to have a difficult time identifying needed supports, focusing on personal needs, and focusing on the needs of their family. Many providers (n=9) highlighted how conversations with families changed as a result of this initiative. The relationship and conversations shifted in focus and were seen to be helpful in assisting parents with problem identification and problem solving; the providers saw the system navigation piece as vital in sustaining the family unit and identifying solutions (n=9). One participant noted:
“Talking with the service provider it looks like the family feel like they have a more sustainable plan than they did before. Gives them control and choice to help them meet their needs.”

[Interview 7]

The benefit of engaging in conversations like this was that it allowed for consideration of the whole family (n=8). Providers pointed out the importance of being able to address many concerns beyond the caregiver and beyond individual medical needs of the child with medical complexity—“not just funding caregivers, but supporting the whole family through the complex system.” Providers felt that it was their role to identify other support services available to families, like March of Dimes or Easter Seals, to ensure funding was being used wisely, and to avoid duplication of services. There was consensus that the discussion and having the opportunity to educate and problem solve with families is often more important than the money itself. Having the conversation housed around the caregiver versus the client is an interesting intervention that is crucial to elevate supports to a different level than is traditionally achieved (n=10). The role of the provider was seen as pivotal; providers emphasized that, even if you hand families the money, the trouble would lie with families not knowing what to do with it and how to access needed supports. Providers thought that the relationship was helpful for families as they were able to make linkages to formal supports (n=3). Interestingly, providers acknowledged that it might be beneficial to allow families the opportunity to navigate the system, but only if they have the capacity (n=6).

Although providers recognized funding as a key enabler, they felt that the focused effort to assess and support families was the most important piece as it helped the family to cope and build sustainable circumstances. One provider emphasized that there should be an increased effort to work with families to build a life plan and to identify trajectories to be anticipated and methods to address the circumstances.

The skill of the provider is especially important (n=11). Being able to negotiate what families might need and problem solve in a disjointed system is very stressful; having a provider who is supportive in this process and capable of these tasks is critical. This approach to care does require a change in thinking; working within a “low rules environment”, providers need to be supported so they can let go of their typical approach which is more of a prescribed understanding of what supports should be provided and how they should be delivered (n=4). Providers identified the benefits of having flexibility with resources. The flexibility of this program is ideal for allowing
out-of-the-box thinking and providing out of the box/flexible problem solving as highlighted by one participant:

“This allows for problem solving and out of the box thinking, so this is a good group to use for this type of intervention because it demands out of the box/flexible problem solving.” [Interview 1]

Providers noted that the primary benefits result from the flexibility offered through the initiative. Families can access supports and services that the CCAC is unable to provide. The flexibility is important and providers believe it allowed them to support families in meaningful ways (n=11). The initiative was able to expand beyond the rigidity of typical home and community care guidelines allowing providers and families to work more collaboratively to meet the needs of the family from the perspective of the family- a different approach than what is typically taken. Pushing the envelope in this way allowed the typical medical model based approach to be a little more flexible to address families from a more holistic perspective (n=4).

Providers pointed out that the medical piece is often the primary focus; as a system we fail to consider social factors, which can be equally difficult for families to sort out. Often, the medical piece can be the smallest stressor for families when complex social factors are at play. For example, many families struggle with the logistics of how to get their children to school (n=4). Providers believed that being able to access supports that otherwise would not have been available, even with an obvious need, was a valuable outcome of the initiative. The flexibility allowed providers to work with families on developing longer-term capacity building by focusing on familial relationships (i.e. parent date nights, family outings) and/or supporting home/vehicle modifications. As one participant noted: “Supports should be for the whole family, not just caregivers or child, bigger than just on member – whole family should be targeted.”

Specifically, providers believed that encouraging families to work towards maintaining relationships by ensuring families could engage in meaningful events together was seen as an important approach to sustaining caregiver wellbeing. Providers suggested that, if the familial relationships begin to break down, it would affect everyone. Providers emphasized that longer-term benefits for families would also result from connecting families to community supports as noted by one participant “Really tried to focus on the long-term, a lot of the linkages were focused on community supports”. Participants also highlighted that purchasing medications, diapers, or
formula might not solve problems over the longer term, but focusing on unfunded home modifications, or supporting families to find and maintain meaningful employment would be investing in the continuing capacity of the family (n=6).

4.4.2.3 Opportunities, Challenges and Benefits: A Focus on Societal Level Resources

Providers noted that caregiver stress would not likely be a useful measure of success for an initiative such as this, arguing that parents of children with complex needs experience stress, and stress fluctuates independent of the intervention (n=2). One provider thought that a positive outcome of the initiative might be a caregiver’s ability to continue to be engaged, maintain or increase employment, and demonstrate an ability to identify, access and/or use resources.

Providers highlighted that, as a result of the initiative, they were able to support caregivers by providing them with necessary resources and connecting them with appropriate services which were more likely to sustain families in the community. Providers argued that once caregivers are better able to cope, the need for ongoing support might be reduced, resulting in better use of appropriate resources than how those resources are currently being applied (n=4): “If a family feels like they can’t support their child, often times they will remain in acute care”. This program allowed providers to address needs flexibly to support the families to cope in the community by identifying and getting families access to community resources available beyond the supports offered through hospitals. One participant highlighted:

“This conversation is huge to have that conversation and elevate it at this level – even if there was no money. The collateral stuff that goes along with the medical needs – medical concerns are all closed up – but now how do I get them to school – all the other stuff. The medical piece is sometimes almost the smallest piece”. [Interview 6]

The providers recognized the benefits of this initiative, and wanted to see it develop into a “model of care”. However, the providers stressed that systemic issues may impact the long-term effects that an initiative like this would have, arguing that there needs to be a centralized agency with caseworkers who have a small enough case load to allow for the development of ongoing relationships. It was suggested that the current system is not family friendly; this initiative is a
step in the right direction allowing providers to engage with families and access supports that are not available within the current system as one participant exclaimed:

“A lot of times we feel helpless when we are caring for these kids, this gave us reinforcement to do a little more – financial issues become challenges for healthcare providers that they can’t usually address, this allowed them to explore other solutions – more ability to go that bit further of care of families (better respond to needs).” [Interview 8]

Several providers specified that communication between providers and organizations needs to be improved. Those involved in the initiative saw an improvement in communication and collaboration but pointed out the need to bridge to the broader support system. Providers believed that the organizations involved improved the use of resources by reducing duplication of services among these groups (n=3). Providers thought that involved organizations improved communication and that even other providers within the organizations became a helpful resource, even though they were not technically involved in the initiative. As one provider noted: “it works because the organizations are working together.” Providers suggested that it would be helpful to establish these relationships. For example, providers singled out their relationships with hospital social workers as being extremely helpful; yet determining who is responsible for supporting families to meet certain goals identified in their care plans would be useful. Providers believed that the success of the initiative was partially a result of the organizations working together. Here they emphasized that the initiative needs to be embedded within an integrated system and worried that, if it is a standalone model, the system challenges will preclude any of the benefits that an initiative like this might produce (n=7). As one provider stressed:

“What are we using resources to fill other gaps that the system wasn’t fulfilling? Are we working to address caregiver burden or to support the holes in the system in other places” [Interview 7]

### 4.4.3 Summary of Key Findings: CSP Provider Focus Groups and CF Provider Interviews

#### 4.4.3.1 A Focus on Bonding Ties

Providers and administrators discussed the central role of the family unit; both in terms of assessing familial needs as well as ensuring members are able to spend quality time together as a method to maintain the unit. Service providers stressed the importance of ensuring the bonding
networks between family members remained intact and worked with the families to identify the best possible options to support the family as a unit.

Services and supports that were leveraged to improve bonding ties include:

- Respite, where parents could attend dinner or spend time with other siblings, or where a daughter caregiver could have a romantic evening with her husband.
- Travel, to have additional familial supports accessible to families or to pay to have a geographically distant relative come to assist with care.
- Family outings, supporting travel or day trips with additional care.

It was also seen as valuable to encourage bonding ties among formal providers. Service providers suggested that bringing together the case managers could provide a forum for discussion of assessments, a setting to discuss and challenge assumptions and promote a shared understanding and vocabulary. The opportunity for providers to bond with providers was thought to have potential benefit for the providers and, as a result, the families.

4.4.3.2 A Focus on Bridging Ties

There was overall agreement that caregivers and families benefited from developing the relationship with the case manager. Supporting these relationships was thought to “build up trust [for caregivers and families] in the case manager and in the service provider agencies.” Many service providers and administrators highlighted the extended benefits for families who have a case manager willing to engage in and develop an established relationship with the family. Participants stated that case managers need to be highly skilled, specifically that case managers need to be capable of “developing a therapeutic relationship gaining knowledge of families’ needs and an understanding of the complex system is important in order to identify and support individual familial needs.” Having one case manager who works with the family was also seen as an improvement upon the current system where multiple providers are engaging with caregivers and families which often results in inconsistencies. The providers emphasized that there was a benefit to ensuring consistency for both the provider and the family; these relationships encourage thoughtful conversations that place families in more trusting and comfortable situations.
The tie between case managers and families was seen to be the intervention most beneficial in sustaining the familial unit. Providers stated: “this is huge to have that conversation and elevate supports at this level- even if there is no money.” With one provider stressing: “Families are already in a better position if they have someone they trust who they can contact Monday to Friday.” Case managers and families were encouraged to “look at how best to support and assess the needs, to build coping and care plan approaches that build a sustainable situation.” A more intensive, holistic case management approach was thought to be “what these families need.” The assessment tools and the goal-setting approach were seen to build rapport with families and allowed families the opportunity to “open up”. Providers suggest this trust and rapport is important in developing family buy-in and willingness to engage.

Service providers emphasized that the support initiatives allowed for bridging ties, which extended beyond the case manager and caregiver/family relationship. Caregivers were isolated, so allowing them the time off for social activities (e.g. to visit with friends, participate in exercise groups, attend the theater), was seen as a crucial support to encourage their ongoing involvement in the caregiving role.

Bridging ties were also seen to be crucially important and effective among providers and organizations. However, it was not clear if these initiatives alone encouraged the providers and organizations to increase collaboration. The service providers did acknowledge the barriers to supporting families when multiple organizations that serve the same population do not collaborate. Service providers and administrators emphasized integrating care as a means to streamline communication and provide more effective and reliable care. The lack of collaboration and integration was seen as an issue not only in terms of streamlining care for families and for relieving the burden on care coordinators, but also in terms of system effectiveness by supporting a reduction in duplication of services.

The providers suggested that collaborating with experts in the field would only strengthen the initiatives and improve the overall sustainable benefits to caregivers and families. Providers identified a concern that “providers out there are struggling to care for these families; we need to focus on making a team to support and build provider and familial capacity.” Providers emphasized the importance of having the care teams get together to ensure everyone is on the
same page; while “communication between organizations has improved,” there were still gaps evident in organizational collaboration.

4.4.3.3 A Focus on Linking Ties

Providers and administrators highlighted the role that initiatives such as the CF and CSP play in providing caregivers and families access to additional formal connections beyond what they would normally have access to, emphasizing that needs were being met in “novel ways”. Providers also pointed out that certain needs cannot be addressed through “OHIP-funded services and pre-existing community programs.” The providers emphasized the importance of working with families to identify what services are available, where they exist, and how to access them.

Families are less likely to bargain for themselves within political and organizational structures; often times “they accept what they get or don’t get.” These initiatives allowed providers and families to use resources flexibly to achieve longer-term goals. For example, one caregiver wanted to obtain employment, but did not have the resources to look for meaningful work; this initiative allowed her the flexibility to retain employment. The ability to work with families and link them up with supports, above and beyond what they typically could provide under the current system, was a hugely beneficial component. It was pointed out that producing these ties was “really filling system gaps.”

Providers highlighted the importance of linking themselves up with additional formal resources, to ensure on-going training and to receive coaching and regular crosschecking opportunities. Here providers noted that they are working in a “low rules” environment, which is beneficial to maintain the flexibility but is an uncommon scenario outside of these initiatives. The providers also emphasized the value of having the right people at the table for decision-making processes. Individuals who are high-level government stakeholders were seen to be ill-equipped to be making decisions which impact families; involving healthcare providers who work closely with families, as well as families themselves, at the decision making table was seen to be an important and effective strategy to ensure future decisions better meet the needs of these complex families.
4.4.3.4 Access to Personal, Social, and Societal Resources leading to improved resilience

The field notes highlighted several indications suggesting that support initiatives that consider an individual’s personal resources (material possessions or symbolic/psychological possessions), social resources (social connections) and societal resources (resources available as a result of various formal and political developments) as a means to target, as well as develop appropriate care packages of support are likely to build caregiver resilience.

It was suggested that having access to support initiatives such as the CF and CSP was “really beneficial for those who are low income”. Families with low income often are unable to obtain additional community supports and the case managers are required to “brainstorm agencies that they can access.” Financial needs become challenging for healthcare providers and families when they are unable to fully address these needs. Working within these initiatives, service providers were able to explore alternative options and assist families further resulting in a better response to their needs. The challenges associated with a family of low financial resources were slightly mitigated within these initiatives as they allowed for some funding freedom in a “structured and unforgiving system.”

While the providers and administrators highlighted the importance of targeting and supporting people with financial need, many also highlighted the importance of additional personal factors, which should be considered when developing support initiatives to sustain families. It was evident that the service providers and administrators involved with these two initiatives generally believed that targeting caregivers based on financial need is not sufficient, but, rather, providers should explore broader social and emotional contexts. When supporting families, various personal and social factors should be considered, including the availability of family or social support; possible cultural or language barriers; mental health concerns; and the physical health and well-being of the primary caregiver(s).

Of particular relevance, the service providers highlighted the important role that social resources can play in sustaining an individual’s overall well-being and resilience. The field notes highlight that being involved in these initiatives allowed service providers to target, assess and support the family as a whole rather than focus on the individual. Providers felt it was important to flag families who have a break down or lack of social supports with “no availability of people to come
in and support the caregiver.” Along the same lines, care providers identified the importance of considering circumstances more broadly to include “social and contextual components in order to create more sustainability.”

The field notes also demonstrated that service providers believe that the societal and contextual piece plays a factor in a family’s ability to be sustained. In fact, some mentioned “without addressing systemic issues this is likely not a long-term impact.” However, even within the current system that “isn’t designed to support families”, the initiatives did offer some flexibility, which was seen as essential in supporting families. Additional comments point out that flexibility in funding is not necessarily going to “solve issues.” Services first need to be available, and secondly, they need to be flexible; these circumstances are “more complicated than just needing money.”

4.5 Chapter Summary

The two case studies in this analysis used similar interventions to support the needs of informal caregivers and broader networks on separate populations. While these initiatives were focusing on two separate populations, the findings suggest similar overlapping constructs demonstrating the importance of families having access to personal, social, and societal resources (resources associated with building resiliency) as well as noting how broader network ties can improve access to these resources. Both initiatives attempted to respond at the bonding, bridging, and linking levels to further support the personal, social, and societal resources available to these caregivers and their support networks. The two initiatives employed specially trained care coordinators who provided ongoing problem identification and problem solving. Using a modest budget of approximately $300/month/client, case managers connected informal caregivers and families to needed health and social support. Providers involved in both initiatives believed there was opportunity for a classic “self-management” model, for caregivers and families who had the capacity to manage the budget and access necessary supports. These initiatives leaned more towards a “supported self-management” model where caregivers and their families received support from experienced professionals who understand the system and have skills to navigate across multiple providers and organizational silos.

The two case studies used for this dissertation focus on two distinctly different populations. However, the findings suggest that informal caregivers involved in both the CF and the CSP are
likely to face challenges associated with personal resources like age, sex, ethnicity, and financial capacity. It appears within these two case studies, informal caregivers of high need individuals experience similar personal dynamics and formal constraints.

In terms of the mix and volume of services organized through the two initiatives, there appeared to be a focus on providing both social care and direct supports. This is likely a direct result of the importance that the key workers placed on ensuring social resources were fostered and encouraging the importance of bonding ties for these families. The packages included a range of supports, which became quite difficult to label and identify comparisons around the “types of supports” offered. The value from these two initiatives is likely that the supports are not provided from a “menu” (making them difficult to categorize). But it appears that, in order to benefit families in the community, the supports need to be more than the sum of the specific services/supplies that were purchased as a result of the funds from these two initiatives.

The interviews and focus groups conducted with the providers of these two initiatives further highlighted that it was not necessarily about the services provided or the money received. Providers acknowledged that the interventions which worked were being able to communicate with families on a different level than what the current system allows for and to engage families in identifying needed supports that extend beyond the traditional formal medical model to support their needs and build resilience. Acknowledging that additional respite is important, but knowing how to access additional respite and how to utilize that time to engage in meaningful activities extends the value of that service. These models of care extend beyond the typical line-by-line, individualized, medical-model approach to the home and community care sector.

The interviews and focus groups with providers highlighted that these initiatives provided opportunities at multiple levels to develop a family’s personal and social resources through supporting and fostering relationships at the bonding and bridging levels. The societal resources available to these families remained low, and our current system is not designed to support families, emphasizing that, without addressing systemic issues, it will always be a challenge to focus on the needs of the family unit to support their resiliency. However, these initiatives did allow for flexibility and creativity to address the needs of families, allowing providers to fill gaps in services and consider the social needs of families above and beyond the medical needs of individuals.
Chapter 5
Qualitative Semi-Structured Interviews: Case Studies

5 Introduction

This chapter reports the findings from qualitative interviews conducted with project management staff and case managers involved with the two Toronto-based caregiver-support initiatives. The primary goal of the interviews was to identify if providers perceived benefits from building bonding, bridging and linking ties and whether or not these ties were seen as crucial to improving access to personal, social and societal resources – resources which are commonly associated with building resilience. The interviews were conducted to determine if service providers involved in the two caregiver-support initiatives saw particular interventions as being more likely to produce long-term benefits by building resource heavy networks of support. Specifically, whether resilience results from support of personal level resources and circumstances, or from social capital built through various-level networks and improved access to resources within these networks.

The findings within this chapter specifically acknowledge the benefits that can come from developing bridging and linking ties in supporting an informal network’s access to personal, social and societal resources. Participants saw long-term potential in supporting caregivers and families by developing and improving upon their personal level resources (particularly through supporting their financial and educational needs). Participants also acknowledged that supporting caregivers to engage in bridging-like networks improved their access to personal, social and societal resources, which otherwise may not have been possible. This demonstrates that long-term benefits and resilience likely stem from interventions that focus on interventions that support the development of crosscutting ties that improve access to resources beyond the personal level (i.e. exclusively funding).

The consensus was that context should be considered when designing supports for caregivers. Flexibility in design was seen as crucial in order to meet the complex and individual needs of caregivers and their networks of support. Participants acknowledged that an informal network’s ability to access personal, social and societal resources should be considered when developing flexible packages of support. Participants noted the importance of focusing beyond personal
characteristics and medical needs of care recipients, and, as such, providers believed that the problem solving conversations that occurred with the caregivers as part of the initiatives should exist as a consistent formal support.

There were several providers who highlighted that these initiatives were overall extremely valuable and unprecedented. However, the participants did note several key insights that, as a society, we need to consider in moving forward. These insights became particularly evident when discussing formally supporting the role of the informal caregiver beyond local initiatives.

5.1 Bonding: Improved Access to Social Resources

The providers involved with the CSP and CF for CMC identified bonding ties as important. However, as it relates to improving access to resources and supporting resilience, the providers acknowledge that encouraging and supporting bonding ties were mostly helpful for improving access to social resources. The participants also noted the benefits that can come from supporting the engagement of the family unit to ensure familial stability (i.e. marital relationship or sibling relationships).

One participant highlighted the benefits for one particular family where the initiative supported improvement in their social world:

“I know there has been situations where it helped their social world. One family was like ‘we don’t want any help – we are coping’ but when you read the assessments you see their lives are only about what is happening in the home. We had to give them some support to get them out of the house and have at least a night. This does help socially – you need to network and receive the support from the community – and it goes right back to health.” [Interview 1]

Four participants noted that being a part of the initiatives supported the improvement of immediate familial relations. Participants also believed that, as a result of these initiatives, caregivers felt acknowledged and supported which ultimately resulted in improved relationships between the caregiver and the care recipient:

“I think it really helps to alleviate some of the tensions in their relationships…People feel somewhat resentful sometimes being in the role of caregiver…you know they feel their efforts
which are often significant are not appreciated by anyone. So acknowledgment of their efforts and the role of the caregiver is significant for them.” [Interview 6]

Similarly, another participant highlighted that, when a caregiver is able to relieve some stress, it can equate to being able to provide better care stating: “For the caregiver to alleviate stress it allows them to provide better care in the end. So that does help the relationship, it comes full circle” [Interview 8]. Another participant expressed a similar trend, suggesting that supporting the caregiver has an ultimate effect on the care recipient: “I really believe it has made an enormous difference in the lives of recipients [caregivers] and as a result a difference in the lives of the ones they are caring for” [Interview 1].

There was overall consensus that supporting the caregiver and care recipient relationship, whatever that might look like for any one dyad was beneficial because, simply put: “you receive different care when it is from a loved one” [Interview 1].

Many participants highlighted that individuals who find themselves in a caregiving role tend to lose friendships along the way (N=5) most often, as a result of not being able to get out and connect. Participants felt that these initiatives made it possible to support informal caregivers to re-connect either by supporting within family connections or by encouraging caregivers to extend their social networks.

5.2 Bridging: Improved Access to Personal, Social and Societal Resources

The participants saw significant value from developing bridging ties among families and providers as a means to improve access to personal, social, and societal resources and lead to an informal networks overall resilience. Participants noted that in order for bridging connections between families and providers to be most effective in improving access to resources, they needed to be built on a foundation of trust. Beyond that, participants saw connecting informal networks to other informal networks, while not a specific component of the initiatives, as a likely crucial bridging connection that would improve access to personal and social resources. The most common approach to connecting informal networks to other informal networks is through informal caregiver support groups.
5.2.1 Personal Resources

Many participants acknowledged that the financial component of these initiatives was extremely valuable for the caregivers and families that were involved, particularly when combined in a package, which included education. The resources allowed them to access supports and services above and beyond what they would have been able to receive through the publicly funded home care services provided through CCAC (i.e. transportation, purchasing support necessary to attend social activities). Additionally, the participants did note that above and beyond providing financial support there should be a focus on management of funds, providing caregivers and families with the necessary knowledge and education to improve their personal-level resources.

Participants acknowledge that some caregivers might already have the personal-level resources (highlighting specifically knowledge and capacity) necessary to identify and access supports without additional navigational support: “There are some caregivers who are great advocates and can do their own research but there are other caregivers – for whatever reason, could be language barriers, can’t do that on their own” [Interview 1]. Many providers highlighted that there are some caregivers and families who might require additional support beyond simply receiving financial resources: “Some caregivers you could just send the money to. But this wouldn’t be appropriate for every client” [Interview 4]. This is where participants acknowledge the benefits of having personal resources in terms of capacity to problem solve and navigate the system highlighting the benefits of being able to understand and speak fluent English. Here, they note that, without these personal resources, even if you are financially well endowed without being rich in other personal resources an individual is less likely to be self-sufficient over the longer-term.

Providing caregivers and families with knowledge and support to identify needs and navigate appropriate solutions to meet those needs was seen as a beneficial component of these initiatives. This support was arranged by having providers work alongside caregivers and families to identify needs and problem solve solutions. This process was seen to be successful because caregivers were working with a professional who is rich in personal resources (i.e. knowledge of the formal system) and not only understands the needs of the family but also is familiar with the complex nature of the formal system and has the formal tools to identify and access resources.

“I think the problem solving therapy was really therapeutic for people and I would be afraid families wouldn’t know what to do with the $1,500.00 if it was just given to them.” [Interview 3]
Again, personal level resources consist of more than financial resources. While an individual actor may have access to financial resources, inadequate knowledge may limit the benefits of having access to financial resources. It became clear that participants saw massive benefits from developing bridging ties and connecting families to formal providers who had access to knowledge allowing families to identify and access supports.

There was overwhelming consensus that these initiatives, through the combination of cash, counselling, and education, improved access to services both traditional (additional PSW or nursing hours) and non-traditional (support to attend the gym, church or massage therapy) for caregivers and care recipients. Participants acknowledge that being involved in these initiatives helped caregivers and families “access resources a bit more and to actually see what is out there” [Interview 3]. This improved access to community resources was seen to help “them [caregivers] take control of the situation and led to a better outlook” [Interview 3].

Access to additional traditional support was seen as a valuable component: “Well you see they have the maximum hours of support and some cannot afford to buy extra supports… so with the extra supports it is often helpful” [Interview 4]. Another participant similarly identified that this initiative is allowing caregivers and families to receive supports and services that they otherwise would not have been able to access: “This support allows them to make choices they might not have had otherwise” [Interview 5].

Many participants felt that the financial component was a beneficial intervention as it improved caregivers’ personal resources, and was thought to be the element, which opened the doors for caregivers to access non-traditional supports (i.e. gym memberships, massage therapy, social outings). However, participants acknowledge that funding should not be considered the sole intervention that is needed to support and build informal caregiver resiliency:

“The coaching component is really important…really open to the possibility that it really is not [just] about the money. I don’t think it should be about the money.” [Interview 2]

Similarly, another participant highlighted that:
“The financial support is definitely one of the key factors but as well the connection to different community agencies... that helps the families a lot. A lot of them don’t even know where to begin.” [Interview 8]

Participants acknowledged that these initiatives opened caregivers up to a range of supports that could address varying and individual needs: “There is such a range of what people will choose. There is a huge array of how people chose to use the resources” [Interview 5]. While trying to consider which components of these initiatives are more likely to support caregivers and families over the long term, it became clear that service providers working alongside these networks and being able to support their needs flexibly was identified as a crucial component above and beyond providing the financial resources. Participants highlighted that some caregivers and families are better able to pinpoint their needs and identify supports to address those needs than others. Other caregivers might not have the resources necessary to look beyond immediate challenges to isolate needs and identify supports to address those needs as one participant stressed:

“Some of them couldn’t think beyond more immediate needs so capacity for them would be very different... But what we saw with caregivers even the ones that were financially well off but couldn’t problem solve. So its difficult to say just because you have financial resources that everything is fine, there has to be a bit of a balance in terms of what is the actual skill or capacity of the caregiver in terms of their ability to cope and problem solve and then you can layer on and assess their financial needs.” [Interview 7]

This participant stressed that personal resources are essential, but alone are not sufficient to enable these networks to build a bridge to access social and societal level resources. Participants acknowledged that the financial resources along with access to formal navigational support allowed caregivers and families to connect to additional community supports. This was seen as a beneficial outcome as they believed it contributed to a caregiver’s overall wellbeing and resilience. Additionally, the financial support could be used to further develop one’s personal resources by allowing caregivers the freedom to attend educational programming as one participant highlighted:

“We gave her an opportunity to take a class. And at the end of the year she reported how much better she felt about herself. Developing herself and it was also a bit of a stress reliever because
she was able to leave and go to class and also developing skills because of the class.” [Interview 7]

5.2.2 Social Resources

The participants highlighted the importance of insuring informal caregivers engage with social networks at various levels, specifically highlighting the importance of bridging ties in supporting informal caregivers to re-connect with the community.

Seven of the nine participants made mention that there is benefit in supporting informal caregivers and families to engage socially with individuals and groups beyond their internal familial network. Some of the participants believed that within the initiatives they were able to successfully encourage those connections. Others believed these relationships could have been encouraged more, suggesting that there might have been additional avenues available to develop bridging networks that were not fully explored.

Participants highlighted that some families involved with the initiatives were provided with the supports and tools necessary to comfortably get out of the house, engage in social outings, and reengage with the community. As one participant highlighted: “There were a few cases where we acknowledged that they needed a night out to reconnect with the community and to help them make that effort” [Interview 1]. Another participant agreed that as a result of the initiative:

“it did connect them on a more social level. I wouldn’t say that it happened in all cases but certainly in a few we saw there was a real branching out and an opportunity for people to go beyond just their immediate caregiving needs.” [Interview 7]

Supporting families to re-engage with the community was seen to benefit the mental health and resilience of caregivers. As one participant exclaimed: “Mental health – if you are locked up in your house for a week you will get stir crazy, especially if you are with children all day there is a lack of adult conversations it does take a toll on you” [Interview 1].

The initiatives allowed caregivers and families to feel comfortable to get out and socialize. Participants stressed that within the current system caregivers often experience a lack of confidence in their service providers as a result of staff turnover and an overall inconsistency of service providers and therefore caregivers often do not build a trusting relationship with the front
line providers. One participant highlighted this thought by saying: “Some families needed to get out of the house and know someone they can trust was there” [Interview 3].

Participants highlighted that they “feel a better connection to clients and families.” Many providers also highlighted the benefits, which can come from families being connected to a provider who understands them as well as the system: “They [informal caregivers] probably know best what their needs are but we [formal service provider] also know how the system can meet those needs and in some cases that would be financial needs and in other cases it is not” [Interview 2].

One participant highlighted that caregivers can often feel isolated as a result of not being able to talk about their experiences to persons who fully understand and appreciate their circumstances. This highlights the important role, which service providers can play in reducing isolation and supporting informal caregivers in their role:

“There is a lot of resistance to caregivers when they try and talk about their concerns, which can make them feel even more alone. So something to build there resilience would be to give them someone to talk to, a therapist or someone who is actually listening and understands what they are going through – not only to validate their feelings but to give them suggestions on ways to process their experiences.” [Interview 5]

Participants also acknowledged that caregivers building connections with other caregivers or families in similar circumstances could be extremely beneficial. As one participant explained: “Support groups are so valuable because they are sitting with others who are experiencing similar things” [Interview 5].

Encouraging the connection between families was not well established within these initiatives but providers saw this connection as a positive possible resource for families “you can learn from others… learning about services or even going to the dentist who understands the population – you can’t dial up any dentist and expect them to treat your child correctly” [Interview 1].

Participants saw value in supporting these bridging networks but unfortunately experienced barriers in attempting to develop these networks. As one participant explained: “Nice if anonymity wouldn’t have been an issue and we were able to bring the families together as a
group… I would see that as being a great community for them – they could also learn from each other” [Interview 1].

While these connections were not explicitly addressed within the initiatives, they were encouraged and supported, and participants unanimously saw value in developing family-to-family or caregiver-to-caregiver connections. For example, one participant expressed: “I would support a greater effort in developing these [family to family] connections” [Interview 2].

5.2.3 Societal Resources

Eight of the participants highlighted how in order to support caregiver capacity and resiliency there needed to be support interventions in place generated through formal political avenues, which would encourage bridging ties. Specifically participants stressed the crucial relationship that was created between the formal case manager and the informal caregiver and families. Additionally, some participants highlighted that, on a societal level, we should be encouraging bridging networks throughout the life course, focusing particularly on community engagement, suggesting it would prove to be beneficial for individuals and communities over the long term.

The relationship that was developed between the formal case manager and informal caregiver/families was identified as being very helpful for pinpointing problems that the informal caregivers and their networks faced. Even more, this relationship was crucial for working together to find creative and individualized solutions (n=5). One participant highlighted this:

“You don’t always know what you need on the surface right away- I think people are often good at solving problems or putting out fires in the moment but we have huge expertise here to help people sort out longer-term goals and options.” [Interview 2]

While participants agreed that this relationship was effective in “challenging caregivers to think beyond the now and what my child needs now” [Interview 1] and “getting them beneath the surface of the immediate issue” [Interview 7], participants also believed that being able to engage in this conversation was within itself very therapeutic as one participant explained (n=4):

“It was great to develop connection between caregivers and case managers, it was like we finally got to sit down with them and hear their stories I believe that was very therapeutic in most cases.” [Interview 3]
Participants felt that the relationship between the caregiver and the case manager supported caregivers to delve deeper beyond surface level concerns. The relationship also provided caregivers with the tools to address their needs as they were linked in with providers who were able to work the system more efficiently. Participants felt that encouraging these bridging networks that are supported through these formal means was beneficial as it made “strong linkages with an expert who can help navigate both the needs and the system” [Interview 9]. This can be particularly challenging for individuals living with complex, chronic and on-going needs that attempt to function within a fragmented formal system. The solution then should involve considering both individual needs and broader contexts.

Participants stressed that the coaching and the connection to additional community supports was a crucial component to sustaining caregiver capacity and resilience (n=4). Being able to tailor supports to the particular needs of the caregivers and their families was seen as a crucial component to producing caregiver capacity:

“I think it is the coaching and the Linking. I think it’s the linkages with people who are experts in accessing resources and understanding needs from literally working with hundreds of families over and over again with the individual kind of acknowledgment that a family might require something that is quite unique to their circumstance.” [Interview 2]

All participants highlighted that the dynamic between the formal case manager and informal caregiver looked different than the relationship that normally exists within the home and community care sector. Mainly, it was the conversation that took place between the case manager and informal caregiver that participants highlighted as being particularly different from the norm. Typically, in the home and community care sector, caregivers are not considered clients in their own right and as a result “most times when we are in the house we conduct the assessment and have to gloss over the emotional impact that it has on the caregiver even though we know it’s there” [Interview 3]. Another participant highlighted:

“These are not conversations that ordinarily happen within our system. But as we move out of the acute care setting and more and more people are living in their own homes we have to think about who helps them navigate where to live and how to live.” [Interview 9]
While most participants focused on the importance of bridging relationships between the caregivers, families and formal service providers, they also stressed the importance of organizations and providers collaborating to support individuals more effectively. One provider highlighted: “We are very strong in collaboration here I think it is essential because so many different organizations are involved in providing care. If we work in silos then it would work less well” [Interview 5]. Participants believed that it was a combination of the social and emotional support with caregivers being a part of a team that fully supported their overall wellbeing as one participant stated:

“I think the social and emotional support is necessary and just that recognition that they become an extension of the team is beneficial. Every team member needs support, so the family member would be no different. They can collaborate or consult with other members of the team or be linked in with other services or supports that they might require.” [Interview 7]

Another participant similarly highlighted the benefits of collaboration and suggested that a multidisciplinary team should work alongside the family to address areas of concern and develop a “life plan” that would highlight what to expect over a set time frame and resources or supports that can be available during those times. For example, one participant stated: “Building a life plan. Getting everyone in a room and discussing a life plan about how this dyad will develop in tandem” [Interview 1]. Participants highlighted the overall benefits that can come from supporting the on-going and longer-term needs of these caregivers and families through developing goals, “life plans”, and future planning.

5.3 Linking: Improved Access to Personal and Societal Resources

Participants stressed various systemic issues as being a major barrier to supporting informal networks of care over the long-term. Linking ties, insuring there is improved connections between formal institutions and between formal care sectors was seen as a necessary intervention to ensure informal networks of care have access to personal as well as societal resources which sustain them and build resilience.
5.3.1 Personal Resources

Two participants highlighted that caregivers more broadly, as a population, do not receive the appropriate recognition through formal avenues. One participant stressed that: “caregivers are not a feature of the system that is appreciated enough” [Interview 8]. However, there was consensus that the informal caregiver role more recently has been receiving increased attention. While participants stressed the caregiver role needs further recognition there was some uncertainty regarding what the involvement of the state should be in supporting and recognizing the informal caregiver role more formally:

“I don’t even know where you would start. It can’t be some type of policy that the government creates that says oh every caregiver gets so and so amount of money every week. It wouldn’t be enough. That would be the first thing I would think of that caregivers will get some type of money from the government but that’s not even enough.” [Interview 8]

Additionally, participants highlighted the benefits of insuring accessible and equitable services across the board. Participants acknowledge that the financial component to these initiatives might be crucial for some caregivers but not entirely necessary for all caregivers and families. Stressing that “the counseling, education, referral, support system, and system navigation becomes the core component to supporting informal caregivers” [Interview 9]. This highlights that providers believe that in order for caregivers and networks to access resources at other levels, they are likely to require additional support, above and beyond financial support. Participants identified that in order for initiatives to become fully equitable there would “need to be a provincial, or better yet, a national program”, which includes a “minimal barrier or test to ensure they require the financial component. This isn’t to say they shouldn’t be enrolled in the program” [Interview 5], rather it acknowledges that the additional components, extending beyond the financial support, of the initiatives are crucial to caregiver resiliency. Another participant highlighted:

“It should be regulated through government because we can’t really leave people to their own devices – just because people can’t make their own decisions, not because we don’t want to but we don’t know how…people aren’t informed so that’s where the care professional and the relationship becomes important. “ [Interview 9]
Participants also stressed that the care coordinators’ own personal resources would affect the overall success of the initiative in supporting caregiver well-being. A care coordinators education and skill set would impact how well they were able to engage caregivers in a successful problem solving discussion. One participant noted:

“Care coordinators have to be very well trained as to how to have the conversation now which was a huge hurdle in the beginning...getting care coordinators to think about the needs specifically of caregivers.” [Interview 9]

This underscores that personal resources like educational support are important not only for the informal caregiver, but also for the formal service providers who are working closely alongside informal caregivers and their families in the home and community care sector. This suggests that improving personal resources for informal caregivers and formal services providers should be considered when developing support interventions for informal caregivers and their networks.

5.3.2 Societal Resources

As briefly mentioned above participants highlighted that these initiatives allowed caregivers and families to engage with the system in a manner that is unique. Participants noted that the formal and vertical relations that currently exist within our system do not traditionally allow formal service providers to engage caregivers and their broader networks at a level that can systematically and flexibly address individual issues and concern. As one participant stated: “It isn’t often that you have the opportunity to talk about your own needs or your family’s needs within a system that can actually help you to address those” [Interview 2].

Overall, participants saw the connection between the caregivers and case managers as a crucial component to the initiatives. Participants believed this formal connection with a case manager, in combination with the funding, allowed caregivers to begin to learn how to use funds in a manner which linked them with various individualized formal options:

“It is hard for them to use their own funds on them. When they access a day program they are not only getting connected to the day program but they are linking with all of the care that goes beyond the day programs. Geriatricians, foot care, outpatient physiotherapy – people are getting linked to these things and it empowers the caregiver.” [Interview 3]
While much of the feedback and comments were positive, participants did comment that there needed to be adequate time for case managers to engage with clients and families. Many participants highlighted that the problem solving approach was very effective, yet time consuming and suggested that case managers required appropriate case loads and time to be sure appropriate solutions are identified and system level solutions can be tailored to meet an informal caregivers specific needs. The current system was thought to lack the time that is necessary to fully engage and address longer-term capacity with caregivers and families as one participant stated:

“Maybe they felt crunched for time because they have all these case loads – and this was another thing added to their case load. I worry if they wouldn’t have the time to really get into it.... The case managers really know what’s what- its just giving them the time to really apply it.”

[Interview 1]

Providers warned that current system capacity is dwindling. “Time and capacity everybody is stretched so thin now, and expectations are getting bigger, quality will suffer” [Interview 1]. Participants stressed that in order to support case managers in this role the system needs to be adapted to limit caseloads and provide appropriate training for case managers. While all participants believed these initiatives to be worthwhile for both clients and the system many believed that system level structures would need to be adapted if these initiatives were to be spread and sustained over the longer term. One participant identified the time commitment involved with engaging families in problem solving therapy: “This is great to be able to offer this to clients but you know with workloads and time constraints initially it did take quite a bit of time to go through problem solving therapy with families” [Interview 3].

Similar to what was discussed above, formal providers need to be adequately and formally supported to develop their own personal resources to ensure these initiatives support caregivers and families as intended. Another participant made note that case managers involved with these caregivers and families should be adequately trained to ensure reliable processes and adequate support:

“Skilled clinicians won’t develop overnight and so I would put a lot of investment in that core expertise and matching that core expertise with families would be very valuable. If the core expertise is not there I think it would be difficult to have things materialize.” [Interview 2]
For example, traditionally these providers are not accustomed to engaging with caregivers or families in this manner as one participant highlighted: “The client has never been the caregiver so in some ways it feels a little awkward to get the personal information… it just seems a little strange sometimes” [Interview 3]. Supporting the case managers in this transition through support and education was thought to be an effective approach to addressing this shift in client focus (n=4).

Some providers, thinking systemically, highlighted the possible benefits to using funds to support the hiring of non-traditional providers, essentially giving families the option of hiring individuals they are familiar with while also providing similar levels of supports at a lower cost, which would also build informal networks of support:

“I think to make that dollar stretch a bit…if there was some list out there with private caregivers it doesn’t need to be a registered PSW. So maybe even funding a neighbour or something like that.” [Interview 3]

Three participants highlighted concerns with regards to equitability, people who end up having access to these initiatives were seen as ‘lucky’ because they either have a coordinator who is familiar with the initiative or they live in the appropriate geographical location. One participant highlighted:

“It should be broader I don’t like that the model is contingent on where you live. I don’t think that is how we should think about universal healthcare in Canada. It should be about capturing our high needs populations and making sure we best serve them.” [Interview 2]

This is acknowledging that, within our current fragmented system, access to services varies but often initiatives begin as pilot projects and rarely spread to develop equitable access across geographical barriers. Participants believed these initiatives needed to be broadened and this should be a model of care developed into a strategy or overarching government initiative:

“Lobbying work to get something that is more sustainable something that is long-term and reliable…. Something that is part of a system and structure of services so it is more equitable, sustainable and long-term.” [Interview 5]
All participants stressed that while we might be providing caregivers with longer-term benefits in the sense that they are being connected to formal level supports, that they otherwise may not have been connected to, there is a possibility that the benefits of these initiatives will slowly fade if they are not developed and sustained as an on-going model of care. One provider highlighted the possible short-term nature of the initiatives by stating: “Band-aid solution because you don’t know when the program or initiative will end” [Interview 3]. Participants noted encouraging ‘initiatives’ to become mainstream and spreading them across the province for equal access is a necessary step to ensure initiatives are not simply ‘band-aid’ solutions.

5.4 Chapter Summary

This chapter highlighted that the providers and staff involved in the two Toronto based initiatives saw great potential in these models of care. Overall, they believed the initiatives were a positive stepping-stone in terms of supporting caregivers and families over the long-term. The participants acknowledged that the flexibility of the initiatives to support individual needs and individual circumstances was a key driver for producing caregiver capacity. While these initiatives were targeting caregivers individually, participants stressed the benefits of supporting caregivers within their context, which includes broader networks and considers their access to personal, social, and societal level resources.

Participants focused heavily on the importance of bridging networks in supporting an informal networks access to resources and providing them with the necessary coping tools. They believed that while the funding was an integral platform to begin these conversations these relationships should not begin and end with money as one participant explained: “We shouldn’t be having these conversations because there is money on the table. We should be having these conversations because there is a need there” [Interview 2].

Participants highlighted that these initiatives were able to build on current systems of support, but argued there needed to be more formal and political involvement through the development of bridging and linking ties. Participants acknowledged that political involvement was needed in order to develop an equally accessible model of care which would incorporate broadening the current unit of care, encourage interdisciplinary teams and urge flexibility in care planning. Participants believed that without the societal level resources being developed, caregiver-support initiatives would lack the potential to build longer-term sustainable benefits overall.
Additionally, the findings suggest that individual-level supports focusing on supporting personal level resources (caregiver tax credit), while a good starting place, may not be sufficient to build sustainable networks of support over the long-term producing longer-term collective benefits. For example, money, in the form of caregiver allowances may not do the trick if caregivers of people with multiple chronic needs can’t access the formal supports that they need (either because they do not exist or are unable to identify and locate such supports), or if they are isolated socially. In fact, even interventions, which ‘work around’ inadequate formal systems and social isolation, may not be longer-term solutions per se. If caregiver supports are primarily there to justify the cost shifting to caregivers, politically speaking, the end result may not be what you want, which is ultimately to support individual caregivers as well as build the informal care base.
Chapter 6
Qualitative Semi-Structured Interviews: Caregivers and Provider from Across Ontario

6 Introduction

This chapter outlines the findings from qualitative interviews conducted with caregivers (n=7) and services providers (n=6) from across Ontario. The interviews were conducted to determine what providers and caregivers highlight as crucial priorities when attempting to support informal, formal, and social networks in the community. Specifically looking to identify what interventions might be more likely to support caregiver resiliency and develop resource heavy networks.

This chapter identifies how providers and informal caregivers from across Ontario perceive the importance of encouraging both formal and informal networks and improving access to personal, social, and societal resources. There was consensus that encouraging the development of and supporting bonding, bridging and linking ties would be crucial to ensure informal networks of support can access resources and maintain/build resiliency. During the interviews the participants began to push the importance of improving access to societal level resources. Participants saw access to resources through network ties (bonding-, bridging-, and linking-levels) as intertwined, and noted a lack of formal supports (societal level resources) and lack of access to these supports (developing trusting bridging and linking networks) would limit an informal caregivers ability to maintain resilience.

The findings within this chapter acknowledge that bonding ties are important to sustain informal networks of support, particularly as they relate to improving access to social resources and the participants highlighted several formal level approaches and responsibilities which should be considered to support these ties. Participants agreed that supporting these networks to receive education was an important element; yet likely should not be the primary focus for insuring ongoing caregiver resiliency. Similarly, participants also stressed that developing more vertical and formal connections (linking ties) for caregivers would be far more effective in sustaining their caregiving role. Participants discussed connecting caregivers with supports and organizations that can improve one’s personal resources. For example, participants outlined the benefits of encouraging educational (both as it relates to their caregiving role and formal public education).
and financial supports for improving a caregivers overall ability to continue to care as well as their potential re-engagement with society post caregiving responsibilities.

The chapter then goes on to highlight the benefits that could develop from supporting and encouraging bridging-level ties. These relationships, particularly when formed on the foundation of trust were thought to improve access to personal resources (information), social resources (supporting opportunities to connect socially and creating extensive networks), and societal-level resources.

Having access to societal-level resources was seen to be the most critical aspect for supporting resiliency. Participants urged the importance of supporting and encouraging both bridging and linking ties as a means to improve societal level resources – noting particularly bridging ties can only be as effective as the system allows. The participants saw a need for linking ties where organizations are connected and providers are similarly linked in. It was the bridging and linking ties to improve access to societal-level resources that were seen as indispensable if to build sustainable support networks over the long-term.

6.1 Bonding Ties Improve Access to Personal and Social Resources

Several providers (4 out of 6) highlighted that developing and encouraging personal-level resources among bonding networks (familial, close network relationships) were important for a caregiver’s overall well-being and resilience. However, three providers specifically identified that while these relationships are important, as a priority, services and policies should look to focus on broader networks of support.

Participants highlighted several possible opportunities to develop bonding networks through formal interventions. The concern begins with families and caregivers becoming increasingly isolated. Participants noted that perhaps as a formal structure we should begin to develop systems of support that might address these concerns by encouraging bonding networks to become active participants and to remain involved as an informal network of support.

Participants acknowledged that currently organizations and health sectors offer very individualized approaches to care, which often neglect to consider broader contexts of informal support networks. Participants’ noted that this is particularly evident in the hospital sector, but
also stressed that it needs to be improved in the home and community care sector as well.

Participants recommended that organizations should take on a:

“‘family systems approach’ so what affects one member of the family affects the whole family, then if you use that in the backwards sense in terms of support - what supports one family ultimately could support the whole family, but you have to have everybody on the same page.” [Provider 2]

This approach could include a formal intervention where families do not necessarily have to ask for help themselves. But there is a “support system in place that will reach out to family and friends to see if there is any interest or support that can happen” [Provider 4]. Here participants identified that a navigator role that could not only help them access the formal system but:

“Help them do outreach to other family and friends as a point of education so that the family themselves don’t have to go to the sister or the brother or the guy next door and explain what’s happened in their family. They barely understand what’s happened in their family.” [Provider 4]

Participants emphasized that there should be a formal understanding that ‘family’ doesn’t necessarily mean blood relatives. Here participants noted that “perhaps there are different ideas of family…we define it as your circle of care. So oftentimes that would be your friends, because people don’t have a mother, father, brother, siblings, cousins that sort of thing. So the family can be defined as your good friends” [Provider 5]. It was suggested that the definition be broadened systemically, so we understand that ‘family’ might look different for each client. Yet understanding that supporting these networks is crucial. If certain caregivers fall through the cracks because they are not perceived as a member of the circle of care this would affect their overall ability to continue as one participant noted “I think it is manageable if they get the right supports. But they don’t always get them” [Provider 6]. Additionally another participant illustrated:

“it was very difficult to have input into the kind of care plans that the homecare program was developing for my husband. They would interview him separately and not even ask the wife, not to mention the adult children and everybody else that was going to be involved in the care. There was no appreciation. A lack of insight.” [Caregiver 5]

Involving caregivers as a part of the “circle of care” or care team was seen as a crucial intervention of support. Without acknowledging informal networks of support as a crucial component to the care team participants believed they would be less willing and less able to
continue. Participants suggested, involving informal networks in care decisions ultimately builds their supports thereby improving their overall ability to continue care over the long-term.

Supporting these networks means insuring caregivers receive supports to maintain a healthy relationship between the caregiver and care recipient. As highlighted: “The wear and tear on the caregiver and therefore the need for respite. And respite is the way to help them maintain the good relationship between the caregiver and the care recipient” [Caregiver 2]. As a system the participants believed that it is increasingly “dumping the load on the family. They called it community care. But what they really meant was we’ll divest ourselves of a lot of the load” [Caregiver 2]. Participants believed that: “society itself has to change and say, hey, we are aware of it. The problem is going to get bigger. What are we going to do?…..Unfortunately, I think, we deal with everything in crisis management. But it doesn’t help people” [Caregiver 3].

The idea of developing formal interventions that would support bonding networks extended beyond bringing informal networks of support together to include supporting professionals to develop networks amongst each other. Participants identified that providers themselves need to build their own networks to encourage professional and interdisciplinary collaboration, which, as highlighted above, should involve informal networks as a member of the care team.

6.1.1 Personal Resources

Caregivers and providers from across Ontario made note that personal level resources are crucial. Of particular focus was providing individuals, families, friends, and society as a whole with the proper education to develop sound understandings of the particular challenges that informal caregivers and care recipients face.

Caregivers (4 out of 7) similarly highlighted the benefits that can come from maintaining healthy familial networks and ties to close family and friends.

Interestingly, both providers and caregivers stressed that adequate education and information sharing might be the best means to encourage these connections and keep them intact. One provider highlighted:

“I am quite familiar with the needs of the care recipient, the needs of the informal caregiver, and some of the misunderstandings or lack of support that comes from extended family. So I do think educating extended family can be helpful.... Educating family members about the nature of the
difficulties or impairments the person is suffering, the course of recovery, and how they can be helpful, I think that could be a good support.” [Provider 3]

Education was seen to be a crucial component to develop the understanding and compassion among other family members and friends who otherwise would not be able to fully comprehend the care needs and overall stress that primary caregivers experience. It was expressed that for family members and friends, who might not live the role, often don’t have a full understanding of how to help. One provider highlighted:

“The other family members don’t really appreciate the struggles, strains and impairments that the loved one is facing. Nor do they really experience the stresses of being a caregiver and because of this they don’t really know how to support the informal caregiver.” [Provider 3]

Participants consistently agreed that often family and friends are unaware of how to be of support, or are unaware of the particular challenges associated with the caregiving role. Additionally, participants highlighted this is further exacerbated by caregivers having an overall unwillingness to reach out to family or friends. One participant noted:

“Because the family at the moment does not have the skills or ability to do it. They are overwhelmed. They don’t know what to ask for. They do not want to burden other family or friends... It is very rare to find a family that is so competent in an emotional crisis that they can reach to family and friends and ask for the support they need. That is so rare.” [Provider 4]

It was also identified that friends who do not understand the dynamics often challenge and question a caregiver’s willingness to continue to provide care. “Having close networks of friends asking ‘why are you doing this?’ or ‘it doesn’t make sense. I wouldn’t do this, just put [care recipient] in a home’” [Caregiver 3] was disheartening and made caregivers feel further alone. Providers and caregivers both stressed the importance of educating caregivers that in times like these, “don’t be surprised if friends pull away, and don’t take it personally, it is their existential sort of reaction to the situation” [Caregiver 2]. Here, developing personal resources by educating both informal caregivers and their networks of support to develop further understandings behind the complex dynamics were seen as crucially important to sustain a caregivers overall well-being.

Participants highlighted that it is hard for caregivers to ask for help, some caregivers defined it as a “form of shame” in some cases and this feeling is challenged when “you have to separate the not well meaning offers – ‘oh, call me any time’ – and you do but they don’t help” [Caregiver 2].
The importance of education and information sharing with other family members and close networks of friends was seen to be crucial in order for overall success for family units and informal networks:

“We focus on take home lessons, so when caregivers are back in their homes they can reflect on their lessons and we can support them when they are home through what they have learned and the feedback was that the whole family kind of needs to learn it too in order for them to be successful...So their overall support hinged on their family members understanding. So that was evident to us that we need to make sure the families are informed. We are limited with what we can do...but allowing more family programs.” [Provider 2]

Beyond education as a personal resource caregivers highlighted that it can be quite cumbersome to ensure that resources are in place to allow for caregivers to connect with family and friends. For example, if family lives out of town it will requires an extensive amount of time for a caregiver to travel and visit family. One participant highlighted: “So it becomes an expense issue as well. Some things are covered but not all. Even if I drop [the care recipient] off, at 8 am, it’s hard for them to be in a strange situation for 8 hours. So then what do you do, and how do you get back home to pick them up and take them back home?” [Caregiver 1]. This participant highlighting how without access to appropriate support, it becomes increasingly difficult to maintain bonding networks.

6.1.2 Social Resources

There were a total of four providers and six caregivers who highlighted supporting social connections among bonding ties was important in order to sustain the caregiver in their role. However, three participants highlighted that while these particular close knit networks are helpful and important, they may not be the most critical aspect to support caregiver well-being. One caregiver expressed: “I find that particularly when you get into the senior stage, the children are busy with their own lives, and they really don’t have the time to know what is going on. So it is important but it is not critical” [Caregiver 6]. It became clear that participants in general feel differently about the value of supporting these networks and that supporting these relationships might be more critical for some caregivers and networks over others.

The benefits of having the close familial and friendship networks came from being able to engage with people who support the caregiver and so caregivers can continue to ‘live’. One participant highlighted how it was “a kind of support group” by saying:
“The support when you get together with your family, is that you don’t have to talk about the disease. You go through...you just live... it gets you away from worrying about someone. You just... you need the family for other events – celebrating birthdays, you know, that kind of thing. You need to have that.” [Caregiver 1]

Having these relationships and engaging in the social aspects of ‘life’ were seen as a beneficial. On the other side, participants noted, that family and friends often begin to pull away leaving it difficult to engage in these family events. One participant highlighted:

“The biggest problem of being a caregivers is that, for whatever reason, people have distanced themselves. They are not around for support. And you know, it’s really a shame. I don’t know why they are. I guess people have problems. They have their own problems and they need to resolve it. I always said that it takes a village to raise a child but it is going to take a village to care for the informal and dying loved ones at home for as long as possible.” [Caregiver 3]

Participants also highlighted that all families and close networks are different, suggesting that not all families and close networks are functional. As one participant noted: “there could be histories of abuse and neglect and psychiatric issues. And taking the family issue as a whole isn’t an automatic panacea for how we’re going to provide care in the home” [Caregiver 3]. While also highlighting that ‘familial’ networks might look different for different people, suggesting that when considering supporting close knit networks there needs to be flexibility in terms of what constitutes these networks and include non-traditional ideas of support in response to these networks. Along these lines participants highlighted that family is changing in the sense that people are either having fewer children or no children at all, marriages are less likely to be successful, and children are more mobile. One participant highlighted:

“Well, I think what’s happening, like in my generation, I was raised... I never felt like I had to take care of my parents. And that’s never something that we ever talked about. But for me, in a family of 6 siblings... you don’t normally have this in the newer generations, a large sibling base. You might have 1, 2, or 3 kids in a family. They don’t always live at home. They are scattered, they are travelling, and they are more mobile.” [Provider 6]

The participants noted the benefits of supporting an informal caregiver’s ability to engage in bonding networks. However, participants also stressed that social connections at this level might not be the most crucial area to focus on in terms of sustaining an informal caregiver in their role.
6.2 Bridging Ties Support Access to Personal, Social and Societal Resources

6.2.1 Personal Resources

Providers highlighted that supporting personal resources through encouraging and developing bridging networks of support would be hugely beneficial to sustaining an informal caregiver’s capacity. All providers (n=6) specifically highlighted that providing caregivers with education through bridging connections would support them in their role, where as only 2 caregivers (out of 7) made particular note of the benefits that could come from encouraging these connections, as it related to personal resources (i.e. improving education or access to knowledge). This might be a result of the sample selected for this research. Caregivers were selected through the Ontario Caregiver Coalition and are likely a politically adept and knowledgeable group that may not have seen this particular tie as useful or necessary for improving access to their own personal resources.

Providers highlighted that connecting caregivers with a formal service provider who would be able to negotiate services, navigate the complex system, and provide them with disease specific information would be a crucial intervention of support for caregivers and families. One provider nicely highlighted:

“Somehow educating and helping these people see the importance of learning about some of these things. But also being respectful. I mean I think a big part of my role is to listen and to see where people are at and to meet them there and help them navigate the system from that point.” [Provider 1]

Providers highlighted that being able to provide this type of support meant that relationships between the professionals, caregivers and families needed to be developed and fostered with mutual understanding and trust:

“I’ll use the term case manager, if they have somebody consistently in that role that they know and they trust. That person can have such a big role in terms of the educational piece and in terms of helping the person understand what’s happening with the recipient while also steering the caregiver to some support groups or other forms of educational supports that they will trust are good things because of the relationship”. [Provider 1]

Building the relationship between service provider and caregiver was seen as a crucial connection that is necessary if we expect there to be any positive outcomes as a result of the bond. There was
emphasis that this role needs to be filled by one individual who can build relationships with caregivers and their broader networks (which would include additional formal providers, community members and even immediate familial or friend networks). Another provider stressed:

“Frequently they are embarrassed. They don’t know what to ask for. They don’t know how to ask for it. They don’t even know how to represent what is going on. So somebody who is familiar with what that family is going through and is going to be going through over the long-term, who they can trust, would be invaluable.” [Provider 4]

This highlights that the formal provider role is beneficial in supporting caregivers and families through the care trajectory, a concept which most caregivers are unfamiliar with. Additionally, it was highlighted that the relationship can be useful to bridge caregivers with other families, friends, and even organizations providing them with additional information and resources to support those relationships. This “navigation role” could be helpful for negotiating the different social clubs that a caregiver could access, further expanding their extended networks. One provider stressed:

“That navigation role even to pull people together. I am sure that a community organization, if they knew that they were a caregiver, could certainly offer more supports to them. You know, say ‘what do you need?’ Maybe they don’t want them in their home all the time. Sometimes that can be confusing...they could just cook up a meal, drop it off. Helpful things like that.” [Provider 6]

This relationship can allow caregivers an opportunity to identify possible future concerns as well as highlighting how to address and cope with the changing circumstances. One caregiver expressed a need for “provision of advice, especially in the case where, for instance, the caregiver had not been responsible for the financial matters” [Caregiver 2]. Another participant stressed this point by stating:

“The more access they can have, the more information, the more preparation. The hospitals do not do a good job with that....The psychodynamics of what is going to happen - the family are very ill-prepared. They are waiting for information about how to help their injured member or ill member. They have very little information on how it is going to impact them and what’s going to be expected of them. The pressure and the fact that in some cases, the family member that has been injured or ill may never be the same person. And they are not educated as to what it means to have an almost stranger back [in the home].’’ [Provider 4]

Participants were aware that often families are not sure of what to expect or do not understand what is coming next. Many providers believed that this was an important focus and identified
having a consistent, well informed provider working closely with caregivers and families would be an excellent approach to meeting these needs. Another provider identified:

“That person would have to be very familiar with the dynamic of what the injury or illness is for that individual and the system that the family is going to have to navigate. So those people will have to know that. And sometimes, I have seen this a lot and I have been in the position a lot, It is not just one condition, it can be multiple things that the family is going through.” [Provider 4]

Similarly, providers also highlighted the benefits of insuring they were working on their own networks and improving their own personal resources by educating themselves and connecting with others who might have the necessary knowledge, which they lack. Highlighting that often providers themselves will not know everything, but being able to connect with other providers and educating themselves would be a valuable resource that would impact the support provided to informal caregivers. One provider exclaimed: “They don’t expect me to be fully informed about all the different resources related to their needs. But I mean one of the things that I do is partner with local organizations so we have a co-leader who is quite well versed in some of the local resources” [Provider 3].

Improving a caregiver’s personal resources through financial means was also discussed as a likely beneficial intervention to support caregiver well-being, in that it would provide them with the opportunity to access transportation to attend various educational programming. Transportation to and from various supports was highlighted as a significant barrier to access. Providers and caregivers highlighted that we need to be realistic, in the sense that, even if we offer educational programming, we have to be sure caregivers and families can attend these supports: “we need to be realistic about the transportation piece. Can they drive themselves; can they get out in this weather? If not, we need opportunities to bring things to them or to arrange transportation” [Provider 1]. There was discussion highlighting that caregivers often do not have “extra income to throw around and pay for extra support. So caregivers tend not to take the support” [Caregiver 1].

Providers noted that offering caregivers and families additional financial support with some flexibility would be beneficial to purchase the extra supports that can be difficult to access without additional resources. One provider highlighted: “So money. I mean money buys you that freedom and that peace” [Provider 5]. Similarly, one participant mentioned the idea of improving personal resources to fill the transportation gap by saying: “Giving money to folks for that type of
thing. To purchase the transportation. I think that would be fantastic. The other thing could be if
the group itself has access to an accessible van or something” [Provider 1].

6.2.2 Social Resources

Many providers (n=5) and two caregivers highlighted the opportunities that could come from
encouraging bridging networks of support to access social resources. That is, encouraging
connections among individuals who are in different positions (i.e. connecting providers with
caregivers, connecting caregivers with other caregivers; connecting care providers with other care
providers). Here, participants noted that connecting informal caregivers and the care recipients
with consistent formal providers and supporting opportunities to engage with extended social
networks would provide additional social supports that they believed would be crucial for
sustaining an informal caregiver over the long-term.

Participants noted that the relationships between front line providers and informal caregivers are
extremely critical for sustaining the unit in the home. These relationships were seen to be better
fostered if there was consistency in service providers to allow for trust and an overall sense of
caring to develop. In certain communities participants believed this relationship was more likely
to be developed and participants saw great benefit from allowing these formal/informal relations
to foster. One participant provided an example:

“I see such wonderful things happening in our communities when these relationships do develop. In
terms of those natural supports. I see folks who do not have any adult children living in the city
and have the regular front-line staff coming in three times a week. When we have that snowstorm
it is that regular front-line person who is calling them to say ‘oh my gosh Mr. Smith can you get
out of your drive way today? I can get there at 4 o’clock if you need me to come and shovel’ or
phoning ahead and asking ‘are you guys okay with groceries do you need me to pick you up
anything on my way to see you’. ” [Provider 1]

When these relationships develop and are supported providers are more likely to be sure the little
things get done. Providers suggested that it is ‘the little things’ that support people in their homes.
Highlighting these are the relationships where providers begin to “do the extras to make sure they
are, you know, getting out for a walk and eating properly. You know all of those things that
contribute to good health” [Provider 1]. Another participant noted that having a formal provider
who a caregiver can work closely with and can develop bonds with would be beyond helpful
providing caregivers with piece of mind to “really know that somebody does legitimately care. And you can tell” [Provider 6].

Building this trust between the formal provider and informal caregiver(s) was also seen to encourage an informal caregiver’s willingness and ability to leave the care recipient in the care of the provider. These relationships built on trust and mutual respect allows caregivers to feel confident while they attend their own appointments and/or visit with friends and engage in social activities. One participant noted:

“It allows the caregiver to know that he or she has time to go for a walk. You know just that feeling good about life in that sense you can trust and do things and your family member has good care and you have some time to take care of yourself. When you are in that constant cycle of stress and wondering, and unsure and unsafe, it contributes to ill health.” [Provider 1]

There was an overall agreement that encouraging caregivers to engage in social outings was important. As highlighted by one participant: “We know social and emotional health is very very important so we need to look at opportunities for them to be able to do those things and to sustain those things” [Provider 1]. Participants believed that having front-line provider and caregiver relationships based on a foundation of trust was a crucial intervention in order to achieve this socialization.

As highlighted in the previous section, family and friends tend to pull away, or caregivers’ distance themselves, which results in caregivers often feeling alone. As one participant noted:

“Frequently they do not socialize... those connections fall apart because the family member is so...the members are so trying to reorient to a new life that they lose contact and they are not interested in having dinners. The relationships start to disintegrate.” [Provider 4]

Participants highlighted that as a result it is crucial to support caregivers to develop other forms of support to fill the social void. Often, within their previous social networks, caregivers feel like they can’t openly discuss how they are feeling. One participant stated, “so you keep that, all of the things that you are going through, deep inside” [Caregiver 1]. Participants believed that if caregivers do not have a safe environment to communicate openly with people who understand, caregivers might end up building resentment. One participant stated:

“The problem I felt, is going back to the whole process, is the anger and the guilt and I pushed people away. But really the whole nature of things, you shouldn’t push people away. So caregivers should be connected to other caregivers who are engaged in a support group for them
to realize they are not alone. So that they can hear stories from other people and say, hey, that’s how I feel.” [Caregiver 3]

Encouraging these social relationships and bonds was seen to be crucial for caregiver well-being as another provider exclaimed:

“Sometimes previous friendships are not understanding of where they are at or they don’t have as much in common but where they can connect with other caregivers who are going through similar things I think again as human beings we are always attracted to people who are dealing with similar things. So I think this is very important.” [Provider 1]

These connections were also noted as being beneficial for caregivers in improving their personal resources, by educating one another based on personal experiences. However, these relationships were also seen as a crucial intervention providing social support and participants acknowledged that the social and emotional support between these individuals should be encouraged. One participant noted:

“Being able to send them in with some information that they can gain. But again offering opportunities where they can get out and have that social part. So for some folks whether that is an opportunity for a formal meeting and then some social time afterwards where they can have coffee or they do a supper with a speaker. Those types of things.” [Provider 1]

These opportunities allow for “some wonderful friendships” and participants stressed, “these have been really important” [Provider 2]. There was discussion around bringing family groups together as a means to reduce overall family isolation – encouraging family-to-family networks (this particular idea was discussed primarily in relation to families who have a child with medical complexity, or where it is a young carer providing a significant portion of informal support). One participant noted: “Having family nights, they can connect with other caregiving families to reduce the family isolation that they might feel” [Provider 2].

One particular participant highlighted that even groups, which are designed specifically as an educational group, are often also a good starting point to encourage caregivers to meet on an ongoing basis stating. In one providers words: “So the group is designed to be an educational group that offers support as well and then as a jumping off point for more informal get-togethers or support longer-term” [Provider 3].

Developing these relationships among caregivers and families was thought to be a process, recognizing that it takes time to develop connections and bonds among one another. Allowing
these networks to develop gives them “a sense of belonging” [Provider 2]. Similarly, it was discussed that these relationships are very helpful and without formal interventions to encourage these relationships it would be challenging for caregivers to come together. This particular idea was highlighted by one participant who stated: “I think these groups help a lot. It seems to be one of the only interventions for getting caregivers together. So I think it helps a lot, it is something that helps to foster these relationships” [Provider 3].

Here participants described how encouraging families and caregivers to engage in extended networks was beneficial to improve their overall social world. Participants noted that these networks improve caregivers’ personal resources and allows caregivers to develop additional networks of support where there is no judgment and an innate understanding, which was discussed as often lacking in their more close knit bonding networks. Allowing these connections and encouraging the social components of these networks, above and beyond the traditional support group approach was seen as an extremely valuable resource for caregivers. As one participant nicely highlighted: “I was looking down at who all was there. It was very different ages, very different needs, and very different circumstances. But everyone came and cheered and came together. Just connecting” [Provider 2].

6.2.3 Societal Resources

Five of six providers and one caregiver specifically mentioned that they saw value in supporting formal level supports aimed at encouraging bridging-like networks, ties between dissimilar people. Here participants stressed that relationships are key. Of particular attention was the relationship between formal providers and informal caregivers, care recipients, and their networks of support. Specifically, participants noted that building these relationships to foster trust was imperative. For example, one participant noted “it’s about building those relationships with frontline staff and keeping consistent staff in there who know the families and who they can trust and feel comfortable with” [Provider 1]. Much discussion focused around developing formal level supports that would allow for consistency in service providers. The participants also highlighted the need to politically develop interventions where providers and organizations are able to collaborate and support clients as a team improving access, reducing duplication, and encouraging consistency of care.
Participants noted that great benefit would come from politically supporting and formally encouraging these bridging networks. One participant identified that consistency in providers is key. Highlighting, that we are taking steps in the right direction by formally recognizing the important role that personal support workers (PSWs) play in the home and community care sector:

“When we start changing the front line staff. That to me is so important. So we have made progress to the province recently in terms of recognizing the role of the PSWs with the wage increase.” [Provider 1]

Part of insuring consistency in care is developing a work environment where the providers feel comfortable and supported “you can tell from the staff turnover that they are not happy places to work” [Caregiver 6]. Having this lack of consistency was highlighted as being very demanding on caregivers and care recipients as one participant noted:

“That family could have say, 20 hours of support coming in and out of their house once a week. So that is very intrusive for any family regardless of how much you like people or not. And when you do not have the regular same people coming in all the time it is a nightmare. So this is where I think things break down in our system right away and why we have so many people going to the emergency right away and as quickly as they do. I think that it is difficult for our clients to have these strangers come into their house and to constantly have to train them to feel safe enough to leave their family member with people they don’t know so they can run to the grocery store or whatever else they might need to do.” [Provider 1]

Another participant stressed similar challenges exist when the faces of front-line providers are consistently changing:

“The changing faces through the process for any kind of rehabilitation process is overwhelming. The family has developed a very brief relationship with somebody and, and then that person is gone and its another person. And the story has to be told all over again, it is exhausting for families to do that.” [Provider 4]

Working to develop a system where providers are able to remain consistent providing care to the same clients on an on-going basis was argued to benefit the informal network as well as the formal system overall. Providers highlighted with consistency in providers comes an understanding of the base-line health of clients that otherwise would not be possible. One provider explained:

“When they have the same folks going in every week they are familiar with that the person’s baseline is and what good health is for that persons at the moment. So when you have someone
coming in inconsistently they have no idea, and they don’t have a vested interest in that family.” [Provider 1]

Similarly, participants noted that having one individual ‘navigator’ who would work with caregivers from initial point of access to the formal system to support formal system navigation and assess on-going needs would be hugely beneficial for sustaining families in their homes. One provider stated:

“They really do need somebody at that point to help them focus, track and stay with them for a while. Frequently by the time I see people, family members, they are absolutely burnt out. They don’t understand the systems. They have been fighting with everybody to try to get some kind of support. They don’t really know what they are asking for because they don’t understand what’s gone wrong. And it becomes an advocate for the family. Families need that.” [Provider 4]

From a systems perspective participants noted that these relationships could be fostered with this ‘navigator’ role who would be a families ‘go-to’ person for an extended period of time. As highlighted by one participant: “if that navigator could be with them, and that family knows that this is a longer-term relationship, and that this person is going to navigate the psychosocial issues with them, the supports for that, the family/friends issues, the other professionals issues. They are sticking... That is their go-to person” [Provider 4].

This relationship was seen as lacking from the current system of support and was thought to be a beneficial formal solution to smooth many of the current systemic issues experienced by users. Participants noted that every time a provider changed the informal networks trust was reduced. It was noted that often care recipients are treated as an illness or ailment and are transitioned from formal provider (speech language pathologists) to formal provider (occupational therapy), who often do not work collaboratively. As a result, families and care recipients consistently need to re-live their stories as highlighted by one participant:

“Perhaps somebody in physio. Now they have to go to speech or they may have to go to.... They were in an acute psychiatric ward, and now they have to go to the community resource. Well, every time you do that, your story has to come out. Over and over. If that’s something that a navigator can do in preparation for the family, like here are the details for this client. It can be 2, 3, and 4 years where these families are in these systems. And it is just repetition, repetition. And it’s re-living and it’s frustrating.” [Provider 4]

Participants also identified that developing a system where providers and organizations can work collaboratively would be beneficial for families, informal networks and the formal system.
Developing a system that works together would reduce duplication and improve client flow as one participant noted:

“we are limited into how much we can work together but I think if the family is open to ... the more we know the more we can do and refer to some of our community partners. So if our family isn’t sharing everything it limits our capacity. And I mean our capacity is already limited. But we have worked really hard to strengthen our community connections so we absolutely will pick up the phone and call for a family if we know we can do that.” [Provider 2]

As a result of informal networks having to continuously re-tell their stories, they become more reluctant to share their stories. Participants stressed that it is easier for them to work collaboratively and support families more effectively with the ‘whole picture’, yet the longer the networks have been subjected to fragmented systems of support the less willing they are to openly express their stories.

“Change can be really upsetting to them and having to tell their story again just the little nuances and in and outs – the history- those things are so important to them and now they are starting all over again. They get fearful about those things. They clam up and you don’t get the whole picture”. [Provider 1]

Similarly, participants noted that families need to feel supported and comfortable in order for them to disclose their full story. For example, one participant noted: “eventually they have gone so long without asking or telling that it becomes too overwhelming to begin to invite people in to tell them their story” [Provider 4]. Without a relationship clients and families may feel stigma and an overall fear that they may fall into a ‘family services situation’ as one participant noted: “They don’t want to be in a child welfare situation because they feel guilty about what their children have to do in the home” [Provider 2]. Additionally caregivers noted that typically, they are not a part of the team and that it really isn’t about them as one participant noted: “It’s usually about the person with the illness. It is not usually about the caregiver” [Caregiver 1].

The participants acknowledged that developing community connections often falls on the backs of the providers within organizations, with potentially minimal support or encouragement. If they are not keen on attending various ‘tables’ they often will remain unaware of what else is happening on the ground, limiting the communities ability to engage and support one another. One participant highlighted their own involvement in finding and maintaining connections:

“You never know where these connections will be made and these connections were made in an area that I wasn’t even anticipating networking at. But unless you know what other people are
The lack of ‘bridging’ networks within the system between providers was seen to cause disjointed care that is bad for the care recipient, their formal and informal networks of support, and the larger healthcare system. There was agreement among participants that a navigator role that works with families over the long-term throughout the healthcare system would likely reduce many of the current systemic limitations to building and sustaining bridging networks of support.

6.3 Linking Ties to Improve Access to Personal, Social and Societal Resources

6.3.1 Personal Resources

Four providers and four caregivers highlighted the importance of improving vertical and formal relations as a means to improve the personal resources for caregivers and families. Linking ties involve relationships between people who are interacting among more formalized power boundaries. Here participants noted the crucial role in connecting caregivers to supports that would allow them to re-integrate into society. There was discussion around what this might look like for various forms of caregivers. For example; a younger adult caring for an ailing parent, a sandwich-generation child caring for a parent, parents caring for a medically complex child, or an older adult spousal caregiver may all experience similar challenges yet, the need for vertical and formal linkages to support personal resources might need to look slightly different for various combinations of caregivers.

Both providers and caregivers highlighted that personal level resources, particularly education and finances were important for a caregiver’s overall well-being and stressed that in certain circumstances it can be crucial for a caregiver’s ability to re-engage with society. As one provider noted, we have young children caring for ill parents who are unable to participate in traditional educational and employment pathways and may require additional supports to assist with re-engagement:

“When it comes to post secondary goals and employment goals for young caregivers it is about supporting that. Helping build up life skills. If mom dies you are going to have kids now who are not educated being an adult in our society who will need support. Not because they were not wanting to do those things with their lives. So when it comes to transitioning into young
adulthood it is supporting them whether it be financially or providing caregiving support, like respite, so they can go to school or work.” [Provider 2]

Similarly, participants noted having access to the revamped compassionate care benefit, would not fully support all caregivers as one participant noted:

“It’s absolutely almost not applicable to us in ALS because first of all, to find out which is the 6 weeks you want to take out of, in my case, 7 year journey, would be rather problematic. And we think it should be expanded. If you have children with a critical situation, you can get something like 50 weeks. So we’re looking for something more along those lines. And all that to say that quite often, depending on what the disease is, what the situation is – terminal cancer, COPD, congestive heart failure situations – people at home over some extended period of time, you’re looking at a severe financial situation”. [Caregiver 1]

It was evident that the providers and caregivers saw benefit in creating a formal caregiver program. They saw this program as needing to be an integrated initiative that would include family physicians, as they believed physicians are often the primary point of contact. Participants highlighted that they were aware of various caregiver-support initiatives but argued that they are “patchwork and they depend on the knowledge of the family to access them. This knowledge is rare” [Provider 4]. Evidently, access to knowledge through formal avenues was identified as a potential solution, arguing even the most educated of individuals will struggle to identify sources of support within the current system. Similarly a caregiver noted “There is never going to be enough money to throw in. You have to be able to educate people. There is an old saying - you can fish to feed somebody but if you teach them how to fish, they’ll live prosperous and feed their family” [Caregiver 3].

Participants noted that formal programs and vertical formal connections that can improve a caregiver’s knowledge not only in terms of supporting their educational needs, but informing them of various support options would be crucial for sustainability. While caregivers and providers acknowledge that the caregiver tax credit “was nice”, it only reaches a small minority of caregivers as one participant noted:

“Tax credits are not good enough because they are only geared to people with income. But most people who leave the profession to go to take care have no income. They don’t qualify. So it’s just smoke and mirrors to say ‘we are helping’. But they are not helping. And they have to realize that even the caregiver tax credit, the $300.00, I tried to claim it but I can’t because I don’t have employment income. So it does exist but it doesn’t do anything. Only a small percentage can even claim it.” [Caregiver 3]
The participants did stress that focusing solely on “money, isn’t enough” [Provider 5; Caregiver 3] yet highlighted that for caregiver’s financial barriers further challenge their circumstances. One provider highlighted nicely that the government cannot do it alone, stating:

“There is the pension, like right now there is the government funded pension. You contribute to it and when you retire you get paid back – but people are contributing to that. There are no funds for caregivers. There is never going to be enough in the government to fund the caregiver. So it has to be through education, through community support to come together. The government can’t do it by themselves.” [Caregiver 3]

Overall participants highlighted, all caregivers are different and formal and vertical relationships could be helpful to support an individual’s personal resources. Participants specifically highlighted the need for education (either about the formal healthcare system or formal schooling) and financial support as two crucial areas to consider if attempting to support and address the needs of informal caregivers.

6.3.2 Social Level Resources

Few participants acknowledge the role in which linking networks of support might encourage improved social resources. Two providers and one caregiver noted that there might be a place for formal and vertical relations to develop that could encourage social level resources at both the organizational level and client level.

In order to encourage these formal and vertical relationships participants noted that providers have to be willing to engage with organizations and work on an on-going basis to build these formal networks. Participants highlighted that you need to get out into the community and network in order to develop connections with other formal organizations. One participant noted:

“It is those face to face interactions that people value...You end up sitting beside people and when you call they know who you are and the conversations go a little differently. It is not as formal and it is more helpful. Attending chamber of commerce events or attending sessions that United Way invites you to.” [Provider 2]

It was noted that organizational structures could be improved to support networks of caregivers coming together from across organizational boundaries. As highlighted by the following statement: “We have partnered with community living. So it is a whole family support once a month and the community living clients come for their programing and their parents come and we can work with the siblings” [Provider 2]. Providers saw a benefit in merging programming with
other community organizations, building these formal relations to encourage broadening social opportunities for families and caregivers.

Developing cross-organizational formal networks was seen as beneficial to open opportunities and extend networks of support not only formally but also for caregivers and care recipients. One participant noted: “So we need to unite people—stakeholders, organizations—and say, okay, we have this program, we are going to help in anyway we can. And that might resolve some of the issues” [Caregiver 3].

6.3.3 Societal Level Resources

When it came to discussing vertical and formal networks (linking networks) participants focused a lot on the idea of developing and using funding interventions as a way to facilitate the bridging relationships previously discussed. However, participants also discussed the need for collaboration among organizations (i.e. between CCAC and other community agencies). Participants saw a need for an integrated system, where connections can easily be made. As one participant noted: “So independent of the injury or illness, a caregiver system, thinking more broadly about a sort of caregiver integrated system” [Provider 3].

Participants also acknowledge that as a society we need to look more broadly about what it means to be a caregiver and who caregivers are. One participant noted that in the UK, legislation was passed so young caregivers are identified by ID cards and are respected by emergency responders and emergency room professionals. Currently, in Canada, we do not recognize young caregivers and all too often they are ignored and their roles are not respected. One participant concluded: “I guess we could say legitimize the role, which could help with the self-esteem behind that role, and help with all these challenges experienced in this role” [Provider 2].

Similarly, when caregiver organizations like the Canadian Caregiver Coalition works alongside government to develop strategic plans participants noted that the process should incorporate many vested interests and classify ‘caregiver’ in a broad sense. Organizations supporting all types and forms of caregivers need to collaborate and work together. One provider acknowledged “it is really hard to have a national strategy or a provincial strategy when we are just trying to do our own thing here in our neck of the woods when other caregiving advocacy groups are not recognizing all caregivers. We aren’t working together” [Provider 2]. Here caregivers need to be
classified above and beyond adult caregivers, young caregivers and family caregivers to consider broader networks of individuals who might be supporting someone who requires assistance to remain at home. Likewise, participants noted, that as a system we are not working together, as noted by one participant:

“You have a lot of resources. They are all disconnected. You know, there are a lot of silos. You need some people to start to pull this together, to break down the barriers. Silos themselves will not break themselves. They are self-sustaining, and they look at everything else as a threat.” [Provider 4]

Turf wars were seen to be a major barrier to supporting overall system integration. Participants believed the way the current system is funded encourages various organizations and sectors to protect themselves and perpetuates a provider driven system. One provider noted:

“Everybody is protecting their own turfs and, you know, the budgets with the LHINs and even in the hospitals, and even with the doctors. And then, you know, if it’s a capital budget expenditure, and then somebody has to pay it out of their budget but the savings are in another area…Everybody is in the sandbox wanting to protect.” [Provider 5]

Participants acknowledge that in our current system the funding interventions are not built to incentivize client flow and client outcomes. While participants are reluctant to suggest vertical integration of funding where one sector or organization (i.e. a hospital) is responsible for the outcomes of the healthcare system flow, they were highlighting that perhaps that might be one effective intervention to improve integration and linking ties between sectors and organizations. Along these lines participants noted that even when initiatives are introduced the funding has to flow through so many layers of administration that the “funding is not streamlined, to get it to where it needs to go” [Provider 6].

Participants also discussed, as a result of the silos and lack of communication, that clients and their informal networks often have to fill out piles of paper work to access multiple programs of support. One participant stated: “we are weighted down in paperwork. I know it’s supposedly for protection. But you know it gets very frustrating. They need to communicate with less paper, and just get to action” [Caregiver 1]. An overall lack of system integration was seen as a major challenge for formal and informal networks of care attempting to navigate and access supports as one participant noted:
“From a broad perspective, the system needs to be easily accessed. Which it is not. It needs to be easily accessed. And once you have accessed the system, it needs to be shared with other associations, it needs to be shared with other providers so that okay, we can’t help but maybe this provider could help. You have your tree and then you have all your branches. And you shouldn’t have to go through each branch individually.” [Caregiver1]

While CCACs were often discussed as an option for developing a centralized location for responsibility and client flow, many participants noted that “their mandate has changed” and suggested either we adapt the mandate or have the LHIN work with another organization which can “Act like the HQO [Health Quality Ontario], have research, and give government recommendations, to see if we can do policy change” [Caregiver 3].

Participants stressed that as a society we need to develop overarching strategies to support caregivers. Again, recognizing that caregivers can be anyone. Many participants acknowledge that while there are many initiatives and programs in place to support caregivers they are rather ‘piecemeal’ and while these programs do good work, these supports do not reach a greater span of Canadian caregivers. As highlighted by one participant:

“There isn’t anything being done to try and have that national recognition or launch these supports in other communities. So we can blab all we want about caregivers but we only serve our region we are not really doing anything for Canadian [caregivers].” [Provider 2]

Participants overwhelmingly agreed “adding more of this support or that little program, is just another thing that ends up getting lost in the shuffle” [Provider 4]. Solutions to support caregivers need to expand beyond pilot projects and regional programs.

While participants believed this was a common concern throughout Ontario, and Canada as a whole, they suggest that the more rural you go the more ‘patchwork’ the systems become. One participant stressed, “the biggest issue I find is that the services now are very much fragmented” [Caregiver 3]. Participants overall believed the “the whole system is broken. Very broken” and noted that rural communities are losing more and more of their services as they transfer them to bigger regions “leaving people in smaller communities without access” [Caregiver 6].

It became clear that participants acknowledged the benefits of programs, supports and resources for caregivers in particular regions, yet also stressed that the benefits of these supports will never reach a broader impact and produce long-term sustainable benefits if these programs and initiatives are not mainstreamed and available to broader networks of caregivers.
6.4 Chapter Summary

This chapter discussed the various interventions of support that providers and caregivers from across Ontario saw as important to support the overall well being and resiliency of informal and formal networks. The findings from this chapter explored a much broader perspective, yet the findings similarly acknowledge a lot of system level concerns that can impact an informal networks ability to develop or maintain resiliency.

Table 7 below highlights the key findings of the qualitative interviews with providers and caregivers from across Ontario. The findings suggest weighted benefit of focusing on encouraging particular ties over others. Additionally, the findings suggest that access to resources can subsequently improve network ties – particularly access to societal level resources.

Table 7 Summary of Key Findings

<table>
<thead>
<tr>
<th>Ties</th>
<th>Access to Resources</th>
<th>Importance for Improving Resilience</th>
<th>Rationale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bonding</td>
<td>Social</td>
<td>Important – but not sufficient</td>
<td>Healthy bonding ties can offer beneficial social resources</td>
</tr>
<tr>
<td>Bridging</td>
<td>Personal, Social, and Societal</td>
<td>Crucial – yet can only be as effective as the system will allow</td>
<td>If based on trusting and consistent relationships bridging ties can offer enhanced knowledge and ingress to supports that improve access to social and societal resources.</td>
</tr>
<tr>
<td>Linking</td>
<td>Personal, Social, and Societal</td>
<td>Extremely Crucial – supporting access to resources as well as the development of other ties</td>
<td>Linking ties can offer improved access to societal level resources particularly if providers, organizations, and sectors are linked.</td>
</tr>
</tbody>
</table>

There was agreement that supporting family and close friend bonding networks in obtaining personal, social and societal resources were important, yet might not be the most crucial focus for addressing and supporting resiliency using formal interventions of support. Specifically, as identified in Table 7, bonding ties were most often seen to improve access to social resources more so then personal or societal resources.
Participants noted that supporting the development of bridging networks (connecting people who otherwise wouldn’t have been connected, who exist in different positions or are likely to support each other in ‘getting ahead’) would be quite beneficial in assisting informal networks of support over the long-term. Here participants stressed the importance of connecting informal caregivers to formal providers, who they can build strong trusting relationships with, as well as other caregivers, who could improve both social and personal level resources.

Linking ties were seen to be of utmost importance and participants noted the current system was seen to lack consistency in service providers, negatively impacting on access and the trust caregivers have with the formal system. Participants noted the current funding structure allowed for silos and ‘turf’ wars which create a provider driven system, suggesting funding should be used to encourage linking networks between organizations and sectors and ultimately improve ‘patchwork’ services so supports can spread to reach broader populations improving access to needed services. Interestingly, societal level resources were seen to be imperative to develop in order to encourage and strengthen bridging and linking networks. Participants argued the importance of formally recognizing the role of informal caregivers, highlighting that ‘caregivers’ could be anyone of any age. Providers noted that formally recognizing the informal caregiver role would encourage organizations and sectors to expand their focus beyond the traditional ‘individualized’ approach to include informal networks of support.
Chapter 7
Discussion: Policy Implications and Conclusions

7 Introduction

This chapter outlines the key findings of this dissertation and highlights how these findings can be interpreted in light of social capital theory. Additionally, this chapter discusses how the findings can be applied to inform the development of interventions aimed at improving caregiver resilience. The chapter begins by outlining the theoretical contributions of this research followed by a discussion of the policy implications associated with the research findings.

A combination of changing demographics, social trends, and shifts in policies are affecting the demands placed on informal caregivers. Informal caregivers play a crucial role in supporting the health, wellbeing, functional independence, and quality of life of growing numbers of persons of all ages who are unable to manage on their own. Not only do informal caregivers contribute to the independence and quality of life of these individuals, they are seen to contribute to the sustainability of formal care systems (Sinha, 2012). As a result, there has been an increase in formal-level supports aimed at supporting the informal caregiver role.

This dissertation presented the ‘conventional wisdom’ associated with supporting informal caregivers (see Figure 1 in Chapter 2). Targeted at either the care recipient or the informal caregiver, this approach aims to build caregiver resilience or improved willingness and ability to continue to care. These interventions typically use individual and personal-level attributes as a way to assess eligibility as well as outcomes. This dissertation argues that caregiver characteristics and medical needs of the care recipient are only a part of the complex set of factors that can affect an informal caregiver’s resiliency.

In the literature, informal caregiver resilience is a multifaceted concept that is enhanced through access to personal-, social-, and societal-level resources. The application of this concept often fails to conceptualize how caregiver resilience is influenced and supported by broader societal-level constructs. Additionally, there remains a lack of understanding regarding how to leverage an individual’s access to resources. This dissertation draws on the theory of social capital to fill that gap by identifying external factors and broader context in which resilience emerges and is sustained (see Figure 2 in Chapter 1). The primary proposition of this dissertation is that policy...
interventions that consider caregivers within their broader context and work to support and build all forms of social capital (bonding, bridging, and linking) will lead to enhanced access to personal, social, and societal resources, and improved caregiver resilience.

This dissertation applied a three phase, mixed methods, convergent parallel design. Phase one was an analysis of two case studies, phase two included qualitative interviews with front-line providers directly involved with the two case studies, and phase three included qualitative interviews with formal providers and informal caregivers from across Ontario. These methods were employed to better understand what supports might produce the development of bonding, bridging, and linking ties; how and if these ties improve a network’s access to personal, social, and societal resources; and what providers and caregivers perceive to be crucial to consider when developing policies to support familial, formal, and social networks in the community.

This dissertation aimed to determine whether evidence exists to suggest how policy interventions that build social capital (bonding, bridging, and linking ties) can influence access to personal, social, and societal resources and improve caregiver resilience. The findings suggest there are benefits to developing support models which are multidimensional and focus on supporting not only individual and personal level needs but also more broadly address social- and societal-level barriers impacting a caregiver’s ability to be resilient.

The findings of this dissertation substantiate both the social capital and resilience literature by identifying the role that network ties can play in improving access to resources, and the importance of accessing resources for sustaining a caregiver in their role. The research findings indicate that heterogeneous and/or weaker connections, mainly bridging and linking ties, might be more effective than bonding ties in improving a caregiver’s ability to maintain resilience. Additionally, improved access to personal resources (a common focus for current policy interventions), is necessary, but on its own insufficient.

The resilience literature stresses that, in order to be resilient, an individual needs to have access to the three levels of resources (Windle, 2011). Yet, the literature has generally failed to distinguish how one can improve access to these resources. This dissertation extends this thinking by highlighting, from the perspectives of formal providers and informal caregivers, the various system-level barriers to becoming resilient. The findings from this dissertation suggest that social capital (ties at the bonding, bridging, and linking levels) will improve an individual’s ability to
access resources. Interestingly, the findings indicate that there might be a weighted benefit if policy interventions particularly target efforts to improve bridging and linking ties—yielding the best results in terms of improving an informal network’s access to resources. Similarly, the findings suggest that the relationship between network ties and improved access to resources is not linear – meaning improved access to resources can simultaneously improve access to and development of network ties and vice versa.

The findings from this research have several policy implications. Namely, policy interventions aimed at individual caregivers, outside of their broader social and societal contexts, that only support access to personal-level resources, are likely to offer short-term benefits. A broader policy framework aimed at: targeting clients and caregivers at first point of contact; assessing the need for personal-, social-, and societal-level resources; and offering incentives for interdisciplinary and inter-organizational collaboration, was seen to be crucial to develop long-lasting benefits for informal networks of care, formal service providers, and health care systems at large.

Within the policy literature, there has been an increased recognition for supporting the needs of people and their informal caregivers (Donner, 2015; Government of Ontario, 2015a, 2015b). Policy and academic literature continue to focus primarily on ‘patients’, caregiver burden, burnout, and resiliency. However, based on the findings from this dissertation, this focus continues to be too narrow. The findings support the necessity of having a broader framework to identify, address, and assess formal and informal networks of care over the long term. This dissertation emphasizes that, beyond personal- and social-level characteristics and needs, formal systems and public policies can contribute to a negative cycle of caregiver stress, and these systems need to adapt if we hope to support caregivers and formal health systems over the long term.

7.1 Theoretical Implications

Access to resources was seen as a critical component of building an informal network’s overall resilience. In order to develop policy solutions to build resilience over the long term, we need to first understand the importance of networks and encourage the development of both formal and informal networks of supports. Similarly, caregiver burden and inability to continue to care result not only from individual-level circumstances, but from access to a combination of personal-,
social-, and societal-level resources that intermingle to affect an informal network’s ability to continue to care.

As identified by Windle’s (2011) conceptualization of resilience, access to personal, social, and societal resources is important for an individual to be resilient. Though personal-level resources remain important when supporting informal networks of care, ensuring these networks have access to social- and societal-level resources is equally important, if not more so, to supporting a network’s ability to be resilient.

Social capital theorists similarly argue that it is not just about having access to networks, but rather it is the resources available within and through these networks that are particularly relevant (Keating et al., 2005; Lin, 2001). The findings from this dissertation identify similar trends, summarized in Figure 6. While bonding ties were perceived as important, providers and caregivers alike stressed the benefits which can come from strengthening bridging networks and connecting caregivers and providers to extended networks. They felt that this would improve access to additional personal (i.e., knowledge), social (i.e., social connections and relationships), and societal (i.e., formal supports, community agencies) resources, thereby developing mutually beneficial relationships.
The original conceptual model presented in Chapter 2 (Figure 2) suggested social capital and all network ties are equally important for accessing resources. However, as shown in Figure 6 above, this dissertation identified that certain network ties might be more effective in improving access to resources. These relationships are identified by the solid arrows in Figure 6. Additionally, the findings suggest improved access to personal resources are necessary, but not sufficient. Improving access to social and societal resources was thought to be crucially important. Access to social and societal resources was seen to best be supported through the development of bridging and linking ties. Bonding ties were not unimportant, but were most often seen to improve access to social resources. The results, as noted in the remainder of the chapter, suggest that heterogeneous groups (bridging and linking) generated from weaker connections would produce a more valuable benefit, and developing these connections would improve access to resources.

The original conceptual model (Figure 2 in Chapter 1) suggested a unidirectional impact of network ties and access to resources. Conversely, as shown in Figure 6 above, the findings from
this dissertation suggest a *bi-directional* path between ties and access to resources. As access to resources becomes available, network ties improve. This was particularly evident when participants discussed a lack of societal resources, indicating that a lack of societal resources would likely negatively impact the benefits of bridging networks. Overall, the results corroborate the social capital literature and suggest that developing ties at multiple levels is likely to improve access to personal, social, and societal resources. More specifically, the findings note it is important to support the development of personal resources (4) by improving access to education and knowledge for both formal and informal networks of care. Additionally, opportunities to improve access to additional financial supports should be available. The findings also identify the benefits of improving social resources (5). Participants saw great value in support for increased social outings and broadening of social support networks. Lastly, the findings suggest improving societal resources (6) by developing formal-level frameworks that encourage collaboration and improve both access to and awareness of additional formal resources for both informal and formal networks of care.

### 7.1.1 Interventions to Encourage Bonding Ties

The results from this dissertation acknowledge bonding ties as important, yet not the most important in terms of improving access to resources. When considering interventions that support informal networks of care, bonding ties were seen to be necessary but not sufficient.

Supporting bonding ties was often seen as an option to improve a network’s access to social resources by supporting family engagement in meaningful activities. Interestingly, it was bridging networks based on a foundation of trust that were thought to be the necessary interventions to adequately support and encourage bonding ties.

Bonding ties were seen to degrade as care needs progressed. Improving access to personal resources of a network was seen as a way of discouraging family and friend networks from deteriorating. Improving access to personal resources—particularly, knowledge about disease progression and caregiving expectations—was thought to be best supported through a consistent and trusted relationship built with a formal provider (Bridging Ties (2)). When discussing interventions that would support and sustain bonding ties, the following were identified:
• Respite to support date nights (among parents or children caregivers and their partner), and/or sibling outings.

• Support travel arrangements for visiting family, or to allow for geographically distant relatives to visit and assist with care.

• Support for family to allow for day trips that would potentially require additional care or travel supports.

• Support with information sharing/education to allow close family and friends to be more aware of the illness and the caregiving role.

Beyond this, there was evidence to suggest that supporting similar frontline providers (nurses to nurses; PSW to PSW) to develop relationships (i.e., bonding ties) among one another would further improve access to resources and promote a shared understanding and vocabulary. When discussing what interventions would support within-professional-network bonding ties, participants proposed:

• Formal forum for discussions to work together through challenging cases, assessments, and care plan development.

Improving bonding ties was seen to support improved access to personal resources (primarily knowledge), social resources (outings with friends, family), and societal resources (improving understanding of options and supports).

7.1.2 Interventions to Encourage Bridging Ties

The results from this dissertation stress the importance of bridging ties in terms of improving access to personal, social, and societal resources.

Bridging networks between informal caregivers and formal service providers was seen to be extremely crucial, not only in terms of supporting an informal network’s access to resources, but also to improve health systems. This relationship needed to be based on a foundation of trust, developed as a result of consistency in formal front line providers. When discussing what interventions might be used to support bridging ties, the following were highlighted:
• Consistency in formal providers.

• Encouraging bridging networks throughout the life course.

• Providing adequate support and education for formal providers.

Supporting the development of informal networks with other informal networks was thought to be of utmost importance. These relationships were seen to facilitate access to personal resources (mainly additional knowledge), social resources (where tight bonds can develop between individuals living under like circumstances), and societal resources (sharing of information and identifying additional supports). These relationships were fostered through two main interventions, caregiver/family support groups and socials. Developing additional avenues to encourage these connections was thought to be important.

Lack of interdisciplinary collaboration was discussed as a major barrier to care within the healthcare system. Developing teams of support (which include informal network(s) of care) was noted as an important tool to ensure providers were able to adequately support the informal network of care. These teams (bridging networks) were seen as necessary to work with the family to develop a comprehensive approach to care. Often, individual providers may not have access to all the information required to adequately support the psychosocial and medical needs of an informal network. Support through interdisciplinary teams would improve their knowledge base and access to personal (knowledge) and societal (awareness of and connection to additional supports) resources. Creating these bridging networks was seen as crucial to improving system flow and consistency of care. Interestingly, successfully establishing interdisciplinary collaboration hinged on bridging ties among organizations and linking ties between health sectors.

There was a perceived challenge in supporting informal networks of care when multiple organizations were involved. Collaboration between organizations was seen as a necessary bridging tie in order to improve one’s access to resources, reduce duplication of services, improve communication, and provide reliable care. Developing inter-organizational collaboration would not only improve an informal network’s access to societal resources and possible social resources, but also improve system flow. Additionally, this bridging tie would improve formal providers’
access to and understanding of additional societal resources. When discussing inter-organizational and interdisciplinary collaboration the following was highlighted as important:

- Offer support and encouragement for providers within organizations to attend forums and round tables.
- Combine programming between and across organizations.

Bridging ties were believed to be critical to support and foster connections between caregivers and broader networks and improve access to personal, social, and societal resources. The current system lacks formal interventions to support these bridging ties and, as a result, leads to a disjointed system of care that is ineffective for the care recipient, their formal and informal networks of care, and larger health systems.

7.1.3 Interventions to Encourage Linking Ties

This dissertation suggests that the following linking ties are crucial: formal providers being connected to institutions (i.e., hospitals or community service agencies), cross-sector connections, and an informal network’s access to community agencies/institutions. The findings from this dissertation suggest formal and vertical connections can improve access to personal (knowledge and formal education) and societal resources.

Left to their own devices, an informal network of care may have a difficult time identifying political or organizational structures that can support their needs. While the findings from this dissertation focus specifically on better supporting an informal network’s access to institutions and formal service providers, it also observes the importance of front-line service providers being connected to additional agencies and other elements of the formal healthcare system (allowing for and encouraging interorganizational teams). Beyond that, when decision makers are around the table making decisions that will impact complex populations, participants within this research urged the necessity of including frontline providers and individuals from within the population. When discussing interventions to support the development of linking ties, the following were noted:
• Front-line providers should be supported to access additional resources such as ongoing training, education, coaching, and/or cross-checking. Thereby, improving opportunities for both interdisciplinary and inter-organizational collaboration.

• Engaging broader networks of individuals who have firsthand experience with complex populations (e.g., members of the Ontario Brain Injury Association, the Ontario Caregiver Coalition) should be engaged at the decision-making table.

• Formal recognition of the role of informal caregivers and involving them as part of the care team.

• Developing consistency in care across geographical boundaries.

• Vertical integration and/or funding incentives to encourage collaboration among and between health sectors. Vertical integration would focus responsibility for client outcomes and system flow and improve integration and linking ties between organizations and sectors.

Consistent with findings identified in a recent report of the expert group on home and community care, the findings from this research note the current system is “patchwork” and “fragmented”. This fragmentation was seen to encourage bad system flow, duplication of services, and inconsistent access. Improving linking ties was thought to address these current challenges and improve access to personal, social, and societal resources. As a result of pilot projects and regional programming, participants believed that possible supports and connections are often not made – or, if they are made, they do not last. This is a flaw of the fragmented healthcare system. Where formal supports will see best value for money is when organizations and initiatives are mainstreamed and available to broader networks.

The findings of this dissertation build on the theory of social capital presented by Coleman (1988) and Lin (1989, 1999, 2001, 2004) and establish it as a construct to inform a broader policy framework aimed at sustaining formal and informal networks of care. This dissertation also builds on the concept of resilience as presented by Windle (2011) by identifying how one can improve access to resources that support resilience. The findings identify that personal characteristics and resources are important, but that concentrating on them alone is too narrow of a focus to support
caregiver resilience over the long term. While the academic literature tends to focus more on the insights offered from informal caregivers, the healthcare sector tends to focus on the individual needs of the care recipient. A fundamental shift is required to acknowledge needs from multiple perspectives and structure supports that meet the needs of those providing care in the community (Kemp et al., 2013). While the recent Donner (2015) report noted that the “client” needs to be expanded to include “family”, the findings from this dissertation, building on the conceptual application of social capital theory, suggest expanding this concept even further to acknowledge the multiple networks of support that can be developed within a community setting.

7.2 Applied Policy Implications

By applying social capital theory, we gain a broader understanding of how context may impact (positively and negatively) caregivers’ abilities to maintain resilience. Additionally, this research identifies how to apply these more abstract social capital and resilience concepts on the ground. This dissertation stresses the importance of the system and ensuring people are connected to and within the system.

7.2.1 Context Matters

While an overall lack of personal resources is a key targeting point for initiatives, providers suggested that, even if the personal level resources like financial support were available, caregivers may still lack the knowledge (personal resource) to identify sources of support in a “fragmented and unforgiving system”. Similarly, language barriers can exacerbate the challenges of identifying needs and navigating sources of support. As we heard across the board, developing an early warning system to identify caregivers at first point of contact (i.e., when someone is diagnosed with cancer or Alzheimer’s) was seen to be a crucial approach for actively targeting and supporting networks of care. For example, those involved with the CF for CMC noted that connections and assessment of needs should be done in the hospital, prior to the family returning home. The participants within all phases of the research stressed that assessment of caregiver needs should consider key personal and social resources including: availability of family or social support; possible cultural or language barriers; mental health concerns; and the physical health and wellbeing of the caregiver.
The findings highlight that caregivers need to be formally recognized. Formal recognition could be accomplished at several levels: a caregiver recognition act; case managers being formally trained to engage with and acknowledging informal caregiver needs; and to be recognized as a valued member of the circle of care. There is a need to acknowledge that the typical idea of the “family caregiver” is not always the case and could be “anyone of any age” and of any relation to the care recipient. Not all caregivers are the same, and all have very different circumstances, capacity, and access to resources. Often it is believed that those most in need of support are those with low levels of personal resources (education, language barriers, low socio-economic status).

While the findings do not disagree that these factors affect one’s ability to cope, they also highlight that, even for caregivers who have higher education levels and access to financial resources, there are system-level impacts that will make coping difficult. Similarly, the findings note that solutions to address capacity over the long term need to consider the impact of the broader context. Highlighting that additional and flexible funding will not “solve all of the issues”, services need to first be available and second be flexible, acknowledging that these circumstances are “more complicated than just needing money”.

Rarely are informal caregivers or informal networks of care considered part of the circle of care (Donner, 2015; Kemp et al., 2013; Peckham et al., 2014b). The two case studies presented within this dissertation are essentially work arounds to the flaws of the broader system. The case studies do engage caregivers in a more meaningful way than the current system allows, yet they are still not a part of the mainstream and therefore contribute to the ‘patchwork’ and ‘postal code lotteries’. The findings align with the Donner (2015) report and identify that the current system is not designed to support families and highlight the importance of broadening the circle of care to include informal caregivers. However, Donner’s classification is still quite narrow, and this dissertation indicates that the circle of care should include the broader support network beyond family members to include community organizations and volunteers. Expanding these (formal and informal) bridging networks and formally recognizing their importance and involvement in sustaining individuals and caregivers would encourage organizations and providers to think beyond the traditional individualized approach to care and acknowledge the role in which the broader context can impact one’s ability to get ahead.

Even when we do formally recognize or support caregivers more broadly, as did the two case studies presented in this dissertation, we often only get them at ‘point of crises’ which was seen to
be ‘too late’. The basic prevention-focused concept of “get them early, keep them late” was noted to be important for sustaining caregivers over the long-term. Again, the findings suggest there is a need to develop societal-level resources which encourage consistency in formal providers who work with families to identify needs and negotiate services. Societal level resources focusing on developing trusting relationships would improve challenges associated with adverse events while also offering opportunities for preventative measures. Consistent trust worthy relationships could improve access to, if needed, personal resources (education, finances), social resources, and societal resources. These findings are in alignment with the literature suggesting that “after the fact” support is far less effective in building sustainable situations.

### 7.2.2 The Importance of Bridging and Linking Ties

Building networks at the bonding, bridging, and linking levels was found to be an important factor in sustaining an informal network of support over the long term. These networks, when encouraged and supported, and when trust could be developed, were seen as avenues to improve access to resources at all levels. Participants involved within this research noted that developing trust among these networks might best be achieved through consistent relationships.

The importance of societal-level resources was evident from the interviews and case studies. Much of what the providers saw as “supporting caregiver(s)” and their network’s personal and social resources could stem from ensuring access to certain societal-level resources. As noted below, this dissertation demonstrates that the “caregiver problem” extends well beyond an individual-level concern, and bridging and linking ties become critical.

**Support Development of Bridging Networks: Consistent and Trustworthy Formal Provider**

The participants involved within this research were unwavering in identifying the need for a consistent provider to develop ongoing relationships with families and noted that this role should serve as some form of system navigation. However, a consensus on who should fulfill this role and the educational background necessary for this navigator position did not emerge. Some participants asserted that it should be based on disease-specific experts, and others opined that perhaps they should be “generalists” who are extremely well-versed in navigating the formal healthcare system. Whichever approach is taken, ensuring these front-line providers are respected, adequately trained (developing their own personal resources), and supported (developing bridging
and linking networks of support) was seen as a crucial aspect in maintaining their ability to
remain resilient and continue in their formal role. Respecting front-line providers and supporting
their access to resources was suggested as a way to improve turnover rates – a factor that needs
attention if attempting to improve consistent trusting relationships between providers and informal
networks of care. The navigator role was repeatedly identified as a solution to the systemic and
personal-level challenges associated with providing informal care. As such, many of the
“actionable” findings identified in this dissertation could be facilitated by such a role. The recent
Donner Report similarly highlighted the current lack of and need for planning and system
navigation (Donner, 2015). Both the literature and this dissertation concur that there is evidence to
suggest benefits could come from a “self-management” model, for caregivers and families who
have the capacity to manage the budget and access necessary supports. However, many of the
participants saw the benefits of a “supported self-management” model where caregivers and their
families received support from experienced professionals who understand the system and have
skills to navigate across multiple providers and organizational silos.

The findings from this dissertation suggest that there are numerous barriers to families and
informal networks working with formal providers. Challenges include inconsistent and
incomplete client stories, and an overall lack of trust of providers and formal systems.
Incorporating a navigator role where informal and formal networks were aware that this was a
longer-term partnership was identified as a good starting point to build system capacity in meeting
both informal network access and formal provider communication. This partnership would allow
for navigation of both psychosocial and medical needs. Building trust within these relationships is
necessary and has been argued to promote social stability and collaboration (Lin, 2001). The
findings from this research highlight the importance of building trust among and between families
and service providers. The participants within this research believed consistency in care providers
was a primary contributor to developing trusting relationships.

The provincial government responded to the Donner Report (2015) with a “Patients First” action
plan (Government of Ontario, 2015a; 2015b), with the promise to promote “bundled care teams”
discussed in more detail below) who work with a single budget and care teams that remain
mostly the same and provide client care in the hospital and their homes (Ministry of Health and
Long-Term Care, 2015). This approach aims to improve consistency in service providers by
keeping the “majority of their healthcare team the same”. Participants overwhelmingly agreed that inconsistent care teams was a major barrier to adequately support informal networks of care.

**Support Informal Networks of Care: Expanding the Conceptualization of the ‘Circle of Care’**

The academic and policy literature is in broad agreement that informal caregivers need to be formally recognized and should be considered members of the circle of care (Donner, 2015; Keating et al., 2003; Keefe et al., 2014; Kemp et al., 2013; Martin-Matthews et al., 2012; Peckham et al., 2014b). While often considered an important resource for system sustainability, they are often not engaged in the political debates nor formally considered in overall care systems (Keefe, 2011; Leveine, Halper, Peist, & Gould, 2010). The findings from this dissertation align with these arguments. However, the findings suggest building upon the idea of what it means to be an informal caregiver and stress the benefits of broadening it to involve informal networks of care. The findings also highlight that, where informal networks of care are not present, they could be encouraged through formal avenues (i.e., a consistent formal provider who has developed trust with the immediate informal caregiver/care recipient dyad to support broader community engagement). For example, where extended networks are minimal, access to additional community supports such as volunteer agencies should be supported to encourage an increase in bridging networks and broader networks of support. This dissertation underscores that all parties involved with care have essential knowledge and resources to provide high levels of support and, as such, should be encouraged to engage in the formal circle of care.

The literature is beginning to address the possible benefits of acknowledging the role of the informal caregiver in assessing the needs of both the care recipient and the caregiver, individually as well as collectively (Keefe et al, 2014; Kemp et al., 2013). This is indeed considered a step in the right direction. However, as social capital theorists would suggest, there is great benefit in ensuring these networks expand to build and include both bridging and formal linking levels of support. Keefe et al. (2014; 2015) are refining this understanding in a similar direction, noting the benefits of shifting from our current “provider-centered” approach to “person-centered” approaches and stressing the importance of shifting the focus one step further to a “network-centered” approach. The findings from this dissertation suggest an approach to care planning that considers individual needs as well as collective needs. This approach would be preemptive, where
choices are not made at points of crises but rather proactively through discussions and outlining of future care trajectories. An example of this “before the fact” approach is taken by Ontario’s First Link initiative (Sinha, 2012), which identifies older adults with dementia at the point of diagnosis and connects them with dementia-specific training, counselling, care planning, and supports (McAiney et al., 2012). Likewise, policy recommendations are beginning to acknowledge the importance of building sustainable communities as a means to improve opportunities for the development of informal networks (Kemp, 2015). For example, Sinha (2012) identified the importance of encouraging the Ministry of Health and Long-Term Care and the Local Health Integration Networks to develop networks with municipal councils to strengthen the role of elderly-person centers throughout Ontario.

A key function of this would enable the team to identify top areas of concern and develop and target supports to caregivers preemptively, addressing issues and reducing the need for “just-in-time” supports. This would shift the focus, which is currently very individualistic to address both the individual and collective needs of these networks.

Support Access to Personal, Social, and Societal Resources: Financial Resources are Necessary but Not Sufficient

The findings highlight that benefits can come from using flexible budgets to support the varying needs of informal caregivers, care recipients, and their networks. The case studies particularly highlighted the benefits of using a modest budget to support the needs of the families involved in the initiatives. However, it was clear that it was not necessarily the money as an intervention in and of itself that was encouraging caregivers to continue. Rather, it was the access to a provider who communicated with them on a different level, negotiating needs of the care network above and beyond medical concerns, and using the funds to fill system gaps. Again, providing additional respite and caregiver-direct supports is helpful and important, but knowing how to access these resources, be it directly or through the support of a case manager, and providing caregivers and families the opportunity to engage in meaningful activities, extends the value of that service.

This research clarified that caregivers and care recipients are heterogeneous – all have different needs, and there are several ways to address those needs. Their needs, access to resources, and network levels vary. Therefore, there is no single service that ensures caregiver resilience. Their complex circumstances and experiences require complex and flexible approaches to support.
Providing these care networks opportunities to engage with one another and with a consistent and long-term health systems expert would support caregivers to engage in what matters to them and broaden their networks. While the financial component of the caregiver initiatives in the case studies supported the access of additional supplies and direct services, it became clear from the providers that the initiatives attempted to foster opportunities at multiple levels. The benefits were seen to come from supporting families to develop personal and social resources through bonding and bridging ties.

Unfortunately, while addressing system gaps and system-level barriers, these supports continue to be patchwork. The system is not designed to support families; without addressing systemic issues, it will always be a challenge to focus on the needs of the informal networks, thereby producing benefits over the long-term. These initiatives did identify the benefits of supporting networks of care, addressing the medical and social needs of each unit individually as well as collectively.

**Support the Development of a Policy Framework: Intermittent Initiatives will not Support Long-Lasting Benefits**

This message was evident within the findings where providers and caregivers discussed the variations in organizations involved in attempting to provide care in the home and community care sectors. As a result of the lack of collaboration and differentiation of organizations involved with providing care within this sector, there is an increased need to develop interdisciplinary, inter-organizational, and inter-sectoral collaboration. Participants discussed the disjointed nature of the current formal system and urged that collaboration be encouraged and “turf wars” be discouraged by using various models and incentives (i.e., vertically integrated models of care).

This is likely to become increasingly important as more organizations become gradually relevant within this sector (i.e., hospitals, community agencies). It will soon become crucial to think about both formal and informal networks of care and methods that can support the bridging of these networks. As informal networks develop to include community organizations and volunteers, there will be an increased need to promote community wellness through organized community efforts. With such a wide range of services and supports, the need for inter-organizational efforts will become even more pronounced (Axelsson and Bihari Axelsson, 2006; Kodner, 2009). The organizations involved in the home and community care sector span beyond just those providing healthcare. A challenge identified by participants was a current lack of bridging among these
organizations. Building these inter-organizational connections is crucial to achieve network-centered care aimed at improving client and caregiver wellbeing (Kodner, 2009).

An inter-organizational system would improve collaboration and communication among providers and organizations. Improving these connections would support the “navigator role” allowing ease of access to other providers and support networks more broadly, which was seen as a huge barrier to achieving informal caregiver resilience. The home and community sector involves many organizations and does not function within one collaborative structure. The integration of these networks currently has to be voluntary, and as identified by participants in this research, the responsibility often falls to keen providers within these organizations. Providers call for more formalized support to encourage building these bridging and linking networks among organizations and between sectors (Smyth, 2009). Participants acknowledged that a single, hierarchical model incentivized by funding could be an option. Another acknowledged option is use of the navigator role as the key player to engage these networks between organizations and sectors. Some would argue that CCAC Case Managers should be responsible for building this integrating network; unfortunately, while they can refer individuals to community service agencies and identify various options of supports, they cannot directly coordinate and monitor such services (Williams et al., 2009).

As identified in the interviews with caregivers and providers from across Ontario, in order to build a national, or even provincial, strategy, there needs to be more collaboration among advocacy groups. The findings suggest the importance of individuals, organizations, providers, and sectors working together to collaborate and improve the wellbeing of informal networks of support. “Everyone needs to stop doing their own thing” as it creates piecemeal approaches to care which can further erode access. The recent Donner Report (2015) similarly notes in several of the recommendations that various organizations need to improve collaboration and work to achieve system performance indicators, highlighting the idea of bundled care models as an option.

While there are positive initiatives throughout Ontario, they tend to remain exemplary instances, with limited ability to spread across Ontario or Canada. We continue to work in silos. The recent Patients First action plan (Government of Ontario, 2015a) has identified “ten steps to strengthen home and community care”, two of which are of particular relevance to this dissertation. One step highlights the need to integrate healthcare services, and the other suggests that all providers must
work together by means of bundled funding, where a group of providers are given a payment to cover all care needs of an individual client. An example of a vertically integrated system of care (one example of bundled care) was initiated in Hamilton, Ontario as St. Joseph’s Health System’s integrated comprehensive care demonstration project (St. Joseph’s Health System, 2013). The action plan not only highlights this specific initiative as representative but also notes the concept of bundled care as a viable approach for system change and promoting integration. This integrated comprehensive care model, out of St. Joseph’s, aims to bridge hospital and communities through a team of providers who work collaboratively within the hospital and continue to support the client as they transition back to their home. Clients and families have access to members of the team on a 24/7 basis, and each team member is accountable to work with the client and other members of the team (St. Joseph’s Health System, 2013). More recently, Ontario announced the expansion of the “coordinated team approach” of the Hamilton Niagara Haldimand Brant LHIN to five new communities and plans to expand to additional communities “based on the results of these projects” (Ministry of Health and Long-Term Care, 2015).

The Patients First action plan also proposes offering self-directed care, which would improve flexibility and access to supports. Yet, as the case studies indicate, self-directed approaches are not necessarily the most effective approach when caregivers and care recipients do not have the resources necessary to identify how to access supports (Williams et al., 2014). Another step was to expand caregiver supports, which will seek to offer training and educational programs for caregivers. While both steps would improve flexibility of services and increase access to a caregiver’s personal resources through education and training, there remains a need for improved access to social and societal resources. An important recommendation would be to develop a single point of entry at the first contact to the formal system. A single point of entry could be a useful tool – a component of integrated care – to foster the use of a standardized assessment and screening tool.

The action plan also identifies the need to enhance support for personal support workers (PSW), as noted above. Improving the wage of PSW supports in the home and community care sector is a step towards improving their employment experience and likely is a step in the right direction to decrease turnover rates. Lower turnover would benefit clients and caregivers who are continuously re-training and re-telling their stories to frontline professionals in their home (Government of Ontario, 2015a).
The findings suggest that there are several approaches to supporting caregivers that will improve their overall wellbeing, yet also highlight particular combinations of supports that might be more likely to support an informal network’s resiliency over the long term. The findings from this dissertation highlight that a failure to consider the broader context when attempting to support informal caregiver resilience will limit the long-term benefits of the supports put in place. All supports will be helpful because, at the very least, they identify and validate the crucial role which informal caregiving networks play. However, without supporting access to resources at the informal and formal levels through the development of bridging and linking networks, informal caregiver supports will remain individually focused and postal-code sensitive, and, overall, will produce shorter-term benefits.

The two Toronto-based caregiver initiatives explored in this dissertation were seen to be valuable in that they provided an opportunity to work around bridge gaps within the current system. The findings from this dissertation point to the challenges associated with not addressing barriers at the system level, noting specifically the importance of acknowledging informal networks of care as a component of the circle of care and building formal systems which encourage collaboration and integration. Without addressing the systemic issues and improving access to societal-level resources, we will continue to see patchwork initiatives and pilot projects which never become mainstream, further perpetuating fragmented systems, “postal-code lotteries”, overall lack of access, and limited capacity to produce sustainability over the long term (Williams, et al., 2015).

7.3 Limitations

There are a number of limitations to this research. Findings from this dissertation were not informed by interviews with caregivers involved with the two Toronto-based caregiver initiatives. Caregivers of the two initiatives were indeed invited to participate. Their unwillingness to participate is likely a result of the considerable stress they experience as caregivers of high needs persons, and because they themselves face a range of health, mobility, and literacy issues, their ability and willingness to participate was limited. Given the complex and vulnerable population of interest, this is a concern that extends beyond this dissertation and will require thought and consideration for policy-makers planning to push the caregiving agenda forward. The limited capacity to access vulnerable caregivers when planning a caregiver or even a dementia strategy is an important factor for future consideration, particularly because, as the findings from this
dissertation suggest, there is consensus that those who the strategy targets should be consulted during the development phases.

While there was a significant voice in identifying the overall effects of these initiatives in phase one (particularly caregiver voice through the inclusion of the ‘one-minute evaluations’), it was deemed useful to gather a supplementary sample of participants (which included formal service providers and informal caregivers) to expand upon the findings in a secondary analysis (phase two) and qualitative interviews (phase three). However, since this sample was identified through a “gatekeeper” approach using the Ontario Caregiver Coalition, those who responded are likely a politically active population of caregivers and providers who potentially have a unique (yet context-sensitive) perspective of their needs. Therefore, this research may have neglected to identify more isolated, marginalized caregivers who may have perceived different or additional factors as crucial to support their longer-term needs. As a result of the particular sample representation and the nature of qualitative research, generalization might not be favorable. The challenges with accessing vulnerable populations of clients and caregivers needs to be addressed when conducting future research or, more importantly, when including caregivers in decision-making. This dissertation did identify theoretical implications and relevance, particularly noting the importance of conceptualizing the nature of the problem on a broader and systemic scale. This dissertation also highlighted the importance of developing bonding, bridging, and linking networks and improving access to personal-, social-, and societal-level resources as it relates to sustaining formal and informal networks of care.

7.4 Strengths and Contributions

There are several strengths within this dissertation. This mixed-model design allowed for an in-depth investigation of multiple research questions that would have otherwise not been achievable. The analysis of the case studies, combined with the qualitative interviews informing and validating the results of the case study analysis, pointed to some key themes. The additional qualitative interviews with caregivers and providers from across Ontario were integral to the further exploration of the effects of the broader context in supporting what providers and caregivers identified as crucial to building sustainability over the long term. Including multiple perspectives of those directly involved in the case studies, as well as the perspectives of caregivers and providers more broadly, resulted in perspectives that span a range of populations
and involvement within the system. This research was able to offer a contribution, highlighting the importance of societal-level resources and of improving upon networks to access said resources, which have not been fully explored within the political or academic literature. Findings from this research make important contributions both to social capital theory and the concept of resilience. This dissertation revealed the importance of focusing on broader impacts upon a caregiver’s ability to maintain resiliency and suggests there are benefits to encouraging informal and formal networks of support to ensure access is available to resources at the personal-, social-, and societal-levels. Conceptually speaking, this research applied social capital theory to a new context using it to intellectualize the informal caregiver “problem”. This dissertation demonstrated that, while any caregiver support will be helpful, the long-term effect of these supports depends upon building and encouraging networks which include and extend beyond those of the immediate family to involve not only formal providers, but also extended networks of support involving community organizations and various health sectors. This research demonstrated that the sustainability of informal networks involves several societal-level shifts, which include various levels of collaboration, suggesting that formal interventions be in place to build incentives to achieve collaboration.

7.5 Future Research

This research provides a deeper understanding of the political- and societal-level factors which impact one’s ability to continue to care. This dissertation begins to shape an understanding of the importance of supporting care networks, acknowledging that support stems from multiple avenues, and these networks of supports should be encouraged. More research should engage broader populations of caregivers, providers, and clients. Efforts should focus on identifying how best to encourage formal and informal networks of care within communities and how to sustain the development and collaboration of these networks. To do this would require research using multidisciplinary mixed model approaches and collaboration with broader communities (i.e., employers, family, volunteers, and a variety of community and formal support service providers). With little research achieving even the perspective of care recipient and caregiver as a dyad, there needs to be further examination of the broader context and how it affects the interdependency embedded within both formal and informal caregiving networks.
7.6 Conclusion

This dissertation argued that in order to design policy interventions that work there needs to be a conceptualization beyond that of the individual. This dissertation highlights that, where social capital is strong, access to personal, social, and societal resources will be improved, thus leading to improved resilience. Additionally, the findings indicate that there might be a weighted benefit if policy interventions particularly target efforts to improve bridging and linking ties—yielding the best results in terms of improving an informal network’s access to resources. The findings also suggest that the relationship between network ties and improved access to resources is not linear.

The findings from this dissertation stress that the “caregiver problem” is a complex phenomenon that requires a larger policy framework extending beyond one-off initiatives that are arbitrarily implemented and contingent upon on-going funding. The findings particularly underscore that this is not simply an individual problem requiring individually-focused solutions. This dissertation argues the importance of conceptually understanding informal care networks from a broader perspective, acknowledging that caregiver resilience may be an individual-level phenomenon but can be supported or hindered by broader social- and societal-level impacts. This research applied social capital theory to the highly political topic of informal caregiving. While experts are beginning to extend the concept more broadly to include unit-of-care dyads and networks of care (Donner, 2015; Government of Ontario, 2015a; Keefe & Krawchenko, 2015; Kemp, 2015; Peckham, 2014b), this dissertation stresses the need to push this conceptualization even further. Using the theory of social capital, this dissertation identifies the benefits of developing broader social and societal constructs to support increased access to resources for both formal and informal networks of care.

Overall, this dissertation suggests that caregiver-support initiatives, which focus on individual-level supports by improving a network’s personal resources (i.e., through a caregiver allowance and/or education), while a good starting point, may not be sufficient to build long-term capacity. Improving access to financial- and personal-level resources may not provide these informal networks of support with the extended resources needed to identify and access formal services. In fact, even caregiver-support interventions, which attempt to “work around” inadequate formal systems in isolation, are not solutions in and of themselves, leading to concerns about equality and access. As an end result, we want to not only support informal caregivers but strengthen the care
base by building sustainable networks of support into the future. This is particularly crucial as the traditional care relationships evolve and change as a result of our flexible social structures. This dissertation furthers the conceptual thinking when considering supports to build informal caregiver capacity, identifying the importance of bridging formal and informal networks and adapting institutional arrangements. This dissertation argues that, without these broader structural supports, individuals, families, and broader-level community networks would not be able to overcome individual adversity and barriers to access.

Individual supports and limited support initiatives, while beneficial at some level, remain inadequate to ensure ongoing benefits at broader social and system levels. Broader social and system level supports are necessary to consider if we are to support ongoing caregiver resilience. Social capital theory was useful in acknowledging that, without theorization, the formal system will continue to function based on a biomedical, individualized model, which this dissertation argues is an inadequate approach to address the informal “caregiver problem”.
References


Appendices

Appendix 1: Examples of Ontario Caregiver Supports

Wesway

Wesway is a flexible respite service offered in Thunder Bay, Ontario. Wesway offers personalized respite support services to families who provide care to a family member(s) who lives with them. The care recipient must have a disability or chronic condition, although eligibility is assessed on an ad hoc basis based on the care recipient and family unit. Service planning is done in an individualized manner to meet the specific needs of each individual familial unit.

Wesway has a variety of respite options that include:

- **Host families**: A family will provide short-term respite by opening up their home to a caregiver for a few hours, or, at times, overnight.
- **Community friends**: A volunteer will enjoy a few hours of social activities weekly or monthly.
- **In-home service**: Trained respite workers carry out typical care routines which the informal caregiver would typically provide.
- **Respite homes**: Respite services provided within Wesway’s home-like setting.
- **Family directed respite funding**: Wesway allows families to determine how best to receive respite and Wesway pays the associated costs.

Reitman Centre for Alzheimer’s Support and Training

The Reitman Center for Alzheimer’s Support and Training Program provides targeted and skill-building interventions to support family caregivers and equip them with the tools to manage care of their loved ones. The program aims to enhance an informal caregiver’s practical skills as well as improve the coping and management of stressful circumstances associated with providing informal care.

Family Service Toronto
Family Service Toronto offers counselling support to seniors and their informal caregivers. They focus primarily on diverse communities including new immigrant communities, low-income populations, and the gay and lesbian community. Counselling is offered in a variety of forms including group counselling, advocacy, training, and educational sessions on a vast array of topics including:

- Communication
- Community services
- Stress management for caregivers
- Coping with change and loss
- Healthy caregiving
- Anger and guilt

Alzheimer Societies

There are 32 Alzheimer Societies across Ontario that offer support programs, educational resources, and referral services for caregivers and families. Specific services vary from branch to branch but generally include:

- Education and information sessions
- Support groups
- Private and family counselling
- Respite care—short-term and overnight stays
- Therapy programs (art and music)

The Alzheimer Society has also developed an innovative program called First Link, which provides information and can link individuals to services and supports available to them. The goal of the program is to connect individuals and families to support and information as early as possible by allowing physicians and community providers to connect families to the Alzheimer Society (McAiney et al., 2012).

Children’s Treatment Network

Children’s Treatment Network (CTN) of Simcoe York is an initiative which involves a partnership of agencies and organizations that collaborate to provide supportive and
comprehensive care to children who have multiple complex needs and their families in the Simcoe Country and York Region. The network involves over 50 partners, including schools, hospitals, rehabilitation providers, and social and community services.

The inter-professional team (includes the family) coordinates together to determine and implement a plan of care to achieve family-related goals. CTN creates a culture of sharing through the use of rules of engagement. There is a plan-of-care coordinator who works closely with the team to ensure ongoing collaboration.

**City of Ottawa’s Caregiver Support Program**

The city of Ottawa caregiver-support program aims to promote a community that values informal caregivers and to provide caregivers with community-resource information. This program offers telephone support and counselling, as well as referrals and information on community resources available to them. This program also offers education and support sessions in collaboration with the family service center of Ottawa-Carleton.

**Care-Ring Voice Network**

Care-Ring is a tele-learning program aimed at providing caregivers and families with information and support and offering workshops that provide caregivers an opportunity to learn from various healthcare professionals.

Care-Ring not only promotes the sharing of valuable coping methods and health information, but aims to bring informal caregivers together and to create “peer-to-peer caregiver networks”. The care-ring workshops allow caregivers to connect and learn from professionals while simultaneously connecting them with individuals in like circumstances.

**Young Carers Initiative- Powerhouse Project**

The young carers initiative is a non-profit agency in the Niagara and Haldimand-Norfolk regions, which aims to support the overall resilience of young carers and their families. This particular project focuses on supporting young carers and their families by offering a range of services aimed at reducing social isolation, improving life skills, and investing in peer support programs.

**Family Caregiver Connections**
Family Caregiver Connections is a partnership of seven Jewish community organizations (Baycrest, Circle of Care, Bernard Betel Centre, Chai Tikvah, Jewish Family and Child, JIAS Toronto, and Reena) who work collaboratively to support family caregivers. The program is funded through the Central LHIN and aims to support seniors and families as a means to sustain them living independently in their own homes. Specifically, the Family Caregiver Connections program provides the following services:

- Caregiver services for Russian speaking clients
- Educational workshops
- Educational materials
- Group education and support
- Transportation services
- In-home respite
- Individual counselling

Information and referral through the caregiver information telephone line
Appendix 2: Ethics Letter of Approval

PROTOCOL REFERENCE # 28338

March 11, 2015

Dr. Paul Williams  Ms Alexandra Peckham
INST OF HEALTH POLICY, MANAGEMENT & EVALUATION
DALLA LANA SCHOOL OF PUBLIC HEALTH

Dear Dr. Williams and Ms Alexandra Peckham,

Re: Your research protocol entitled, “Caring for caregivers: Building social capital”

We are writing to advise you that a member of the Health Sciences Research Ethics Board (REB) has granted approval to an amendment (Received February 26, 2015) to the above-referenced research protocol under the REB’s delegated review process. This amendment approval letter only applies to what was outlined in the request form under section 5a) or otherwise marked in the revised protocol.

Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.

Best wishes for the successful completion of your research.
Appendix 3: Invitation to Participate Caregiver Framework for Children

Dear XX,

In October 2011, the Hospital for Sick Children (Sickkids) in partnership with the Toronto Community Care Access Centre and Holland Bloorview Kids Rehabilitation Hospital initiated the Caregiver Framework (CF) for Children with Medical Complexity. This framework provides supports to caregivers of children living with medical complexity.

My name is Allie Peckham, and I am a PhD student at the University of Toronto. As part of my PhD requirements I am responsible to conduct research that will inform the development and implementation of caregiver-support initiatives similar to the CF.

I am writing to invite you to participate in either a telephone or face-to-face interview that will last approximately 30 minutes. I would like to discuss, based on your firsthand experiences, what types of supports seem to work best for informal caregivers and their loved ones over the long term. As a result of your extensive involvement over the first three years of the framework and your firsthand experiences working with caregivers, you have valuable insight into caregiver supports, and your expertise would be of value to my research.

I am conducting an independent review of your experiences and I would like to know based on your firsthand knowledge, what aspects of the CF seem to give caregivers and their families the longest lasting benefits.

Whether or not you choose to participate in an interview is completely up to you; it will have no impact on your employment. However, by sharing your valuable first-hand experiences, thoughts, and ideas, you can help to improve the CF and the development of similar initiatives aimed at supporting caregivers.

If you choose to participate, please take a moment to review the information package and call or e-mail Allie at the University of Toronto to schedule an interview time at your earliest convenience. You can reach Allie by phone at xxx.xxx.xxxx or by e-mail at allie.peckham@mail.utoronto.ca.

I look forward to hearing from you.

Sincerely,

Allie Peckham

Allie Peckham, MSW, PhD Candidate
Institute of Health Policy, Management and Evaluation
University of Toronto
allie.peckham@mail.utoronto.ca
Appendix 4: Invitation to Participate Caregiver Support Project

Date, 2013

Dear XX,

In October 2011 the Alzheimer Society of Toronto (AST) in partnership with the Toronto Community Care Access Centre initiated the Caregiver Support Project (CSP). This framework provides supports to caregivers of older adults living in the home.

My name is Allie Peckham, and I am a PhD student at the University of Toronto. As part of my PhD requirements, I am responsible to conduct research that will inform the development and implementation of caregiver-support initiatives similar to the CSP.

I am writing to invite you to participate in either a telephone or face-to-face interview that will last approximately 30 minutes. I would like to discuss, based on your firsthand experiences, what types of supports seem to work best for informal caregivers and their loved ones over the long term. As a result of your extensive involvement over the first three years of the project and your firsthand experiences working with caregivers, you have valuable insight into caregiver supports and your expertise would be of value to my research.

I am conducting an independent review of your experiences, and I would like to know based on your first-hand knowledge, what aspects of the CF seem to give caregivers and their families the longest lasting benefits.

Whether or not you choose to participate in an interview is completely up to you; it will have no impact on your employment. However, by sharing your valuable first-hand experiences, thoughts, and ideas, you can help to improve the CSP and the development of similar initiatives aimed at supporting caregivers.

If you choose to participate, please take a moment to review the information package and call or e-mail Allie at the University of Toronto to schedule an interview time at your earliest convenience. You can reach Allie by phone at xxx.xxx.xxxx or by e-mail at allie.peckham@mail.utoronto.ca.

I look forward to hearing from you.

Sincerely,

Allie Peckham
Allie Peckham, MSW, PhD Candidate
Institute of Health Policy, Management and Evaluation
University of Toronto
allie.peckham@mail.utoronto.ca
Appendix 5: Informed Consent for the CF for CMC

In October 2011, the Hospital for Sick Children (Sickkids) in partnership with the Toronto Community Care Access Centre and Holland Bloorview Kids Rehabilitation Hospital initiated the Caregiver Framework (CF) for Children with Medical Complexity. The CF provides supports designed to assist the well-being, capacity and resilience of caregivers.

Background

Informal caregivers play a crucial role at both the individual and systems level. In fact, informal caregivers provide the bulk of the care in the home and community care setting.

Many long-term care policies are based on the assumption that informal caregivers will be there to provide care to dependent family members or friends. Unfortunately, fragmented formal ‘non-systems’ of care that are not well equipped to serve the needs of children and older adults requiring multiple services from multiple providers in different fields (e.g. hospital, home care, community supports, rehabilitation), adds to the challenge of being a caregiver.

The literature often provides inconsistent and often conflicting evidence about whether, or under what conditions, formal supports for informal caregivers support caregivers over the long-term.

The lack of systematic evaluation of different caregiver supports leaves considerable room for debate surrounding the costs and consequences. Currently, the development, implementation, and evaluation of informal caregiver initiatives often fails to consider that in addition to immediate, short-term outcomes, there may be a range of longer-term gains connected to the establishment or strengthening of social networks. Therefore, the question is not whether caregiver supports hold promise; it is which supports work best for which caregivers and under what conditions?

This research aims to narrow the intelligence gap by generating evidence that provides insight into designing effective interventions to support informal caregivers and their networks over the long-term.

What you are being asked to do

I am inviting you to participate in an interview focused on exploring how you perceived the CF to meet the needs of informal caregivers and whether or not you see the CF having no impact, a short-term impact or a long-term impact on the overall well-being of informal caregivers and their loved ones.

The interview will last approximately 30 minutes. Your answers will be audio recorded and detailed field notes will be taken. However, this is solely for analysis purposes and your responses will be kept secure and your identity will remain confidential.

What We Guarantee

Your right to refuse to participate, your right to refuse to answer any questions, to withdraw at any time, or to have the notes and audio recordings of your responses destroyed without any consequences. This consent form indicates that only the researcher will know who does or does not participate and that findings will be reported without identifying individuals. In addition, should you wish to receive a summary of the findings, please check the appropriate box and provide an address for us to send you a copy.

If you have any questions, please feel free to contact Allie or the Office of Research Ethics, University of Toronto.

Thank you for your help with this important research.
By signing this form I indicate that I understand the following:

Conditions for participating

• My participation is completely voluntary; only the researcher will know who has (or has not) participated.
• I can leave the interview at any time and ask that my responses not be included in the research results with no penalty or consequences to me or my employment.
• I may refuse to answer any questions without penalty.
• I have the right to speak off record at any time.
• I understand that field notes and audio recordings from the interview will be analyzed in such a way as to make it impossible for me to be directly identified.
• I understand that field notes and audio recordings will be protected on a password-protected computer that only the researcher can access, and that they will be used solely for the purposes of the research.

Risks and Benefits

• I understand that the results of this research will be communicated through a final report and/or publications in peer-reviewed academic journals and will be used as a resource for policy-makers and researchers.
• I understand that my participation will not affect my employment in any way.

For more information

• Should you have any questions about the interview process or this research please contact:
  o Allie Peckham xxx.xxx.xxxxx or allie.peckham@mail.utoronto.ca
• Should you have any questions about your rights as a participant, please contact the Office of Research Ethics, University of Toronto, at 416.946.3273 or ethics.review@utoronto.ca

Summary of the Research Results

Please indicate if you would like to receive a final copy of the research findings when it becomes available (Check the box to the left). My e-mail address is:

______________________________________________________________________________

I hereby certify that I am signing this form of my own free will, with no pressure from others to do so, and that I do so after having been given all the facts that I need to make this decision. In witness thereof, I have signed this form on this the _____ day of __________, 2014.

______________________________________________________________________________

Full Name (Printed)  Signature
Appendix 6: Informed Consent for the CSP

In October, 2011 the Alzheimer Society of Toronto (AST) in partnership with the Toronto Community Care Access Centre initiated the Caregiver Support Project (CSP). The CSP provides supports designed to assist the well-being, capacity and resilience of caregivers.

Background

Informal caregivers play a crucial role at both the individual and systems level. In fact, informal caregivers provide the bulk of the care in the home and community care setting.

Many long-term care policies are based on the assumption that informal caregivers will be there to provide care to dependent older adults and fragmented formal “non-systems” of care that are not well equipped to serve children and older adults requiring multiple services from multiple providers in different fields (e.g. hospital, home care, community supports, rehabilitation) adds to the challenge of being a caregiver.

The literature often provides inconsistent and often conflicting evidence about whether, or under what conditions, formal supports for informal caregivers support caregivers over the long-term.

The lack of systematic evaluation of different caregiver supports leaves considerable room for debate surrounding the costs and consequences. Currently, the development, implementation, and evaluation of informal caregiver initiatives often fails to consider that in addition to immediate, short-term outcomes, there may be a range of longer-term gains connected to the establishment or strengthening of social networks. Therefore, the question is not whether caregiver supports hold promise; it is which supports work best for which caregivers and under what conditions?

This research aims to narrow the intelligence gap by generating evidence that provides insight into designing effective interventions to support informal caregivers and their networks over the long-term.

What you are being asked to do

I am inviting you to participate in an interview focused on exploring how you perceived the CSP to meet the needs of informal caregivers and whether or not you see the CSP having no impact, a short-term impact or a long-term impact on the overall well-being of informal caregivers and their loved ones.

The interview will last approximately 30 minutes. Your answers will be audio-recorded, and detailed field notes will be taken. However, this is solely for analysis purposes, and your responses will be kept secure and your identity will remain confidential.

What We Guarantee

Your right to refuse to participate, your right to refuse to answer any questions, to withdraw at any time, or to have the notes and audio recordings of your responses destroyed without any consequences. This consent form indicates that only the researcher will know who does or does not participate and that findings will be reported without identifying individuals. In addition, should you wish to receive a summary of the findings, please check the appropriate box and provide an address for us to send you a copy.

If you have any questions, please feel free to contact Allie or the Office of Research Ethics, University of Toronto.

Thank you for your help with this important research.
By signing this form I indicate that I understand the following:

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• My participation is completely voluntary; only the researcher will know who has (or has not) participated.
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• I may refuse to answer any questions without penalty.
• I have the right to speak off record at any time.
• I understand that field notes and audio recordings from the interview will be analyzed in such a way as to make it impossible for me to be directly identified.
• I understand that field notes and audio recordings will be protected on a password-protected computer that only the researcher can access, and that they will be used solely for the purposes of the research.

Risks and Benefits

• I understand that the results of this research will be communicated through a final report and/or publications in peer reviewed academic journals and will be used as a resource for policy-makers and researchers.
• I understand that my participation will not affect my employment in any way.

For more information

• Should you have any questions about the interview process or this research please contact:
  ○ Allie Peckham xxx.xxx.xxxx or allie.peckham@mail.utoronto.ca
• Should you have any questions about your rights as a participant, please contact the Office of Research Ethics, University of Toronto, at 416.946.3273 or ethics.review@utoronto.ca

Summary of the Research Results

☐ Please indicate if you would like to receive a final copy of the research findings when it becomes available (Check the box to the left). My e-mail address is:

____________________________________________________________________

I hereby certify that I am signing this form of my own free will, with no pressure from others to do so, and that I do so after having been given all the facts that I need to make this decision. In witness thereof, I have signed this form on this the _____ day of __________, 2014.

__________________________________________________________
Full Name (Printed)  Signature
Appendix 7: Interview Schedule for CF and CSP

I would like to talk about your overall experiences with the CF or CSP and discuss how and if you perceive the project to meet the needs of informal caregivers and their loved ones.

Let’s start by talking about your overall experiences and understanding of the CF or CSP.

1. What has your overall experience with the caregiver initiative been like?
   a. **Probes**: Positive, negative

2. What was the best part of the caregiver initiative?
   a. **Probes**: the money, access to a key worker, learning about services, families making connections with other families, caregivers and families feeling valued, feeling recognized.

3. What was the worst part of the caregiver initiative?
   a. **Probes**: The money, access to a key worker, administrative components

4. What, if anything, would you change about the caregiver initiative?
   a. **Probes**: administrative component, money component, key worker component, different targeting, different triaging

5. Overall, how has the caregiver initiative impacted informal caregivers and their families?
   a. **Probes**: well-being, mood, family, services, ability to connect with friends, ability to ‘get out’ or attend recreational activities—Are these short-term or longer-term changes and why?

6. Overall, do you see the caregiver initiative as improving a caregiver’s ability to continue to care over the short-term; over the long-term?
   a. **Probes**: If not, why not and what do you think would help? If so, why and how?

7. Did the caregiver initiative meet the needs of informal caregivers and their families?
   a. **Probes**: How? What components were most effective? Do you believe these effects are short-term effects or longer-term effects?

8. Do you feel the caregiver initiative encouraged families to connect with one another?
   a. **Probed**: If not, why? If so, how? Do you believe this would impact on their ability to cope, share information, feel as though they were part of a group?

9. Do you feel the caregiver initiative improved an informal caregiver’s connection with formal service providers?
   a. **Probes**: you believe these changes are short-term or longer-term changes?

10. What do we need to do (as a system/society) to be sure that informal caregivers are appropriately and effectively supported?

If provider was directly involved with either the CSP or CF:

11. Do you feel as though you are better connected to other service providers as a result of being connected to the CSP or CF?
   a. **Probes**: do you have stronger ties with formal providers? Has your understanding of the formal system improved? Do you believe these changes are short-term or longer-term changes?

Characteristics

Lastly, I would like to ask some questions about you. You answers to these questions are solely to help me better categorize your responses.

12. What year were you born?

13. What is your relationship with the CSP/CF/Formal system?
Appendix 8: Invitation to Participate for General Caregivers and Providers

My name is Allie Peckham, and I am a PhD student at the University of Toronto. As part of my PhD requirements I am responsible to conduct research that will inform the development and implementation of caregiver-support initiatives. My research focuses on the role of the informal caregiver and I am particularly interested in developing an understanding of what types of supports might benefit caregivers and their families over both the short and the longer terms.

I am looking for individuals who have firsthand experience either as an informal caregiver or as a professional who has considerable knowledge of the informal caregiver experience and/or an understanding of “what works best for whom”.

I am writing to invite you to participate in a telephone interview that will last approximately 30 minutes.

As a result of your first-hand experience, I would like to discuss:

- What types of supports seemed to work best for informal caregivers and their loved ones over the long term?

Given your firsthand experiences as either a caregiver or as a professional who works with caregivers, you have valuable insight to support the development of this research and inform an understanding of what supports would be more likely to give caregivers and their families the longest lasting benefits.

Whether or not you choose to participate in an interview is completely up to you. However, by sharing your valuable first-hand experiences, thoughts, and ideas, you can help to improve the development of initiatives aimed at supporting caregivers and their families.

If you choose to participate, please call or e-mail Allie at the University of Toronto to schedule an interview time at your earliest convenience. You can reach Allie by phone at xxx.xxx.xxxx or by e-mail at allie.peckham@mail.utoronto.ca.

I look forward to hearing from you.

Sincerely,

Allie Peckham

Allie Peckham, MSW, PhD Candidate
Institute of Health Policy, Management and Evaluation
University of Toronto

allie.peckham@mail.utoronto.ca
Appendix 9: Informed Consent for General Caregivers and Providers

**Background**

Informal caregivers play a crucial role at both the individual and systems level. In fact, informal caregivers provide the bulk of the care in the home and community care setting.

Many long-term care policies are based on the assumption that informal caregivers will be there to provide care to dependent older adults and fragmented formal ‘non-systems’ of care that are not well equipped to serve children and older adults requiring multiple services from multiple providers in different fields (e.g. hospital, home care, community supports, rehabilitation) adds to the challenge of being a caregiver.

The literature often provides inconsistent and often conflicting evidence about whether, or under what conditions, formal supports for informal caregivers support caregivers over the long-term.

The lack of systematic evaluation of different caregiver supports leaves considerable room for debate surrounding the costs and consequences. Currently, the development, implementation, and evaluation of informal caregiver initiatives often fails to consider that in addition to immediate, short-term outcomes, there may be a range of longer-term gains connected to the establishment or strengthening of social networks. Therefore, the question is not whether caregiver supports hold promise; it is which supports work best for which caregivers and under what conditions?

This research aims to narrow the intelligence gap by generating evidence that provides insight into designing effective interventions to support informal caregivers and their networks over the long-term.

**What you are being asked to do**

I am inviting you to participate in an interview focused on exploring how/if you perceived certain factors to be crucial in meeting the needs of informal caregivers and whether or not you see them as having no impact, a short-term impact or a long-term impact on the overall well-being of informal caregivers and their loved ones.

The interview will last approximately 30 minutes. Your answers will be audio recorded and detailed field notes will be taken. However, this is solely for analysis purposes and your responses will be kept secure and your identity will remain confidential.

**What We Guarantee**

Your right to refuse to participate, your right to refuse to answer any questions, to withdraw at any time, or to have the notes and audio recordings of your responses destroyed without any consequences. This consent form indicates that only the researcher will know who does or does not participate and that findings will be reported without identifying individuals. In addition, should you wish to receive a summary of the findings, please check the appropriate box and provide an address for us to send you a copy.

If you have any questions, please feel free to contact Allie or the Office of Research Ethics, University of Toronto.

Thank you for your help with this important research.
By signing this form I indicate that I understand the following:

Conditions for participating
• My participation is completely voluntary.
• I can leave the interview at any time, and ask that my responses not be included in the research results with no penalty or consequences to me.
• I may refuse to answer any questions without penalty.
• I have the right to speak off record at any time.
• I understand that field notes and audio recordings from the interview will be analyzed in such a way as to make it impossible for me to be directly identified.
• I understand that field notes and audio recordings will be protected on a password-protected computer that only the researcher can access, and that they will be used solely for the purposes of the research.

Risks and Benefits
• I understand that the results of this research will be communicated through a final report and/or publications in peer reviewed academic journals and will be used as a resource for policy-makers and researchers.
• I understand that my participation will not affect me in any way.

For more information
• Should you have any questions about the interview process or this research please contact:  
  ○ Allie Peckham xxx.xxx.xxxx or allie.peckham@mail.utoronto.ca
  ○ Should you have any questions about your rights as a participant, please contact the Office of Research Ethics, University of Toronto, at 416.946.3273 or ethics.review@utoronto.ca

Summary of the Research Results

☐ Please indicate if you would like to receive a final copy of the research findings when it becomes available (Check the box to the left). My e-mail address is:
____________________________________________________________________

I hereby certify that I am signing this form of my own free will, with no pressure from others to do so, and that I do so after having been given all the facts that I need to make this decision. In witness thereof, I have signed this form on this the _____ day of ___________ 2015.

____________________________________  ______________________________
Full Name (Printed)                              Signature
Appendix 10: Interview Schedule for General Caregivers and Providers

Through the course of my research I have heard a range of ideas about what might work best to support caregivers over the long-term. I would like to understand if you perceive similar ideas and how we might begin to support them.

**Building, sustaining, and encouraging bonding relationships:**

1. Do you think one of the aims of caregiver supports should be to encourage and support relationships with your immediate family and friends?
   a. If so, why? If not, why not?
   b. What would it take to support those relationships?
      i. Indirect supports—supports for the care recipient (bathing, day programs)?
      ii. Direct supports—supports for the caregiver (respite, counselling)?
      iii. Financial supports—Tax credits, work leave arrangements?
      iv. Alternatives? Combinations? Flexibility?
   c. How important are these relationships to sustaining a caregiver’s ability to continue to care?

**Building, sustaining, and encouraging bridging relationships:**

2. Do you think one of the aims of caregiver supports should be to encourage relationships with other caregivers in similar circumstances?
   a. If so, why? If not, why not?
   b. What would it take to support those relationships?
      i. Indirect supports
      ii. Direct supports
      iii. Financial supports
      iv. Alternatives? Combinations? Flexibility?
   c. How important are these relationships to sustaining a caregiver’s ability to continue to care?

**Building, sustaining, and encouraging linking relationships:**

3. Do you think an aim of caregiver supports should be to develop a caregiver’s network to professional providers and organizations as a crucial priority?
   a. If so, why? If not, why not?
   b. What would it take to support those relationships?
      i. Indirect supports—supports for the care recipient?
      ii. Direct supports—supports for the caregiver?
      iii. Financial supports
      iv. Alternatives? Combinations of supports?
   c. How important are these relationships to sustaining a caregiver’s ability to continue to care?

4. Do you think an aim of caregiver supports should be to ensure that organizations and providers are connected together?
   a. If so, why? If not, why not?
   b. What would it take to support those relationships?
   c. How important are these relationships to sustaining a caregiver’s ability to continue to care?

**Overall:**

5. Do you think a caregiver would be better able to continue to care if polices did encourage the development of these relationship at the familial, social, and formal levels?
   a. What do you think this is important?
b. Which do you think is most important? Family relations, broader social connections, linkages to formal providers and organizations?
c. Where should policy makers start?

Characteristics

Lastly, I would like to ask some questions about you. Your answers to these questions are solely to help me better categorize responses.

1. What year were you born?
2. Are you a spouse, daughter, relative, friend neighbour, provider?
3. What are the extent of your caregiving roles/ professional services?

How long have you/were you a caregiver/service provider