Exploring the Role of Resilience in the Experiences of Family Caregivers of a Patient Requiring an Alternate Level of Care

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
Institute of Health Policy, Management and Evaluation
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Abstract

Patients requiring an Alternate Level of Care (ALC) wait in the hospital for an appropriate discharge setting despite being cleared for discharge. The increasing ALC rates have negative implications for health system performance and patient and caregiver health and wellbeing. To date, there are few studies focusing on caregiver perspectives during the ALC period and no research has been conducted on caregiver resilience during this period. This thesis describes the development of a conceptual framework on resilience and family caregiving. Using this conceptual framework, a secondary analysis of qualitative data was undertaken to explore how resilience was impacted and reflected in family caregivers who are caring for a patient who requires an ALC. Three themes were identified: becoming an advocate, variable communication with the healthcare team and searching for balance. Findings from this study shed light on how the health system can support caregivers during this stressful time.
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Chapter 1

1 Introduction

1.1 Overview of Thesis

Aging populations and rising health care expenditures across developed nations have raised concerns among policy planners, who are emphasizing the need for high quality care and efficient use of health care resources (Canadian Medical Association, 2013). To ensure high quality and efficient healthcare, it is imperative that the health system can accommodate patients in care settings most appropriate for their needs. Currently, there are increasing concerns that resource intensive settings, including hospitals and post-acute care facilities (e.g. continuing care and rehabilitation hospitals), are being occupied by patients who no longer require the level of intensive care that is provided in these settings. In Canada, these individuals are referred to as patients who require an Alternate Level of Care (ALC). Despite being cleared for discharge by a physician, patients who require an ALC are stuck in hospital as they wait for a more appropriate care setting (such as long-term care, assisted living, or homecare) for their needs (Walker, 2009).

Waiting in the hospital for an appropriate discharge setting not only impacts the patient and broader health system, but also their family caregivers who continue to provide care to the patient during this time (McCloskey et al, 2015). Family caregivers are typically unpaid family members, friends or neighbours who provide care to an individual who requires support for their health, social and psychological care needs (The Change Foundation, 2016). The caregiving journey is often associated with various degrees of stress, however, there seems to be diversity in how caregivers respond to stress and adversity. A significant adversity in the caregiver journey may be the hospitalization of the care recipient and the ALC period. During this vulnerable time and transition in care, caregivers may find it difficult to adjust to the stress of hospitalization due to changes in their daily routine, unknown patient health status, and managing their personal lives (Cressman et al, 2013). ALC often leads to greater uncertainty due to the resource constraints in the appropriate discharge settings (CIHI, 2009). The perspectives of these family caregivers are often not incorporated into ALC research (Cressman et al, 2013; McCloskey et al, 2015).
Resilience is defined as the ability to adapt to significant stress and adversity (Luthar, Cichetti & Becker, 2000). Previous resilience research in the context of family caregiving, has focused on caregivers for an individual with specific health conditions including dementia/Alzheimer’s disease (Donnellan, Bennett & Soulsby, 2015; O’Dwyer et al, 2017; Sun, 2014), autism spectrum disorder (Bekhet, Johnson & Zauszniewski, 2012; Bekhet & Matel-Anderson, 2017), and cancer (Ye et al, 2017). No studies have considered resilience among caregivers who are caring for an individual transitioning from one setting of the health care system to another or experiencing a delay during a transition. Such delays can be times of uncertainty and stress; thus, the needs of caregivers may be significant during this period (Cressman et al, 2013).

The role of resilience in the caregiver experience of caring for a patient who requires an ALC has yet to be explored. It is important to examine what caregiver resilience looks like in the context of ALC to create interventions to bolster resilience.

The purpose of this research is to understand how caregiver resilience is impacted and reflected in caring for a patient who requires an ALC. Despite their readiness for hospital discharge, patients who require an ALC are those who continue to wait in the hospital for an appropriate discharge setting for their care needs (Walker, 2009). The hospitalization is considered, in this study as an example of an adverse event, particularly the subsequent ALC designation of the care recipient.

This thesis aims to address the following research questions.

1. What is the state of the current evidence on resilience and the experiences of family and friend caregivers?
2. How is caregiver resilience reflected in and impacted by caring for a patient who requires an Alternate Level of Care?

The remainder of this chapter provides an overview of existing ALC literature and outlines the study objectives, research questions, and implications of this research.

The second chapter addresses the first research question through a mapping review. Chapter two also outlines the mapping review methods and provides an overview of the evidence base on
resilience and family caregiving. The development of a conceptual framework that will be used to guide the supplementary secondary analysis is described.

The third chapter discusses the methods for the supplementary secondary analysis of qualitative data on caregivers of patients who require an ALC. This includes the study design, previous data collection, data analysis, and a discussion on rigor.

The fourth chapter addresses the second research question. More specifically, the findings of the secondary analysis will examine resilience among caregivers, how resilience was impacted and how resilience was reflected during their ALC experience. Anonymized quotes from caregiver interviews are used to illustrate findings.

Lastly, the fifth chapter discusses the findings in relation to the literature, identifies areas for future research, outlines implications for practice, policy and research as well as the strengths and limitations of the study.
1.2 Background

Delayed hospital discharge is a health systems issue experienced worldwide (Canadian Institute for Health Information [CIHI], 2012; Challis et al, 2014; Lim et al, 2006). Delayed discharge occurs when patients have completed their hospital care and are waiting for a more appropriate discharge setting (post-acute care or long-term care) for their health and social care needs (CIHI, 2009; Walker, 2009). The Canadian construct for delayed hospital discharge is Alternate Level of Care (ALC). ALC is a designation applied to patients who remain in hospital when there are issues with capacity in out-patient settings (Barnable et al, 2015). Studies have reported that patients that are designated as ALC generally receive less attention from medical staff and have fewer opportunities to ambulate, placing them at an increased risk of functional decline and falls risk in addition to all of the other risks associated with being in hospital (e.g., exposure to hospital borne infections) (Barnable et al, 2015; Costa et al, 2012).

In Ontario, patients designated as requiring an ALC account for a large number of in-patient hospital beds. As of January 2018, 4,807 patients were designated as ALC (Ontario Hospital Association [OHA], 2018). As of December 2017, patients who required an ALC accounted for 15.9% of hospital beds in Ontario. In Northwestern Ontario (the study setting), the proportion of patients who required an ALC was two-fold at 35% (OHA, 2018). The most common discharge destination for these patients was long-term care (41%). It is projected that the proportion of ALC patients will continue to increase as the Canadian population ages (Barnable et al, 2015; CIHI, 2012).

1.2.1 ALC and the Healthcare System

Based on the care needs of patients who require an ALC, acute care is a costly alternative to other discharge settings (Barnable et al, 2015). Discharge settings that are typically more appropriate for patients designated as ALC include: long-term care homes, retirement homes, supportive or assisted living, or the community with formal home and community care services (Barnable et al, 2015). However, due to the lack of capacity in the long-term care and home and community care sectors, these patients are left waiting in the hospital where care has been described as sub-optimal for their needs (Barnable et al, 2015; Walker, 2011). Therefore, ALC
has negative consequences for health system performance and generates significant costs to the healthcare system (CIHI, 2009). ALC contributes to overcrowding in hospital emergency departments and creates inefficiencies in the health system by reducing patient flow, increasing wait times for emergency care, reducing the number of elective surgeries that can be performed, and reducing the number of new hospital admissions (Costa & Hirdes, 2010; Costa, Poss, Peirce & Hirdes, 2012; Landeiro et al, 2015; Ovens, 2011; Rogers et al, 2014; Sutherland & Crump, 2013; Walker 2011). In addition to health system inefficiencies, the health of the patient and the patient experience is often compromised when they are designated ALC.

1.2.2 Characteristics of ALC Patients

Patients who require an ALC tend to share similar characteristics such as: older age, cognitive impairment, presence of multiple chronic conditions, and high functional dependence (Barnable et al, 2015; Bo et al, 2015; Challis et al, 2014; Chen et al, 2012; Costa et al, 2012; Rogers et al, 2013). The quality of care received during this vulnerable time may further compromise their health and place them at an increased risk of nosocomial infections, functional decline, depressive symptoms, immobility, falls, and hospital-induced delirium (Barnable et al, 2015; Costa et al, 2012; Costa & Hirdes, 2010; Covinsky et al, 2003; Hendy et al, 2012; Hwabejire et al, 2013; Lim et al, 2006). Further, patients who remain in hospital for an extended period of time may experience a decreased quality of life as a result of lost autonomy and social isolation (Costa et al, 2012; Landeiro et al, 2015; McCloskey, Jarrett & Stewart, 2015). Although the clinical characteristics of ALC patients are important predictors of hospitalization and subsequent delays, health system factors such as waiting for a long-term care bed and inefficient hospital processes are significant predictors of the number of days a patient is designated as ALC (Challis et al, 2012; Costa & Hirdes, 2010; Hwabejire et al, 2013; Rogers et al, 2013).

1.2.3 Caregiving

Caregiver support is critical to the health and well-being of patients. Caregivers provide a range of support including (and not limited to) providing transportation, assisting with housework, coordinating care, assisting with medical treatment, and providing personal care (Sinha, 2012). In Canada, the majority of caregivers are female and are between 45 and 64 years of age and
over a quarter of caregivers also provide support to a child under the age of 18 years (Sinha, 2012). Overall, their contributions to the healthcare system are significant, saving the healthcare system an estimated $25-26 billion annually (Hollander, Liu & Chappell, 2009). However, caregiving can compromise the physical and psychological health of caregivers (Kim & Knight, 2016; Schulz & Sherwood, 2008). When family caregivers are providing care to an individual with declining health and increasing functional needs, the magnitude of social isolation, emotional strain, and financial loss tends to increase as the caregiving journey progresses (Bo et al, 2015; Costa et al, 2012; Lim et al, 2006). Patients who have a caregiver experiencing burnout are at an increased risk of hospitalization and subsequent delay in discharge (Costa & Hirdes, 2012; McCloskey et al, 2015). A large proportion of the existing caregiving literature focuses on the negative aspects and needs of caregivers (Peacock et al, 2010).

1.3 Caregivers and the ALC Literature

Existing research has primarily focused on ALC in the context of health system performance through a quantitative approach. To date, there are very few studies that used a qualitative approach to explore/understand the experiences of those affected by ALC. Of these few existing studies, the majority of them focus on the patient experience of being designated as ALC rather than the caregiver experience of caring for a patient who requires an ALC. Previous research has shown that although caregivers of ALC patients are experiencing burnout or are highly susceptible to burnout, they do not experience relief of their caregiving duties when patients are hospitalized and designated ALC (Costa et al, 2012). In one study, during this time, caregivers received minimal emotional and social support from the hospital staff, resulting in feelings of anxiety and stress (Higgins et al, 2007). Further, the lack of information regarding the patient’s condition can result in uncertainty for the caregiver, making it difficult for caregivers to make decisions on behalf of the patient or plan for their future (Cressman et al, 2013; Higgins et al, 2007).

In a narrative study undertaken by Cressman et al (2013), the authors explored the experiences of an ALC designation on four family caregivers and sixteen patients. Caregivers characterized their delayed discharge experience as a time of uncertainty and frustration due to the lack of
information regarding diagnosis, prognosis, and wait times. The lack of information made it difficult for caregivers to make care decisions and future placement arrangements for the patient. One caregiver noted the financial hardships of paying for personal housing expenses and the ALC co-payment (a fee the hospital charges per day during the ALC period that is equivalent to the daily cost of living in a long-term care facility) (Cressman et al, 2013).

In a qualitative study by McCloskey, Jarrett & Stewart (2015), the ALC experiences among four family caregivers and five patients were explored. In the period leading up to hospitalization, family caregivers noticed that patients were increasingly emotionally and physically dependent on them, which resulted in social isolation for both the caregiver and patient. Although caregivers found it difficult to manage their increasing caregiving duties at home, many caregivers perceived their situation to be normal. As a result, caregivers did not seek formal support and were generally unaware of the community supports that were available to them. Although the pre-hospitalization period was a stressful and challenging time for many caregivers, they continued to provide support to patients during the hospital period as well because their loved ones received less attention from hospital staff. Financial implications were also noted; all families were charged with an ALC co-payment in addition to expenses they incurred for hospital parking and transportation (McCloskey, Jarrett & Stewart, 2015).

In a report by Doleweerd & Berenzy (2009), authors highlighted the experiences of twenty-one patients and their caregivers (dyadic perspective) on their transition from the hospital to a long-term care facility. Caregiver fatigue was a major contributor to hospital admission in many cases. Many of these families believed that the hospitalization could have been prevented if they were provided with caregiver education and relief. The transition was a difficult process as most families did not make long-term care arrangements prior to hospitalization due to feelings of guilt. When families began to plan for a long-term care placement, they felt anxious due to the lack of information regarding wait times, insufficient support from hospital staff, and lack of transparency in the application process. The lack of pre-planning and the complex application process increased the amount of time the patient spent in ALC in most cases (Doleweerd & Berenzy, 2009).

Lastly, in a study by Kuluski, Im & McGeown (2017), the experiences of fifteen caregivers caring for an ALC patient was explored. The quality of care the ALC patients received during
their hospital stay was inconsistent and often resulted in poorer health outcomes. To address the lack of personal care, fatigued caregivers continued to provide care to fill the gaps in care delivery. Caregivers were providing care in hospital while also balancing commitments in their personal lives. All the patients were wait-listed for long-term care, and the process of waiting for long-term care was often uncertain and confusing. While waiting in the hospital, the community care access centre (a government funded agency that facilitated access to home and community care services in the province of Ontario at the time of the study) staff suggested that some of the patients wait for their placement at home. In these cases, all caregivers refused to have the patient return home (Kuluski, Im & McGeown, 2017).

Although the qualitative studies described above did not use a resilience lens, various levels of resilience may be evident in the experiences of caregivers. Resilience is defined as the ability to adapt despite adversity (Luthar et al, 2000; Zauszniewski, Bekhet & Suresky, 2010). For example, despite feeling stressed, caregivers continued to provide care to the care recipient during the ALC period. Further, caregivers who perceived a reduced quality of care from hospital staff took it upon themselves to assist the patient with basic care needs such as bathing, toileting and feeding (Costa & Hirdes, 2010; Higgins et al, 2007; McCloskey et al, 2015; Doleweerd & Berenzy, 2009). Lastly, although the process of applying for long-term care homes was often complex and lacked transparency, some caregivers were able to navigate the system successfully, while other caregivers had to deal with longer waiting periods (Cressman et al, 2013; Doleweerd & Berenzy, 2009).

1.4 Introduction to Resilience

Resilience was previously seen as a personality characteristic in early research (Luthar et al, 2000). Resilience research often focused on child development and the individual characteristics of children. However, researchers later recognized the role of external factors, such as social resources, on resilience (Luthar et al, 2000; Masten & Garmezy, 1985; O’Leary, 1998). Recently, resilience is viewed as a psychological concept and is defined as the ability to manage or adapt to adversity (Luthar et al, 2000; Zauszniewski et al, 2010; VanBreda, 2001). Furthermore, resilience research explores the differences in adaption to stress among individuals
Research on resilience crosses multiple disciplines and can focus on individual resilience or resilience of groups (Boston University School of Public Health [BUSPH], 2015; Ledesma, 2014). In the context of this study, the focus will be on individual resilience among family caregivers.

By focusing on the vulnerabilities and needs of caregivers, positive aspects of caregiving may be overlooked (Peacock et al, 2010). In the context of significant stress, resilience models focus more on the strengths of an individual rather than their vulnerabilities (O’Leary, 1998; Rutter, 1987). Resilience is viewed as a dynamic process and is influenced by the interaction of risk factors and protective factors, rather than a personality characteristic (Luthar et al, 2000; O’Leary, 1998; Rutter, 1987; Zauszniewski et al, 2010).

To explore resilience, an individual must first experience a significant adversity in their lives (Luthar et al, 2000). Risk factors and protective factors may vary depending on the individual and the context of the adversity (Southwick et al, 2014). Risk factors interfere with an individual’s ability to overcome or deal with stress (O’Leary, 1998; Zauszniewski et al, 2010). Protective factors are those that have the potential to moderate or mediate the effect of risk factors (Rutter, 1987; Zauszniewski et al, 2010; Zhao et al, 2016). When risk factors outweigh protective factors, individuals are at a higher risk of poor physical and/or psychological health outcomes (Luthar et al, 2000; Rutter, 1987). However, when protective factors mediate or moderate the effect of risk factors, individuals are at a lower risk of negative health outcomes despite the challenges they may endure (Rutter, 1987; Zhao et al, 2016). It is important to acknowledge that levels of resilience are not static and can change over time depending on a number of factors (BUSPH, 2015).

Resilience may play a role in the caregiver experience of caring for an ALC patient. In the context of this study, the significant adversity refers to hospitalization and subsequent delayed discharge of the patient. The existing literature base does not explore the role of resilience during the ALC experience and the factors that enable or hinder a caregiver’s ability to provide care during this critical period in the caregiving journey. A hospital admission that results in ALC is a period in the caregiving journey where stress may be at its peak. By exploring the impact of risk factors and protective factors (in relation to resilience) on ALC, the protective
factors that enable some caregivers to continue in their role and the factors that may contribute to breaking points will be illustrated.

Looking at protective factors, in particular, supports a strengths-based approach to resilience and will provide insights on how to support caregivers during the ALC period (Peacock et al, 2010). Caregivers who experience chronic and uncontrollable stress are highly susceptible to risk factors such as burnout, a reduced quality of life, anxiety, and depression, which are known to compromise resilience (Southwick et al, 2013; Zauszniewski, Bekhet & Suresky, 2009). One study found that ALC coincide with caregivers reaching a breaking point where they could no longer provide adequate care or a safe environment for the patient (Costa & Hirdes, 2012). However, factors such as love for the care recipient, strengthening of relationships and faith can be protective against stress (Bekhet & Matel-Anderson, 2017; Bremault-Phillips et al, 2017; Peacock et al, 2010). Although caregivers may experience the stress of ALC, there may be diversity in the ability to adapt to stress.

The ALC period may exacerbate risk factors that compromise resilience, which may ultimately reduce a caregiver’s ability to adapt to the patient’s circumstances. On the other hand, some caregivers may be able to successfully adapt to their situation despite being in a stressful situation due to factors that foster their resilience.

1.5 Rationale

A substantial amount of research has focused on the clinical and demographic characteristics of ALC patients and the factors that influence length of stay and delayed discharges (Barnable et al, 2014; Bo et al, 2015; Challis et al, 2014; Costa & Hirdes, 2010; Costa et al, 2012), with several of these studies emphasizing the need to focus on the perspectives of caregivers during the ALC period (Costa & Hirdes, 2010; Challis et al, 2013; Cressman et al, 2013; Kydd, 2008; Swinkels & Mitchell, 2009). A hospital admission and ALC period is a time of adversity among family caregivers’ due to hospitalization and subsequent care transitions. Their ability to adapt to this adversity may be influenced by their level of resilience. Therefore, it is important to examine how resilience is reflected in the caregiver’s experience of caring for a patient who requires ALC in order to understand the strengths of caregivers and reduce the impact of ALC
and healthcare transitions on family caregivers.

The current literature typically focuses on resilience from a quantitative lens, using resilience scales to objectively measure health outcomes of caregivers (Zhao et al, 2016). A scoping review by Zhao et al (2016) found that the current literature fails to address resilience from the lived experiences of caregivers. Furthermore, current resilience research is focused on the broader caregiving journey of caregivers of individuals as opposed to significant points in the caring trajectory.

The role of resilience in caring for a patient who requires an ALC has yet to be explored. It is important to examine what caregiver resilience looks like in the context of ALC as well as explore how a family caregivers’ resilience is impacted by ALC.

The purpose of this research is to understand how caregiver resilience is reflected in and impacted by caring for someone who requires an ALC.

This thesis aims to address two research questions:

1. What is the state of the current evidence regarding resilience and the caregiving experiences of family caregivers?
2. How is caregiver resilience reflected in and impacted by caring for a patient who requires an Alternate Level of Care?

1.6 Significance

This thesis will provide researchers with an enhanced understanding of how resilience is reflected in the family caregiver experience. By drawing on ALC as an example, we will unpack how resilience may be impacted by a situation that tends to be stressful and uncertain.

The findings of the study will inform future work including what is required, in terms of programs and interventions, to support family caregivers in their role. The findings may illuminate the protective factors that bolster resilience during hospitalization and transitions in care (Zhao et al, 2016). By fostering resilience in caregivers, the healthcare system may be better able to support caregivers in their role leading up to, during and after the hospital stay.
These strategies and interventions may result in higher quality care experiences for both patients and caregivers.
2  Mapping Review

2.1  Mapping Review Methods

The mapping review was developed by the Evidence for Policy and Practice Information and Co-ordinating Centre at University College London (Cooper, 2016. The purpose of a mapping review is to provide an overview of existing research by mapping characteristics of interest (e.g. country of origin, study design, sample characteristics) from articles that meet the identified inclusion criteria. Mapping reviews can identify gaps in the literature, identify specific research questions, and inform areas for future research (Cooper, 2016; Grant & Booth, 2009). In comparison to a systematic review, a mapping review addresses a broader research question and therefore widens the body of literature that is reviewed. However, by providing an overview of comprehensive literature, a researcher may oversimplify the concepts presented in the literature (Grant & Booth, 2009). Another weakness of conducting a mapping review is often the exclusion of a rigorous quality appraisal process for included literature (Grant & Booth, 2009).

A mapping review was conducted to answer the first research question of the thesis: What is the state of the current evidence on resilience and the experiences of family and friend caregivers? The objective of this mapping review was to identify and map the literature on the role of resilience in adapting to stress and/or adversity along the caregiving journey.

2.1.1 Initial Planning Phase

During the initial planning phase, the objective and scope of the project were identified and approved by the thesis committee. The mapping review focused on the concept of resilience, among family caregivers (Luthar et al, 2000; VanBreda, 2001). In an initial review of the literature, the researcher was unable to identify research specifically on resilience among family caregivers during a hospital discharge delay (when the person the caregiver is looking after is designated as ALC) and very few studies focused on care transitions generally in the context of family caregiving and resilience. Therefore, the focus of the mapping review was broadened to
incorporate resilience and family caregiving, generally. This larger scope would allow for a broader understanding of resilience in this population.

2.1.2 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria were based on the scope identified in the planning phase. Following the iterative process of refining the inclusion and exclusion criteria with the thesis committee, the following inclusion and exclusion criteria were applied to all the records (Clapton, Rutter & Sharif, 2009):

**Inclusion Criteria**

1. Qualitative or quantitative research study
2. Concept of resilience in the context of healthcare
3. Focus on unpaid family and friend caregivers
4. Published articles within the last ten years

**Exclusion Criteria**

1. If unable to obtain the full text article
2. Not written in English
3. Resilience in children and child development
4. Resilience in patients / care recipients

2.1.3 Selection of Databases and Searching

The three research databases selected for the review were: OVID Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. Prior to conducting the search, search strings were piloted in consultation with the thesis committee and a University of Toronto librarian to generate the most relevant literature on resilience and family caregiving. Within these databases, the following keywords were utilized for the review: “family caregiver”, “informal caregiver”, “caregiver”, “carer”, “resilience”, “resilient”, and “resiliency”.
The search yielded a total of 1,447 records: Medline (463 records), CINAHL (261 records) and PsycINFO (723 records). These records were imported into a reference manager (Mendeley) and duplicate records removed. Following the removal of duplicate records, the inclusion and exclusion criteria were applied to 982 abstracts. After the initial screen, 115 records were retrieved in full-text for further screening. Following the full-text screen, 70 records were included in the mapping review (See Figure 1 for details). Articles were excluded at this stage if they were not available in full-text or not available in English.

2.1.4 Data Extraction

After the full-text screening was completed, a keywording tool was developed. The purpose of the keywording tool is to consistently extract data from the included articles to provide an overview of the literature (Clapton et al, 2009). The keywording tool was developed and refined by members of the research team (RL and KK) by piloting the tool on a subset of included studies. The keywording tool consisted of three sections: 1) study characteristics (author, year of publication, country of origin, study type, study design, study methods), 2) sample characteristics (health condition, relationship to the care recipient, length of caregiving) and 3) evidence on resilience (risk factors, protective factors, outcomes of resilience). The primary researcher then extracted the data from the remaining articles.
Figure 1. PRISMA Flow Diagram
2.2 Background

As noted earlier in this thesis, resilience is defined as the ability to manage or adapt to significant stress or adversity (Luthar et al, 2000; VanBreda, 2001; Zauszniewski et al, 2010). Many other definitions exist in the reviewed literature; however, existing definitions share many similar characteristics. Resilience is viewed as process that is influenced by the interaction of risk factors and protective factors, rather than a personality characteristic (Luthar et al, 2000; O’Dwyer et al, 2017; VanBreda, 2001; Zauszniewski et al, 2010). Further, many of these studies found that levels of resilience are amenable to change through direct interventions (Bekhet, Johnson & Zauszniewski, 2012; Bitsika, Sharpley & Bell, 2013; Cherry et al, 2013; Deist & Greeff, 2017; Gaugler et al, 2007; Sun, 2014). Direct interventions include formal education and formal caregiver training, which enable caregivers to navigate the health and social care systems, have meaningful conversations with care providers, and provide appropriate care for a given condition (Bremault-Phillips et al, 2016; Cherry et al, 2013; Sun, 2014). Exploring the concept of resilience in the context of healthcare has implications for supporting family caregivers in their role and ensuring their physical and psychological well-being are not compromised (Bekhet & Matel-Anderson, 2017; Bremault-Phillips et al, 2016; Chappell & Dujela, 2008; Donnellan, Bennett & Soulsby, 2015; El Masry, Mullan & Hackett, 2013; Fernandez-Calvo et al, 2016; O’Rourke et al, 2010).

2.3 Mapping Review Findings

The primary researcher identified 70 articles published between January 2007 - September 2017 that met the inclusion criteria and exclusion criteria. Findings from the included studies were extracted using a keywording tool that was developed by the research team (Clapton et al, 2009). The keywording tool extracted the following information from each article (if applicable): year of publication, country of origin, study design, study methods, health condition(s) of the care recipient, the caregiver’s relationship to the care recipient, length of caregiving, risk factors, protective factors and outcomes of resilience.
2.3.1 Year of Publication

In recent years, there appears to be increasing interest in resilience and family caregiving, with the number of publications increasing within the last decade. Figure 2 displays the study count by the year of publication.

![PUBLICATIONS BY YEAR](image)

**Figure 2.** Study Count by Year of Publication
2.3.2 Country of Origin

The majority of the publications in the mapping review originated from the United States, Australia and United Kingdom. Figure 3 displays the study count by country of origin.

Figure 3. Study Count by Country
2.3.3 Study Design

In regard to the study design, the majority of studies were descriptive in nature followed by secondary analyses. Figure 4 displays the study count by study design.

Figure 4. Study Count by Study Design
2.3.4 Study Methods

In regard to study methods, there was an even amount of quantitative methods and qualitative methods used by these studies, with a few studies using both quantitative and qualitative methods. Figure 5 displays the study count by study methods.

Figure 5. Study Count by Study Methods
2.3.5 Caregiver Type

The types of caregivers were largely unspecified family members and unspecified informal caregivers (family and friend caregivers). Figure 6 displays the study count by caregiver type.

![COUNT BY CAREGIVER TYPE](image)

**Figure 6.** Study Count by Caregiver Type
2.3.6 Illness Type

The most common illnesses or conditions of the care recipients were Alzheimer’s or dementia, autism spectrum disorder, and mental illness. Figure 7 displays the study count by illness type.

**Figure 7.** Study Count by Illness Type
2.4 Overview of Risk Factors and Protective Factors

Caregivers often experience chronic stress and are highly susceptible to risk factors such as caregiver burnout (Donnellan, Bennett & Soulsby, 2016; Southwick et al, 2013; Zauszniewski, Bekhet & Suresky, 2009; Zhao et al, 2016). The diversity in the response to stress may be partly dependent on their level of resilience (Rutter, 1987). A caregiver’s level of resilience is determined by the interaction of the risk factors and protective factors they experience throughout their caregiving journey (Luthar et al, 2000; Gaugler, Kane & Newcomer, 2007; Zauszniewski et al, 2010).

Risk factors interfere with a caregiver’s ability to overcome or deal with stress (Zauszniewski et al, 2010). When risk factors outweigh protective factors, caregivers are at a higher risk of poor physical and/or psychological health outcomes (Luthar et al, 2000; Rutter, 1987). On the opposite end of the spectrum, protective factors are those that have the potential to moderate or mediate the effect of risk factors (Wilks & Vonk, 2008; Zauszniewski et al, 2010; Zhao et al, 2016). With higher levels of resilience, there appears to be an increased ability for caregivers to adapt to stress, resulting in greater morale, improved wellbeing, and positive emotions (Fernandez-Calvo et al, 2016; Wilks & Vonk, 2008; Zauszniewski et al, 2010). Several resilience factors were identified in the mapping review and will be described shortly.

2.5 Conceptual Framework on Resilience and Family Caregiving

The terms ‘theoretical framework’ and ‘conceptual framework’ are often used interchangeably in the literature (Green, 2014). To clarify, conceptual frameworks differ from theoretical frameworks; conceptual frameworks are based on concepts rather than established theory. Conceptual frameworks assist researchers in understanding the potential relationships between concepts that are derived from existing research (Green, 2014; Saunders et al, 2015). Conceptual frameworks visually represent the relationships between concepts found in the literature in relation to a specific phenomenon (Saunders et al, 2015). Frameworks are beneficial for guiding qualitative research and can be utilized by researchers to develop research questions, guide the study design, provide structure to the analysis of qualitative data and generate meaningful
results (Green, 2014; Saunders et al, 2015). However, it is important to acknowledge that conceptual frameworks can often oversimplify the literature and overlook the complexities of the phenomenon (Saunders et al, 2015).

After reviewing the seventy articles that met the inclusion and exclusion criteria outlined previously in this chapter, a mapping exercise was undertaken to further understand the concept of resilience in family caregivers. This review identified multiple risk factors and protective factors that compromise or enhance resilience among caregivers. These risk factors and protective factors were extracted from the seventy research articles using the keywording tool (Appendix 1). To ensure consistency when extracting factors from the articles, definitions and guiding examples from the included studies were established prior to the full extraction (Appendix 2).

The mapping exercise began with a list of risk factors and protective factors that were derived from the literature. To understand how these factors were related, the researcher brainstormed potential relationships between risk factors and protective factors (e.g. the relationship between social isolation (risk) and social support (protective) from the literature (Saunders et al, 2015). Next, relationships between risk and protective factors were refined in consultation with the research committee. Subsequently, these risk and protective factors were grouped into larger resilience factors. To visually depict the relationships between the concepts, the conceptual framework on resilience and family caregiving was developed (See Figure 8).

The conceptual framework on resilience and family caregiving exhibits the continuum of resilience factors and demonstrates how each factor can be protective or pose a risk in adapting to stress. This framework (visual depiction of the findings) presents the main resilience factors in the middle, which includes: family relationships, formal resources, cognitions and coping strategies, social support, access to information, caregiving context (such as stigma and feelings of burden) and personal factors (such as faith and spirituality). Risk factors are factors identified in the literature that compromised or interfered with the caregivers’ ability to manage stress and adversity. These risk factors are presented on the left of the resilience factors. Protective factors were factors identified in the literature that enhanced the caregivers’ ability to manage stress and adversity. These protective factors are presented to the right of the resilience factors. For each
resilience factor, the corresponding risk and protective factors are delineated. This allows for better understanding of how risk and protective factors influence caregiver resilience.

<table>
<thead>
<tr>
<th>Adversity: hospitalization, long-term caregiving, healthcare transitions, alternate level of care designation</th>
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<tbody>
<tr>
<td><strong>Risk Factors</strong></td>
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<td>Family conflict</td>
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<tr>
<td>Lack of access</td>
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<td>Guilt</td>
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<td>Grief</td>
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<td>Social isolation</td>
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<td>Uncertainty</td>
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<td>Patient dependency</td>
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<td>Feelings of burden</td>
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<td>Conflicting priorities</td>
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<td>Stigma</td>
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<tr>
<td>Financial strain</td>
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<td>Poor physical/mental health</td>
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</table>

**Figure 8.** Conceptual Framework on Resilience and Family Caregiving
2.6 Narrative Synthesis

This section will describe the risk factors and protective factors identified through the mapping review, which is visually depicted in the conceptual framework (Figure 2). Each section will provide an overview of the evidence related to resilience factors and their relevance to caregivers.

2.6.1 Resilience Factor: Family Relationships

Family members and close friends can be an important source of support for caregivers or an additional source of family strain. The relationships with family members, however, can change throughout the caregiving journey (Deist & Greeff, 2017). In the face of adversity in the caregiving journey, family relationships can remain stable, be strengthened or become strained (Bekhet & Matel-Anderson, 2017; O’Dwyer et al, 2013). Strained family relationships caused additional stress along the caregiving journey and can lead to feelings of resentment and anger (Bremault-Phillips et al, 2016; O’Dwyer et al, 2013). Ultimately, strengthened family relationships can increase caregiver resilience by providing caregivers with the motivation to provide care (Deist & Greeff, 2017).

Risk Factor: Family Conflict

Family conflict was a risk factor that was identified in six of the seventy included studies. These studies, however, did not specify whether the family tension existed prior to caregiving or if the family tension emerged as a result of caregiving. A major source of family conflict surrounded decision-making, whereby family members would question the decisions the caregiver made on behalf of the care recipient (Bremault-Phillips et al, 2016; O’Dwyer et al, 2013). Another source of family conflict involved poor communication between family members. Poor communication led to disagreements or arguments over guardianship, financial matters (O’Dwyer et al, 2013; Sun, 2014), long-term care placement (Sun, 2014), and unequal distribution of caregiving responsibilities (Bremault-Phillips et al, 2016). Among caregivers with young children, caregiving interfered with their ability to raise their family due to time constraints (Cohen et al, 2011; Kitter & Sharman, 2015; McCann, Bamberg & McCann, 2015). Family conflict was often
associated with feelings of anger and helplessness among caregivers (Bremault-Phillips et al, 2016; O’Dwyer et al, 2013).

Protective Factor: Strengthening Family Relationships

On the contrary, in seven of the included studies, strengthening of family relationships was identified as a protective factor of resilience. The emotional support provided by family members to the primary caregiver made the caregiving experience less burdensome and provided the caregiver with motivation to continue providing care for their loved one (Deist & Greeff, 2017). Furthermore, caring for a family member or loved one often strengthened relationships within the family unit (Bayat, 2007; Bekhet & Matel-Anderson, 2017; Chen & Clarke, 2010; El Masry et al, 2013). The existing emotional relationships were further strengthened and developed through the caregiving experience as members of the family unit effectively communicated with one another (Bekhet & Matel-Anderson, 2017; Kim et al, 2017; Weisser et al, 2015).

2.6.2 Resilience Factor: Formal Resources

Formal community resources, such as home care, adult day programs, and respite care can be sources of support for care recipients and their caregivers (Donnellan et al, 2015; Fernandez-Calvo et al, 2016;). The availability of formal resources can vary among jurisdictions and illness types. Despite the volume of available resources, there are issues with accessibility, where some caregivers may have difficulties securing formal resources at a reasonable cost (Bekhet & Matel-Anderson, 2017; Bremault-Phillips et al, 2016). Other literature suggests that accessing social support programs increases resilience (Bremault-Phillips et al, 2016; Deist & Greeff, 2017). Ultimately, when formal resources are available and accessible to caregivers, caregiver resilience was enhanced (Dias et al, 2015; Gaugler et al, 2007; Whitehead et al, 2015).

Risk Factor: Lack of Formal Resources/Access to Resources

The lack of formal resources to support family caregivers and care recipients was identified as a risk factor in seven of the included studies. Although formal resources may have been available in the community, there were multiple barriers to accessing services (Bekhet & Matel-Anderson,
2017; Bremault-Phillips et al, 2016; Zauszniewski et al, 2010). The lack of resources was a risk factor for lower levels of resilience among caregivers caring for an individual with a serious mental illness (Bekhet & Matel-Anderson, 2017), persons with dementia (Sun, 2014), and patients nearing the end-of-life (Turner et al, 2016). Accessing services were difficult for caregivers who were not familiar with service availability and how to navigate the healthcare system (Bremault-Phillips et al, 2016; Kitter & Sharman, 2015). When information and education was provided to caregivers, it lacked information specific to the care recipient’s condition (Bremault-Phillips et al, 2016). Caregivers emphasized that they needed more formal community resources, caregiver education, and assistance with service coordination (Kahana et al, 2015; Kitter & Sharman, 2015; Turner et al, 2016).

**Protective Factor: Availability of Formal Resources/ Access to Formal Resources**

On the contrary, in ten of the included studies, availability of and access to formal resources helped caregivers adapt to the stress of caregiving. Access to formal resources often allowed caregivers to provide care in the community for a longer period of time, which often delayed long-term care admissions (Fernandez-Calvo et al, 2016). Specifically, respite care was often cited as a formal resource that provided them with temporary relief and the opportunity to participate in recreational activities (Bremault-Phillips et al, 2016; Deist & Greeff, 2017; Donnellan et al, 2015; O’Dwyer et al, 2017). Along with providing medical and practical support, formal providers were also a source of emotional support for some caregivers. Among caregivers of persons in palliative care and for those with dementia, formal providers motivated caregivers and provided them with guidance to effectively care for the care recipient (Giesbrecht et al, 2015; Parkinson et al, 2016).

**2.6.3 Resilience Factor: Cognitions and Coping Strategies**

Caregivers may experience a combination of positive and negative cognitions throughout their caregiving journey. Negative cognitions that were identified in the mapping review include guilt and grief. These negative cognitions made it difficult for caregivers to continue providing care and led to feelings of helplessness (Bremault-Phillips et al, 2016; Weisser et al, 2015). Positive cognitions and positive coping strategies often promoted well-being and countered negative
emotions among caregivers (Joling et al, 2017; Kitter & Sharman, 2015; Ong et al, 2006). The positive cognitions that were identified as protective factors of resilience in the literature include: acceptance, hardiness, mastery, hope, self-efficacy, and sense of coherence. It is important to attend to these positive cognitions as they help caregivers overcome the negative emotions they are experiencing (Kitter & Sharman, 2015; Fernandez-Calvo et al, 2016; Ong et al, 2006), remain positive during periods of stress (Deist & Greef, 2017; Tang et al, 2013), adapt to their role (Doutre et al, 2013; Zauszniewski et al, 2009), reduce feelings of burden (Bekhet et al, 2012), and provide the caregiver with the motivation needed to provide care along the caregiving journey (Doutre et al, 2013).

**Risk Factor: Guilt**

In five of the seventy studies, guilt was identified as a risk factor that compromised resilience. Guilt was most cited among caregivers who could no longer provide care to the care recipient due to burnout or patient dependency. In these cases, caregivers were in the process of applying for long-term care or placed the care recipient into a long-term care facility, even if the care recipient wanted to remain in the community (Bremault-Phillips et al, 2016; Kitter & Sharman, 2015; Shuter, Beattie & Edwards, 2014). For caregivers more actively involved in caregiving, caregivers felt guilty for wanting a break from their caregiving duties and have time for themselves to partake in recreational and leisurely activities (Bremault-Phillips et al, 2016; El Masry et al, 2013). Due to feelings of guilt, caregivers had a difficult time asking others for caregiving assistance and often resulted in feelings of helplessness (Bremault-Phillips et al, 2016; Weisser et al, 2015).

**Risk Factor: Grief**

Grief was a risk factor of decreased resilience that was experienced by caregivers in a small number of the included studies (3 studies). For caregivers, grief lingered over a long period of time in the caregiving journey. Due to their increasing caregiving duties, caregivers grieved the loss of their personal lifestyle and their loved one (Bremault-Phillips et al, 2016; El Masry et al, 2013; McCann, Bamberg & McCann, 2015). Grief was more pronounced among caregivers who were caring for a spouse, as they were grieving the loss of one of their closest companions (Bremault-Phillips et al, 2016). Ultimately, feelings of grief increased with the decline of the
care recipient’s health and functional ability (Bremault-Phillips et al, 2016; El Masry et al, 2013).

**Protective Factor: Acceptance**

Acceptance refers to an individual’s ability to tolerate or embrace their thoughts and feelings during a stressful situation (Deist & Greeff, 2017; King et al, 2009; Zauszniewski et al, 2010). Acceptance was identified as a protective factor in nine of the included studies. By accepting their loved one’s conditions, caregivers could manage caregiving expectations and determine what their responsibilities were (Hayas de Arroyabe & Calvete, 2015; Leone et al, 2016; Rosa et al, 2017). Once caregivers were able to accept that the caregiving role was a part of their lives and the condition/prognosis was relatively unchangeable, it was easier for them to provide care (Deist & Greeff, 2017; Zauszniewski et al, 2010). Acceptance increased over time and required the caregiver to set realistic expectations of themselves and their ability to provide care (Bekhet & Matel-Anderson, 2017; Nguyen et al, 2015). This protective factor helped caregivers view their role from a positive lens and helped to set out realistic expectations based on the condition of the care recipient (Zauszniewski et al, 2010).

**Protective Factor: Hardiness (Endurance)**

Hardiness is defined as the ability to positively appraise and endure a challenging situation, despite stressful circumstances (Cherry et al, 2013; Zauszniewski et al, 2010). Hardiness was identified as a protective factor in twelve of the studies. In some cases, hardiness was fostered through the support of the family unit, where family members motivated one another to continue providing care (Chen & Clarke, 2010; Deist & Greeff, 2017; McCann et al, 201). Although their role was challenging, they were able to appreciate their role and found their experience to be rewarding (Cherry et al, 2013; Kitter & Sharman, 2015). Some caregivers were grateful for being able to spend time with a loved one during a period of deteriorating health (Turner et al, 2016). In some cases, hardiness increased over time, after caregivers were adjusted to their caregiving role (Nabors et al, 2013). A high level of hardiness was associated with increased life satisfaction (Kim & Knight, 2016; Rosa et al, 2017), less anxiety (Nabors et al, 2013), and an increased capacity to deal with challenging situations (O’Dwyer et al, 2013).
Protective Factor: Mastery (Personal Control)

Individuals with a high level of mastery believe that, to some degree, they have control over their life (Dias et al, 2015; Zauszniewski et al, 2010). Mastery was identified as a protective factor in ten of the included studies. Mastery was a positive cognition that enabled caregivers to feel autonomous and competent (Dias et al, 2015; Joling et al, 2017), resulting in the belief that their actions had a direct effect on their future. Caregivers who felt a sense of personal control were more likely to seek information when needed and reach out to family members to resolve any issues that arose (Fernandez-Calvo, 2016; King et al, 2009). A higher level of mastery was associated with greater psychological well-being (Fife et al, 2009; Harmell et al, 2011; Zauszniewski et al, 2010), increased life satisfaction (Kim & Knight, 2016), and reduced caregiver burden (Joling et al, 2016; Zauszniewski et al, 2010).

Protective Factor: Hope (Optimism)

Hope can be defined as the anticipation of a positive outcome. However, this anticipation is often accompanied by feelings of uncertainty (King et al, 2009; Zauszniewski et al, 2010). Hope was a protective factor that was identified in six of the included studies. Among caregivers of a person with autism spectrum disorder, there was an optimistic and persistent belief that their role would become more manageable as time progressed (King et al, 2009). Among caregivers of persons with schizophrenia, hope helped to counter feelings of stress and allowed caregivers to look beyond stressful situations (Hernandez, Barrio & Yamada, 2013). Some caregivers hoped the care recipient would recover from their condition, which was critical in preventing negative cognitions, even if not realistic (Nguyen et al, 2015; Ye et al, 2017). Ultimately, hope reduced caregiver burden, promoted positive thinking, and reduced negative cognitions (Parkinson et al, 2016; Zauszniewski et al, 2010).

Protective Factor: Self-efficacy

Self-efficacy is defined as the confidence to *endure* challenging situations (Harmell et al, 2011; Zauszniewski et al, 2010). Self-efficacy was identified as a protective factor in six of the included studies. When caregivers had confidence in their caregiving abilities, they were more likely to feel enabled to provide care and were less likely to experience negative cognitions.
(Harmell et al, 2011; Parkinson et al, 2016; Seoud & Durcharme, 2015). Those with a high level of self-efficacy were likely to experience less stress (Dias et al, 2015; Zauszniewski et al, 2010), greater well-being (Seoud & Ducharme, 2015), and fewer negative cognitions (Shaffer et al, 2016).

**Protective Factor: Sense of Coherence (Making Meaning out of Adversity)**

An individual with a strong sense of coherence feels their life is manageable and they are able to find meaning during times of adversity (Cherry et al, 2013; Zauszniewski et al, 2010). Sense of coherence was identified as a protective factor in twelve of the included studies. Caregivers with a strong sense of coherence were more likely to view their caregiving role as manageable and positive (Fernandez-Calvo et al, 2016). Over time, caregivers experienced a sense of personal growth (Fernandez-Calvo et al, 2016; Nguyen et al, 2015) and were able to find meaning in their caregiving role (Bayat, 2007; Das et al, 2017; Kim et al, 2017; Seoud & Ducharme, 2015). Caregivers with a high sense of coherence were likely to experience less caregiver burden (Suresky et al, 2014), fewer depressive symptoms (Shaffer et al, 2016), fewer feelings of anger (Shaffer et al, 2016), greater family cohesion (Fernandez-Calvo et al, 2016), and an improved ability to adapt to adversity (Parkinson et al, 2016).

2.6.4 Resilience Factor: Social Support

Social support can be characterized as instrumental, emotional or informational; throughout the caregiving journey, access to social support and the quality of social support can vary (Taylor, 2012). The lack of social support can result in social isolation, which can compromise resilience due to poorer mental health and feelings of loneliness (Joling et al, 2016). On the contrary, the literature suggests that social support (instrumental, emotional and informational) may improve the mental well-being of the caregiver and reduce negative emotions (Donnellan et al, 2015; Kitter & Sharman, 2015; Taylor, 2012). It is important to ensure caregivers have access to the appropriate social support to enhance resilience.
Risk Factor: Social Isolation

Social isolation was a risk factor identified in seven of the seventy included studies. Being a caregiver for a longer period of time coincided with increasing likelihood of disengaging from social networks (Cohen et al, 2011; Donnellan et al, 2016; El Masry et al, 2013). Caregivers with a source of social support were more likely to become distant from their sources of social support due to personal time constraints (El Masry et al, 2013) and family conflict (O’Dwyer, Moyle & van Wyk, 2013). Individuals within these social networks often did not understand the demands of caregiving and were less likely to invite the caregiver to social gatherings over time (Cohen et al, 2011; Donnellan et al, 2016). Among caregivers of persons with autism spectrum disorder, caregivers felt socially isolated when they did not receive adequate emotional support from their social network (Ntinda & Nkwanyana, 2017). Overtime, the social isolation these caregivers faced were associated with feelings of loneliness, poorer mental health, and increased caregiver burden (Fernandez-Calvo et al, 2016; Joling et al, 2016).

Protective Factor: Access to Social Support

On the other hand, social support was a protective factor among caregivers in twenty of the included studies. A few studies found that the size of the caregiver’s social support network was not a strong determinant of resilience (Dias et al, 2015; Donnellan et al, 2016). Rather, the quality of support-- frequency of interaction with peers, perception of support, and satisfaction with the support received—was a stronger determinant of resilience (Dias et al, 2015; Donnellan et al, 2016; Joling et al, 2017). The type of support caregivers preferred varied. Practical support -- providing transportation, helping with household duties, and caring for the care recipient -- was sought out by caregivers to ease the burden of caregiving (Bremault-Phillips et al, 2016; Dias et al, 2014; Giesbrecht et al, 2015; O’Dwyer et al, 2016; O’Dwyer et al, 2017; Rosa et al, 2017; Shuter et al, 2014). Emotional support was sought by caregivers to feel supported, offload emotional stress, and share their burden with others ((Bremault-Phillips et al, 2016; El Masry, et al, 2013; Giesbrecht et al, 2015; McCann et al, 2015; O’Dwyer et al, 2017; O’Dwyer et al, 2013; Shuter et al, 2014). Among caregivers of persons with chronic disease(s), caregivers preferred practical support over emotional support from their family members (Donnellan et al, 2015; Donnellan et al, 2016). However, caregivers of persons with severe mental illness and dementia preferred emotional support from their family members (McCann et al, 2015; Shuter et al,
Informational support was found to be beneficial for caregivers of persons with autism spectrum disorder (Whitehead et al., 2015). All three types of social support, practical, informational and emotional, were associated with greater adaption to stress (Kahana et al., 2015), strengthened family relationships (Kim et al., 2017), and fewer negative emotions (Kitter & Sharman, 2015; Hayas et al., 2015; Nabors et al., 2013; Nguyen et al., 2015; Parkinson et al., 2016).

2.6.5 Resilience Factor: Access to Information

Access to information is important for providing effective care to the care recipient and accessing formal resources (Bremault-Phillips et al., 2016; Deist & Greeff, 2017). Those who are unable to access information or process complex information experienced uncertainty regarding their future and caregiving role, which contributed to additional stress (Bekhet & Matel-Anderson, 2017). Resourceful caregivers were often successful in accessing appropriate information and are able to secure resources when needed, thereby enhancing their resilience (Zauszniewski et al., 2010). Ensuring caregivers have access to information that is relevant for their needs may have implications for enhancing resilience and easing the burden of caregiving (Donnellan et al., 2015; Suresky et al., 2014).

Risk Factor: Uncertainty

Uncertainty about the future course of the illness or condition was a risk factor identified in nine of the seventy included studies. As with many illnesses, uncertainty about the future is common. Uncertainty was often a source of stress for caregivers when they were unsure about the length of time they would have to provide care as this impacted their ability to plan for their own futures (Bekhet & Matel-Anderson, 2017; Weisser, Bristowe & Jackson, 2017). Many caregivers worried about the course of illness, unanticipated health-related events, functional decline of the care recipient, and death of the care recipient (El Masry et al., 2013; Kitter & Sharman, 2015; Nabors et al., 2013; Ye et al., 2017). Due to the lack of guidance, awareness, and education available to caregivers, some caregivers found it difficult to understand the diagnosis (Bremault-Phillips et al., 2016; Turner et al., 2016) and felt ill-prepared to care for their loved one (El Masry et al., 2013; Kitter & Sharman, 2015; Ntinda & Nkwayana, 2017).
Protective Factor: Resourcefulness

Resourcefulness was identified as a protective factor in nine of the seventy included studies. Resourcefulness refers to the ability to seek and secure assistance with their caregiving duties when it is needed (Zauszniewski et al, 2010). Caregivers who were resourceful often sought information on how to manage the health condition and how to effectively provide care for the condition (Deist & Greeff, 2017; Weisser et al, 2015). Resourceful caregivers were better able to express their needs as a caregiver and access services for the care recipient’s needs from the health and social care systems (Giesbrecht et al, 2015; Nguyen et al, 2015). Together, these studies indicate that resourceful caregivers were more aware of available services and were better able to take advantage of community programs to ease the burden of caregiving (Bekhet et al, 2012; Donnellan et al, 2015; O'Dwyer et al, 2016; Suresky et al, 2014).

2.6.6 Resilience Factor: Caregiving Context

Caregiving context factors are factors that are directly related to caring for a care recipient. Risk factors that compromise caregiver resilience include feelings of burden and patient dependency, competing priorities, and the stigma associated with the care recipient’s condition. Feelings of burden and patient dependency as well as competing priorities made it challenging to provide care while balancing multiple roles in their lives (Weisser et al, 2015). Stigma regarding the care recipient’s condition often led to feelings of shame and psychological stress among caregivers (Chen et al, 2016). Love for the care recipient was identified a protective factor that enhanced resilience as caregivers were more likely to positively appraise their role when they had an intimate relationship with the care recipient (Monin et al, 2015). Attending to these factors are important to decrease feelings of burden while providing care to the care recipient.

Risk Factor: Feelings of Burden & Patient Dependency

The most common risk factor identified in seventeen of the seventy studies were feelings of burden, which was closely tied to patient dependency. Many caregivers found their role to be both burdensome and challenging, which affected their functioning in other life domains (Bremault-Phillips et al, 2016; Kahana et al, 2015; Kitter & Sharman, 2015; McCann et al,
2015; Suresky et al, 2014; Turner et al, 2016; Ye et al, 2017). Caregivers found it difficult to provide care for other family members (Bremault-Phillips et al, 2016) while also attending to their own physical and mental health needs (Kitter & Sharman, 2015; McCann et al, 2015; Ye et al, 2017). Caregivers who experienced caregiver burden experienced fewer positive cognitions (Bekhet, Johnson & Zauszniewski, 2012; Zauszniewski et al, 2009), felt physically and emotionally drained (McCann et al, 2015), and found it difficult to enjoy personal activities (Bekhet & Matel-Anderson, 2017). Ultimately, these studies found that increased patient dependency and caregiver burden interfered with resilience and the ability to adapt to adversity (Cherry et al, 2013; Gaugler, Kane & Newcomer, 2007; Kahana et al, 2015; Kim et al, 2017; Leone, Dorstyn & Ward, 2016; Saria et al, 2017; Scott, 2013; Wilks & Vonk, 2008; Zauszniewski et al, 2010).

Risk Factor: Competing Priorities

Competing priorities were identified as a risk factor in five of the included studies. Aside from providing care, managing multiple priorities (such as parenting, maintaining employment, and social and community engagement) with competing demands made it difficult to deal with the stressors of caregiving (Cohen et al, 2013; Perkins, 2010; Weisser et al, 2015). Caregivers were especially vulnerable to stress if they were caring for young children in addition to the care recipient as their time had to be divided (Doutre, Green & Knight-Elliot, 2013; Perkins, 2010). Among patients with a chronic illness, spousal caregivers often took on a more parental role due to their partners declining functional abilities (Bremault-Phillips et al, 2016). Competing priorities required caregivers to balance multiple responsibilities, thereby potentially increasing the burden of caregiving.

Risk Factor: Stigma

Stigma associated with the care recipient’s medical condition was identified as a risk factor in four of the included studies. Studies suggest that stigma existed from the onset of these conditions and were associated with feelings of shame and psychological stress among caregivers (Chen et al, 2016; Kahana et al, 2015). Stigma was present among caregivers of persons with dementia (Sun, 2014), schizophrenia (Chen et al, 2016), serious mental illness (Suresky et al, 2014) and autism spectrum disorder (Kahana et al, 2015). Due to stigma
associated with these conditions, caregivers avoided disclosing the care recipient’s condition due to the fear of discrimination and loss of social status (Chen et al, 2016; Sun, 2014). Further, stigma was a barrier to seeking professional help and interacting with members of their social network, thereby increasing social isolation for both the caregiver and the care recipient (Kahana et al, 2015; Suresky et al, 2014).

**Protective Factor: Love for the Care Recipient**

Seven of the included studies identified love for the care recipient as a protective factor against stress (Bekhet & Matel-Anderson, 2017; El Masry et al, 2013). These studies indicate that despite the challenges of providing care, caregiving can be a rewarding opportunity for some caregivers (Bremault-Phillips et al, 2016; Doutre, et al, 2013; Ntinda & Nkwanaya, 2017). When caregivers had an intimate relationship with the care recipient (spouse, child, parent), they felt their role was less burdensome; therefore, these caregivers were more likely to positively appraise their role (Monin et al, 2015). Some caregivers felt a sense of duty to provide care for their loved one and to reciprocate for the support they received in the past from the care recipient (Bremault-Phillips et al, 2016; Fernandez-Calvo et al, 2016). Among caregivers who provided care to their child, the love for their child motivated them to provide care, which ultimately strengthened their relationship with their child (Bekhet & Matel-Anderson, 2017; Ntinda & Nkwanaya, 2017).

**2.6.7 Resilience Factor: Personal Factors**

Personal factors refer to the risk and protective factors that can affect caregiving behaviours and personal lifestyle. Financial strain and mental/physical health problems of the caregiver were risk factors that compromised resilience. The financial strain of caregiving compromised many aspects of their personal lives, financial strain made it difficult for caregivers to retire, support their family, and afford formal resources (Bekhet & Matel-Anderson, 2017; Weisser et al, 2015). Existing physical and mental health problems reduced the caregiver’s capacity to provide care while attending to their own needs, which contributed to compounding stress (El-Masry et al, 2013; Ong et al, 2006). The personal risk factors that enhanced resilience include faith and spirituality and self-care. In regard to faith and spirituality, a higher power often motivated
caregivers to provide care and accept their situation (Deist & Greeff, 2017). Self-care allowed caregivers to engage in recreational activities and focus on their own well-being, which reduced feelings of stress (Deist & Greeff, 2017; Parkinson et al., 2016). Although these factors may not be directly related to caring for the care recipient, they impact the caregiver’s abilities to continue on in their role and adjust to the stress associated with caregiving. Attending to these factors are important as they will address broader issues that affect a caregiver’s ability to provide care.

**Risk Factor: Financial Strain**

The financial consequences of caregiving for both the caregiver and the care recipient was identified as a risk factor in nine of the seventy included studies. The direct costs of caregiving included the cost of social services (Bekhet & Matel-Anderson, 2017), health services (Bremault-Phillips et al., 2016), transportation, prescription drugs, and nursing care for the care recipient (Sun, 2014). Caregivers noted being unable to access services due to financial strain and the shortage of affordable options for mental health services (Kitter & Sharman, 2015; Zauszniewski, Bekhet & Suresky, 2010). The cost of these services had implications for their lives beyond caregiving. In one study, caregivers of individuals with a serious mental illness had to mortgage or remortgage their home to afford mental health services (Bekhet & Matel-Anderson, 2017). Caregivers of patients with neurodegenerative diseases emphasized the importance of secure employment because they were unable to contribute to their pension and support their families (Weisser et al., 2015). Other caregivers were unable to continue on in their career path and found it emotionally difficult to find new employment opportunities (Bremault-Phillips et al., 2016). The loss of financial security, reduced salaries, and the increase in precarious employment made it difficult for caregivers to afford mortgage payments, child care, medical services and recreational activities (Bremault-Phillips et al., 2016; El Masry, Mullan & Hackett, 2013; Kahana et al., 2016; Nabors et al., 2013). Financial strain disproportionately affected older caregivers in a few studies (El Masry et al., 2013; Sun, 2014).

Financial assistance may be available to caregivers through government programs and subsidies, however, the eligibility criteria was commonly based on age and employment status (Bremault-Phillips et al., 2016). Young caregivers are at a disadvantage for obtaining financial assistance, as policies tend to favour older caregivers (Bremault-Phillips et al., 2016). All these financial
pressures required families to pass up on employment opportunities, prioritize their expenses, and re-allocate funds that were initially dedicated to recreational activities, retirement, and their family (El Masry et al, 2013; Sun, 2014; Weisser et al, 2015). It is evident that finances play a large role in caregiving, indicating the need for financial support to increase the ability to provide care.

**Risk Factor: Mental/Physical Health Problems**

Six of the included studies identified caregivers with existing mental and physical health as a risk factor for lower levels of resilience. With existing health problems, older caregivers had a reduced capacity to provide care, making it more difficult to tend to their own healthcare needs and adjust to stress (El Masry et al, 2013; Gaugler et al, 2007; Sun, 2014). Research suggests that older caregivers may have fewer competing priorities in comparison to their younger counterparts, making them better equipped to transition into the caregiving role (Tang et al, 2013). On the contrary, some older caregivers were more likely to experience negative events (death of a loved one, multiple chronic conditions, caring for a spouse), resulting in compounding stress (Ong et al, 2006). Among caregivers of persons with dementia, existing physical and mental health problems among caregivers was identified a barrier to providing care and were related to thoughts of suicide (O’Dwyer et al, 2013; Hayas et al, 2015; Shuter et al, 2014).

**Protective Factor: Faith and Spirituality**

Faith and spirituality was identified as a protective factor in ten of the included studies. The level of resilience among caregivers tended to increase with the frequency and duration of spiritual activities (Wilks & Vonk, 2008). The most common spiritual activities were prayer and meditation (Bremault-Phillips et al, 2016; Das et al, 2017; Deist & Greeff, 2017; Wilks & Vonk, 2008). In a few studies where the caregiver believed in a higher power, the higher power provided them with the strength to pursue their caregiving duties (Deist & Greeff, 2017; Nabors et al, 2013; O’Dwyer et al, 2013). Faith and spirituality enabled caregivers to cope with and accept the situation, as they believed their role served a meaningful purpose (Bayat, 2007; Das et al, 2017; Fife et al, 2009; Hayas, 2015; O’Dwyer et al, 2013; Shuter et al, 2014).
Protective Factor: Self-Care/Personal Time

In eight of the included studies, self-care and personal time was identified as a protective factor in increasing resilience. Caregivers often had the tendency to overlook or neglect their personal needs to address the needs of the care recipient. Thus, they emphasized the importance of having time to themselves, away from the care recipient, to invest in their well-being (Deist & Greeff, 2017; Parkinson et al, 2016). However, some caregivers were able to use personal time as an opportunity to re-energize and de-stress (Donnellan, et al, 2015; Nguyen et al, 2015). Personal time gave caregivers an opportunity to cope with stress through recreational activities and hobbies (McCann et al, 2015; O’Dwyer et al, 2017). Engaging in recreational activities such as exercising, gardening, dancing and using social media helped alleviate stress and improve their perceived quality of life (Kitter & Sharman, 2015; Parkinson et al, 2016; Sun, 2014). Other caregivers sought out professional counselling as a means to help them cope with their caregiving duties (McCann et al, 2015). Respite care, a service meant to provide temporary relief to the caregiver for a short period of time, provided caregivers with time away from the care recipient, indicating the importance of respite care in increasing caregiver resilience (O’Dwyer et al, 2017).

2.7 Summary of Findings

This review synthesizes both quantitative and qualitative resilience literature, including the factors that enhance (protective factors) or compromise (risk factors) resilience among family caregivers. Collectively, these studies help elucidate the critical role of resilience in adapting to stress and adversity in the caregiving journey. In recent years, there has been an increasing emphasis on resilience and family caregiving in the literature, indicating the increasing interest in this area of research. The findings from the mapping review suggest that resilience is dependent on a variety of factors, can vary by disease or illness type, and is reflected differently among caregivers. The interdependencies of the risk factors and protective factors were evident, resulting in a range of resilience levels among caregivers. The conceptual framework on resilience and family caregiving synthesizes the available literature on resilience within the past decade. Individual studies often focused on a limited number of risk/protective factors.
However, this framework incorporates a wide range of resilience factors identified across the 70 resilience article and illustrates how each factor may pose a risk or enhance resilience. Therefore, this comprehensive framework can be validated, utilized or extended in future research on resilience along the caregiving journey.

The most common protective factor and risk factor identified in this review were social support and caregiver burden, respectively. These findings indicate the importance of socialization and support from social networks, especially among caregivers experiencing burnout. This mapping review identified many cognitions, both positive and negative, that affected resilience. However, many of these studies emphasized the positive cognitions associated with resilience. Therefore, this review identified a need to explore the interaction between positive cognitions and negative cognitions and how these cognitions can change over time in future studies. It is important to explore how cognitions may fluctuate to understand the impact of varying cognitions on overall resilience.

The role of demographic factors, such as sex/gender, education and marital status, on caregiver resilience is unclear in the reviewed studies. Dias et al (2016) found that gender and marital status were not associated with resilience. However, this study had a relatively small sample size and the majority of the sample (>75%) were female and married. Thus, the ability to draw conclusions may be limited. On the contrary, Cherry et al (2013) reported that male caregivers tend to feel less burdened with their caregiving role in comparison to their female counterparts. In regard to education, Ye et al (2017) and Joling et al (2016) reported that higher education is associated with increased resilience. Other studies did not explore or report demographic factors, perhaps due to homogenous samples or small sample sizes. Future research is needed to explore the role of these demographic factors on resilience among caregivers to understand how resilience impacts different groups of individuals.

The impact of length of caregiving on caregiver resilience is unclear in the reviewed study. Perhaps due to the large range in caregiving duration, which could range from months to years, the included studies did not draw conclusions based on length of caregiving on resilience within their sample. However, it could be anticipated that the length of caregiving may have a negative effect on resilience because as the length of caregiving increases, patient dependency and
caregiving burden may also increase. In addition, older caregivers who may have been providing care for a longer period of time, may be more likely to have physical and mental health problems that may impact their ability to provide care (Sun, 2014). Therefore, an increasing length of caregiving may negatively impact resilience.

Levels of resilience are subject to change over the caregiving journey. Among caregivers of persons with dementia, increasing functional dependencies over time were associated with greater caregiver burden and increasing social isolation (Deist & Greeff, 2017; Donnellan et al, 2016; Joling et al, 2016; Scott, 2013). However, the increasing risk of social isolation was sometimes mitigated when caregivers were satisfied with the types of support (informational, emotional and functional) and the quality of social support they received from members of their social network (Donnellan et al, 2016; O’Dwyer et al, 2017). These caregivers commonly expressed the need for respite care and caregiver education to learn more about the condition and how to support persons with dementia (Deist & Greeff, 2017; O’Dwyer et al, 2017).

For mental health related conditions, there were a lack of mental health services available in the community, which further contributed to feelings of burden and stress among these caregivers (Suresky et al, 2014; Sun, 2014). Lack of access to mental health services was further exacerbated due to feelings of stigma, where caregivers found it difficult to disclose the care recipient’s condition (Sun, 2014). However, Chen et al (2016) found high levels of resilience helped mediate the effect of stigma on stress. Therefore, caregivers with a higher level of resilience were seemingly less likely to experience stress due to stigma. These studies indicate the importance and need for bolstering resilience and increasing access to community supports for caregivers of persons with mental health conditions.

Caregivers with pre-existing physical and mental health problems were more vulnerable to experiencing caregiver burden and negative cognitions (El Masry et al, 2013; O’Dwyer et al, 2013). This may be attributed to the stress of managing their own chronic conditions while providing support for an individual with functional dependencies (Ong et al, 2006; Sun, 2014). In a study conducted by O’Dwyer et al (2013), authors found that caregivers with existing health conditions were more likely to have thoughts of self-harm and suicide. This emphasizes the need to ensure caregivers with existing physical and mental health problems have enough support to care for both themselves and the care recipient.
Depending on the interaction between the factors, caregivers with a high level of resilience were better equipped to adapt to adversity. Caregivers with a higher level of resilience experienced fewer depressive symptoms (Dias et al, 2016; Ong et al, 2006; Simpson et al, 2015), accelerated recovery from stress (Bitsika et al, 2013; Ong et al, 2006; Simpson et al, 2015; Tang et al, 2013), increased morale and psychological wellbeing (Cassidy et al, 2014; Tang et al, 2013; Zauszniewski et al, 2010), decreased burden (Cassidy, 2013; Dias et al, 2015; Kenneson & Bobo, 2010; Simpson & Jones, 2012), and greater life satisfaction, (Castellano-Tejedor & Lusilla-Palacios, 2017; Chappell & Dujela, 2008; Dias et al, 2016; Kenneson & Bobo, 2010). On the other hand, caregivers with lower levels of resilience were more likely to place the care recipient in a long-term care facility (Gaugler et al, 2007), experience greater depressive and anxiety symptoms (Bitsika et al, 2013; Kenneson & Bobo, 2010; Simpson & Jones, 2012), and experience more burden (Chappell, & Dujela, 2008).

Research has shown that direct interventions, such as caregiver education and access to formal resources are beneficial in fostering resilience in this population (Zhao et al, 2016). However, certain resilience factors such as love for the care recipient and spirituality are factors that are unlikely to directly benefit from intervention as they are intrinsic factors that are dependent on the individual. This review suggests a need to further explore the types of interventions that are effective in fostering resilience and how specific resilience factors may be directly and indirectly impacted by these interventions.

### 2.8 Future Directions

Research on resilience and family caregiving have largely originated from the United States, Australia, and the United Kingdom. Currently, less than 10% of research on resilience and family caregiving included in this review was conducted in the Canadian context. This indicates that there is a need for further exploration among Canadian caregivers, as health system performance and health care policies vary from country to country. A considerable amount of literature has been published with caregivers of persons with dementia or Alzheimer's (40%) at various points in the caregiving journey. The remaining studies largely focus on long-term caregiving, with a few studies looking at a specific period in the caregiving journey. More
research is needed on how resilience is impacted during *specific* points in the caregiving journey. This will have implications for better understanding how to support caregivers at specific times, particularly times of high uncertainty.

This thesis will address some of the gaps that were identified in this literature review. To date, there has been no detailed investigation on resilience and family caregiving among caregivers of patients who require an alternate level of care. During this period, caregivers and patients are waiting in hospital for their next discharge location due to lack of available resources. This is often a crisis point for caregivers who must address care gaps during this healthcare transition (McCloskey et al, 2013; Higgins et al, 2007). It is critical to explore how resilience is impacted during this period in the caregiving journey to enable caregivers to adapt in stressful situations and advance our knowledge of resilience during this period. The secondary analysis detailed in the subsequent chapters examines how resilience plays out for caregivers during the ALC period.
Chapter 3

3 Methods

3.1 Introduction to Methods

This thesis explores how resilience is impacted and reflected in family caregivers’ experience of caring for a person who requires an Alternate Level of Care (ALC) using qualitative methods. Qualitative research is a rigorous form of scientific inquiry that is commonly used in social sciences research. Qualitative research commonly explores ‘why’ and ‘how’ questions to develop an in-depth understanding of a phenomenon through the lived experiences of individuals (Kuper, Reeves & Levinson, 2008; Miller, 2010; Sofaer, 1999). Qualitative research offers a range of methods for researchers to generate rich descriptions, however, it is critical that the method of choice aligns with the purpose and goals of the research (Sofaer, 1999). Similar to quantitative research, qualitative research can be used to develop a theory or test existing theories. In addition, qualitative methods can help researchers understand a phenomenon in a specific context, explore the role/influence of contextual factors, understand the variation between participants, and provide meaningful insights for policy and practice (Johnson & Waterfield, 2004; Sofaer, 1999). Qualitative research stems from the constructivist/interpretivist paradigm, a worldview that postulates knowledge is ‘constructed’ by individuals and shaped by their lived experiences (Crotty, 1998; Kuper et al, 2008). Therefore, multiple realities regarding a phenomenon exist as individuals construct knowledge through their own subjective experiences (Crotty, 1998). This study used a constructivist position, where the truth is subjective and dependent on experiences and personal beliefs of caregivers (Crotty, 1998; Giacomini, 2010).

Methodology guides the research process and justifies the research methods that are chosen to generate knowledge (Carter & Little, 2007; Kelly, 2010). Methods refer to the tools that are used to collect data (e.g. focus groups, interviews) and includes the analysis of data to generate knowledge. This chapter will describe how resilience concepts were used as a theoretical framework to conduct the research and the methods used to collect and interpret the data (Kelly, 2010).
3.2 Study Design

A secondary analysis of an existing qualitative dataset was conducted to answer the second research question: How is caregiver resilience impacted and reflected in caring for a patient who requires an Alternate Level of Care?

A secondary analysis involves repurposing existing data, often from one or more research studies, to investigate novel research questions (Heaton, 1998; Heaton, 2008). Although no additional data are collected to address a new research question, a new conceptual focus generates additional knowledge and meaning from an existing dataset (Irwin, 2013). Therefore, secondary analyses are appealing and emerging in the empirical literature because they are cost effective, less resource-intensive, feasible under time constraints, and less burdensome for the study participants (Heaton, 2008; Szabo & Strang, 1997). However, this study design is not without limitations. First, researchers are unable to probe participants to gather additional information about the phenomenon through the use of an existing dataset (Szabo & Strang, 1997). In addition, there are many methodological considerations with the study design specific to the context of the original study and the appropriateness of a secondary analysis that will be discussed further in this section.

Qualitative data used for a secondary analysis can be self-collected data from previous research studies, shared formally through public/private institutions or archives, or shared informally by other researchers (Heaton, 2008). One of the major criticisms of formal and informal data sharing is that important contextual information may be overlooked if the secondary analysis research team had minimal to no involvement in the conceptualization of the original study or data collection procedures (Heaton, 2008; Irwin, 2013). However, along with sharing the data with the team, KK (Supervisor of the primary researcher of this thesis) was also an active member of the secondary analysis team. The primary researcher (RL) regularly consulted with KK, who provided RL with contextual information about the purpose of the original study, data collection procedures, and the study setting (Northwestern Ontario). Further, KK was involved in the conceptualization of the secondary research design and played an integral role in helping the primary researcher interpret and report the data findings (described in the following chapter).
Another criticism of conducting a secondary analysis surrounds the ability to re-use previously collected data for another purpose (Heaton, 2008). Although the data was not collected for the secondary purpose, the exploratory nature of the original study design (guided by qualitative description) and use of semi-structured interviews produced a rich and comprehensive dataset. This provided the foundation for a new perspective on the data that was not previously addressed in the initial analysis conducted by Kulski et al (2017) (Heaton, 1998; Heaton, 2008). An in-depth exploration of a new concept or research question that was not addressed in the original analysis is classified as a supplementary secondary analysis (Heaton, 2008).

The purpose of the original study was to understand the experiences and needs of hospitalized patients and their family caregivers during the ALC period. The primary researcher was interested in conducting a supplementary secondary analysis to focus on resilience among family caregivers during the ALC period. The purpose of the secondary analysis was to understand how caregiver resilience is impacted and reflected in caring for a patient who requires an ALC. Therefore, a secondary supplementary analysis was an appropriate study design to address the research question.

3.2.1 Ethical Considerations

Prior to commencing a supplementary secondary analysis, it is important to ensure the use of existing data does not harm the participants (Heaton, 1998). To ensure ethical conduct, the research team sought ethics approval through two research protocol amendments. Ethics approvals for the protocol amendments were granted from University of Toronto Research Ethics Board (REB # 31675) on June 28, 2017 and St. Joseph’s Complex Continuing Care and Rehabilitation Facility (REB # 2015010) on July 7, 2017.

Considering the purpose of the secondary analysis aligned with the broader purpose of the original study, the study participants were not at risk of harm with the secondary analysis. Therefore, the researchers were not required to contact the participants and/or re-consent participants to conduct the analysis. As per the original study protocol, study data will be destroyed seven years following the completion of the study.
3.3 Conceptual Framework

The conceptual framework on resilience and family caregiving as presented in Chapter 2 was used as a framework to analyze the data and convey findings (Giacomini, 2010). Any reference to theory from herein refers to this conceptual framework.

In the literature, resilience is defined as the ability to manage or adjust to stress and/or adversity (Luthar et al, 2000; Simpson & Jones, 2012; Shaffer et al, 2016). Levels of resilience are dependent on the interaction between risk and protective factors. Protective factors are factors that moderate or mediate the effect of risk factors to enhance the ability to manage stress/adversity in the caregiving journey. Risk factors are factors that compromise an individual's ability to manage stress/adversity in the caregiving journey (Luthar et al, 2000; O'Dwyer et al, 2017; VanBreda, 2001; Zauszniewski, et al, 2010). These guiding principles were used to guide the qualitative inquiry, analyze the data, and suggest meaningful implications for policy research and practice (Giacomini, 2010; Kuper et al, 2008).

Deductive reasoning in the context of a content analysis uses a theory or framework to guide the analysis and generate themes. The general aim of deductive reasoning is to validate a theory. Inductive reasoning in a content analysis uses open coding to understand the data and generate categories to characterize the phenomenon. In some cases, inductive reasoning can generate theory (Elo & Kyngas, 2008). The conceptual framework on resilience and family caregiving was used to deductively analyze the data and determine how resilience was impacted and reflected among family caregivers. A deductive approach was used to determine how the conceptual framework could be applied to the sample of caregivers in this study (Elo & Kyngas, 2008). Aligned with the directed content analysis approach, to understand how the research findings may diverge from the conceptual framework, data that did not align with the conceptual framework was still considered in the analysis. This coding strategy provided an opportunity to extend the conceptual framework of resilience, particularly as it related to caregivers who were caring for an individual who required an ALC.
3.4 Methods

3.4.1 Original Study Methods

As this thesis used secondary analysis design, no new data collection activities were required. Therefore, this section provides an overview of the original study design, data collection and management, and a description of participant characteristics.

3.4.2 Sampling and Recruitment

Participants included in the original study were recruited in Northwestern Ontario. A purposive sampling strategy was used to recruit caregivers of patients who required an ALC. The caregivers included in this study were caring for patients who were cognitively impaired and were unable to provide informed consent to participate in an interview. The recruitment facilities included in the study were Thunder Bay Regional Health Sciences Centre and St. Joseph’s Complex Continuing Care and Rehabilitation Facility in Thunder Bay, Ontario (the latter which included two sites, one specifically for ‘overflow’ - patients requiring an ALC). To be eligible for the study, participants had to be a family caregiver of a patient in Thunder Bay who: 1) was waiting for a LTC placement from hospital (at one of the three participating study sites); 2) had previously received publicly funded home care services organized by the Community Care Access Centre (CCAC) prior to being designated as ALC; and 3) was looking after someone who was unable to participate in the study due to cognitive decline or lacked the capacity to make informed decisions. All participants spoke English, agreed to participate in an interview, and provided informed consent prior to the interview.

Recruitment began with a North West CCAC staff member compiling a list of eligible caregivers of patients receiving (currently or previously) home and community care services but now waiting in hospital as a designated ALC patient. The caregivers approached were caring for a patient waiting for an appropriate discharge location from the hospital and a few caregivers were caring for patients who were transferred back home as they waited for long-term care. The CCAC staff subsequently informed the eligible caregivers about the research study. Interested participants were provided with the option to contact the research team directly or have a member of the research team contact them for further study information. All eligible participants
requested to be contacted by a member of the research team. A member of the research team contacted all of the potential participants via telephone to provide study details and answer questions. If the caregiver expressed interest in the study, an interview was scheduled at a time and location that was convenient for the research participant.

### 3.4.3 Data Collection and Management

Interviews were conducted between October 2015 – February 2016 by an experienced qualitative researcher. Informed consent was collected from each participant by a member of the research team prior to the interview. Each interview followed the semi-structured interview guide that was developed by the research team and lasted approximately 30-60 minutes. The caregiver semi-structured interview guide consisted of 13 open-ended questions. The questions focused on caregiver characteristics, the factors that led to the hospitalization of the care recipient, the use of community supports, and long-term care planning (See Appendix D).

All interview data were previously transcribed verbatim by a professional transcriptionist and checked by a member of the original research team. Transcripts were stripped of personal information to protect the privacy of the research participants. Interview recordings, consent forms and interview transcripts were stored on a secure server in the private office of the principal investigator. These files were transferred onto an encrypted hard drive that was only available to members of the research team.

### 3.4.4 Participant Characteristics

The 18 caregivers who were providing support to a patient who required an ALC were included in the original study. In two cases, multiple caregivers opted to be interviewed together, resulting in a total of 15 transcripts (caregivers of 15 patients). Caregivers were predominately female (61%). The majority of caregivers were caring for either their mother or father (61%), however, 83% of caregivers did not live with the care recipient. On average, caregivers were caring for a patient aged 78.2 years. Please refer to Table 1 for detailed characteristics of the caregivers.
The majority of care recipients were hospitalized due to falls and frailty (including delirium). The remainder of the care recipients were hospitalized due to a physical injury, cancer, and mental health issues. The majority of these patients had multimorbidity and all patients were experiencing cognitive decline during their hospitalization. Prior to their hospitalization, nine out of fifteen (60%) patients were receiving publicly funded homecare services for their care needs. The remaining patients did not receive publicly funded homecare services (27%) or refused these services (13%). Please refer to Table 2 for detailed characteristics of the patients.

Table 1. Caregiver Characteristics (n = 18, based on a total of 15 care recipients)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>Male</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td><strong>Relationship to patient</strong></td>
<td></td>
</tr>
<tr>
<td>Child</td>
<td>11 (61.1)</td>
</tr>
<tr>
<td>Spouse</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Parent</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Extended family</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2 (11.1)</td>
</tr>
<tr>
<td>N/A</td>
<td>1 (5.6)</td>
</tr>
<tr>
<td><strong>Living with Patient?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>3 (16.7)</td>
</tr>
<tr>
<td>No</td>
<td>15 (83.3)</td>
</tr>
<tr>
<td><strong>Patient Age</strong></td>
<td></td>
</tr>
<tr>
<td>Average age</td>
<td>78.2 years ±</td>
</tr>
<tr>
<td><strong>Patient Receiving Community Based Services Prior to Hospitalization</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9 (60)</td>
</tr>
<tr>
<td>No</td>
<td>*6 (40)</td>
</tr>
</tbody>
</table>

± Based on 12/15 patients
*although CCAC care coordinators noted they were reaching out to caregivers of former homecare clients, 6 caregivers indicated no such services (there is a possibility that no care plan was put together following the assessment).
<table>
<thead>
<tr>
<th>Patient</th>
<th>Sex</th>
<th>Caregiver ID</th>
<th>Caregiver Relationship to Patient</th>
<th>Living Arrangement</th>
<th>Reason for Hospitalization</th>
<th>Receiving Community Services?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Male</td>
<td>CG-01</td>
<td>Wife</td>
<td>Home (with caregiver)</td>
<td>Fall</td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td>Female</td>
<td>CG-02</td>
<td>Son</td>
<td>Assisted living facility</td>
<td>Fall</td>
<td>Yes</td>
</tr>
<tr>
<td>3</td>
<td>Female</td>
<td>CG-03</td>
<td>Mom</td>
<td>Home (alone)</td>
<td>Cancer</td>
<td>No (refused)</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>CG-04</td>
<td>Husband</td>
<td>Home (with caregiver)</td>
<td>Mental health</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>CG-05, CG-06, CG-07</td>
<td>Son/ Daughter (2)</td>
<td>Home (with spouse)</td>
<td>Fall</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>CG-08, CG-09</td>
<td>Extended family</td>
<td>Home (alone)</td>
<td>Delirium</td>
<td>Yes</td>
</tr>
<tr>
<td>7</td>
<td>Female</td>
<td>CG-10</td>
<td>Daughter</td>
<td>Home (alone)</td>
<td>Fall</td>
<td>No (refused)</td>
</tr>
<tr>
<td>8</td>
<td>Female</td>
<td>CG-11</td>
<td>Daughter</td>
<td>Home (with spouse)</td>
<td>Fall</td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td>Female</td>
<td>CG-12</td>
<td>Son</td>
<td>Home (alone)</td>
<td>Stroke</td>
<td>No</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>CG-13</td>
<td>Son</td>
<td>Home (alone)</td>
<td>Fall</td>
<td>Yes</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>CG-14</td>
<td>Mother</td>
<td>Home (alone)</td>
<td>Acquired Brain Injury</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Male</td>
<td>CG-15</td>
<td>Sister</td>
<td>Home (alone)</td>
<td>Cancer</td>
<td>Yes</td>
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<tr>
<td>13</td>
<td>Male</td>
<td>CG-16</td>
<td>Daughter</td>
<td>Home (with caregiver)</td>
<td>Delirium</td>
<td>Yes</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>CG-17</td>
<td>Son</td>
<td>Home (alone)</td>
<td>Fall</td>
<td>Yes</td>
</tr>
<tr>
<td>15</td>
<td>Male</td>
<td>CG-18</td>
<td>Daughter</td>
<td>Assisted living</td>
<td>Fall</td>
<td>Yes</td>
</tr>
</tbody>
</table>
3.4.5 Secondary Analysis Methods

The data presented in this thesis was shared by Dr. Kerry Kuluski (KK), the principal investigator of the original study and the graduate supervisor of the primary researcher (RL). Audio recordings and de-identified interview transcripts were originally stored on a secure server in the private office of the principal investigator. These files were transferred onto an encrypted hard drive that was only available to members of the research team (RL and MN).

Data Analysis Methods

A qualitative content analysis is an interpretive method for systematically coding and analyzing data (Elo & Kyngas, 2008; Hsieh & Shannon, 2005). A directed content analysis is a structured method that aims to confirm the concepts of a framework and/or further develop the conceptual framework through deduction (Elo & Kyngas, 2008; Hseih & Shannon, 2005). The following section will describe the primary researcher’s engagement with the data, the coding process and the identification of three core themes.

No further data preparation was required as all transcripts were previously stripped of any identifying information. All transcripts were imported into NVivo, a qualitative data management software that is designed to organize interview transcripts. To thoroughly engage with the qualitative data, the primary researcher reviewed the transcripts on multiple occasions and listened to the audio recordings to become familiar with the data (Bengtsson, 2016). To capture all aspects of resilience, the analysis process began with highlighting all text that was related to the caregiver adjusting to or managing stress (Hsieh & Shannon, 2005). Next, coding involved applying the pre-determined codes (risk/protective factors from the conceptual framework) to the highlighted text. Pre-determined codes that were not applicable to the remaining text were assigned new codes (Hsieh & Shannon, 2005).

Prior to coding the entire dataset, RL and KK independently coded two transcripts and held a consensus meeting to discuss the codes that they identified in the transcripts. Meeting notes were documented to capture any discrepancies in coding. The two researchers agreed upon the majority of codes that were identified independently (e.g. the positive cognitions, negative cognitions, faith, and provider/caregiver communication). Following the consensus meeting, the primary researcher proceeded to independently code the remaining transcripts using the coding
framework outlined earlier. This coding process allowed the primary researcher to refine and extend the conceptual framework as it relates to caregivers who care for a patient who requires an ALC (Hseih & Shannon, 2005).

The codes identified in the coding process (within and outside the conceptual framework) were both included in the analysis. It was evident that there were relationships between the codes, and these codes were therefore categorized into larger groups based on the relationships between them. The analysis process involved organizing and reorganizing data to understand how resilience was reflected or impacted in the sample to arrive at themes. Within each theme, sub-themes were identified to capture the differences in resilience. To ensure the themes accurately reflected the data, the primary researcher re-read the transcripts multiple times to ensure accurate representation (Elo & Kyngas, 2008). There was evidence of both risk and protective factors from the framework among these caregivers. Rather than reporting on discrete resilience factors that were identified in the analysis, themes were developed based on the interplay of these factors on the level of resilience.

The primary researcher developed an analytical memo to describe patterns in the data. The analytic memo was ultimately refined to show the creation of core themes presented in the results section. This memo was reviewed and refined by the research team through multiple iterations. Memos were beneficial for facilitating conversation between members of the research team and allowed for a more in-depth analysis of the data by all members of the team (Birks, Chapman & Francis, 2008). More specifically, the memo allowed other members of the team to see what the primary researcher was thinking and how she was interpreting the data.

3.5 Methodological Rigour

Enhancing trustworthiness in qualitative research is critical to ensure methodological rigour. To analyze the data, a directed content analysis was an appropriate method of analysis as a conceptual framework was used to guide the analysis. However, the use of a conceptual framework in qualitative analysis may pose a few challenges. A conceptual framework may introduce bias, as the researcher may focus on concepts presented in support of the framework (Hseih & Shannon, 2005). In addition, the overreliance on concepts to deductively code data
may blind the researcher from the broader aspects of the phenomenon (Hseih & Shannon, 2005). To address this issue, the primary researcher highlighted all text that was related to resilience prior to applying the codes from the conceptual framework. This ensured the primary researcher was not restricted to concepts from the framework and allowed the primary researcher to capture emerging codes that were not a part of the initial coding framework that related to the phenomenon of resilience. This provided an opportunity to build on the framework as it relates to caregivers during the ALC period.

To increase credibility of the research findings, a second reviewer (KK) reviewed and helped refine the codes prior to completing the analysis (Hseih & Shannon, 2005; Vaismaoradi, Turunen, & Bondas, 2013). This process ensured that RL and KK were in alignment with the codes identified in the transcript (Elo et al, 2014). To enhance the confirmability of findings, two types of memos were created. First a descriptive memo was created for each transcript and provided a high-level overview of the caregiver’s ALC experience. The second, an analytical memo, was used to develop and describe core concepts and themes in consultation with the thesis committee. The analytical memo provided detailed findings and supporting quotes in addition to interpretive comments. This memo allowed the committee to provide a critical lens to the analysis and have in-depth discussions about the themes and sub-themes (Birks et al, 2008; Elo et al, 2014). All members of the research team agreed on the themes identified from the data.

### 3.6 Funding

The funding for the initial project was provided by Ontario’s Ministry of Health and Long-Term Care and the Health System Performance Research Network (HSPRN) at the University of Toronto. Rebecca Lum was supported with a University of Toronto Fellowship and Ontario Graduate Scholarship from the Ministry of Education, Colleges and Universities.
Chapter 4

4 Results

This chapter addresses the second research question of this thesis: How is caregiver resilience impacted and reflected in caring for a patient who requires an Alternate Level of Care?

This chapter presents findings from the qualitative interviews with accompanying quotes from caregivers. The caregiver participants (background characteristics described in chapter 3) were assigned identification codes to ensure their confidentiality as well as the patients they were caring for. For interviews containing multiple caregivers, each caregiver was provided with a unique identification code to ensure the individual representation of each caregiver. This chapter will discuss the findings in relation to the conceptual framework, provide an overview of themes, and provide an in-depth description of each theme.

4.1 Conceptual Framework

As described previously in chapter 2, the conceptual framework on resilience and family caregiving developed through this research, was used to analyze the data through deduction. Concepts from the framework that applied to caregivers in the secondary analysis of ALC caregiver interviews are highlighted below in the table of themes. These concepts include: strengthening of family relationships, lack of access to resources, guilt, grief, mastery, acceptance, self-efficacy, hardiness, hope, access to social support, uncertainty, resourcefulness, patient dependency, feelings of burden, competing priorities, love for the care recipient, financial strain, poor physical/mental health, self-care and faith and spirituality.

Although many of the resilience factors identified in the mapping review were present in the experience of study participants, not all concepts were identified. Concepts that were not clearly apparent include: sense of coherence (cognition), stigma, family conflict, and social isolation. In the data, there was evidence of many of the concepts in the conceptual framework, which indicates the applicability of the framework among caregivers during the ALC period. Rather than reporting on the discrete resilience factors, overarching themes are presented. While the
discrete factors outlined in the conceptual framework outline risk and protective factors for resilience, the themes described in this chapter capture the interplay of risk factors and protective factors and how they influence levels of resilience. These themes are discussed in further detail in the subsequent sections.

4.2 Overview of Themes

Caregivers described their personal experiences leading up to the hospitalization as well as their experience waiting for an appropriate discharge location. The results presented in this chapter will largely focus on ALC period as well as some of the events leading up to the ALC period. Three core themes of their experience were identified: becoming an advocate, variable communication with the healthcare team, and searching for balance. These core themes are summarized in Table 3. Comprehensive descriptions of these themes with representative participant quotes follow.

Table 3. Summary of Core Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Sub-Themes</th>
<th>Concepts from Framework</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Becoming an Advocate:</strong> advocating for the patient’s care needs were met with different outcomes. Many risk and protective factors played a role in the ability to advocate for the patient.</td>
<td>➢ Advocating with favourable outcomes ➢ Advocating with unfavourable outcomes ➢ Feeling powerless</td>
<td>➢ Resourcefulness ➢ Self-efficacy ➢ Mastery ➢ Guilt ➢ Grief</td>
</tr>
<tr>
<td><strong>Variable Communication with the Healthcare Team:</strong> messaging from the care team led to mixed responses from caregivers. The type of communication appeared to impact other risk and protective factors.</td>
<td>➢ Clear Messaging ➢ Mixed messaging</td>
<td>➢ Uncertainty ➢ Acceptance ➢ Hardiness ➢ Hope</td>
</tr>
<tr>
<td><strong>Searching for Balance:</strong> caregivers described their attempts to adjust to the change</td>
<td>➢ Adapting to change ➢ A temporary balance</td>
<td>➢ Personal factors (financial strain, physical/mental)</td>
</tr>
</tbody>
</table>
in their caregiving duties.  
Resilience was reflected in their ability to balance their personal lives with their caregiving duties, which was influenced by multiple risk factors and protective factors.

➢ Struggling to find balance
➢ Caregiver context (conflicting priorities, patient dependency /feelings of burden, love for the care recipient)
➢ Family relationships, social support, formal supports
➢ Cognitions (grief, hope)

Although caregivers faced similar adversities (hospitalization and ALC period), caregivers exhibited various levels of resilience throughout their experience.
4.3 Theme One: Becoming an Advocate

An overview of the first theme is outlined in Figure 9 below.

![Figure 9: Theme One: Becoming an Advocate]

Patients were designated as ALC once their acute care was complete and they were cleared for discharge by a physician. While waiting for a place in long-term care, patients remained in the hospital or post-acute facility. During this time, caregivers perceived a decline in the quality and quantity of personal care and medical care by the care team. To address issues with care, some caregivers advocated on behalf of the patient during the hospitalization and ALC period. Advocating included voicing their concerns regarding patient care, resisting provider recommendations for discharge and demanding answers from the healthcare team to ensure the overall well-being of the patient. Some caregivers consistently advocated for their needs and the needs of the patient, while others felt powerless to change the situation. The act of advocating resulted in different outcomes for the caregivers and patients. Caregivers who were unable to achieve a favourable outcome tended to experience more stress during the ALC period. As outlined in Figure 9, cognitions and access to information were present in people’s account of their experiences and influenced the ability to advocate for the patient. Specific to the ALC experience, there were elements of persistence and feelings of powerlessness that influenced the ability to advocate.
Advocating with a favourable outcome

Some caregivers consistently advocated for the patient during the ALC period. When these caregivers identified problems or inconsistencies with care, they were not reluctant to vocalize their needs until the issues were seemingly resolved. Successfully advocating (i.e., realizing a particular desired outcome) for the patient required the caregiver to be persistent, as concerns were usually only addressed by care providers when caregivers constantly expressed their concerns.

Many caregivers described the patients’ care as sub-optimal during the ALC period. In many cases, the sub-optimal care was perceived to result in further functional decline of the patient. Vocalizing needs to achieve a favourable outcome seemed to require a higher level of *mastery*, where caregivers felt they had personal control over the situation. To prevent further functional decline, one caregiver described her experience of vocalizing her concerns regarding rehabilitation services. Initially, her father was receiving minimal rehabilitation and was slowly becoming incontinent. She mentioned having to consistently vocalize her concerns to resolve the issue and have her father transition to another unit. Reflecting on her experience, she said that her father would have eventually become incontinent if she had not been advocating on his behalf.

“... nobody’s taking him to the bathroom, nobody’s getting him up, nobody’s getting him dressed...I’m convinced that if I hadn’t been advocating...my dad would be laying in a bed in a hospital just with a diaper... if I hadn’t pushed it and pushed it, my dad would have gone straight downhill.” (CG-18)

Although the caregiver faced a great deal of stress, she took the necessary steps to ensure her father’s needs were met.

Other caregivers advocated for geriatric assessments to ensure appropriate diagnoses. One caregiver noticed her mother was not adjusting well to the hospital environment and was unsure of the cause. She mentioned having to push for the assessment multiple times before the care team agreed to conduct the assessment. In this case, the assessment identified her mother’s
depression. After her diagnosis of depression, her mother was able to receive the appropriate treatment for her depression.

“...I really wanted a geriatric assessment ... I had been trying and trying and trying to get for her...they did call in the geriatric team and they did assess... primariliy what was wrong with mom was depression...” (CG-10)

Another caregiver advocated for a geriatric assessment to confirm that his great-aunt was not able to make informed decisions. During this time, he was legally not able to make decisions on her behalf, which was concerning to him because of his great aunt’s cognitive decline.

“...The dementia was that bad, it was obvious that she couldn't be at home...we had asked to have an assessment done right away... we wanted to have [physician] come in and check her over...the geriatric psych assessment...” (CG-08)

After the geriatric assessment, this caregiver became the power of attorney for his great-aunt. This provided him with the assurance that he could make crucial decisions on her behalf.

When one caregiver was notified that a long-term care bed was available for her mother, she flew in from another province to facilitate the move. However, during that period, her mother broke her elbow and required surgery prior to moving into long-term care. The caregiver vocalized her concerns to the care team and advocated for her mother to be prioritized for surgery as her mother was at risk of losing the long-term care bed. Although her mother was not initially prioritized for surgery, after vocalizing her concerns, her mother was able to have surgery on the same day. The caregiver was confident she could endure the situation (self-efficacy) and was ultimately able to transition her mother from the ALC unit to her reserved place in long term care. Resourcefulness played out in this situation where the caregiver knew how to successfully navigate the system.

“ [LTC facility] ... had a bed...then Sunday night she fell and broke her elbow, and ended up in hospital and had to have surgery... I’m about to lose her long-term care bed...we were between a rock and a hard place because on the surgical priority list, mom wasn’t a high priority... I explained to them...
that it was really difficult for me to take my mom physically over and bring her back when she could get called to the OR [operating room] any minute, and I don't want to miss that either. So she got her surgery that afternoon I just went over anyway and moved all her stuff in anyway…[laughs.” (CG-10)

Ensuring consistency was important to caregivers to prevent any medical errors. To ensure medication was being appropriately administered to patients, some caregivers consistently reminded care team members on when and how to administer medication. One caregiver mentioned that she noticed her father’s Parkinson’s medication was not being administered correctly by the nursing staff. After multiple medication errors, she advocated for the care team to administer medication at the appropriate time. Her ability to ensure her father’s medication was being consistently administered may have prevented additional adverse events and further decline.

“…his medication…it’s supposed to be given one hour before he eats... if you take it and then eat proteins, they fight against each other and it's not effective... I had to ask over and over and over again because they were giving it with his meals...there were 2 med errors...” (CG-18)

Another caregiver who was providing care for her mother with dementia noticed the staff responded to her mother’s agitation with medication. The caregiver did not agree with this approach and communicated her concerns with the nurses. She had requested the nursing staff contact her when her mother was agitated, as she had the ability to calm her mother down without the need for medication. She successfully ensured that her mother was not receiving unnecessary medication and experiencing the potential side-effects. However, this required the caregiver to be in physical contact with her mother on a regular basis to calm her mother down.

“… at least 2 or 3 times a week, I was getting a call, and I’d be spending the night because she... couldn't calm down...sometimes it will take an hour or two but sometimes all she has to do is see my face and she calms down... I had said to the nurses was please, when she gets like that, medication is not the first thing. The first thing you do is call me…” (CG-16)
The same caregiver also asked staff to change the timing of her mother’s medication regimen, so she could have the opportunity spend time with her when she was lucid. This involved the nursing staff delaying the administration of her medication to ensure the caregiver could spend quality time with her mother.

“...This one nurse’s routine was to give mom her medication as soon as she came on shift...By the time I get there...mother is now in la-la land. So that half hour or hour that I would always have with my mom to feed her, to do the hugs and kisses... I couldn’t have that because the meds that she has knocks her out. So it was simple. All I had to do was say family requests that we give the medication with breakfast.” (CG-11)

Many caregivers advocated for themselves when the care team recommended that the patient return home. In these cases, caregivers mentioned they were unable to bring the care recipient home due to the lack of community supports. Although the care team made the suggestions for the patients to return home on multiple occasions, these caregivers were persistent to ensure their wishes were respected by the care team.

“... they seemed to be very pushy in... getting him out of there [hospital]...They were suggesting that he come home. And we said no because I don’t know if I could cope with that and I think it would have been too much for me. And they suggested that he come home for 90 days...we didn’t want him to come home because I knew I couldn't handle him.” (CG-01)

One adamant caregiver told the care team that their recommendation to have the patient return home was unacceptable, unless the patient received 24-hour care.

“... We knew it didn’t matter what [community care agency] said, we knew he couldn't go home. [community care agency] kept on telling me, “Well, we can send him home with support.” And I said, “You’ve got 24 hour support?” And they said, “Well, no, morning and night.” I said no, that’s not acceptable...He’ll never ever manage at home.” (CG-15)
In these cases, caregivers were successful in resisting the recommendation to transfer the patient home. This involved fighting for their needs as caregivers, as they would be responsible for caring for the care recipient in the community.

Caregivers who used their knowledge of the healthcare system as a resource seemed better equipped to advocate for the patient. In many instances, these individuals were healthcare professionals who were aware of what the appropriate standard of care and how to navigate the health system. One caregiver who had siblings in the healthcare field had the guidance and support from his siblings to ask the right questions. The caregiver acknowledged that he was privileged to have support from siblings who work within the healthcare system.

“...I’m here all the time. But if I need some medical terms... I’m a dumb engineer... They’re in the medical field. So I’ll just phone them [siblings]...then they’ll tell me to ask these questions... And then I can get some answers.” (CG-02)

One caregiver who was caring for his great-aunt experiencing cognitive decline noticed that she was losing a significant amount of weight due to her lack of appetite. As a nurse, he knew that she required a specific medication to stimulate her appetite. The caregiver then requested the medication through the patient’s physician. After administering the medication, the patient’s appetite was stimulated, and she was able to regain her strength.

“... while she was in hospital, she stopped eating... we actually thought that she was going to die ...She went downhill so fast... I also started her on some medication to help stimulate the appetite back when she was in the hospital...I know a lot of these things from my cancer patients...” (CG-08)

When caregivers were left out of crucial conversations and were lacking information, they were not hesitant to approach multiple healthcare providers to gather information. These caregivers advocated for themselves to be actively involved in decision-making with the care team. One daughter felt she was left out of crucial conversations by the nursing staff regarding her brother’s care. After multiple attempts to confront the nursing staff, she eventually needed to convince managerial staff that she deserved to be involved in decision-making.
“They wouldn't give me anything...I had a hard time getting information...I finally had to go to the nurse manager and say... I need to have this information. I am part of the circle of care when I'm the family... then finally this one nurse in particular started to share information with me.” (CG-15)

Often, care plans are composed with inputs from providers across various disciplines. Another caregiver expressed the need to be a contributing member of the care team to ensure that everyone agreed on the care plan for the patient.

“...I want to feel like I’m part of a team... we were there for 3 months... and I’m there every day. So wanting to make sure that we’re all on the same page about mom. And so the social worker was there, and the dietician was there, and the OT and the PT, and the equivalent of a chaplain.” (CG-11)

Caregivers noted the importance and benefit of being able to advocate for the patient and achieve favourable outcomes. These caregivers were also cognizant that not every caregiver has the ability to advocate. One caregiver who had the support of his siblings recognized that those without knowledge of the healthcare system were at a disadvantage.

“... If I didn’t have that background with my siblings, I’d be in the dark. And I know some families that come in, they’re in the dark. They don’t know what to ask and they’re not told...” (CG-02)

In summary, those who were able to effectively advocate had confidence in their actions, were often knowledgeable about the healthcare system, resourceful, persistent, and vocal about the patient’s needs. These caregivers saw the benefit of their advocacy efforts and were generally satisfied with the healthcare team response.

Advocating with unfavourable outcomes

For some caregivers, their advocacy efforts led to an unfavourable outcome. Some caregivers came to the realization that they would have to lower their expectations or come to terms that they were powerless to change the situation.
In some cases, the caregivers actively advocated for the patient but eventually realized their lack of control and were forced into an unfavourable situation. In one case involving three caregivers, the caregivers worried about their father’s transition from the acute hospital to the post-acute hospital. Based on their experience with previous transitions within the acute care hospital, they noticed their father had a difficult time adjusting to new environments.

“...we voiced our opinions, and maybe I voiced my opinions more than he did. But I just didn’t think it was fair for my dad having dementia or Alzheimer's to go from... one unit and you're settled, and you’ve got these nurses... he went for 5 moves.” (CG-06)

These caregivers felt it was unfair to have their father, who was experiencing cognitive decline, to be subject to changes in the environment and nursing staff. These caregivers felt voiceless in the situation when they were forced to take their father to the post-acute facility to wait for a long-term care bed. They continuously saw other patients being transferred into long-term care and did not understand why their father was still waiting for a long-term care bed after two years.

“...I feel when the time comes to get everyone out ... he's just going to be stuffed somewhere... It's going to be another thing that we don’t agree with. But it's going to be – that’s where he’s going, take it or leave it.” (CG-06)

These caregivers eventually accepted that their father would have to move to the post-acute hospital despite their efforts to advocate for their father. This was met with feelings of fear.

Another caregiver who described his mother as a “smart and strong woman” believed his mother should have been discharged into the community. Although he tried to make alternate arrangements for his mother, the care team insisted on placing his mother in a long-term care home. Although he did not agree with the discharge destination, he eventually accepted that he could not change the situation and felt a sense of guilt when placing her into long term care.

“...I guess we’re going to have to put her in a home. And she doesn’t like it...
I work out of town...I’m back and forth ...she’d rather be by herself in her own place. And I think everything would have been good. But they
recommend I couldn’t… I didn’t like it at all. But you have to do what we have to do. There was some guilt of putting her into LTC.” (CG-12)

Although it may have been unrealistic from the perspective of the care team, the caregiver felt his mother could manage at home with the appropriate supports. In these cases, caregivers were forced into a situation in which they attempted to advocate against. This led caregivers to realize they had relatively little control over outcomes.

Feeling powerless

A number of caregivers who were frustrated with the quality of care the patient was receiving seemed reluctant to voice their concerns. When the healthcare team made decisions on the care recipient’s behalf that the caregiver did not agree with, they experienced grief and felt powerless to change the situation.

Forced transitions led to increased stress among caregivers who were not prepared to have the patient return home. In one case, the hospital unexpectedly discharged a patient with dementia. This negatively impacted the caregiver’s ability to manage his caregiving duties as he was also caring for his wife with a physical disability. This caregiver said he immediately regretted his decision to sign the discharge form. Unfortunately, he felt unable to voice his concerns regarding the discharge and was forced to care for his mother at home.

“…they released her. And I was stupid enough when I did go take my mom out, I signed the release form. And I should have never signed that thing. That was stupid on my part. But even if I didn’t sign it, they still would have released her anyway… So I just felt like I couldn’t do anything…Yeah, caught and powerless. And completely powerless, right, because I just don’t know what to do next.” (CG-17)

Upon the discharge, the caregiver was unsure of how he could manage his mother’s and wife’s needs. This situation appeared to evoke feelings of frustration and anger for the caregiver who felt powerless to change the situation.

Throughout the experience, some caregivers felt they were unable to voice their opinion. One caregiver reflected on her experience of her father becoming incontinent while in the hospital
due to inadequate staffing. Due to staff attitudes regarding personal care, the caregiver felt she could not voice her opinion regarding her father’s care needs. Although she did not voice her concerns to the staff, she had strong feelings on how the nursing staff should have dealt with her father.

“...my dad didn’t like the idea of sitting in a wet diaper... And some of the attitudes were, well, we can change the diaper later. Well, no, no, no, he doesn’t have to have the diaper wet in the first place if you get there with the urinal in time...”

A mother who described her daughter as a “fighter” noticed changes in her daughter’s behaviour in the hospital. She was unsure of what medication her daughter was on and although she didn’t agree with those changes, she felt unable to change the situation.

“...I don’t know whether they gave her some medication or what but she was so confused ... it was awful. And yet nobody there would admit to me that they put her on some kind of medication...they just kept saying she’s just mixed up. Mixed up from what?...” (CG-03)

The caregiver said the care team did not consult her prior to administering the medication and she was no longer able to recognize her daughter.

In summary, many risk and protective factors influenced the ability to advocate. Some caregivers were resourceful and persistent when advocating for the patient. This led to more favourable outcomes. It seemed that those who felt powerless were less familiar with the health system and were unable to achieve a favourable outcome for the patient. Therefore, these caregivers experienced feelings of guilt and grief for being unable to advocate for the patient.

4.4 Theme Two: Variable Communication with the Healthcare Team

An overview of the second theme is outlined in Figure 10 below.
Figure 10. Theme Two: Variable Communication with Healthcare Providers

During the ALC period, communication between the healthcare team and the caregiver was crucial to ensure caregivers were informed of the patient’s condition, next steps in care and discharge plans. Communication was vital for these caregivers who were responsible for making decisions on behalf of these patients experiencing cognitive decline. When describing their conversations with healthcare providers, there were differences in provider messaging and the responses of caregivers. Communication not only affected caregiver resilience but had an impact on other risk and protective factors. As outlined in Figure 10, access to information and cognitions were impacted by communication with healthcare providers. In addition, there was elements of trust and mistrust in the care team during the ALC experience.

When providers were clear with their messaging, caregivers were better able to adjust their expectations for the patient’s recovery and plan for the future. However, when providers were ambiguous with their messaging, caregivers often felt unsettled and worried about the next steps.

Clear Messaging
When healthcare providers were clear with their messaging, they were able to foster a trusting relationship with the caregiver and ease feelings of uncertainty. Overall, caregivers were better able to adjust their expectations about the patient’s care trajectory as a result of clear communication.

Caregivers mentioned how the care team’s honesty and openness about the patient’s trajectory had a role in facilitating acceptance and easing uncertainty. One caregiver initially found it difficult to determine the next steps for her son who sustained a sudden traumatic brain injury. The amount of information she received from the care team was overwhelming at first. However, clear communication regarding the patient’s condition eased feelings of uncertainty and made it easier to process the information.

“The doctor... said... “If you keep him alive, you won’t want to see him in a couple of months.” he was very straightforward. He said he’ll have pneumonia, he’ll have diarrhea from the tube feeds, he’ll have bedsores... It was sort of like this is what you’re looking at...” (CG-14)

In this case, the care team also did not pressure her to make an immediate decision for her son’s care. However, the care team was able to manage expectations for her son’s future. By managing expectations, the caregiver accepted that she would eventually have to place her son in long-term care. This caregiver was very hopeful, which may have been connected to her faith and spirituality. Furthermore, despite the poor prognosis, she was able to positively appraise the situation (hardiness).

“...we really appreciate the medical staff’s honesty... We asked him at that point, okay, what would you do?....because you’re so overwhelmed...the doctor said “well medically we would let him go. We’d go palliative. But as parents, we don’t know what we would do...we’re not pressuring you either way, and we understand whichever route you take.” (CG-14)

When care providers were direct with their messaging, they were able to ease uncertainty among caregivers throughout the ALC period. A daughter caring for her father saw the decline in his cognitive and functional ability prior to his hospitalization. Despite his decline while he was in the community, she did not receive any additional homecare support. Due to her previous
negative experience with homecare services, she had lower expectations for her father’s care moving forward. When discussing the discharge plan with her father’s care team, the team clearly communicated their concerns about him returning home.

“...they said, “No, he is very high risk for falls. He can’t be on his own.” And because he was there and the occupational therapists were working with my dad every day, they got... how his cognitive capacity is not what it should be... they caught onto that – that there were good days and bad days... (CG-18)

The caregiver seemed relieved that all members of the care team agreed that her father should be discharged into long-term care. The care team understood that the patient could no longer be on his own and were able to ease the caregiver’s uncertainty.

In another case, when the interviewer asked one caregiver if it was possible from her perspective to have her mother back home, she mentioned the care team was very clear that he was unable to come home.

“...they said he couldn't go back to his apartment...He would go into long term care because he needed more care than what he could handle at home...That was the therapist and the people at [healthcare facility], and myself included. Because that’s why he ended up in the hospital in the first place. (CG-13)

In summary, clear messaging seemed to provide relief to caregivers by easing feelings of uncertainty as well as facilitating acceptance.

Mixed Messaging

The ALC experience is generally characterized by uncertainty for both caregivers and patients. When healthcare providers were unclear with their messaging or provided inconsistent messaging (mixed messaging), caregivers were unsure of next steps for the patient. It appeared that this type of messaging led to additional stress and feelings of worry among caregivers.

Unclear messaging between healthcare providers and caregivers were often regarding patient care plans. Initially, a few caregivers thought their father would be discharged back into the
community. As a result, the family had made modifications to their home in order to accommodate his functional needs following discharge.

“...they were... giving us hope, and writing discharge, you know, possible discharge date... We get bathroom chairs, you know, shower chairs, and grab bars. And we get everything ready for him to come home. And then they’re saying maybe not...” (CG-06)

Unfortunately, the care team ultimately recommended that their father should be placed in long-term care. This led to disappointment and frustration among the family members who were prepared to have their father back home.

With the limited number of beds for patients, discharge from the ALC unit into the community without consulting the caregiver was not uncommon. One caregiver was told by the admitting physician that his mother required around the clock care, while another physician told him that his mother no longer needed support and could be discharged. The conflicting messaging this caregiver was receiving led to confusion. Eventually, the caregiver felt forced to bring his mother home, without the 24-hour care that the initial physician had recommended.

“...the doctor in Admitting... said, “You know what, she needs 24-hour support right now”...then the doctor at the hospital or the administrator was trying to kind of get her out of there, saying, “This is not a crisis kind of situation going on and we need the bed.” Apparently they had 12 beds for people going through this...where can I get 24-hour support for my mom here in town? There isn’t any. Nothing.” (CG-17)

When this caregiver’s mother was admitted to the hospital, there was a sense of comfort that his mother would get the care she needed. However, he later learned that she would be discharged without the 24-hour care. Due to the mixed messaging, this caregiver was left scrambling to find resources to support his mother.

When caregivers felt that their healthcare providers were not delivering on their care plans for the patient, caregivers felt frustrated by the unfulfilled promises. In one case, a husband caring
for his wife with mental health issues felt that the care team was being unclear about the patient’s trajectory.

“...after she had been there [hospital] for so many months, I asked the doctor, I said, what’s going on? Can you tell me any kind of plan that’s being put in place for her treatment? And they sort of went around about way about answering. You know how professionals do it. They go behind you...” (CG-04)

The lack of clear messaging led to feelings of anger and distrust towards the healthcare team. This resulted in the caregiver demanding to have his wife discharged, even if he had to care for her without the appropriate supports.

Unclear messaging from care providers often led to confusion. In one case, the care team agreed to develop a discharge plan in consultation with the caregiver. However, all the decisions regarding the discharge were made on his behalf by the care team.

“...Another thing that really happened and really got to me, was she was in the hospital, they wanted to release her... they’re supposed to be doing up a plan, a release plan. And I’m supposed to be consulted. I wasn’t...” (CG-17)

Eventually, the care team discharged the patient without consulting the caregiver and providing him with much needed access to formal supports. This sudden discharge left the caregiver to struggle with managing both his mother and wife with a physical disability.

“...I didn’t even know what the plan was. Eight hours of support, what does that mean, what does that consist of... and what else is there other than that? Like nothing...” (CG-17)

In some cases, caregivers were left out of treatment decisions and were unsure of who they could approach to gather more information. One caregiver reported that the care team would not disclose what medications they were administering to her daughter. The team did not consult her prior to administering the medication and failed to communicate the potential side effects of the medication with her. As a result, the caregiver was upset that her daughter was “mixed up” to a point where she could no longer recognize her daughter.
“... nobody there would admit to me that they put her on some kind of medication that...But when I talked to them about it, they just kept saying she’s just mixed up. Mixed up from what? She’s not mixed up now.” (CG-03)

In summary, it appears that clear messaging fostered a trusting relationship between providers and caregivers. Clear messaging also eased feelings of uncertainty and facilitated acceptance among caregivers. On the contrary, mixed messaging often left caregivers unsure about the next steps in the patient’s trajectory, thereby fostering uncertainty. The mixed messaging contributed to negative emotions such as fear among caregivers.

4.5 Theme Three: Searching for Balance

An overview of the third theme is outlined in Figure 11 below.
When patients were hospitalized and eventually designated as ALC, caregivers attempted to adapt to the new phase in their caregiving journey. In nearly all cases, patients were too functionally dependent to return home and were waiting in hospital for a long-term care bed. Although the patient was receiving some level of care in the hospital or post-acute facility, caregivers were managing the patient’s long-term care arrangements, visiting the patient in hospital, ensuring the patient’s care needs were met by staff and providing additional care to the patient while trying to manage their personal lives. Caregivers described their attempts to balance their personal life while ensuring the needs of the patient were met, even if it required making personal sacrifices. As outlined in Figure 11, personal factors, social support, formal resources, cognitions and caregiving contextual factors played a key role in the ability to balance their personal life and caregiving role. In attempts to adjust to this period in the caregiving journey, the interaction of these factors influenced their ability to adapt and manage their personal life.

**Adapting to change**

Overall, caregivers with more personal time adapted to the ALC period, despite some of the challenges or difficulties they encountered. A few caregivers described their relatively positive...
adjustment to the ALC period and the factors that contributed to this adjustment. These caregivers had fewer commitments and competing priorities. As a result, these caregivers had more time to spend with the patient while they were in the hospital and provide personal care to the patient.

Fewer competing priorities allowed caregivers to provide care and engage in *self-care/personal time*. In one case, a retired caregiver was able to visit his mother three times a day to ensure she was eating her meals. Although he perceived a lack of attention from nursing staff, he was able to ensure his mother was eating her meals and getting the support that she needed to prevent further functional decline.

“...I’m here every day, 3 times a day for breakfast, lunch and supper to help my mom. The staff here are wonderful but they’re just over-worked...My mom needs...a little guidance every so often to make sure that she eats. And the staff, as I say, they’re wonderful... okay, I’m retired, I’ll come....” (CG-02)

In another case, a caregiver found she had fewer competing priorities and was satisfied with the quality and amount of care being provided to her husband. Therefore, she was able to engage in *personal and spiritual activities* as a result of her husband being cared for in the hospital.

“Well, right now it is easy because I know that he’s taken well care of there at [hospital]... I’m president of the [church]...I’ve kept that up... So I have been keeping busy. And I joined another ladies group...” (CG-01)

Positive cognitions such as *hope* influenced the ability to adjust to stress. However, a caregiver noted that her positive cognitions can be accompanied by negative cognitions, and that cognitions can vary depending on the day. Overall, she mentioned how her *faith and spirituality* enabled her to be hopeful during this difficult time.

“It’s been heavy-duty. It’s been a struggle of being hopeful versus hope and despair . . . because I wouldn’t want to see [son] stay on at this level forever ... God is no less powerful today than he was then. So I know he can do it. It’s just trusting and asking that he will do it...So it’s been sort of a titter totter balance sometimes hope and despair.” (CG-14)
When caregivers had others supporting them throughout the hospitalization and ALC period, it eased the stress and burden of caregiving. The support that caregivers received from their family was invaluable and often led to a greater appreciation of their social support network. In some cases, the caregiving role strengthened relationships within the family unit and the relationship with the care recipient.

“... one thing I never realized how well the 3 of us got along...We’ve all been sharing the load and everybody’s got their job, and everybody kind of rallies... I mean it hasn’t been without its bumps on the road, as with any family. My mom and I are probably closer than we’ve ever been... [laughs] (CG-10)

One caregiver described her spouse as very supportive throughout the ALC period. The caregiver’s husband would provide both emotional and tangible support to ensure she could continue providing care for the patient.

“... my husband has been very, very supportive of me through everything that I’ve had to do. He has driven me to [city] and back when I’ve had to go there...” (CG-15)

In many cases, the emotional and tangible support provided by family members enabled caregivers to continue providing care.

A temporary balance (risking burnout)

Overall, some caregivers with competing priorities had a difficult time adapting to the ALC period and their caregiving role. However, these caregivers were able to continue on in their role and find a temporary balance. These caregivers attempted to manage their personal responsibilities and the patient’s needs, even if it involved compromising their own well-being and risking burnout.

Some employed caregivers, who were often caring for a parent were dealing with a great deal of stress following the hospitalization. During the ALC period, although they were at risk of burnout, caregivers continued to assist with the patient’s care in hospital for an undefined period of time. Love for the care recipient was evident, as many caregivers prioritized the needs of the
patient over their own personal needs and personal time. One caregiver reflected on the challenges of caring for his father who was in the hospital and his mother in the community. He mentioned it was especially difficult to manage his caregiving role due to his demanding career and also provide care to his mother.

“...she’s looking for a lot of support from everyone around...But to me, what it is, it's the stress. I have to admit, I’m in a busy job. I teach. And then some days, it depends on how it goes, you’ve got to put up with my mother...There are 2 hours I’m not happy with...” (CG-05)

Many patients with behavioral issues often required support beyond what the care team could provide. One caregiver mentioned that their support would still be required in long-term care to calm the patient down when they are behavioral or when they require hospital services.

“...long-term care homes still depend heavily on the families to come in and calm their loved one down when they’re behavioural...you don’t really feel that yeah, she’s in a home and I’m not taking care of her for the night but I’m still going to get that phone call at midnight saying that she needs to go to emerg because she had another fall.” (CG-08)

A compound caregiver, who was caring for his dependent children and great-aunt, found it difficult to prioritize competing priorities. Although he was enduring the situation, he was already experiencing burnout. This caregiver’s wife expressed concern for his well-being and the sustainability of the current arrangement.

“...he’s the primary support in the house because I work out of town... so he’s in charge of taking care of now his great-aunt, getting both our boys to sports, and taking care of the house and everything else that needs to be done. So he’s pretty burnt out...” (CG-09)

One caregiver was spending multiple nights in the hospital while trying to maintain full-time employment. She reflected on how difficult it was for her to go back and forth from the hospital, home and work. Despite the hardships of caring for her mother, she prioritized her mother’s care needs. The sense of duty and love for the care recipient was evident as she ensured the staff
contacted her whenever her mother was agitated to prevent over-medication, even if it meant she had to spend the night in the hospital.

“…at least 2 or 3 times a week, I was getting a call, and I’d be spending the night because she couldn't calm down... And I'm back and forth... trying to work a full-time job, and still sleeping at the hospital some nights...” (CG-11)

Although the hospital experience was challenging for caregivers, there was hope for a balanced lifestyle once the patient was placed in long term care. This provided caregivers with the motivation to provide care during the ALC period.

“...I’d like to get him closer to home here. It will make our lives easier because we have to deal with my mother too. And getting my mother over there and this whole double whammy, we’re going through a double thing...If we get my dad in a home over here, it will be very easy.” (CG-06)

The stress of caregiving resulted in the uptake of negative health behaviors. In one case, a caregiver noted that the stress of caring for his aunt while simultaneously raising his two young children left him with minimal personal time. The stress also resulted in the engagement of increased smoking and alcohol consumption.

“...And you were actually asking about the effects and stressors. I think I probably smoke and drink more than what I used to, to be completely honest...” (CG-08)

These caregivers prioritized their caregiving role to ensure the well-being of the patient. However, in these cases, there appeared to be negative consequences to their own personal well-being (increased risk of burnout, lack of personal time, engaging in negative health behaviors).

Struggling to find balance

In some cases, caregivers sacrificed their personal lives and wellbeing to accommodate the needs of the patient. It seemed that these caregivers were nearing or past their breaking points
and were struggling to continue caring for the patient due to caregiver burden. These caregivers often worried about their ability to manage their overwhelming caregiving duties and personal commitments, which often led to negative emotions. Some of these caregivers did not have the appropriate access to formal resources and had physical and mental health conditions, lack of personal time, financial strain, and competing priorities. The combination of these risk factors left the caregiver struggling to continue on in their role.

Lack of support for caregivers from the health and social care systems led to increased caregiver burden. One caregiver reported that her father’s increasing care needs led to the loss of her personal lifestyle. This caregiver mentioned that her current role was taking on “everything” and it has been “impossible” for her to attend to her own needs, resulting in grief. Along with the financial strain of caring for her father, she was unable to continue on in her career. There seemed to be resentment towards her father as she was unable to focus on her personal career and well-being.

“... So what happens is the person that becomes the dependent loses their usual lifestyle, you lose your usual lifestyle. And then you kind of come to a medium of where you can possibly meet their fun needs and where you can try to meet yours. But their needs tend to supersede your own...It’s just a lot on my plate. And with dad’s ongoing care, it’s just been impossible. Like it’s almost like a burnout situation that you go through to try to get back to your job and just normalize ...So in that way, it’s been taking on a little bit more and a little bit more. And now it’s taking on everything.” (CG-16)

The financial implications of caring for a functionally dependent patient were significant for some caregivers. In one case, a caregiver worried about having the patient return home and her ability to afford formal community resources to support his needs.

“... we could purchase the services to keep him going but that would be crazy outrageous expensive. I can’t imagine how we could afford that.” (CG-18)

Another caregiver described the financial strain of caring for her father in addition to paying for her children’s education. She also mentioned feeling worried about her ability to retire and provide for her family.
“Financially, I’m putting . . . kids through university and dealing with all of those financial issues. And plus, you know, trying to gear up to thinking about being able to retire myself.” (CG-16).

The cost of formal resources was a barrier to accessing resources among many of the caregivers. In many cases, caregivers required more resources than the community was able to offer them due to increasing patient dependency.

Those who had pre-existing health conditions seemed to have a difficult time managing their caregiving duties while dealing with their own declining health. These caregivers worried about who would care for the patient in the event they became a patient themselves.

“…they were telling me too that maybe we should be locking you up too. After reading your medical history, it doesn’t sound good at all. What if something happens to you? Where’s [wife] going to go?…” (CG-04)

One caregiver mentioned her declining kidney function and her decision to not initiate dialysis. She worried that her daughter would have no one to care for her if she were to be hospitalized as well.

“…And the part that’s worrying me, I just had a doctor tell me, my own doctor…that my kidneys, I only have 20% function… you have to go on dialysis, I’m not accepting dialysis… The thing is what I would like to know is what’s going to happen to her when I can’t do it anymore” (CG-03)

Declining caregiver health contributed to additional worries and stress during the ALC period and contributed to caregiver stress.

It was difficult for caregivers to balance their duties when they were caring for multiple individuals with different care needs. When they were caring for multiple functionally dependent individuals, it meant they were caring for the patient in the hospital and caring for another person in the community. It appeared that these caregivers were reaching their breaking point as they worried that they would not be able to manage their caregiving duties.
“...And I’m also a caregiver there now too... It’s too much. It’s too much. It’s him and it’s her. I don’t know if it that’s a proper thing to say or a proper way to describe it but I just feel like...when you take a piece of meat and throw it into a lion’s den, and the lions are...tearing it apart, this side, that side. I just feel like I’m right in the middle of it.” (CG-03)

One caregiver caring for his mother and wife with a disability feared he would be unable to care for both individuals while maintaining his household. It appeared that the caregiver was in a difficult situation where he struggled to provide care for both his wife and mom. From his perspective, his caregiving situation seemed unsustainable. Although this caregiver had access to formal resources for his mother, there was not enough coverage for her needs (lack of access to formal resources).

“...my wife... she’s to the point where she can’t do housework...So I have to do it all...I’m kind of torn. It’s like 2 people you really love, and you’re getting yanked... I’m just kind of doing the best I can...So right now my mom’s at home with 8 hours of support. I can’t be there all night. I have to take care of my wife...And I’m scared. (CG-17)

One caregiver seemed to have reached the point of burnout prior to the hospitalization. When she was convinced by the hospital to enroll her father in the “Wait at Home Program” (a program that provides a patient with 3 months of high volume homecare services at home as they wait for long-term care). She feared her father would not be placed in long-term care within those three months and would have to manage his needs with minimal support.

“...it's been so stressful... it's turned my life upside down ...Still not a day goes by where I don’t get a phone call about my dad...it felt like it had become my full-time job. I honestly thought for a time there that I was going to have to quit working for a period of time because it was just so overwhelming. [tearful]...I would do anything for my dad... This Wait at Home Program only gives him this much support for 3 months...I’m petrified that something is not going to come up in 3 months...” (CG-18)
In summary, caregivers who were able to find an appropriate balance between their personal lives and their caregiving duties seemed to manage stress during the ALC period more effectively than those who were overwhelmed by their caregiving duties. Those who were approaching or had reached their breaking point were more likely to experience more risk factors and demonstrate a lower level of resilience.

4.6 Summary of Findings and Adapted Conceptual Framework

Caregivers in our study described their attempts to advocate for the patient and there appeared to be a range of outcomes. Many caregivers felt the need to advocate due to the lack of personal care during this period. It appears that resilience was enhanced when caregivers were able to successfully advocate for the patient and compromised when there was an unfavourable outcome. Those who were at a particular advantage were resourceful, vocal, persistent and had previous knowledge of the health system. Those who felt they were in control of the situation and felt confident they could navigate the system were able to effectively resist provider recommendations and demand changes to patient care. Those who were unable to achieve a successful outcome were more likely to experience grief and guilt from being unable to resist provider recommendations or vocalize the patient’s needs.

Caregivers in our study described healthcare provider messaging during this stressful period in their caregiving journey. Clear and honest communication from care providers were appreciated by caregivers, even if the news was unfavorable (e.g., poor prognosis). In some cases, transparent messaging was able to ease uncertainty and facilitate acceptance of the situation. Further, some caregivers were able to positively appraise the situation and remain hopeful despite future uncertainty. As a result of the clear communication and honesty, caregivers were more trusting of the care team. On the contrary, poor communication fostered uncertainty. Caregivers also felt that they were unable to trust their care team when they were not included in decision-making regarding treatment decisions and discharge planning.

Caregivers in our study described their attempts to adjust to the change in their caregiving duties. Being able to balance their personal lives and caregiving duties seems to positively influence resilience. The ability to seek balance was influenced by personal factors (financial
strain, physical health, personal time, faith, spirituality), contextual factors (patient dependency, feelings of burden, competing priorities, love for the care recipient), access to formal supports, and social supports. Those who were able to find balance had fewer competing priorities, which allowed them to engage in personal and spiritual activities. These caregivers also had access to social support to assist them with their caregiving duties. A sense of fear was common among caregivers who were struggling to find balance, as competing priorities made it difficult to provide care for the patient. Many caregivers feared their current situation was unsustainable due to lack of formal supports, financial strain, physical health problems, feelings of burden and patient dependency.

Based on these findings, the conceptual framework presented in chapter 2 was adapted to caregivers of patients who require an ALC (see Figure 3). This framework illustrates how the ability to advocate for the patients, the ability to find balance and communicating with the healthcare team can pose a threat to resilience or promote resilience among caregivers.
Figure 12. Adapted Conceptual Framework on ALC Caregivers
Chapter 5

5 Discussion

5.1 Overview of Findings

Resource constraints in the health system coincides with increasing reliance on family and friend caregivers to fill the gaps in healthcare delivery. Caregivers are at risk of poor outcomes including stress and burnout (McCloskey et al, 2015). Exploring resilience during this period is important for understanding how caregivers cope in their day to day activities and understanding what factors enable them to continue.

The purpose of this research was to understand how caregiver resilience is impacted and reflected in caring for a patient who requires an Alternate Level of Care (ALC). Caregiver perspectives of the ALC period are currently underrepresented in the literature (Cressman et al, 2013; McCloskey et al, 2015). It is important to look at resilience during this specific point in the care journey because it is characterized by uncertainty regarding the patient’s length of stay, discharge location and health status (Cressman et al, 2013). It is also a time where both patients and caregiver feel vulnerable. Despite feeling uncertain and vulnerable, caregivers continue providing support to the patient while receiving minimal support from both the health and social care systems (McCloskey et al, 2015).

The hospitalization and ALC period is a stressful time for caregivers, however, their diverse response to the situation suggests that resilience may play a role in their ability to manage stress despite uncertainty. Resilience is the ability to adapt to stress or adversity and is a process that is influenced by risk factors and protective factors (Luthar et al, 2000; Zauszniewski et al, 2010). Based on the findings of the mapping review, a conceptual framework on resilience and family caregiving was developed (See Figure 2). This conceptual framework was used to deductively analyze the data through a secondary analysis of caregivers of patients residing in Northwestern Ontario, a region where over one-third of hospitalized patients are designated ALC (OHA, 2018).
Three themes were identified in this thesis: **becoming an advocate, variable communication with the healthcare team** and **searching for balance**. Through this study, we found that there is a complex interaction of risk factors and protective factors that ultimately influenced levels of resilience. More specifically, risk factors and protective factors were not mutually exclusive and a change in one factor can influence other factors. For example, the ability to successfully advocate for the patient often required the caregiver to be resourceful and be able to secure assistance when needed (Zauszniewski et al, 2010). Further, when providers were clear with their messaging to caregivers, it eased feelings of uncertainty and facilitated acceptance of the situation. Lastly, caregivers with fewer competing priorities had more personal time and may have experienced less burden.

This chapter will provide a general summary of the thesis findings in relation to existing literature and then outline the policy, practice and research implications of the work. The strengths and limitations of this research will also be discussed.

### 5.2 Synthesis of Findings in Relation to the Broader Literature

To date, only a few studies have incorporated the perspectives of caregivers during the ALC period (Cressman et al, 2013; Doleweerd & Berenzy, 2009; Kulski et al, 2017; McCloskey et al, 2015). This study adds to the existing body of literature by applying a resilience lens to the ALC experiences of family caregivers. Using a resilience lens allowed us to understand how caregivers cope during the ALC period.

This study also focused exclusively on caregivers of patients experiencing cognitive decline, a particularly vulnerable subset of patients and caregivers. Previous research indicates that patients who are designated ALC are more likely to have some degree of cognitive impairment (Challis et al, 2015; Costa & Hirdes, 2010) and have multiple chronic conditions (Costa et al, 2012; Costa & Hirdes, 2010). Therefore, the caregivers in our sample were caring for patients that had similar characteristics to other ALC patients reported in the literature.

Despite the uncertainty associated with the ALC period, there was a considerable range of caregiver experiences. The degree to which resilience was negatively impacted varied
considerably among caregivers. This speaks to the potential role of risk factors and protective factors in the caregiver’s ability to manage and adapt to stress. Themes one (becoming an advocate) and two (variable communication with the healthcare team) focus on factors that were present in the hospital and post-acute setting. Within these two themes, caregivers described their interactions with healthcare providers and it is these interactions that appeared to shape their level of resilience. The third theme (searching for balance) focused on the balance between caregiving roles and personal lives. A combination of risk factors and protective factors influenced their ability to adapt to the stressful situation while they were also managing multiple competing priorities.

Previous literature found that patients who were hospitalized and subsequently designated ALC often had a caregiver who struggled to manage their increasing care demands, indicating the potential vulnerability of these caregivers (Costa & Hirdes, 2010; McCloskey et al, 2015). Further, having the patient designated as ALC did not alleviate caregiving duties, which likely further contributed to caregiver stress (McCloskey et al, 2015). Similar to the participants in our study, all caregivers acknowledged that they no longer had the capacity to provide support to the patient in the community. Despite struggling to manage the patient’s care demands prior to the ALC period, caregivers continued to manage both the emotional and personal care needs of the patient. Caregiver support was especially critical for patients dealing with both cognitive and functional decline as healthcare providers were busy providing care to multiple patients. Healthcare providers relied heavily on caregivers to accommodate the needs of patients which often interfered with their personal lives and ability to manage competing priorities (e.g. caring for young children, employment). It appeared that care providers expected caregivers to provide support for patients but did not inquire about the caregiver’s capacity and willingness to provide this care.

In our study, resilience was negatively impacted when caregivers received mixed messaging from healthcare providers. Participants in this study reflected on how this poor communication fostered uncertainty about the future. This finding is congruent with previous studies which have highlighted that a lack of information about the patient’s health status, assessment, diagnosis and future contributed to uncertainty (Cressman et al, 2013; El Masry et al, 2013). Our findings highlight the importance and role of providers in communicating with caregivers during care.
episodes. In our study, some caregivers had difficulties identifying members of the care team that they could approach for information, while some felt as if they were being excluded from crucial conversations. This highlights the importance of healthcare providers including caregivers in decision-making and discharge planning as it will help increase awareness about next steps. Our study illustrates that clear communication can facilitate acceptance of the situation and ease feelings of uncertainty.

Similar to the findings in the ALC literature (Doleweerd & Berenzy, 2009; McCloskey et al, 2015), caregivers in our study perceived a decreased quality and quantity of care when patients transitioned from acute care to the ALC unit. The patients in our study were unable to vocalize their needs due to their frailty and cognitive decline. Therefore, to address the gaps in care, caregivers played a critical role in providing personal care, realizing inconsistencies in care, and ensuring the patient’s needs were met by the healthcare providers. Caregivers in the presented study advocated for rehabilitation services, medication safety, regular toileting, patient assessments, and active involvement in decision-making. However, not all caregivers were able to vocalize their concerns, and many were unsuccessful in their attempts to advocate for the patient.

In this study, there was a group of caregivers who were able to push back against provider recommendations that they did not agree with and demand changes to patient care. This suggests that persistence on the part of the caregiver is critical to ensure their voices are heard by the healthcare team. This raises an important challenge for less vocal caregivers as they may have less access to resources as a result of remaining silent. Those who were unable to advocate were forced into challenging situations (such as sudden discharges) and felt they had very little control over the course of events during the ALC period. These caregivers eventually had to accept provider recommendations, even if the recommendations were not ideal. Considering all caregivers did not have the capacity to provide care outside the ALC unit, it is important to pay attention to those who remain silent and are unable or unwilling to advocate. Providers may have a role in ensuring caregivers feel comfortable voicing their opinions. In addition, it is important to consider caregiving capacity and input during the ALC period and when planning for patient discharge.
5.3 Policy and Practice Implications

With the aging population and the constrained healthcare system, it is imperative to address persistent and complex issues that are impacting the health system. The Institute for Healthcare Improvement’s Triple Aim framework suggests that a high performing health system is incumbent upon: 1) improving the patient experience, 2) improving population health, and 3) reducing costs (Berwick, Nolan & Whittington, 2008). Our study provides insights on how to improve the patient and caregiver experience of ALC. ALC is a health system performance issue that accounts for nearly 16% of Ontario hospital beds (OHA, 2018). This issue contributes to a constrained health system, hospital overcrowding (Ovens, 2011), increased emergency room wait times, and disruptions in patient flow (Costa & Hirdes, 2010; Costa & Hirdes, 2012; Sutherland & Crump, 2013; Walker, 2011). Being designated as ALC can place the patient at an increased risk of functional decline and hospital infections (Barnable et al, 2015; Costa et al, 2012; Costa & Hirdes, 2010). Furthermore, the patient experience is compromised due to the loss of personal autonomy and social isolation (Costa et al, 2012; McCloskey et al, 2015). Caring for patients who no longer require care in the hospital setting is costly to the health system and has negative consequences for patients and caregivers. (CIHI, 2011; Walker 2009).

Addressing hospital overcrowding was a major priority for three of the four major political parties in the 2018 Ontario election. Three political platforms pledged to introduce thousands of long-term care beds over the next decade to increase hospital capacity and reduce hospital wait times (CBC News, 2018). Considering over 40% of ALC patients in Ontario are waiting for a long-term care bed, implementing these changes may help to at least temporarily alleviate hospital overcrowding by shifting patients who no longer require acute care services from the hospital to long term care (OHA, 2018). Increasing the number of long-term care beds is a step towards reducing costs while temporarily increasing patient flow and health system performance. Interestingly, increasing the number of hospital beds and long-term care beds is also thought to be a short term (or band-aid) solution by scholars and policy makers alike. More specifically, ALC has continued to persist over the years despite increasing capacity in long-term care (Sutherland & Crump, 2013). Therefore, solutions to complex issues must be complimented with more creative strategies to reduce costs and improve care (Berwick et al, 2008). Perhaps the experiences of caregivers and patients can provide insights on what can be
done to improve care for patients and caregivers, particularly during complicated care transitions like ALC.

ALC is a unique transition in the care journey as patients are unable to transition to their next discharge destination due to capacity issues in out-patient settings (Barnable et al, 2015). ALC crosses different sectors including, home and community care, long-term care, acute care and housing. However, there is minimal integration across these sectors and policies tend to be sector specific (CIHI, 2009). Due to the lack of integration, wait times for outpatient settings is usually unknown to all stakeholders. Thus, there is pressure on caregivers to continue to provide care to the patient during this period of uncertainty. Consideration on how the health system can provide fair and equitable access to long term care and home and community care to reduce an extended length of stay is required. It is important to consider strategies that can help patients receive the appropriate care in the appropriate setting with attention to the capacity and willingness of caregivers.

To address the issue of ALC (known as delayed transfer of care in the NHS), the NHS introduced the *Delayed Discharges Act* and *Better Care Act* to reduce the number of delayed transfers and improve the integration of the health and social care sectors (Bate, 2017; Shaw et al, 2016). This act requires healthcare providers to conduct discharge assessments on patients and subsequently notify social care authorities when a patient requires social care services to be safely discharged into the community (Bate, 2017). Social care authorities are then responsible for arranging the appropriate services for the patient to ensure a timely discharge (Bate, 2017). For each day the patient spends in hospital waiting for social care services, the social care sector must reimburse hospitals for each day a patient’s discharge is delayed (Bate, 2017; Shaw et al, 2016). This act also encourages healthcare providers to inform caregivers of discharge plans, allow them to be involved in decision-making, and consider their capacity to provide care post-discharge (The Better Care Fund, 2016). These policies and financial incentives are in place to ensure appropriate discharge arrangements are being made by social care authorities and patients are receiving the appropriate and timely care for their needs (Bate, 2017). The NHS provides an example of how policy changes can improve integration across sectors to address the complex issue of ALC. Furthermore, the health system can engage caregivers in the discharge planning process to ensure their preferences and capacity are taken into consideration.
These policies can provide caregivers with clarity on the discharge process and help them cope with the situation.

Caregivers of patients who require an ALC have a vital role in ensuring the well-being of patients and facilitating patient transitions, however, their perspectives are often not incorporated in research or policy (Doleweerd & Berenzy, 2009; McCloskey et al, 2015). To further increase health system performance, a core goal of the triple aim framework is to improve the patient and family experience (Berwick et al, 2008). According to the triple-aim framework, improving the patient experience requires involving patient and caregiver experiences in the development of policies. By incorporating the experiences of caregivers, policy makers will have a better understanding of how they can improve the patient experience. In our study, caregivers knew how to deal with agitation, recognize inappropriate medication regimens, and ensure the overall well-being of the patient.

It is also important to acknowledge the broader context of caregivers, as they are often dealing with multiple competing priorities (e.g. parenting, employment) in addition to caring for the ALC patient. Managing multiple competing priorities was challenging for many caregivers, and in some cases led to feelings of fear, financial strain and caregiver burnout. Ensuring that these caregivers are willing to provide care and/or have the capacity to provide care while managing multiple priorities is imperative to their well-being and ability to manage stress.

In general, there is uncertainty with healthcare transitions due to capacity issues in the acute care setting and in discharge settings (Cressman et al, 2013). This study highlights that the patient discharge location was not always clear to either the caregiver or healthcare providers. Even experienced healthcare providers were unable to predict the patient care trajectory, especially when the patient’s needs fluctuated substantially due to multimorbidity. This points to a larger systems issue, that, despite the best efforts of care providers, they may face significant challenges in developing a clear care/discharge plan. As a result, the lack of clear communication led caregivers to believe healthcare providers were withholding valuable information. These caregivers were negatively impacted when they were not included in discharge planning and the patient was discharged without the appropriate supports. Although there will be uncertainty throughout the ALC period, the transparency with discharge planning
can perhaps facilitate acceptance of the situation, manage expectations and reduce feelings of stress among caregivers.

5.4 Research Implications

Consistent with the general transitions literature, caregivers played a crucial role in becoming an advocate for the patient to ensure patient needs were being addressed during a transition from an acute care setting to a rehabilitation unit (Jeffs et al, 2017). However, our study illustrates that not all caregivers were comfortable vocalizing their concerns, and many were unsuccessful in their attempts to advocate for the patient. Likewise, a study by Coleman & Roman (2015) suggests that some caregivers may remain silent when they are not engaged by the healthcare team or they fear their suggestions would threaten the professional judgement of healthcare providers (Coleman & Roman, 2015). Furthermore, congruent with findings from the transitions literature, caregivers have a critical role during patient transitions by monitoring changes in patient health status and vocalizing concerns to the healthcare team (Bragstad, Kirkevold & Foss, 2014; Coleman & Roman, 2015; Jeffs et al, 2017).

The transitions literature often focuses on planned transitions for patients with acute care needs and the prevention of unnecessary hospital readmissions (Coleman et al, 2004; Coleman & Roman, 2015; Jeffs et al, 2017). With general transitions, healthcare providers may have more information regarding discharge and have the appropriate processes and tools in place to discharge patients. In a study by Dedhia et al (2009), a discharge planning intervention was developed to improve transitions from the acute care setting to the community setting. Healthcare providers utilized standardized assessment forms, informed primary care physicians of the hospital admission, collaborated with providers across disciplines to provide care, and arranged hospital discharge meetings with patients and caregivers. As a result of this intervention, patients were less likely to be re-admitted to hospital and were more likely to positively rate their health in comparison to the control group (Dedhia et al, 2009). In another study by Coleman et al (2004), authors implemented an intervention to support and empower patients and caregivers during a transition. The intervention included a medication self-management guide, primary care and specialist follow-up, and a personal health record. The personal health record outlined outstanding actions that must be taken to safely discharge the patient and included any patient or caregiver concerns (Coleman et al, 2004). Prior to discharge,
the healthcare providers addressed the concerns outlined on the personal health record. The group that received the intervention was less likely to be re-admitted to hospital. Furthermore, patients and caregivers felt more confident communicating with their healthcare team (Coleman et al, 2004).

The ALC period differs from these general transitions as this particular transition is characterized by uncertainty by both caregivers and healthcare providers as the patient trajectory is unknown or unclear due to capacity issues in out-patient settings (Cressman et al, 2013; Walker, 2009). Our study findings extend this body of literature by exploring how caregivers are impacted when healthcare providers are uncertain of the patient trajectory. Healthcare providers may have difficulties communicating the uncertainty of ALC to caregivers, which may result in mixed or unclear messaging. Due to system constraints, healthcare providers rely heavily on caregivers to support the patients who no longer have acute care needs during this time. Furthermore, it may be difficult for healthcare providers to accommodate the preferences of caregivers, which may lead to unfavourable outcomes for caregivers. Future research can explore successful transition interventions in the context of ALC in an attempt to support caregivers through this period.

Although this study recruited from two post-acute sites within one single geographic area, there was a diverse range of experiences and the ability to adapt to stress varied considerably despite experiencing a similar adversity (hospitalization and transition to ALC). Our study shows that despite the uncertainty, some caregivers were better able to adapt to stress. Nearly all the risk and protective factors from the conceptual framework were applicable to the caregiver experience of ALC. However, factors including family conflict, stigma, social isolation and sense of coherence were not clearly apparent during the ALC period. Although these factors may have affected resilience along the caregiving journey and/or in the period of time before ALC occurred, these risk and protective factors may be less pertinent to their resilience in the hospital setting. Future research may benefit from exploring these additional factors and how they may impact resilience during the ALC period.

The conceptual framework on resilience and family caregiving provided a comprehensive view of resilience and includes a broad range of risk factors and protective factors. The findings of
this study confirm previous resilience research by demonstrating the role of risk factors and protective factors on caregiver resilience. Further, our study illustrates the complex nature of resilience by exploring the intersection of risk factors and protective factors during a period of peak stress. Much of the existing literature on resilience focuses on caregiving in the community setting (e.g. caregivers of persons with dementia or autism spectrum disorder). By focusing on resilience and the needs of caregivers during the ALC period, this study emphasizes the need to support caregivers and patients through this difficult time.

By focusing on broader strategies to reduce ALC rates and improve system integration, the patient and caregiver experience of this transition may be improved. Further, it is important to focus on developing direct interventions to enhance caregiver resilience during the ALC period. Previous resilience research has found direct interventions such as formal education and training for caregivers were beneficial for enabling caregivers to navigate the health system and have meaningful conversations with their healthcare team (Bremault-Phillips et al, 2016; Cherry et al, 2013; Sun, 2014). In addition, interventions in the transitions literature have been successful in reducing hospital readmission rates, improving experiences, and empowering caregivers (Coleman et al, 2004; Coleman et al, 2015). These interventions may be beneficial for caregivers with lower levels of resilience as they seem to be most impacted by ALC. Given the crucial role of caregivers during the ALC period, it is important to enhance resilience among caregivers to improve their ability to adapt to the ALC period and reduce their risk of burnout.

5.5 Future Research

Many studies report the factors that enhance and/or hinder resilience, however, the interplay of these factors on resilience during specific periods in the caregiving journey is less explored. Future resilience research can design and test strategies to enhance caregiver resilience during periods of high stress. Enhancing protective factors and addressing risk factors may help to bolster resilience along the caregiving journey. In addition, future research exploring resilience in caregivers of patients who were not receiving home care prior to hospitalization during the ALC period may provide a unique perspective on resilience.

Key questions for further exploration:
1. What strategies/interventions can be implemented to enhance caregiver resilience and/or provider resilience during the ALC period?
2. How can the health system ensure the preferences of patients and caregivers are considered/met during the ALC period?
3. How can the health system work with the personal capacity of caregivers and their willingness to provide care during the ALC period?
4. How can healthcare providers enhance caregiver resilience during the ALC period through their practice?

5.6 Strengths

A diverse range of perspectives were captured as our sample varied in terms of the relationship to the patient (parent, adult child, spousal and sibling caregivers), sex, and the patient living arrangement prior to hospitalization. By using a secondary analysis approach, we were able to capture a range of caregiver-patient relationships and minimize participant burden through the use of existing data.

Furthermore, there were several strategies used to enhance the trustworthiness of the results, as presented in the methods chapter. By using a conceptual framework designed from the resilience literature, we were able to determine the applicability of the framework to caregivers during the ALC period. However, by not exclusively relying on the framework allowed the researcher to capture aspects of the phenomenon that would have otherwise been missed. There were several strategies to increase the trustworthiness of results. To increase the credibility of the findings two reviewers independently coded a sub-set of the transcripts. At a consensus meeting, the two reviewers ensured they were in alignment regarding the identified codes (Elo et al, 2014). To increase the dependability of the results, the analysis process and the use of a conceptual framework was outlined to increase the transparency of the analysis. Further, the three themes were developed using an analytic memo, which allowed all members of the research team to apply a critical lens to ensure the themes accurately represented the data. The use of memos increased the confirmability of the study findings (Birks et al 2008).
5.7 Limitations

The seventy studies included in the mapping review provided a comprehensive view of resilience and family caregiving within the last decade. However, no formal quality appraisal was conducted by the primary researcher. Thus, there may be heterogeneity in the quality of the included studies.

One of the limitations of conducting a secondary analysis was the inability to probe the participants and ask direct questions about resilience. Although the rich dataset provided us with the foundation to conduct the secondary analysis, resilience was not the main focus of the original study. Therefore, participants were not directly reflecting on their ability to manage stress and since the study consisted of a secondary analysis there was no opportunity to further probe participants to gain a deeper understanding of this concept. We predict that if we were able to ask questions specifically about resilience and their ability to manage stress during this period, we may have gathered more in-depth information. The types of questions in the interview guide may have influenced our findings. Some questions focused on how the system could have improved or enhanced their experience and they may have been less likely to reflect on the positive aspects of caregiving. Nevertheless, future research in the area of resilience and ALC can have caregivers directly reflect on factors that promoted or hindered their resilience.

During the analysis phase of the study, it was sometimes challenging to decipher whether the caregivers were reflecting directly on their ALC experience or previous experiences of caregiving. Despite our best efforts to differentiate the two periods in the caregiving journey, our results may incorporate factors that influenced levels of resilience prior to the ALC period. Differentiating the experience was beneficial for how interventions to assist caregivers during this specific period. However, by incorporating the broader ALC experience, we were able to gather more context on how risk and protective factors influenced resilience prior to the ALC period. This speaks to the fluidity of the caregiving role as it is often difficult to parse out resilience in distinct periods in the journey due to the cumulative nature of risks factors and protective factors.

In regard to caregiver characteristics, this sample was highly educated; many caregivers had previously or were currently working in the healthcare system. These individuals may have been
better equipped to advocate, process complex information, and navigate the healthcare system more effectively than those with less education or experience with the health system. Therefore, these findings may not be applicable to those who have less experience with the health system. Further, all the care recipients had received or been assessed for home care services by the CCAC. Therefore, this recruitment strategy may limit the transferability of these findings to people who have some familiarity with the health care system. Lastly, by capturing perspectives of caregivers in the North West, we captured perspectives of individuals from a single community. Within these smaller communities, children are more likely to seek employment in larger cities and live separately from the care recipient. Therefore, the transferability of these findings may be limited to caregivers in a geographical area similar to Northwestern Ontario. However, this identifies the need for further research on resilience among a diverse group of caregivers in terms of education level and ethnicity. To address the issues with transferability of our findings, future research can be conducted among ethnically diverse caregivers and focus on caregivers in urban settings.
Conclusion

This thesis was undertaken to explore how caregiver resilience was impacted and reflected during the Alternate Level of Care (ALC) period through a secondary analysis of qualitative data. The ALC period is a specific point in the caregiving journey that is often characterized by uncertainty for caregivers, patients and healthcare professionals. During this period in the caregiving journey, the contributions of caregivers are invaluable. Although the needs of caregivers may be the greatest during this time, they receive minimal support from the health and social care systems. Caregivers in this study experienced a similar adversity of a hospitalization and delayed hospital discharge, however, their experiences and ability to manage stress varied considerably. Caregiver resilience was impacted by a multitude of factors, many of those identified from the conceptual framework, and most were specific to the ALC period. This study suggests that resilience factors are not mutually exclusive and there is a complex interaction between risk factors and protective factors that influence levels of resilience. This study found that the ability to successfully advocate for the patient, clear communication or messaging from care providers, and finding an appropriate balance between their personal lives and caregiving role positively influenced resilience during this period. Despite the uncertainty associated with the ALC period, this study provides insights into factors that should be considered to support caregivers and enhance resilience during a period of high stress.
References


Appendices

Appendix A. Keywording Tool

This Keywording tool was used to extract data from the seventy articles included in the mapping review. This allowed the researcher to tabulate the following information:

<table>
<thead>
<tr>
<th>Section A. Background, Design &amp; Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Status of the report</strong></td>
</tr>
<tr>
<td>• Published</td>
</tr>
<tr>
<td>• In-press</td>
</tr>
<tr>
<td>• Unpublished</td>
</tr>
<tr>
<td>• Conference presentation</td>
</tr>
<tr>
<td><strong>Country of Origin</strong></td>
</tr>
<tr>
<td>• Canada</td>
</tr>
<tr>
<td>• United States</td>
</tr>
<tr>
<td>• United Kingdom</td>
</tr>
<tr>
<td>• Australia</td>
</tr>
<tr>
<td>• China</td>
</tr>
<tr>
<td>• Etc</td>
</tr>
<tr>
<td><strong>Study design</strong></td>
</tr>
<tr>
<td>• Literature review (including integrative review)</td>
</tr>
<tr>
<td>• Systematic review</td>
</tr>
<tr>
<td>• Secondary analysis of existing data</td>
</tr>
<tr>
<td>• Randomized controlled trial</td>
</tr>
<tr>
<td>• Controlled/Experimental study</td>
</tr>
<tr>
<td>• Longitudinal and/or cohort study</td>
</tr>
<tr>
<td>• Descriptive</td>
</tr>
<tr>
<td><strong>Study methods</strong></td>
</tr>
<tr>
<td>• Qualitative methods</td>
</tr>
<tr>
<td>• Quantitative methods</td>
</tr>
<tr>
<td>• Mixed methods (qualitative and quantitative)</td>
</tr>
<tr>
<td>• Structured surveys and/or validated measures (development of instrument)</td>
</tr>
<tr>
<td>• Economic or resource quantification</td>
</tr>
<tr>
<td>• Other</td>
</tr>
</tbody>
</table>
### Section B. Participants and Sample

| Health condition          | • Autism spectrum disorder  
|                           | • Dementia                  
|                           | • Cancer                    
|                           | • Schizophrenia             
|                           | • Traumatic brain injury     
|                           | • Etc.                      |
| Type of caregiver         | • Informal (unspecified)    
|                           | • Family members (unspecified) 
|                           | • Spouse                    
|                           | • Sibling                   
|                           | • Child                     
|                           | • Neighbour                 
|                           | • Friend                    |
| Length of caregiving      | • __ months                 
|                           | • __ years                  |

### Section C. Evidence on Resilience

<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Factors identified in the literature that compromise resilience and interfere with the caregivers’ ability to manage stress/adversity.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protective factors</td>
<td>Factors identified in the literature that enable resilience and enhance the caregivers’ ability to cope with stress/adversity.</td>
</tr>
</tbody>
</table>
Appendix B. Mapping Review Guiding Examples

The following guiding examples were used to extract risk factors and protective factors from the seventy articles. These examples and definitions were extracted directly from the articles.

**Risk Factors**

<table>
<thead>
<tr>
<th>Stress &amp; patient dependency</th>
<th>“Caring was conceived as a physically and emotionally draining experience. It had detrimental effects on carers’ physical health, making them more susceptible to, and taking longer to recover from, episodes of ill health” (McCann, Bamberg &amp; McCann, 2015, p.205).</th>
</tr>
</thead>
</table>
| Competing priorities/ shunting roles | “Caregivers contend with competing priorities and lost opportunities, particularly those with young families.” (Bremault-Phillips et al, 2016, p.4)  
“They gave up work to care for family members, gave up hobbies, and social events. They expressed a sense of putting life on ‘hold’ as they dealt with the needs of their family and family member with a mental illness.” (Cohen et al, 2011, p.120). |
| Financial strain | “Financial costs included transportation to hospitals, medical examinations, prescription drugs, hospital bills, personal caretakers and homemakers, and nursing home care.” (Sun, 2014, p.808). |
| Lack of (access to) formal resources | “Navigating the system was reportedly akin to traveling through a maze,” with information usually detached from the caregiver’s context. (Bremault-Phillips et al, 2016, p.5)  
“The lack of availability of supportive services, including long-term care facilities for AD patients, left CGs helpless. Several participants expressed disappointment in the lack of assisted living facilities or nursing homes for their CRs” (Sun, 2014, p.810). |
| Uncertainty | “uncertainty about what services and resources existed and about the nature of stroke and the prognosis.” (El Masry, Mullan & Hackett, 2013, p.361).  
“Participants in the study indicated the need for information resources such as knowledge on managing the condition, including the distressing symptoms and behaviour.” (Ntinda & Nkwayana, 2017, p.91) |
| Social isolation | “Caregivers of dementia patients are likely to disengage from their social networks as they must devote more time to caregiving as the disease progresses” (Donnellan, Bennett & Soulsby, 2016, p.1222)  
• “a need for social support and indicated that they received no emotional and financial support from significant others such as spouses, family members, close relative or friends” (El Masry, Mullan & Hackett, 2013, p.90). |
| Family conflict | “legal disputes over money or guardianship, a failure by family or staff to provide urgent practical support, and family or staff questioning the carer’s decisions. All the carers felt such conflict added unnecessary stress to an already difficult experience.” (O’Dwyer, Moyle & van Wyk, 2013, p.757)  
• “Conflicts between family members also arose in participants’ narratives. Conflicts often revolved around who should provide primary care to the CR or whether CR should be placed at a nursing home.” (Sun, 2014, p.809) |
| Existing mental/physical health issues | “CGs’ chronic illnesses (e.g., diabetes, hypertension) limited their physical ability to provide care for the CR” (Sun, 2014, p.808).  
• “Older caregivers expressed health problems more often than younger caregivers, appeared to further exacerbate their burden” (El Masry, Mulan & Hackett, 2013, p.362). |
| Guilt/Grief | “Caregivers expressed feeling guilty or selfish for wanting a break or asking for help.” (Bremault-Phillips, 2016, p.4).  
• “Frequently, carers experienced sadness, depression, and guilt about what they perceived as a significant loss in their lives. They commented about feeling sad at the realization that their parent or spouse was no longer the independent person they once knew” (McCann, Bamberg & McCann, 2015, p.206) |
| Stigma | “The stigma of mental illness can be internalized by caregivers, producing shame and guilt that hinders caregivers from seeking professional help and can lead to increasing social isolation” (Suresky, Zauszniewski & Bekhet, 2014, p.240). |
**Protective Factors**

<table>
<thead>
<tr>
<th>Protective Factor</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>“Acceptance of their children for who they are helped them to feel peaceful and made the care easier” (Bekhet &amp; Matel-Anderson, 2017, p.204-205)</td>
</tr>
<tr>
<td>Hardiness</td>
<td>“Many caregivers expressed how their role has generated a new appreciation of life for themselves. Further, it has provided them with valuable life lessons and continues to be a rewarding experience” (Kitter &amp; Sharman, 2015, p.1089)</td>
</tr>
<tr>
<td>Mastery</td>
<td>“The ability to see opportunities for personal growth in the midst of hardship may distinguish spouses who thrive as compared to others overwhelmed by caregiving demands.” (O’Rourke et al, 2010, p.990)</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>“Self-efficacy and internal locus of control are psychological factors that support the construct of resilience and are associated with less suffering from the negative effects of stress and burden” (Dias et al, 2015, p.17)</td>
</tr>
<tr>
<td>Sense of coherence</td>
<td>“In other words, the belief that life’s challenges provide opportunities to increase one’s skills and self-knowledge is inversely associated with depressive symptoms as later reported” (O’Rourke et al, 2010, p.989).</td>
</tr>
<tr>
<td>Resourcefulness</td>
<td>“Information seeking also seemed to help the participants manage the illness more effectively.” (Deist &amp; Greeff, 2017, p.101)</td>
</tr>
<tr>
<td>Faith/ spirituality</td>
<td>“Many participants talked about the importance of faith, which seemed to foster resilience by providing a framework for reflecting on their experiences…Faith also allowed them to believe the challenges they were experiencing had a purpose, were finite, and would eventually pass. Only” (O’Dwyer, Moyle &amp; van Wyk, 2013, p.758)</td>
</tr>
<tr>
<td>Strengthening family relationships</td>
<td>“working together led to more understanding and, possibly, stronger relationships between the members” (Bayat, 2007, p.709)</td>
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<tr>
<td>Love for care recipient</td>
<td>“Caregivers noted being motivated to provide support out of love” (Bremault-Phillips et al, 2016, p.6)</td>
</tr>
<tr>
<td></td>
<td>“As hypothesized, caregiver compassionate love was significantly associated with less burden and more positive appraisals of caregiving” (Monin, Schulz &amp; Feeney, 2015, p.984)</td>
</tr>
<tr>
<td>Social support</td>
<td>“All carers talked about the importance of receiving support from family or friends and service providers. This included practical and emotional support within the caring role, as well as time away to engage in self-care” (O’Dwyer, Moyle &amp; van Wyk, 2013, p.758)</td>
</tr>
<tr>
<td>Access to formal resources</td>
<td>“Respite services offer much needed help and are invaluable in providing momentary relief” (Bremault-Phillips et al, 2016, p.7)</td>
</tr>
<tr>
<td></td>
<td>“Participants make use of different health and social care services, including day and respite care, home help and support groups. Resilient participants are more likely to acknowledge their own limitations and know when to take a break.” (Donnellan, Bennett &amp; Soulsby, 2015, p.937)</td>
</tr>
<tr>
<td>Self-care</td>
<td>“Across all interviews, caregivers explained how taking time out just for them was important in how they coped. This includes things such as exercise, praying, having a hot bath and using Facebook.” (Kitter &amp; Sharman, 2015, p.1089).</td>
</tr>
<tr>
<td></td>
<td>“CGs engaged in hobbies such as singing, dancing, listening to music, playing computer games, and gardening to help relieve their stressful feelings.” (Sun, 2014, p.810).</td>
</tr>
</tbody>
</table>
Appendix C. Mapping Review Findings

The following series of graphs and citations tabulate publications by year, country, study design, study methods, caregiver type and illness type.

Publications by Year

<table>
<thead>
<tr>
<th>Year of Publication</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
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</tr>
<tr>
<td>2008</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>2009</td>
<td>3 (4.3)</td>
</tr>
<tr>
<td>2010</td>
<td>5 (7.1)</td>
</tr>
<tr>
<td>2011</td>
<td>3 (4.3)</td>
</tr>
<tr>
<td>2012</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>2013</td>
<td>10 (14.3)</td>
</tr>
<tr>
<td>2014</td>
<td>4 (5.7)</td>
</tr>
<tr>
<td>2015</td>
<td>15 (21.4)</td>
</tr>
<tr>
<td>2016</td>
<td>10 (14.3)</td>
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<tr>
<td>2017 (January – September)</td>
<td>14 (20.0)</td>
</tr>
</tbody>
</table>

References

<table>
<thead>
<tr>
<th>Year</th>
<th>#</th>
<th>Citations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>2</td>
<td>Bayat, 2007; Gaugler, Kane &amp; Newcomer, 2007</td>
</tr>
<tr>
<td>2008</td>
<td>2</td>
<td>Chappell &amp; Dujela, 2008; Wilks &amp; Vonk, 2008</td>
</tr>
<tr>
<td>2009</td>
<td>3</td>
<td>Fife et al, 2000; King et al, 2009; Zauszniewski, Bekhet &amp; Suresky, 2009</td>
</tr>
<tr>
<td>2010</td>
<td>5</td>
<td>Chen &amp; Clark, 2010; Kenneson &amp; Bobo, 2010; O’Rourke et al, 2010; Perkins, 2010; Zauszniewski, Bekhet &amp; Suresky, 2010</td>
</tr>
<tr>
<td>2013</td>
<td>10</td>
<td>Bitsika, Sharples &amp; Bell, 2013; Cassidy, 2013; Doutre, Green &amp; Knight-Elliot, 2013; El Masry, Mullan &amp; Hackett, 2013; Hernandez,</td>
</tr>
<tr>
<td>Year</td>
<td>Count</td>
<td>References</td>
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<td>------------</td>
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</tr>
<tr>
<td>2014</td>
<td>4</td>
<td>Cassidy, Giles &amp; McLaughlin, 2014; Shuter, Beattie &amp; Edwards, 2014; Sun, 2014; Suresky, Zauszniewski &amp; Bekhet, 2014</td>
</tr>
</tbody>
</table>
## Publications by Country

<table>
<thead>
<tr>
<th>Country</th>
<th>N (%)</th>
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</thead>
<tbody>
<tr>
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<td>Australia</td>
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<td>United Kingdom</td>
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<td>Canada</td>
<td>5 (7.1)</td>
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<td>Brazil</td>
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Appendix D. Caregiver Interview Guide

This appendix contains the caregiver interview guide that was used to collect data for the original study. As this thesis was a secondary analysis, no new data was collected.

Caregiver Interview Guide

Hello, my name is [insert researcher name] and I am a researcher who is interested in learning, from your perspective, how the health care system can work best for people like you and the people you care for. It is my understanding that [the person you care for] is waiting [was recently waiting] in the hospital for a long-term care bed. For this interview, I would like to learn more about the circumstances that led up to this hospitalization. As noted in the consent form your name or other identifying information will be kept confidential and your decision to participate, withdraw or skip questions will have no effect on your or your [care recipients] current or future care (here at the hospital) or elsewhere. We will probably spend anywhere from 60-90 minutes together but this can be longer or shorter depending on your preference. Do you have any questions before we begin? In the consent form, it is noted that I will tape record the session so I can review the interview later. Is it still okay if I record the session? Okay, I will start the recorder now [researcher turns tape recorder on].

Introduction

1) Tell me a bit about yourself [prompt: are you from the area? How long have you lived in Thunder Bay?]

Caregiver Characteristics and Relationship to Care Recipient

2) What is your relationship to [care recipient] [prompt: spouse, adult child, neighbor, friend]?
3) How long have you been providing care for [care recipient]?
4) Do you live with [care recipient]?
   a. If no, does [care recipient] live alone?
5) What is your relationship with [care recipient] like? [prompt: do you get along most of the time?]

Health Status
6) What kinds of health conditions does [care recipient] have?
   a. How long has [he/she] had these health conditions?
   b. Have [his/her] health conditions gotten worse over time?

Factors that Led to Hospitalization

7) Tell me about the events leading up to [his/her] most recent hospitalization [prompt: did he/she experience a sudden health event? Who decided that he/she should go to hospital?]

Community Supports

8) It is my understanding that [care recipient] was receiving services in the community? If not applicable skip to question 8d.

Before hospitalization:

   a. From your perspective, were these services meeting [his/her] needs? If not, what could have been done differently in order to meet [his/her] needs?
   b. Are there services that [care recipient] needed but could not get? [prompt: could anything have made it easier for you and [care recipient] to manage your health, such as health or social services?] If so, what could have been done differently to meet [his/her] needs?
   c. Did you have a person who works in the health care system, such as a care coordinator who you or [the care recipient] could contact if you had questions?

Ask these questions if the care recipient is now back from hospital. IF NOT SKIP TO QUESTION 9.

Since coming home from the hospital:

   d. Is the person you care for receiving care (such as homecare) in their homes? If so, what services are they getting? **If NOT Applicable skip to 8f.**
   e. Are the services that [care recipient] is currently receiving meeting [his/her] needs? If not, what can be done differently in order to meet [his/her] needs?
   f. Are there services that [care recipient] needs but cannot get? [prompt: can anything be done to make it easier for the person you care for to manage their health, such as health or social services?] If so, what do you think can be been done? what would be ideal?]
   g. Do you currently have access to a person who works in the health care system, such as a care coordinator, who you could contact if you had questions?
9) As a caregiver, do you feel that you are/were supported in your role? [prompts: are there services or programs that would make it easier for you to provide care?]
   a. Do you (or did you) have to give up/scale back on your own personal activities such as work or hobbies, to provide care?

For caregivers of patients still in hospital ask:

10) If [care recipient] was transferred back to the community, would you be able to continue on in your role as a caregiver? Explain.

Long-term Care Planning

11) Did someone in the community (such as a healthcare worker) talk to [care recipient] about long-term care (i.e., nursing home care) such as putting [his/her] name on a waiting list before [he/she] came into the hospital? IF NO, SKIP to question 8
   a. If so, were your involved in this discussion too?
   b. How did you and [care recipient] feel about this conversation? [prompt: was the timing right, are there reasons why [care recipient] was not put on the wait-list? Did you and [care recipient] disagree on what should be done? other reasons?]

12) Do you think anything could have been done, along the way, to change the circumstances that [care recipient] is in today?

13) Is there anything else that you would like to share with me?

End of Interview