Formal Social Support for Caregivers of Elderly Stroke Survivors: A Narrative Synthesis

By

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Abstract

Approximately 15 million people worldwide experience stroke annually, of which five million are left permanently disabled, creating a need for long term support from family and community services. This sudden, unplanned and unpredictable event can have a devastating effect on the mental and physical health of family caregivers. The experience of being a family caregiver, and caring for a person who has suffered and survived stroke is therefore particularly important to understand. Social support, both informal and formal, has been known to increase the resilience of stroke survivors and their caregivers assisting them to maintain good physical and mental health. This narrative synthesis examined the attributes of formal social support programs and their effects in the development of resilience in family caregivers. A broad search of databases of published qualitative and mixed methods studies was conducted. CASP was used to critically appraise the studies. The narrative synthesis consists of four elements: 1) developing a theory; 2) developing a preliminary synthesis; 3) exploring relationships in the data; 4) assessing the robustness of the synthesis. Eleven studies out of 169 articles met the inclusion criteria. Synthesis identified helpful attributes of support interventions as follows: convenience of delivery location, accessibility to and easy comprehensibility of information, face to face connection, learning with and from other caregivers as a group and individually, hands on training, and access to tailored care.

Preface

This thesis is an original work by Elom Adzovie. No part of this thesis has been previously published. This work is based on a synthesis of studies conducted by other researchers and references to these studies have been specifically provided. It comprises of work started on 7th January to June 6th 2016.

This thesis reports on a review of program attributes of formal social support interventions that support the resilience of caregivers. This narrative synthesis enlightened me about the importance of synthesis in evidence based practice.

Dedication

This thesis is dedicated to my children Enam and Aseye for sacrificing your mum for school. My father Seth, a stroke survivor and my mum Patience whose work as a primary caregiver inspired me to choose this topic.

Acknowledgements

I would like to express my sincere gratitude to Dr. Christine Ceci for keeping me focused, her unconditional support, encouragement and guidance throughout this thesis. Special appreciation is extended to Dr.Dorothy Forbes and Dr. Sandra Davidson my thesis committee members for their time expertise guidance and patience throughout the write up and sincere gratitude to Dr. Dela Dolvo for the technical advice.

To my mum and dad, Pat and Seth whose unrelenting support and love has given me the inspiration to pursue my goals despite all obstacles. Without your encouragement the completion of this thesis would not have been possible.

My sister and brother Ellen and Stephen for your constant support in the upkeep of my children Enam and Aseye who had to sacrifice for me to continue my education

To my children, Enam and Aseye: you two were the source of my energy, the reason I go on and brilliance. I owe you lots of fun hours. I could not imagine doing my Master of Nursing without you; you really gave me the reason to continue.

To the Otchie family of Edmonton no amount of words could express how much I appreciate your loving support and kindness throughout my period of education and my time of stay with you God richly bless you.

Table of Contents

List of Tables

List of Figures

Chapter 1

Introduction and Background

Approximately 15 million people worldwide experience stroke annually, of which five million are left permanently disabled, creating a need for long term support from family and community services (World Health Organization (WHO), 2008). Lopez and colleagues (2006) suggest this situation represents a global epidemic, and further note the problem is not limited to western or high-income countries. In Ghana, for example, the latest WHO data (2012) reported stroke deaths at 13,780 per year or 7.34% of total deaths. Although approximately two thirds of persons suffering from stroke survive, the disease is also a major cause of disability, cognitive deterioration, decrease in quality of life, and dependency in one of two patients. Stroke leaves many survivors permanently disabled making this disease one of the main challenges facing healthcare systems (Mackay & Mensah, 2004). Traditionally called “apoplexy”, “stroke” is so called because of the way it strikes people down (Mackay & Mensah, 2004).

Stroke rehabilitation has reduced associated disability, with a corresponding decrease in institutionalised care but has also increased the number of survivors living in the community (McCullagh, Brigstocke, Donaldson, &Kalra, 2005). For those who survive, experiencing a stroke has the potential to affect virtually every aspect of life, including the ability to perform basic activities of daily living as well as carry out family and social roles (Johnston, et al., 2007). Therefore, surviving a stroke not only affects the health and quality of life of the patient, but also that of informal or family caregivers (Mackenzie et al., 2007). For example, van Exel, Koopmanschap, van den Berg, Brouwer, and van den Bos (2005) demonstrated that caregiving for stroke survivors can have a negative psychological influence on family caregivers. Similarly, Hayder and Schnepp (2008) described caregivers undertaking total care of family members as experiencing despair, particularly in terms of the ongoing and time-consuming nature of the work. Caregivers risk being depressed, strained and anxious in the weeks and months following their family member experiencing a stroke (Green & King, 2010), in part related to the unknown trajectory in terms of recovery (Greenwood, Mackenzie, Wilson, & Cloud, 2009). This sudden, unplanned and unpredictable event can have a devastating effect on the mental health of family caregivers. Adaptation to a family members' stroke is known to be a difficult process that is dynamic over time, and although new caregivers tend to adjust to their caregiving responsibilities, they reported that 'balancing it all' is a problem that increased with time (Pierce, Steiner, Hicks, &Holzaepfel, 2006).

The experience of being a family caregiver, and caring for a person who has suffered and survived stroke is therefore particularly important to understand. Informal caregiver burden or worry is a multifactorial concept including physical, social, psychological and financial factors (Bhattacharjee, Vairale, Gawali, &Dalal, 2012; Zarit, Todd,&Zarit, 1986). Care burden has been conceptualized as both objective, including financial and task related factors, as well as subjective, with a focus on individual feelings and perceptions associated with caregiving (Hanson, Magnusson, Nolan, & Nolan 2006). Caregivers are seen as having to balance the dual responsibility of looking after a dependent stroke survivor as well as making modifications to their own lifestyle (Foster, &Chaboyer, 2003). In this context, social support, both informal and formal, has been known to increase the resilience of stroke survivors and their caregivers assisting them to maintain good physical and mental health. Ozbay et al. (2007) have documented that helpful social support can increase resilience to stress, with resilience cited as a contributing factor in counteracting the undesirable outcomes of stress. Like stress, social support is also multidimensional and stems from the relationships and interactions between the individual, family, peer group, and larger social systems (Boyd, 2002).

Given that family caregiving has become an essential element of care provision for stroke survivors, understanding what attributes of formal support systems actually enhance family resilience is a pressing problem. In Ghana, family caregiving is the predominant form of care in the community for older people, and only given up by families and other options taken, when there are no available family members. As well as the significant health system reliance on family caregivers, the caregiving burden may be greater in Ghana because patients are frequently discharged at an acute stage with limited rehabilitation resources. Caregivers are expected to care for these patients almost immediately post stroke, thus the need to provide sufficient formal social supports that support resilience.

This narrative synthesis examined the attributes of formal social support programs and their effects in the development of resilience in family caregivers. As may be apparent, the larger aim is to develop knowledge and understanding of these programs that may be relevant, and possibly transferable, to the author's home country of Ghana. This study begins by overviewing the significance of this narrative synthesis. In chapter 2, the background literature and current state of knowledge is reviewed. Chapter 3 describes the theoretical framework and methodology, while chapter 4 reports the results of the synthesis process. Chapter 5 considers implications of the results.

Significance of the Narrative Synthesis

The significance of this study is threefold. First, is the central role families' play in caregiving in Ghana. Second, are the implications of changing family structures, which impact the ability of families to carry out this role, and third is the lack of formal support services in Ghana generally, and the need to provide evidence based guidelines for the development of these.

Providing home care to the elderly and especially the physically and functionally impaired is a family obligation in Ghana. Traditionally, caregiving is a practice that enables

Ghanaians to see themselves as part of a bigger community, and to reciprocate favour received from elderly people during their childhood (Van Der Geest, 2002). The traditional family structure has been that of the extended family, enabling members to provide informal social support that helped with adaptation to adverse events and increased resilience. However, changes in family structure related to globalization, urbanization and Westernization have decreased the availability of the family as primary caregivers. The increased availability of formal education and urbanisation, coupled with increased cost of living, has contributed to a shift to the nuclear family structure (Assimeng, 2007). Despite these changes, the family is still expected to provide care for its elderly members, including stroke survivors who will need multiple forms of assistance. In Ghana, although family caregiving is assumed, support for family caregivers is not yet on the public policy agenda. Family caregivinghas not received needed attention because it is simply considered to be part of the informal system of care in the country.

Given these changes to family structure in Ghana, coupled with an aging population and subsequent increase in stroke survivors, care needs are not expected to decrease and indeed, the situation results in increased pressures on existing health services. In Ghana, the number of persons relying on family caregivers is predicted to rise from 0.8 million in 2010 to 2.2 million by 2050 (Mba, 2010). This makes it imperative for formal health systems to implement effective measures or programs that will support families taking on the work of caregiving. Findings of this review will offer insight into the types of programs and services that might best support families, thus bridging the gap between informal and formal social support.The specific research question guiding this review is what are the program or intervention attributes that support family caregivers' increased resilience post stroke?

Chapter 2

Background and Supporting Literature

As recommended by Popay et al. (2006), a ‘mapping’ review of research and theoretical literature involving family caregivers was undertaken to clarify and focus the question for this narrative synthesis (p. 9). This section highlights some key understandingsof family caregiver experiences, roles and responsibilities and needs, as well as reviews the concepts of resilience and social support.

Family caregivers

Globally, family caregiving serves as an important extension of formal health care systems and family caregivers make an outstanding contribution to community care (Hanson, Magnusson, Nolan, & Nolan 2006). As noted previously, family caregivers assist care recipients with activities of daily living in addition to normal household chores (Hildon, Montgomery, & Blane, 2009; Netuveli, Wiggins, &Montgomery, 2008). According to the National Family Caregivers Association (2011), in the United States, 80% of adults needing long term care live at home or in the community and 90% of their care is provided by unpaid family caregivers.

In Africa, the family is an essential part of all facets of an individual’s life. The family is described as a group of individuals who are connected by blood ties, marriage or through adoption (Nukunya, 2003). The availability of family caregivers during times of illness is of particular importance to the family unit and the health system (Aziato&Adejumo, 2014). Assimeng (2007) also notes that in Ghana there is an expectation of family commitment to care and support during times of crisis such as illness, with elder members taken care of by the young or other healthy family members. Informal carers thus make a vital contribution to the well-being of the family, providing physical and psychosocial care which may result in increased responsibilities and anxieties that may affect the caregivers’ abilities to cope.

Caregiver Experiences

As noted above, family caregiving may involve a number of stressors. For example, Greenwood, Mackenzie, Cloud and Wilson (2010) reported anxiety as a common experience for informal caregivers of stroke survivors. Similarly, Oupra, Griffiths, Pryor and Mott (2010) found that family caregivers described both physical and psychological strain, finding themselves experiencing burden and exhaustion. Caregivers who participate in greater dependent care (e.g., toileting, bathing) experienced greater emotional distress and greater caregiver burden (Bakas&Burgener, 2002). Thus, Levine, Halper, Pesit and Gould (2010) advised that family caregivers should be regarded as the foundation of long-term care because they are providing more complex and demanding tasks of caregiving that were shifted from the healthcare systems.

Alternatively, Cecil, Thompson, Parahoo and McCaughan (2013) explored factors influencing caring and coping among caregivers of stroke survivors. They found that caregivers identified a sense of pride, feeling useful and improved relationships with stroke survivors as encouraging aspects of caregiving. Plank, Mazzoni and Cavada’s (2012) phenomenological study with new caregivers found that these caregivers were in need of hope and confidence to manage their responsibilities.

Roles and Responsibilities

Family caregiving is understood as an effective approach to caring for elderly and ill family members in a healthful way. Caring for family members requires family caregivers to assist in activities of daily living such as grooming, feeding, and administering medicine (Kim, Chang, Rose, & Kim, 2012; Thrush,& Hyder, 2014). Although most family caregivers assist stroke survivors in activities of daily living, the most challenging task of caregiving was specificto each caregiver (Bhattacharjee et al., 2012). This is because the needs of a stroke survivor vary from physical activity, communication, personal care, and psychological support to adapting to the consequences of stroke. The family caregiver thus plays a crucial role in helping the stroke survivor manage his or her care as well as acting as the primary advocate for the stroke survivor, assisting with key treatment decisions and relaying information from stroke survivor to formal care providers and vice versa (Hubbard, Illingworth, Rowa-Dewar, Forbat, & Kearney, 2010).

Caregiver Needs

The needs of family caregivers vary according to the changing contexts of caregiving, including the level and type of support, the relationships with the stroke survivors, the resources available and the method of caring throughout the phases of stroke (Visser-Meilyet al., 2009). Informational needs are among the most commonly identified needs, having the highest priority among family caregivers in some studies (Huang, Min, Yao, Guo, & Zheng, 2008; Mak, Mackenzie, &Lui, 2007). Clarke, Hanson and Ross (2003) suggest that family caregivers should have a basic knowledge of stroke and its care, as well as practical skills in physical caregiving. Additionally, family caregivers should have information connected to the prevention of stroke recurrence, the protection of stroke survivors from physical injuries (e.g., falls), and about any support services available. Because many stroke survivors are discharged from acute care to continue with rehabilitation in the home setting, caregivers need information regarding community-based care rather than an institution-based approach to rehabilitation (Khondonwe&Mpofu, 2007). Caregivers reported that discussing issues and problems and receiving advice from an “expert” on stroke made asignificant difference post discharge from the hospital, with many caregivers expressing a wish to continue caring but feeling they lacked support and information (Khondowe&Mpofu, 2007). In the study undertaken by Khondowe and Mpofu, informal caregivers of stroke survivors receiving out-patient physiotherapy reported a lack of information, a need for skills training and home based therapy, and financial support. They also suggested better support from their general practitioner, the community nursing service and social services would be helpful. In another study, only a small number of family caregivers identified institutional respite care as an option, with most saying that they would prefer to have additional support in their own home (Kerr & Smith, 2001).

Additionally, providing care at home to stroke survivors may impose needs of psychosocial support among the family caregivers because it may drain the resources of the caregivers (O'Connell & Baker, 2004). Family caregivers require psychological support because they need to manage their time between stroke survivors, themselves and other family members (He & Jong, 2009; Silva-Smith, 2007). Again, the incidence of stroke may have negative effects on the intra-familial harmony as a result of limitations in social activity caused by the survivors' physical disabilities (Brittain& Shaw, 2007; Gillespie & Campbell, 2011). Various types of psychosocial interventions, such as counselling, psycho-education, and social support groups, have been developed to meet the needs of family caregivers (Clark, Rubenach, & Winsor, 2003; Pierce Steiner, Khuder, Govoni, & Horn, 2009).

Although the needs of the family caregivers of stroke survivors have been recognised in many jurisdictions, service and support for the caregivers have received limited attention in Ghana, and this was also found in Hong Kong (Lee, 2004; Sit, Wong, Clinton, Li, & Fong, 2004). A brief educational session on stroke is provided to stroke patients and sometimes to their caregivers before hospital discharge, however the psychosocial well-being of the stroke patients and their caregivers are rarely discussed (Louie, Liu, & Man, 2006). Information provided for the caregiver, such as medical conditions and symptom management, is mainly developed from the viewpoints of nurses and doctors. Consequently, information given to caregivers might not be directly applicable to their day-to-day management decisions (Sit et al., 2004). Furthermore, the services available in the community are mainly focused on stroke survivors' physical recovery and are fragmented (Chui, 2011).Bakas, Austin, Okonkwo, Lewis, and Chadwick (2002) identified informational and tangible needs as necessities of caregivers.

Resilience

Resilience has been a research topic of interest for several decades. The term developed as a result of psychological studies of childhood development trying to comprehend how some children with adverse conditions succeed in adapting to their situation (Garmenzy&Streitman, 1974; Rutter 2006; Wiles, Wild, Kerse, &Allen, 2012). The concept since then has been used in other disciplines and populations, including elders (Hildon, Montgomery, & Blane, 2009; Windle, Woods, & Markland, 2010), and adults who are incapacitated (Braudy, 2008; King, Cathers, & Brown, 2003; Dyer&McGuinness, 1996). Luthar,Ciccetti, & Becker (2000) note that research on family strength during times of crisis started in the early 1900s and although the term "resilience" was not used to describe adapting to family crisis in the literature at that time, the concepts described there might be viewed today as similar to resilience.

Research on resilience and family strength began to appear in the scientific literature in the early 1970s (Luthar et al., 2000). By mid-1970s, "childhood resilience" became a major topic of concern to researchers and focused mainly on identifying qualities that made children resilient. This work promoted further research into understanding specific differences in reaction to negative situations. Werner,Bierman & French(1971) examined the multiple adverse conditions affecting adaptation with 700 children in Hawaii. Areas of focus included socioeconomic disadvantages and associated risks such as maltreatment, poverty, violence, chronic illness, and other catastrophic life events (Luthar et al., 2000). Werner's (1993) work is often hailed as the ground-breaking study of resilience in children. Subsequently, researchers began to recognize the effect external and environmental factors play on resilience in children. For example, Masten and Garmenzy (1985) described three sets of external factors implicated in the development of resilience: attributes of the children themselves, aspects of their families, and characteristics of their wider environment (cited in Luthar et al., 2000).

Resilience had numerous meanings in early research (Garmenzy, 1991; Goldstein, 1997; Vaillant, 1993) but now generally refers to a pattern of functioning indicative of positive adaptation in the context of significant risk or adversity (Egeland, Carlson, &Sroufe, 1993; Kaplan, Turner, Norman, &Stillson, 1996; Ong, Bergeman, &Boker, 2009). Significantly for this review, Twoy, Connolly, and Novak (2007) explored the coping strategies in parents of children diagnosed with autism spectrum disorder (ASD). They concluded that parents of children with ASD were likely to use support systems within the family's social network, that parents sought encouragement and support from friends, informal support from other families who faced similar problems, and formal support from agencies and programs. Thus formal social support was identified as helping family caregivers increase resilience. Smith, Lawrence, Kerr, Langhorne, and Lees (2004) confirmed that caregivers are able to increase their resilience by establishing a routine and most of all by accepting assistance from statutory/voluntary agencies and/or social networks.

Resilience itself is multifaceted and the process of resiliency is linked to several related elements that work to create either positive or negative experiences. Giesbrecht, Wolse, Crooks, and Stajduhur (2015), for example, identified that family caregiver resilience is not individualistic but also influenced by the social environment. The environmental location, housing, educational level, access to facilities, information and social status are socio-environmental factors that contribute to shaping resilience.

Social Support

As with resilience, social support is a subject of interest for a variety of disciplines such as sociology, psychology and social work. Social support is of interest to nursing because of recognition of the impact of social support on health seeking behaviours, health status and well-being, as well as having potential for possible intervention to increase resilience. Appraisals of literature on studies of social support propose that social support is a multidimensional concept (Cobb, 1976; Cohen & McKay, 1984). Stewart (1993) defined it as "interactions with family members, friends, peers, and health care providers that communicate information, esteem, aid, and reliable alliance. These communications improve coping, moderate the impact of stressors, and promote health" (p. 7). Cobb (1976) described social support as a unitary concept and documented two vital but dissimilar types of support. Psychological support represented the provision of information whereas non-psychological support represented the provision of material aid or tangible support.

Conceptualizing social support as multidimensional was continued in the writings of Cohen and McKay (1984). They maintained the category of tangible support but further divided psychological support into the support mechanisms of appraisal (assistance in assessing potential threats and the adequacies of one's own resources for managing the threat), and two types of emotional support, self-esteem and belonging.

Although informal social support may be a factor in meeting the assistance needs of caregivers of the elderly stoke survivor, the focus of this review is the formal social supports available to family caregivers. Schopler and Mesibov (1984) defined *formal social support* as "succour that is social, physical, psychological, or monetary and is provided either for free or in exchange for a fee through an organized group or agency" (p.297). Lin,Ye, & Ensel, (1999), further identified formal resources of social support as community facilities and programs or services**.** In Ghana, community resources are relatively inadequate because traditionally, the family provides comprehensive care for elderly and disabled family members. Furthermore, many caregivers simply do not have the information necessary as to how to access outpatient and community-based services (Turner et al., 2007).

To summarize, in line with Lazarus and Folkman’s (1984) conceptualization of stress, formal support services may serve "to prevent stress by making harmful or threatening experiences seem less consequential, or provide valuable resources for coping when stress does occur" (cited in Ducharme, Lebel, Lachance, &Trudeau,2006, p. 428). According to Fischer, Corcoran, and Fischer (2007), social support “has been found in a number of studies to be an important buffer against family crisis factors, and to be a factor in family resiliency promoting family recovery, and as a mediator of family distress” (p. 413). Therefore, developing effective strategies to improve the social support of family caregivers may help to safeguard the well-being of the family caregivers. Traditionally the family has assumed the responsibility of meeting the needs of their elderly family members. However, because of social changes, the need for formal support resources for the caregivers of elderly stroke survivors has increased in recent years, making it necessary to strengthen the existing resources of informal support and establish formal support resources in the community.

Formal resources of social support refer to the community facilities and programs/services (Lin, et al., 1999). Research suggests that programs such as adult day care centres or respite service allow the people to continue their activities in their environment (Bertilsson, Von Koch, Tham, & Johansson, 2015; Bocchoi& Angelo, 2008: Gosman-Hedström&Dahlin-Ivanoff, 2012; Smith, Lawrence, Kerr, Langhorne & Lees, 2004).

Theoretical Framework

Popay et al. (2006) suggest that use of a theoretical framework in a narrative synthesis may help in identifying how an intervention works and for whom. Theory may also inform the review question and guide the interpretation of results. This narrative synthesis will make use of the McCubbin and McCubbin (2001) resiliency model of family stress, adjustment and adaptation as the theoretical framework. This model is chosen because it focuses on changes and responses that occur in the family as a result of crises. It further explains why some families are more resilient than others and are better able to adjust and adapt to stress, distress and crises by examining the family system as a unit and available social support (Tak&McCubbin, 2002).

The model is based on the idea that actions and communications within the family systems, interaction with community and extended family, community program and services explain the differences in family outcomes, family recovery and changes in the well-being of family members or the condition of the family unit (McCubbin&McCubbin, 2001). Resilience refers to the family's capability to develop strengths that will allow them to meet the challenges of life (National Network for Family Resiliency Children, Youth and Family Network, 1995). Communities play a large role in fostering resilience, and the presence of social organizations is a strong sign of a well organised and supportive community (Garmenzy, 1991). As noted previously, resilience is multifaceted, and influenced by the individual and the wider socio-environmental setting in which they are located (Luthar, Ciccetti, & Becker 2000). The magnitude of the stress experienced by families is determined, in part, by the degree to which the stressor threatens the stability of the family unit or places significant demands on its resources and capabilities (McCubbin&McCubbin, 1989; Patterson, 1988). Adaptive resources refer both to existing resources and to acquired resources that are established and reinforced in response to the demands posed by the stressor event (Tak&McCubbin, 2002).

The family's capability is defined as the potential the family has available for meeting demands. Possible sources of resources are individual family members, the family unit and the community. Social support as an individual, family, and community level resource is most often viewed as one of the primary intermediaries or mediators between stress and psychological well-being. Social support can be defined as a resource that meets needs. Cohen and McKay (1984) have emphasized that social support will be effective if the type of support offered meets specific needs. Thus the support of family caregivers of stroke patients should be specific to their needs. Social support is important as a protective factor and as a recovery factor for the family. In the face of vulnerabilities, the family draws from a network of relationships to facilitate its durability. In the case of a crisis, the family system not only draws from existing sources of support but often times will seek additional forms of support that improves the situation, help improve coping strategies, and, more importantly, help in the family's capacity to adapt to change (Cobb, 1982; McCubbin, Thompson, &McCubbin, 1996).

Social support available for specific needs of the family eases the stress and burden on families. The presence of social support may explain why some individuals experience higher life stresses and strains but do not show a high level of distress (Kazak &Nachman 1991; Patterson &Garwick 1994). For families to be healthy, programs and policies aimed at the well- being of families should be guided by theory and research.

In this study, the resiliency model of family stress, adjustment and adaptation was used to guide understanding of caregivers of stroke survivors’ use of formal social supports in adaptation processes to improve quality of life.

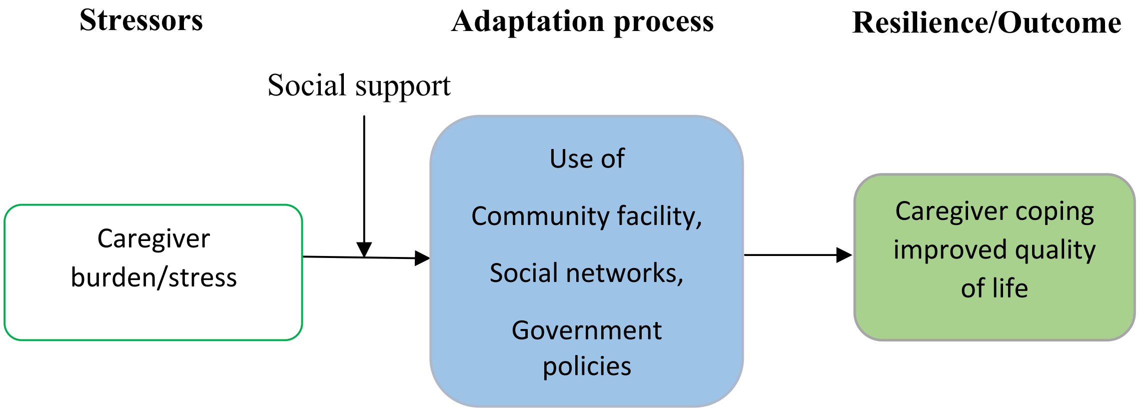


Figure 1*Conceptual Framework: Resilience Through Use of Formal Social Support*

Chapter 3

Methodology: Narrative Synthesis

This research methodology falls within the qualitative research paradigm and is a systematic approach used to synthesize qualitative research findings. This section begins with a description of narrative synthesis as a method, then describes the specific processes to be used in this analysis including the inclusion and exclusion criteria for data selection and screening, data management, the plan for data extraction, quality appraisal and synthesis of selected studies, and ends with the plan for dissemination. The guidance for the conduct of narrative synthesis prepared by Popay and colleagues (2006) was the primary methodological resource for this review.

Systematic reviews seek to identify and synthesize the best available research on a specific question to provide evidence for practice. A narrative synthesis is a textual approach to systematic review relying primarily on the use of words and text to summarise and explain the findings of research (Pope, Mays, & Popay, 2006). Telling a trustworthy story is an important aspect of a narrative synthesis and as Popay et al. (2006) suggest, synthesizing evidence in a way that tells a vivid story of why things are done in a particular way or how things work can bridge the gap between research, policy and practice. Thus, according to Popay et al. (2006), a carefully conducted narrative synthesis must provide an analysis of the relationships within and between studies, as well as an overall assessment of the robustness of the evidence. Further, to create a trustworthy story, the approach used must be rigorous and transparent to reduce the potential for bias (Centre for Reviews and Dissemination, (CRD) 2009).

A robust evidence base was necessary to inform guidelines for practice that will be accepted by health professionals. At the same time, policy-makers and practitioners are increasingly conscious of the limitations of regarding randomised controlled trials as the singular source of ‘evidence’. This situation has given rise to growing calls for more comprehensive approaches to review, so that primary data may be put to better use (Pearson, 2004 cited in Dixon-Woods, et al., 2006). In order to ensure the narrative synthesis developed evidence that was comprehensive, transparent and trustworthy, Popay et al. (2006) outline four elements that provide both a general framework for the process of review and specific tools for the synthesis. As they observe, “the guidance for narrative synthesis was intended to make the process of narrative synthesis more methodical and to reduce bias” (Popay et al., p.5). The four elements are discussed in more detail in the synthesis plan on page 20 (see also Table 1) but are included here to highlight the general process of a narrative synthesis:

- Developing a theory of how the intervention works, why and for whom
- Developing a preliminary synthesis of findings of included studies
- Exploring relationships in the data
- Assessing the robustness of the synthesis (Popay et al., p. 11)

Narrative methodologies are acknowledged as appropriate for examining heterogeneity across primary studies, and thus was a useful approach for reviewing the attributes and influence of different types of social support programs on family resilience. Narrative synthesis was chosen for this research because it uses an organised tactical approach to narrative and has been used successfully in a number of reviews (Arai et al., 2007; Leamy, Bird, Boutillier, Williams & Slade, 2011; McDermott, Crellin, Ridder, &Orrell, 2013).

Identifying Studies

In order to identify studies relevant for answering the review question, ‘What are the program or intervention attributes that support family caregivers increased resilience post stroke?’ key terms were defined and inclusion/exclusion criteria established.

Resilience: According to McCubbin and McCubbin (1989), resilience is the ability to respond to challenges and have the capability to rebound. Resilience is apparent when families function positively notwithstanding stress and challenges by drawing on internal and external resources to promote health (Atkinson, Martin & Rankin, 2009).

Family caregiver: Also known as primary caregivers or informal caregivers, family caregivers are mostly family and close friends who provide ongoing aid in activities of daily living in the home of recipients without remuneration (Fast & Keating, 2000).

Social support: As noted previously, social support is a multifaceted concept (Caplan, 1974; House, 1981; McCubbin, Thompson &McCubbin, 1996). Social support can be formal and informal and include tangible, emotional, and informational supports (House, 1981). McCubbin and McCubbin (2001) suggest that formal social support services arise from government policies that support families, community agencies, facilities and social network. Formal social services when available serve as substitutes and complements to informal social support. To answer my research question, I focused on formal social support.

Inclusion and Exclusion Criteria

Criteria for the inclusion or exclusion of studies arise from the research question and the provided definitions of key terms. The following were the inclusion criteria applied for selection: informal caregivers as opposed to voluntary or paid carers of stroke survivors; primary caregivers (carers providing the most care); a focus on their experience, quality of life, coping strategies; formal support programs; stroke survivors living at home; qualitative studies including the qualitative data of mixed methods studies; studies published between January 1995 – April 2016.

Studies were excluded if they involved paid caregivers of stroke survivors: secondary carers (carers who provide only some of the care and are ancillary to the primary carer); quantitative studies with no qualitative data; articles published earlier than year 1995; articles without primary data (e.g., review or discussion papers).

Search Protocol and Data Management

Systematic reviews seek to identify and draw together all known research evidence on a specific topic. In this synthesis, a comprehensive search approach was used to identify studies related to my question. The search terms used were derived from my research question. According to Dixon et al. (2006), the combination of number of search strategies including searching electronic databases, searching websites, reference chaining and contact with experts contributes to identification of relevant literature for a review question. The expertise of a health sciences librarian was sought in webbing ideas, concept mapping and searching electronic databases for relevant studies for this narrative synthesis. A search for related reviews in PROSPERO and COCHRANE database revealed only one review (Legg et al., 2011) indicating this review is an important one.

Databases such as CINAHL, MEDLINE, EMBASE, Scopus, and SocINDEX web of science were used for this literature search. CINAHL, MEDLINE, EMBASE were searched because they are some of the largest databases for biomedical, clinical, and nursing research. The databases SocINDEX and Scopus offered a wide range of articles from different disciplines. Scopus helps ensure that crucial research from around the world is not missed. The search terms identified included “older”, “elderly” in combination with “stroke”, “cerebrovascular accidents”, as well as “caregiver burden”, “coping strategies” “physiotherapy”, “experience”, “caregiver”, and “carer”. Then “emotional crisis”, “stress”, “quality of life” and “satisfaction of life”. Search terms also included “programmes”, “social support”, “adaptation”, and “resilience”. Reference tracking of selected papers was also carried out through hand searching. The reference lists of articles obtained were checked (including those from previously published systematic reviews) to identify relevant articles. The search was restricted to literature from 1995-2016 to make sure the most relevant and up-to-date information is included, and was limited to the English language.

Some of the search terms were identified from the databases used. The search terms were truncated where appropriate to ensure all relevant articles are retrieved. In order to conduct a comprehensive data search for my review, only published articles on family caregivers of stroke patients were included (Serret, 2006).

Plan for Data Management

The data for this review was managed by Microsoft word, excel spreadsheet and Refworks. Abstracts retrieved from database searches were reviewed for inclusion. Articles whose topics and concepts were related to answering the research question and fulfilled the inclusion criteria were selected and saved in Reworks.

Data Extraction Plan

Data extraction summarizes studies in a common format to support synthesis and logical presentation of data. The data extraction plan for this narrative synthesis made use of a data extraction form to obtain the appropriate and relevant information for the review. The data extraction form contributes to the provision of a structured approach to gathering existing data about the research question (Armstrong, Hall, Doyle, & Walters 2011).

In addition to this form, a quality appraisal tool adapted from Critical Appraisal Skills Programme (CASP) (2006) checklist for appraising qualitative studies was used. This checklist includes ten questions for qualitative studies to assess the relevance and quality of selected studies during data extraction (see Appendix 1). The assessment questions help the reviewer to identify the basic parts of a research article (e.g., sample, data collection, data analysis, and outcomes) and to consider how well the authors presented the steps taken in each of these areas during the study and the rationales for making each of these decisions. This tool was used because it assesses both internal and external validity of articles and this ensures that article appraisal is robust. Appraisal examines the quality of reporting and assessment, the quality of description of sampling, appropriate collection of data and overall rigour. All included articles were appraised by the researcher. To enhance the trustworthiness of the quality appraisal, two reviewers, researcher (EA) and the supervisor (CC) appraised the quality of the selected studies. EA appraised all studies and CC appraised every third included study. In order to maintain consistency in the data collection process, the same data extraction form was used to extract data from all the relevant articles, and the same quality appraisal questions to assess the quality of all included studies.

Synthesis Plan

The purpose of this narrative synthesis was to identify the attributes of formal social support programs that increase resilience of family caregivers of stroke survivors. The goal of synthesis was to explore, describe, and interpret the findings. A synthesis can detect a collection of shared themes and opposing views (Ring, Ritchie, Mandava, & Jepson, 2010), as well as expand understanding of a phenomenon or caregiver experience (Ring et al., 2010). In narrative synthesis, the identification of themes can be used to put different experiences together into a meaningful whole.

As noted previously, narrative synthesis consists of four main elements: developing a theory of how the intervention works, why and for whom; developing a preliminary synthesis of findings of included studies; exploring relationships in the data; and assessing the robustness of the synthesis. Each element was made up of a variety of tools and techniques that were tailored to meet the research needs. Using the guidelines described by Popay et al. (2007), a theory was identified and introduced (family resilience), and steps for developing a preliminary synthesis undertaken. Plans for exploring relationships between data and assessing robustness of the synthesis are described below in table 1.

Table 1*Main elements of synthesis with tools and techniques* (adapted from Popay et al. 2006, p. 12.)

Main elements of synthesis	**Purpose**	**Tools and techniques in developing elements**
Developing a theory of how the interventions work, why, and for whom	To develop an understanding of the theory behind intervention/program in order to inform decisions about the review question and the types of studies to include.	Description of resilience and the need for social support
Developing a preliminary synthesis	To provide a preliminary synthesis and give an account of mapping of articles related to research question identified.	Tabulation of data Textual descriptions Grouping and clustering
Exploring relationships in the data	To subject outcome from preliminary synthesis to further rigorous evaluation and identify any aspects that may explain the differences within and across the included studies	Qualitative case description Idea webbing/ conceptual mapping Investigator and methodological triangulation
Assessing the robustness of the synthesis product	To assess the quality of methods	Best evidence synthesis CASP assessment tool Checking the synthesis with thesis committee. Reflecting critically on the synthesis process

Ethical Considerations

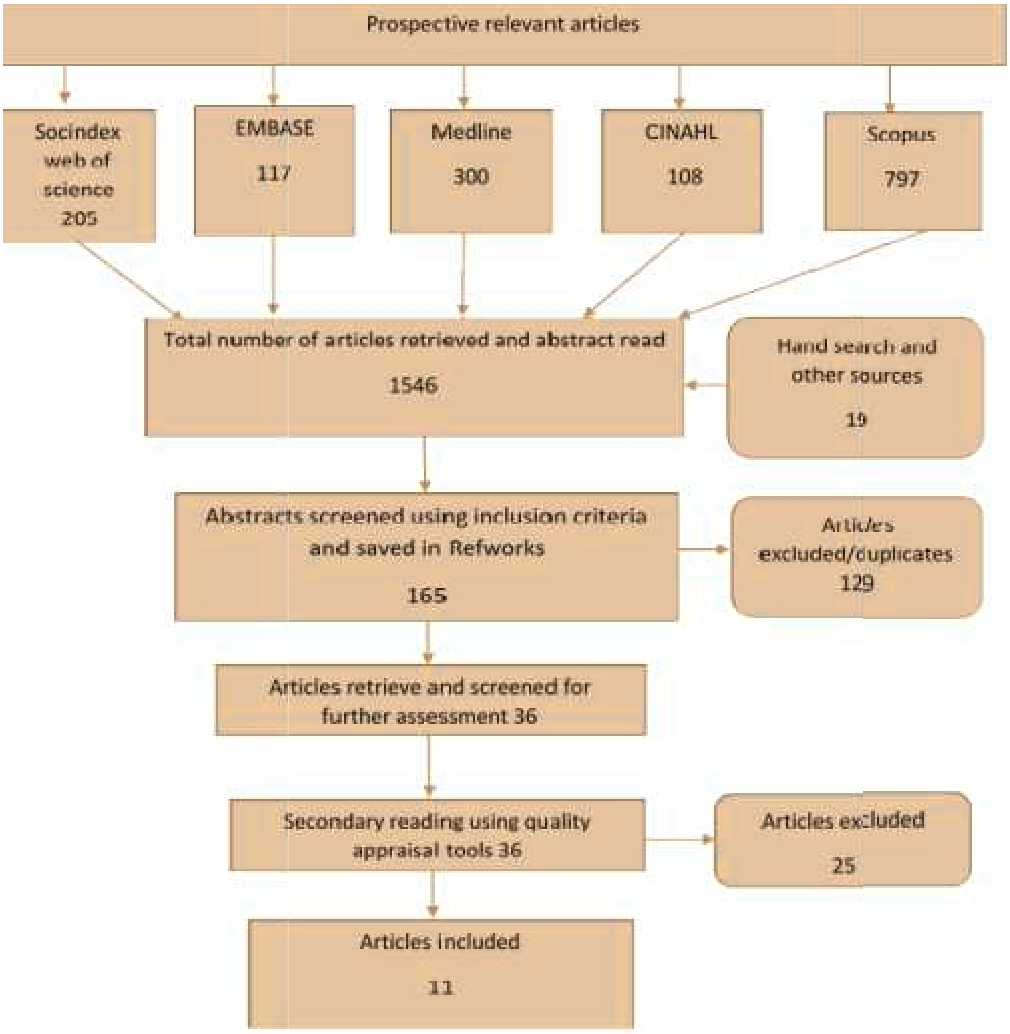
Ethical approval is not usually required because already published data was used in this narrative synthesis. (Hollins-Martin & Martin, 2013). However, confirmation of this was sought from the University of Alberta HREB prior to commencing this study.

Chapter 4

Analysis and Synthesis of the Literature

A focused search of the databases MEDLINE, Scopus, EMBASE, CINAHL, SocINDEX web of science, as well as a hand search of citations and references in key articles was completed on April 14, 2016. The search keywords and meSH terms combined generated 1546 prospective articles and 19 articles werehand searched and reviewed for relevant citations. Of these, 165 articles were identified as potentially meeting inclusion criteria and uploaded to Refworks for further review. After duplicates were removed, 36 were further assessed for secondary reading. Of these, 11 studies were found to fully meet the inclusion criteria. The flow of process for article selection is elaborated in Figure 2.

Figure 2 *Flow Diagram of Retrieved Articles*



Overview of Included Studies

Eleven studies met the inclusion criteria all reporting results related to the provision of formal support programs or interventions for family caregivers. The interventions described were heterogeneous including education, web-based support, early supported discharge, client centred activity of daily living, e-rehabilitation, informal caregiver stroke self-management, peer visitor support and specialist nurse support. Modes of interventions included Internet video conferencing, telehealth, and peer or health professional visitors. All programs were delivered either in the participants' home or at the hospital. Most of the programs did not identify a theoretical framework for the programs or interventions although research by Stewart et al. (1998) and Pierce et al. (2004) was based on a psychosocial perspective.

Of the 11 studies, ten used qualitative methods and one was a mixed methods study. Some studies specified the exact approach used. Of the 11 included studies, one used a qualitative longitudinal design with a grounded theory approach (Bertilsson, von Koch, Tham& Johansson, 2015), two were descriptive studies (Buckley,Tran &Prandoni, 2004; Danzl et al., 2016), one was a qualitative secondary analysis (Keaton et al., 2004), one was a mixed methods study (Mores et al., 2013) and the rest did not specify the precise methodology used describing their approach as some form of qualitative description (Cobley, Fisher, Chouliara, Kerr, & Walker, 2013; Dowswell, Lawler, Young, Forster, & Hearn, 1997; Low, Roderick, & Payne, 2004; Marziali, Donahue, &Crossin, 2005; Pierce et al., 2004; Stewart, Doble, Hart, Langille, & MacPherson,1998).

Assessment of Study Quality

All eleven studies included in this synthesis were assessed for methodological quality using the qualitative checklist of the Critical Appraisal Skills Program (CASP). The CASP guideline includes ten questions which were used to evaluate the quality of the studies that met the inclusion criteria. Each item was checked ‘‘Yes’’, ‘‘Can’t tell’’ or ‘‘No’’. Under each item guiding questions are suggested to assist evaluation. Researcher (EA) did the appraisal for all the eleven included studies and Supervisor (CC) performed the appraisal for every third included article. The results of the appraisals were discussed by EA and CC for all the included articles with particular attention to items that were checked ‘‘Can’t tell’’ or ‘‘No’’ in the appraisal. All independent comments about the studies included on the appraisal form related to study quality were discussed. All included articles met the quality guidelines as outlined on CASP.

Preliminary Synthesis

In reviewing studies for intervention attributes that enhance resilience for caregivers of stroke survivors, the synthesis made use of selected tools and techniques as recommended by Popay et al. (2007), based on their usefulness and applicability to this study (see Table 1). Textual description was used to give vivid detail, and tabulation to give a visual presentation of data which is essential for the distinctiveness of a narrative synthesis, as well as providing a logical summary of data (Arai et al., 2007; Evans, 2002). The steps of the preliminary synthesis included data extraction, tabulating and describing the studies, grouping the studies and then concluding with preliminary thematic analysis.

Data Extraction

The study features extracted from each publication were the name of the authors, year of publication, country, study design, objective of the study, sample size, methods, program/intervention and quality appraisal. As suggested by Arai et al. (2007), a summary of the key characteristics of each study was tabulated (see Appendix 2), followed by a textual description of each study.

Textual Description of Included Studies

In Bertilsson et al. (2015), a qualitative longitudinal design informed by a grounded theory approach was used to explore and describe if and how a client-centred ADL intervention (CADL) was integrated in everyday life during the first year after stroke based on the experiences of significant others. The CADL identified specific strategies for the successful performance of everyday activities. Stroke survivors were taught how to use a daily diary to communicate with significant others involved in their rehabilitation. The intervention captured the experiences of each caregiver in an audiotaped interview. Results indicated that the availability of support was important, and that it gave the caregivers a sense of security and encouraged them to engage in everyday life activities and in the rehabilitation. The significant others were able to create a space in their everyday life, both for their own sake and for the sake of their partners with stroke, which gave them an opportunity to enhance their own wellbeing.

Buckley et al. (2004) used an explorative descriptive study to identify factors that influenced the receptiveness, use, and acceptance of telehealth technologies by caregivers of stroke survivors in the home setting. The telehealth program allowed for a two-way interaction between a nurse and the participants using audio and video transmission. The tele-nurse initially planned and carried out 2 home visits to screen participants for readiness, and followed up with video calls and follow up visits. Analysis was done through reading of notes of the videophone and exit interviews. The main results indicated that telehealth decreased caregiver isolation and stress related to the caregiver role. It provided a reliable method of communication and exchange of information.

Cobley et al.'s (2013) qualitative study investigated patients' and carers' experiences of Early Supported Discharge services to inform future Early Supported Discharge service development and provision. The Early Supported Discharge services made use of a health specialist team to coordinate the discharge of stroke survivors from the hospital unit to the home. The team provided psychological intervention, social care supports and daily stroke specialist rehabilitation in the patient's home. Using audio taped interviews transcribed verbatim and analysed with Nvivo 9, findings indicated caregivers felt that rehabilitation in a familiar environment was conducive and offered time for respite for the caregiver. Thirteen of fifteen caregivers reported they felt deprived of their previous lifestyle in having to take up the new responsibilities of caring for the stroke survivor. Most caregivers indicated that they were not-up-to date in regards to available post discharge formal support systems. Out of fourteen caregivers, ten communicated that they had inadequate understanding of the causes, prevention and trajectory of stroke. They also reported difficulties with access to information, which was also not often tailored to their needs.

Danzl et al.'s (2016) descriptive study examined rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimizing educational interactions and interventions for an underserved population. The health education program implemented by the Kentucky Appalachian Rural Rehabilitation Network (KARRN) made use of a multidisciplinary team including a nurse, physiotherapist, occupational therapist and speech therapist who delivered education about stroke and management of stroke to the family. They derived qualitative data through audiotaped interviews, transcribed the data and consequent coding. Stroke survivors and caregivers were found to rely on health care providers to proactively initiate education and provide needed information. They also suggested that alternate sources of education such as support groups and health system navigators in rural communities are needed. Survivors and caregivers expressed the need to also provide education to extended family and community social support networks. Participants expressed the need for information about the health care continuum (eg. expectations in each setting).

Dowswell et al. (1997) used a qualitative approach to identify whether nurses' interventions influence the process of stroke recovery by using a specialist nurse home visits intervention. The specialist nurses provided tailored support to help improve outcomes for patients and their caregivers during the first year after stroke with at least 7 compulsory home visits. Participants identified the information and advice they would have appreciated in the first year after stroke with the aim of goal setting, problem solving and advice on specific issues. Information packs containing detailed lists of locally available services, booklets published by the Stroke Association and information on benefits were compiled and available to the specialist nurses to distribute and discuss with the patients and caregivers as appropriate. Using transcribed audio taped interviews, findings indicated that advice and information was valued and the specialist nurses were often the only source of reliable advice against which other sources compared unfavourably.

Keaton et al. (2004) performed a secondary analysis of qualitative data derived from email questions received from the caregivers of persons with stroke directed to a nurse specialist and members of an electronic (E)-rehabilitation team. The Caring Web intervention had multiple components that provided education and support to assist caregivers. Caregivers were also encouraged to ask questions of concern at any time through email which were answered by the nurse specialist and a team of experts. An electronic caregiver group was also set up to help caregivers discuss their experiences with other caregivers and the nurse specialist. A mailing list also enabled caregivers who were part of the group to receive any information on caregiving. The E- team was used to answer complex questions that were not in the nurse’s domain. Data collected from questions that caregivers asked nurses and other experts were analysed through a qualitative data management program (QSR N 5). Caregivers were found to be seeking new knowledge and learning about caregiving by exploring facts about stroke and discussing their experiences with family, other caregivers and the specialist nurse. Caregivers were also interested in community resources and government services available to them.

Low et al. (2004) explored the impact of two methods of post-hospital stroke rehabilitation - day hospital and domiciliary care - on both carers' perceptions of the health services offered and their quality of life. The day hospital was a non-residential facility professionally staffed which supported the health, nutritional, social and daily living needs of the elderly. This setting also afforded caregivers respite from the demanding responsibilities of caregiving. In domiciliary care professionals provided healthcare services to stroke survivors in their homes. Interviews were transcribed and content analysis carried out on transcripts using a coding frame to identify themes. Findings indicated that day hospitals provided carers with respite opportunities in that the attendance of the stroke survivor at the day hospital provided opportunities for these carers to have time for themselves. Domiciliary stroke teams provided carers with better educational opportunities to be involved in therapy, thereby increasing carers’ confidence in supporting and encouraging stroke survivors with their rehabilitation. This supported findings that suggested that domiciliary therapists saw one of their functions as educating carers in the rehabilitation process. Domiciliary care was also perceived as being convenient to both carers and survivors. A few carers felt that the day hospital provided better accessibility to a wider range of equipment and more space for therapy than was available with the domiciliary teams. One carer in particular felt that medical care in the day hospital would be better co-ordinated as all the doctors, nurses and therapists were based in the same building and so would have better communication with each other.

Mores et al. (2013) used a mixed methods study to evaluate the content, format and resource materials of the Informal Caregiver Stroke Self-Management program (FICSS) with 11 family caregivers of stroke survivors. The FICSS program is a unique program developed for family caregivers of stroke survivors to participate with peers in a facilitated group without the stroke survivor present. The program was designed to provide the opportunity for caregivers to grow together, as individuals, and develop effective coping strategies to live with their new reality after the stroke event. The program focused on self-management, recognizing that the caregiver is a key player in a therapeutic relationship and an active participant in the stroke survivor's care management. The program aimed to address the seven key ingredients of self-management: (a) providing information, (b) teaching disease-specific and disease-neutral skills, (c) promoting selection of healthy behaviours, (d) developing problem-solving skills, (e) assisting with the emotional sequelae of having a chronic condition, (f) providing continued follow-up, and (g) encouraging individuals to be active participants in the management of their stroke survivor's recovery. Focus group feedback was conducted on all four sessions and key themes were identified, though the process of analysis was not clearly specified. The results of the evaluation suggested the program provided caregivers with tools, strategies and resources to better manage as caregivers. Participants felt more hope and patience after attending the program. They stated that they learned valuable advocacy skills from the workshops and each other. Participants explained that the program informed them of available community services but more importantly, provided the tools and strategies to self-manage and cope with the struggles of being a caregiver. They indicated that the program provided the opportunity for them to gain an alternative perspective and helped to improve their quality of life, as well as that of the stroke survivor. Participants emphasized that the program should be offered earlier on in the caregiving experience, ideally between three and six months post hospital discharge of the stroke survivor instead of 36 weeks.

Pierce et al. (2004) undertook a qualitative study to test the feasibility of providing an internet-based education and support intervention to caregivers living in rural settings, including assessment of caregivers' satisfaction with the intervention. Caregivers used the caring web to find information and receive care maintenance advice. They also sought information for emotional and social support with other caregivers and a nurse specialist.

Stewart et al. (1998) used a qualitative study to measure the impact of a peer support intervention on caregivers' perceptions of their social support, burden, stress, and competence and use of health-care services by stroke survivors. This intervention focused on provision of support to supplement isolated networks of caregivers by providing emotional, informational and affirmational assistance. Participants received two home visits per week for twelve weeks after discharge from hospital after initial stroke. Transcripts of post intervention interviews coded subthemes to identify key themes. New caregivers described the demands of care including providing physical care, managing emotional and behavioural reactions of the stroke survivor as well as coordinating their health care needs. They were also concerned about managing the symptoms. Caregivers regarded the peer visitors' visits as supportive, bidirectional, appropriate and timely. Caregivers' self-esteem increased and they said they felt more capable. They also felt more confident in their role. Peer visiting reduced doubts about the uncertainties they felt as caregivers.

Grouping the Studies: Similarities and Differences

The specific interventions provided in each of the eleven studies were different although their focus on supporting informal caregiving was similar. Although the program studied by Danzl et al. (2016) focused mainly on the education of caregivers, each of the other ten studies (Bertilsson et al., 2015; Buckley et al., 2004; Cobley et al., 2013; Dowswell et al., 1997; Keaton et al., 2004; Low et al., 2004; Marziali et al., 2005; Mores et al., 2013; Pierce et al., 2004; Stewart et al., 1998) also used one form of education as part of their intervention. Two interventions specifically used skills training with caregivers and stroke survivors to improve resilience (Bertilsson et al., 2015; Cobley et al., 2013). The use of formal social support as an intervention method was used by seven out of the eleven studies (Low et al., 2004; Buckley et al., 2004; Dowswell et al., 1997; Keaton et al., 2004; Marziali et al., 2006; Mores et al., 2013; Pierce et al., 2004; Stewart et al., 1998). Additionally, seven out of eleven studies incorporated a problem solving approach for caregivers to support caregiving (Buckley et al., 2004; Dowswell et al., 1997; Keaton et al., 2004; Marziali et al., 2006; Mores et al., 2013; Pierce et al., 2004; Stewart et al., 1998).

Three studies used a web based method for their delivery of the intervention (Keaton et al., 2004; Marziali et al., 2005; Pierce et al., 2004), while others used face to face methods of delivery (Bertilsson et al., 2015; Buckley et al., 2004; Cobley et al., 2013; Dowswell et al., 1997; Keaton et al., 2004; Low et al., 2004; Mores et al., 2013; Stewart et al., 1998) for their intervention. One study made use of both methods (Buckley et al., 2004). The use of peers was also found to be an important mode of delivery of the intervention (Marziali et al., 2005; Mores et al., 2013; Stewart et al., 1998), while others included some form of expert delivery (Bertilsson et al., 2015; Buckley et al., 2004; Cobley et al., 2013; Danzl et al., 2016; Dowswell et al., 1997; Keaton et al., 2004; Low et al.,2004; Mores et al., 2013; Pierce et al., 2004). Almost all the programs (seven) were delivered in the home setting (Buckley et al., 2004; Dowswell et al., 1997; Keaton et al., 2004; Marziali et al., 2005; Pierce et al., 2004; Stewart et al., 1998;). Three studies delivered the intervention or program in the hospital setting (Bertilsson et al., 2015; Cobley et al., 2013; Danzl et al., 2016 Mores et al., 2013), while one compared programs delivered at home and the hospital (Low et al., 2004).

Although most included studies focused on family caregivers as the sample for interventions in various aspects of caregiving (Buckley et al., 2004; Cobley et al., 2013; Danzl et al., 2016; Keaton et al., 2004; Mores et al., 2013; Low et al., 2004; Pierce et al., 2004; Stewart et al.,1998), four focused on the family caregiver and the stroke survivor

(Bertilsson et al., 2015; Cobley et al., 2013; Dowswell et al., 1997; Marziali et al., 2005). These similarities and differences are highlighted in Table 2.

Table 2 *Grouping the Studies*

Authors	**Location**				**Intervention focus**				**Sample type**	
	U.S.A	**U.K**	**Sweden**	**Canada**	**Education**	**Skills training**	**Problem solving**	**Formal social support**	**Focus on only family caregivers**	**Focus on family caregiver and stroke survivor**
Bertilsson et al. (2015)			√		√	√				√
Buckley et al. (2004)	√				√	√	√	√	√	
Cobley et al. (2013)		√			√					√
Danzl et al. (2016)	√				√				√	
Dowswell et al. (1997)		√			√		√	√		√
Keaton, et al. (2004)	√				√		√	√	√	
Marziali et al. (2005)				√	√		√	√		√
Mores et al. (2013)				√	√		√	√	√	
Low (2004)		√			√			√	√	
Pierce et al. (2004)	√				√		√	√	√	
Stewart et al. (1998)				√	√		√	√	√	

Translating the Data: Thematic Analysis of Study Findings

To identify key themes and concepts across the studies, each section of each study identified as "Findings" was subject to a line by line close reading for content and meaning as recommended by Thomas and Harden (2008). The research question was set aside for this process to avoid imposing an a priori framework on the data (Thomas & Harden, 2008). Each identified key idea or concept was added to our collection of 'codes'. This was done independently by EA and CC (for every third included study). The key ideas and concepts identified were then discussed by EA and CC and analyzed to identify patterns of ideas that related to the study focus of enhancing caregiver resilience. The identified concepts were grouped thematically under the following headings: adaption related to new knowledge, skills, and changing roles; balance as a result of shared responsibilities; a sense of security due to availability of resources and information that leads to services; and gaining control as a result of learning skills and managing everyday life. These four concepts appeared to run across the studies regardless of the specific intervention employed.

Adaptation. The first key theme is caregiver adaptation to situation. Accordingly, with increased knowledge (Bertilsson et al., 2015; Cobley et al., 2013; Low et al., 2004) and learning new skills (Danzl et al., 2016), caregivers learned to deal with everyday life. Caregivers confirmed that caregiving alters their own personal time and privacy through increased responsibilities that have an impact on their daily lives. Adaptation to everyday life was found to be a fundamental feature influencing caregiver resilience for those participating in programs. Adaptation was linked to having knowledge about the condition and to the specific help received from services linked with the intervention. For example, a participant in Stewart et al., (1998) stated that "I started taking him to adult care one day a week…. he enjoys that in there and I can leave him and have a day to whatever I want to do" (p. 99). Accepting responsibilities and seeking knowledge and resources to help in managing stroke survivors' recovery helps with adaptation in everyday life (Bertilsson et al., 2015).

Balance. The second theme observed across the data is balance. In the same way, as caregivers shared responsibilities with formal social services available (Bertilsson et al., 2015), having time for self (Cobley et al., 2013; Low et al., 2004), having respite (Cobley et al., 2013; Low et al., 2004; Stewart et al., 1998) and being in a familiar environment helped in caregivers living a balanced life (Cobley et al., 2013). Findings across four different studies showed that shared responsibilities, more family ties and social networks, as well as respite lessens the burden of caregivers, thus helping caregivers live a balanced life. As a participant in Bertilsson et al. (2015) observed, “He takes care of his rehabilitation on his own. It was different in the beginning. It feels good now, in that he does his part” (p. 382). Similarly, a participant in Cobley et al. (2013) reported that “I could get on with the little jobs that wanted doing or I could just put my feet up and have a rest, so it made life a darn sight easier for me” (p. 753).

Gaining control. The third theme was gaining control. As a result of increased knowledge and learning new skills (Bertilsson et al., 2015; Danzl et al., 2016), sharing responsibilities (Mores et al., 2013), learning and practicing (Dowswell et al., 1997; Keaton et al., 2004; Pierce et al., 2004), as well as identifying problems and how to solve these (Buckley et al.,2004), caregivers had increased confidence in their role performance and gained control over their caring act (Mores et al., 2013; Stewart et al., 1998). Gaining control is related to knowledge acquired, respite, sharing responsibilities and developing new skills.According to Bertilsson et al., (2015) participants adjusted their involvement in survivors’ ADL according to their capacity and learning flexibility in performing an activity to achieve a common goal**.** As a participant in Mores et al. (2013) observed, “You felt really connected to the others [other caregivers] and that they really cared about you... we had one common thing we shared... but after that it was much more we learned from each other” (p. 22). Such learning increased control over and confidence in caregiving.

A sense of security. The fourth identified theme was developing a sense of security as a result of knowledge of own expertise (Keaton et al., 2004; Mores et al., 2013; Low et al., 2004; Stewart et al., 1998) and knowledge of the availability of other help (Bertilsson et al., 2015; Cobley et al., 2013; Dowswell et al., 1997; Low et al., 2004; Marziali et al., 2005; Mores et al., 2013). For example, a support group participant in Keaton et al.'s (2004) study stated, "I have found this to be a great escape. You can get great advice, wisdom and real answers to all your questions" (p. 5). Similarly, Stewart et al. (1998) reported a participant commenting about the effect of having a peer visitor stating that the "peer would offer advice or something that had happened in the situation that was similar" (p.105), and that this gave her the confidence to manage her own situation. Furthermore, Mores et al. (2013) also described a participant as saying, "I liked the opportunity to share and brainstorm with other caregivers about resources and caregiving strategies. It is the safest place I have been in months" (p.23).

The thematic analysis of each study's findings section suggests that even though there were differences in the type of interventions implemented, that across the studies, the interventions had effects that seem to support resilience. The next step for this synthesis is to identify and discuss the characteristics of the interventions that seem to be responsible for this effect.

Exploring Relationships Among the Studies: The Narrative Synthesis

In this section, relationships among the studies and findings related to the intervention characteristics that seem to support caregiver resilience are presented in narrative form, as well as through a tabular synthesis (see Table 3) and a concept map (see Figure 3).

Exploring relationships brings together two relationships of interest: the relationships between characteristics of interventions, and the relationships between the findings of different studies. The technique for exploring relationships is comparing and contrasting the textual descriptions of interventions extracted from each study and the key themes identified through the translation of findings. The heterogeneity of interventions and programs, samples chosen and size, multiplicity of research designs and limited explanation of study results limited the direct amalgamation of studies. This study thus focused on the key attributes of interventions used and the relationship of these to the findings of the thematic analysis. Attributes identified from interventions that seem to support resilience in caregivers of stroke survivors were: convenience of delivery location, accessibility to and easy comprehensibility of information, face to face connection, learning with and from other caregivers as a group and individually, hands on training, and access to tailored care.

To begin, convenience of delivery location contributed to caregiver resilience. Among the 11 studies included for the review, two studies (Bertilsson et al., 2015; Mores et al., 2010) used a facility based approach for intervention and identified that caregivers reported that knowledge of and availability of formal support in the facility setting were important for caregiving. Having such support available encouraged caregivers to engage in everyday life activities and in rehabilitation. On the other hand, using home based interventions (Buckley et al. 2004) decreased caregiver isolation and stress related with the caregiver role. In either location, convenience for caregivers of the service delivery location was an attribute of the interventions offered that supported resilience. Caregivers identified that delivery of the intervention in the home setting was convenient and increased their confidence as they performed in their known environment. Similarly, interventions delivered at a facility also created a sense of security as facilities had the logistics to work with every situation. Notwithstanding, Cobley et al. (2013) examined both home and facility- based care reporting that rehabilitation in a familiar environment was conducive to well being and both locations offered possibilities for respite (see also Low et al., 2004).

Accessibility to and easy comprehensibility of information was identified as an attribute of the interventions that is vital for caregiving. Information delivery may be at the doorstep of the caregivers, make use of leaflets or handouts, as well as accessible internet services, and should always be in the language that the caregiver can understand.

Comprehensibility increases the confidence of the caregiver in the information and thus makes it more acceptable for use and practice. Dowswell et al. (1997) reported advice and information was valued, and Keaton et al. (2004) further noted caregivers were also interested in knowing about community resources and government services available to them. Stewart et al. (1998) agreed caregivers' self-esteem increased and they felt more capable with access to information. Danzl et al. (2016) reported participants preferred facilitators with compassionate and encouraging styles of communication which supports Stewart et al.'s (1998) finding illustrated in a participant's comment that "she [the facilitator] was respectful of my emotions and didn't offer me advice except if it was solicited. The timing of information and intervention delivery was important" (p. 104). Face to face meetings with experts also contributed to the resilience of caregivers. While using experts for delivery, Dowswell et al. (1997) purported that advice and information were valued, and that the specialist nurses were often the only source of reliable advice against which other sources compared unfavourably. It appears that it is vital to use experts for education and skills whilst using peer support for boosting the confidence of caregivers. Stewart et al. (1998), on the other hand, found that using peer support visitors for delivery was reported by caregivers to be helpful, bidirectional, apt and timely. Caregivers' self-esteem increased and they felt more capable. They also felt more self-assured in their caregiving role and hesitations they felt as caregivers were reduced. Perhaps delivery of intervention through face to face contact established a personal connection to the expert, or the peer, that made the delivery of information more valuable. It increased the opportunity for the caregiver to verify things not understood and discuss issues at hand directly. This thus decreased isolation, increased knowledge and boosted confidence.

Learning with and from other caregivers as a group and individually (as in peer visitor support) was also noted as an important attribute for interventions possibly because they were able to relate with each other more easily due to the experience of caregiving with similar situations and the ability to share those experiences. All studies used education as an approach for intervention, which suggests that education and creating awareness may be an important aspect of caregiving and must be an important aspect of formal social service for caregivers. Danzl et al. (2016), who used mainly education for both caregivers and stroke survivors, reported that education that provides needed information for caregiving helps in gaining control. Learning is the ability to gain accumulated knowledge in a particular field in the context of stroke and its management. While Keaton et al. (2004) combined education and problem solving, they affirmed caregivers were seeking new knowledge and learned about caregiving by exploring facts about stroke (Buckley et al., 2004). Problem solving also provided a reliable method of communication and exchange of information. Caregivers who were provided with tools, strategies and resources to better manage felt more hope and patience (Mores et al., 2013). For example, Stewart et al. (1998) reported a caregiver as stating, “When [stroke survivor] had seizures I was a bit more prepared because a peer visitor said her father had them” (p.107).Marziali et al. (2005), describing the results of a focus group discussion, noted a participant stating “that’s what makes these sessions meaningful…We’re not alone and we share some of the same experiences and challenges” (p. 401). Likewise, in one to one peer visiting, a caregiver in Stewart et al.’s (1998) study reported that “you just feel connected to other people who are going through the same situation. I feel peer connected” (p.107).

Using skills training is a vital and hands on approach to supporting caregiving and again, an important contributor to resilience. Hands on training gave caregivers an opportunity to practice actively and experience what they were taught. Processes such as caregiving for a stroke survivor need specific knowledge and practice to be able to perform and perfect a needed skill. It is thus important to incorporate skills training in interventions for caregivers. For example, a participant in Dowswell et al. (1997) stated “I can do what I do and what they expect me to do because I have been around to see and practice with them” (p.779). It helps caregivers and stroke survivors to improve their resilience, by boosting their sense of security, balance, gaining control and adaptation to daily life (Bertilsson et al., 2015; Cobley et al., 2013).

Tailored care was an attribute of interventions identified where care is individualized and intervention personalised to meet the needs of caregivers. Caregiving needs may be different for each caregiver and using tailored care interventions is a useful attribute that helps caregivers in coping with caregiving. As a participant in Stewart at al.’s (1998) study stated “I didn’t know whether I was doing the right thing so she showed me the best way to do it and encouraged me” (p.108). And according to Dowswell et al. (1997), stroke survivors and caregivers reported that they valued the flexible, individualized service that had been provided.

Exploring relationships among the studies identified attributes from interventions that seem to support resilience in caregivers of stroke survivors were: convenience of delivery location, accessibility to and easy comprehensibility of information, face to face connection, learning with and from other caregivers as a group and individually, hands on training, and access to tailored care. These key elements when used in interventions contributed to the increased resilience in family caregivers. These findings are summarized in table 3 and figure 3 below.

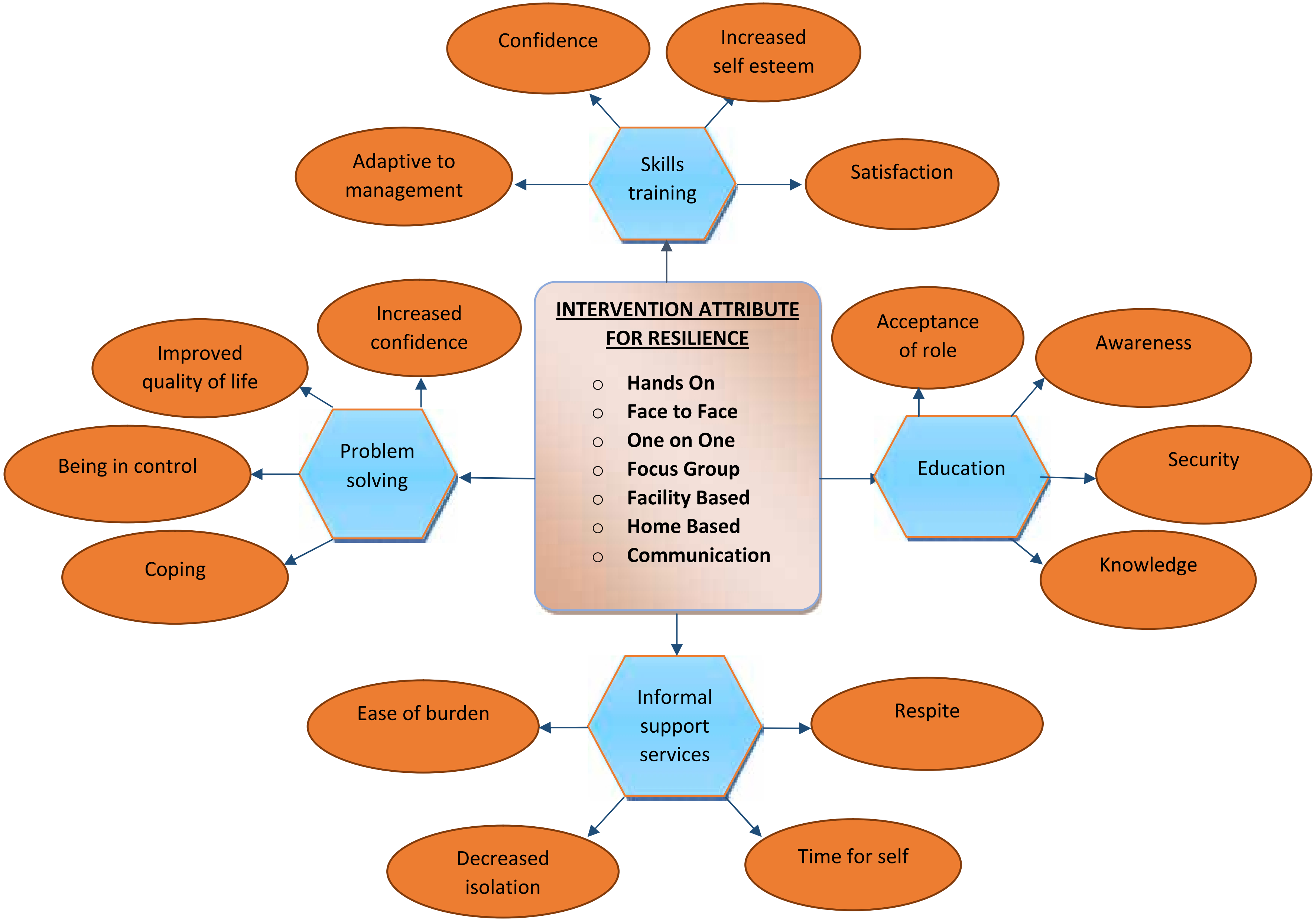


Figure 3 *Concept Map*

Table 2*Tabular Synthesis*

Location and author	**Context**		**Explanatory factors**	
	Focus of intervention	**Setting**	**Caregiver Perception**	**Resilience**
Bertilsson et al. (2015) Sweden	Skills training / education	Hospital	Awareness of the availability of support seemed to be important for caregivers. It encouraged them to engage in everyday life activities and in the rehabilitation.	Sense of security, balance, gaining control and adaptation to daily life
Buckley et al. (2004) USA	Problem solving/education/ support	Home	Decreased their isolation and stress related with the caregiver role. It provided a reliable method of communication and exchange of information.	Sense of security, balance, gaining control and adaptation to daily life.
Cobley et al. (2013) UK	Education/skills training/	Home and hospital	Having rehabilitation in a familiar environment was conducive and a time of respite for caregiver.	Sense of balance, gaining control and adaptation to daily life.
Danzl et al. (2016) USA	Education	Hospital/ Community	Education provide needed information for caregiving.	Gaining control.
Dowswell et al. (1997) UK	Problem solving/education/ support	Home	Advice and information was valued and the specialist nurses were often the only source of reliable advice against which other sources compared unfavourably.	Sense of balance and gaining control.
Keaton et al. (2004) USA	Problem solving/education/ support	Home	Caregivers were seeking new knowledge and learn caregiving by exploring facts about stroke. Care givers were also interested in community resources and government services available to them.	Adaptation to daily life and a sense of security.
Marziali et al (2005) USA	Problem solving/education/ support	Home	Having a support group to discuss problems with was helpful and reassuring.	Sense of security
Mores et al. (2013) Canada	Problem solving/education/ support	Hospital	Caregiver were provided with tools, strategies and resources to better manage, felt more hope and patience. Equipped with valuable advocacy skills and informed of available community services.	Sense of security, balance, gaining control and adaptation to daily life.

Location and author	**Context**		**Explanatory factors**	
	Focus of Intervention	**Setting**	**Caregiver Perception**	**Resilience**
Low et al. (2004) UK	Education/support	Home/ Hospital	Intervention provided respite opportunities, and allow caregivers to have time for themselves. Caregivers also had better educational opportunities gaining confidence through supporting during rehabilitation.	Sense of security, balance, gaining control and adaptation to daily life.
Pierce et al. (2004) USA	Education Problem solving/Social support	Home	Intervention a viable tool for providing support and education to caregivers of persons with stroke in home settings.	Sense of security, balance, gaining control and adaptation to daily life.
Stewart et al. (1998) Canada	Social support Problem solving /education	Home	Caregivers regarded the peer visitor visits as supportive, bidirectional, appropriate and timely. Caregivers self-esteem increased and felt more capable. They also felt more confident in their role. Peer visiting reduced any doubts about the uncertainties they felt as caregiver.	Sense of security, balance, gaining control and adaptation to daily life.

Strengths and Limitations of the Evidence: Assessing the Robustness of the Synthesis

The narrative synthesis examined the attributes of formal social support programs and their effects for the improvement of resilience in family caregivers. In this section, the strengths and limitations, as well as the overallrobustness of the synthesis will be discussed. In order to attain robustness in developing evidence about helpful attributes of care practices with family caregivers of stroke survivors, this synthesis followed the methodological guidelines set out by Popay et al. (2007). Research reports included were selected systematically, scrutinized and carefully reviewed for this study using the CASP quality assessment checklist tool for qualitative studies. The CASP tool checklist assesses credibility, transferability, dependability and confirmability and all included studies were positive in terms of the checklist criteria. However, this quality appraisal tool simply provided an assessment of quality of individual studies which were scored but not weighted. Thus there is the possibility of differences in the strength of the studies themselves. This was addressed, in part, in that only peer reviewed articles were used in this study and also a second reviewer (CC) appraised every third study increasing credibility and trustworthiness of the process.

Nevertheless, it is still important to discuss thestrengths and limitations of this study. First was a small sample size of eleven, as a limited number of articles met inclusion criteria. Again although the search for articles was extensive only studies written in English were included and other noteworthy studies in other languages might have gone unnoticed. Although the focus and emphasis of each study was on caregivers, the heterogeneity in method, setting,sample population, interventions, methods, and duration of studymade analysis complicated.

Synthesising across the included studies must be interpreted carefully because of this heterogeneity. Although all included studies were methodologically sound according to the

CASP quality assessment, they differed in terms of the richness of included qualitative data. For example, Bertilsson et al. (2015) included a rich report of data on caregivers while Marziali et al. (2005) and Keaton et al. (2004) included less qualitative data in their findings. Similarly, Mores et al. (2013), in reporting on a mixed methods study, included a limited amount of qualitative findings. The implications of this difference among studies are that studies with richer data may have contributed more to the final synthesis. An attempt to mitigate this possibility was carefully reading across all studies during the process of thematic analysis.

Second, the differences in settings in terms of country could influence the outcomes of intervention. The eleven studies that met the inclusion criteria were from different countries, three from Canada, four from USA, three from United Kingdom and one from Sweden. This made the study valuable as it added to the variations in interventions and sample used. On the other hand, although the included studies were undertaken in different countries and continents, all could be described as western industrialized countries with well-developed health care systems. This may limit transferability to developing nations, such as the author's country Ghana. However, although extracting the characteristics of interventions was helpful, rather than analyzing the program itself, may go some way to mitigate this limitation.

Similarly, the culture of caregiving might be different from one continent to the other, and from one country to the other. For example, Danzl et al.'s (2016) participants included members of Kentucky's indigenous population whose belief in family caregiving may easily make them more resilient to the demands of caregiving. Nevertheless, the included studies present some diversity in participants that may support the possibilities of using the extracted attributes as a basis to develop similar interventions. Study participants varied in terms of ages and gender, as well as some variation in ethnicity and socioeconomic status, and these variations could affect the outcome of intervention.

As expected, the content and mode of delivery of the interventions used varied quite widely - from CADL to early supported discharge. While this gave an opportunity to assess a wide range of programs available, and their useful attributes, as well as the potential strengths and limitations of each intervention, the heterogeneity also brings complexity. Acknowledging the complexity of interventions, and their multiple attributes, possibly beyond those identified in this study, means that identified attributes should be used with caution in planning interventions. For example, differences in length of timing of interventions could affect variations in outcomes. Stewart et al. (1998) has originally intended to recruit participants up to a year post discharge, but because of recruitment issues included participants who were up to 18 months post discharge when caregivers may have already adjusted to the situation. Similarly, Mores et al. (2013) also recruited caregivers in the adaptive phase, that is at least 3-6 months and 36months post discharge of the stroke survivor, while Cobley et al., (2013) focused on early supported discharge.

Despite these limitations, the use of a narrative synthesis methodology made it possible to synthesize data across studies and develop findings related to the attributes of formal social support programs that support the development of resilience in family caregivers.

Chapter 5

Discussion

Summary of Key Findings

This narrative synthesis sought to examine the attributes of formal social support programs and their effects for the improvement of resilience in family caregivers. Relatively few studies met the inclusion criteria. As well, there were variations across the included studies in terms of methods and intervention. Despite these limitations, the findings from the synthesis indicated that caregivers, as a result of interventions, are better able to adapt to the new situation of caregiving as a result of new knowledge, skills, and changing roles; achieve greater balance as a result of shared responsibilities; have a sense of security due to availability of resources and information that leads to services; and gain control as a result of learning skills and managing everyday life.

The ability to increase resilience in family caregivers is through interventions that will be of benefit to both caregivers and stroke survivors. Interventions examined through the included studies had attributes that helped in the effective delivery of support service and improved outcomes. In delivering formal supportive interventions such as education, problem solving, skills training and social support, the attributes of interventions that seemed to be most related to enhanced resilience during transmission of interventions were: face to face contact, tailored care, learning with/from other caregivers, convenience of delivery location, accessibility of information and hands on training for caregivers.

In using tailored care for intervention, stroke survivors and caregivers valued the flexible, individualized service had been provided (Dowswell et al., 1997). Hands on training gave caregivers an opportunity to practice actively and experience what they were taught (Bertilsson et al., 2015). This boosted their sense of security, helped them to live a balanced life, gain control and adapt to daily life. Learning with and from other caregivers as a group and individually (as in peer visitor support) gave caregivers an opportunity to relate with each other more easily due to sharing the experience of caregiving with those in similar situations. Caregivers were supported to better manage situations (Mores et al., 2013).

Convenience of location decreased caregiver isolation and stress related with the caregiver role (Buckley et al., 2004). Having knowledge of support available encouraged caregivers to engage in everyday life activities and in rehabilitation. Interventions in the home setting were convenient and increased their confidence as they performed in their known environment (Cobley et al., 2013), while interventions delivered at a facility also created sense of security as facilities had the logistics to work with every situation and offered possibilities for respite (Bertilsson et al., 2015; Low et al., 2004). Finally, accessibility to and easy comprehensibility of information increases the self-confidence of the caregivers and makes it more acceptable for use and practice and valued (Dowswell et al. (1997), caregivers self-esteem increased and they felt more capable with access to information (Stewart et al.,1998). Each attribute identified from included studies contributed to resilience of caregivers.

Previous reviews of quantitative research on interventions for caregivers (Brereton, Carroll, & Barnston 2007; Visser- Meiley, van Heugten, Post, Schepers, & Lindeman, 2005) focused on measuring effectiveness of interventions for caregivers of stroke survivors, specifically psychosocial interventions (Ho Yu et al., 2013) and non-pharmacological interventions for caregivers of stroke survivors (Legg, 2011). According to Brereton et al. (2007), all eight included studiesfocusing on interventions such as social problem-solving partnership, psycho- educational support group, a nurse led support group, education program and support program reported some benefits for caregivers in all the interventions. Similarly, a critical review by Visser-Meiley et al. (2005) of 22 studies with four types of support programs (specialist services, (psycho)education, counselling and peer social support) found that ten out of the 22 included studies in their review reported positively on outcome domains for caregivers and three of the studies reported negative outcomes for caregivers. Ho Yu et al.'s (2013) meta-analysis reported limited evidence from 18 included studies (16 psycho-education and 2 social support).Legg et al. (2011) studied 8 RCTs categorised as vocational training/teaching procedural knowledge, support and information and psycho-educational types of interventions also reported limited evidence supporting effectiveness.

While it is evident from this brief overview of previous reviewsutilizing quantitative methods that interventions for caregivers of stroke survivors may not be yet well established in terms of measurable effectiveness, in comparison, this narrative synthesis suggests that there are attributes of formal support programs that may be linked with improved resilience. More research is need to identify the most effective arrangements of these asidentifying attributes of interventions that increase resilience is crucial for planning of interventions.

Importance of the Narrative Synthesis Methodology for Nursing

In the quest to answer my research question concerning the program or intervention attributes that support family caregivers' increased resilience post stroke, I used a narrative synthesis methodology. A narrative synthesis is a textual approach to systematic review relying primarily on the use of tabulations and texts to synthesize, summarise and explain the findings of multiple studies research (Pope, Mays, & Popay, 2007). Narrative synthesis is a logical method that blends and allows the findings of heterogeneous studies to be made apparent and thus is a powerful way of contributing to evidence in nursing practice.

The need to use evidence in nursing practice is supported when the findings of primary studies can be incorporated into an all-inclusive understanding of a topic. Synthesis is used to emphasize the importance of understanding how the results from single research studies are woven into a network with the greater body of knowledge on a topic. Practicality and usefulness of interventions can be made more consequential by conducting synthesis of comprehensive literature for evidence. Supporting and using findings from a single study could cause more harm than good (Fleming, 2007). Synthesis of reviews may help to ensure that findings of studies are grounded on scientific methods with adequate evidence to confirm the practicality and usability of findings.

Implication for Nursing Practice

This review gives an immediate insight into attributes of interventions for caregivers of stroke survivors. A number of interventions show promise in increasing resilience in caregivers such asconvenience of delivery location (Bertilsson et al., 2015; Mores et al., 2010),accessibility to and easy comprehensibility (Danzl et al.,2016;Dowswell et al., 1997; Keaton et al. 2004; Stewart et al. 1998). Learning with and from other caregivers as a group and individually (Buckley et al., 2004;Danzl et al.,2016;Marziali et al. 2006;Mores et al., 2010; Stewart et al., 1998). Again using skills training(Bertilsson et al., 2015; Cobley et al., 2013;Dowswell et al. 1997),tailored care (Dowswell et al. 1997; Stewart et al. 1998)and face to face meetings(Dowswell et al. 1997; Stewart et al. 1998). Thus the need to incorporate those attributesin interventions programs for caregivers in nursing management to enhance nursing practice.

This synthesis publicised the nurse as an important member of the health and rehabilitation team and it is very important for nurses to take an active role in the holistic care of the stroke survivor thus seeing the caregiver as an important asset to patient care. Caregivers identified the nurse as a valuable source of information (Danzl et al.,2016; Stewart et al., 1998) thus it behoves the nurse to make sure all facts on information on caregiving are valid and up to date.

The caregiver should be seen as a unique individual and a logical approach used in assessing their special needs and resources available identified. Caregivers will only use facilities and services that they believe useful to them thus care tailored to meet the individualised needs of the patient/caregiver will prevent unnecessary use of resources. Caregivers treasured the flexible, personalized service provided for them (Dowswell et al., 1997).

Nurses should recognize caregivers as partners in caregiving and should involve and allow them to play an important role in the caregiving process of stroke survivors to facilitate easy transitions into care services. According to Danzl et al. (2016) caregivers advocated for being included in informative procedures and considered as significant team members. Thus nurses should empower caregivers, give them rich and concise information and involve them in all processes of caregiving for effective results.

There should be adequate discharge planning for caregivers including education about the condition, the need for rehabilitation after discharge from acute care and strategies to cope and better adjust with changes and trajectory of disease condition. Cobley et al. (2013) recommended discharge planning with patient and caregivers directed to suitable formal support services available. Finally, the nurse as a team member should plan educative and informative programs for caregivers in conjunction with other health professionals and should be able to ask and verify questions which are not in her domain from other team members (Keaton et al., 2004).

Implication for Policy

The synthesis findings address questions important to decision making for policy makers (Popay et al., 2007). Policy makers can make use of this synthesis findings by considering the attributes found to support family caregiver resilience (i.e. convenience of delivery location, accessibility to and easy comprehensibility of information, face to face connection, learning with and from other caregivers as a group and individually, hands on training, and access to tailored care) when making decisions on planning and implementation of interventions for caregivers of stroke survivors. Policy makers can make use of findings of this synthesis and collaborate with other stakeholders (i.e. practitioners, caregivers) to plan good, beneficial and quality programs for caregivers. Danzl et al. (2016) collaborated with all stakeholders to make educational programs for Appalachian Kentucky rural community successful.

Most the programs from studies were easily accessible to participants (Bertilsson et al., 2015;Cobley et al. 2013; Dowswell et al. 1997; Stewart et al. 1998). Policy makers should provide excellent accessible programs for caregivers with appropriate funding and need to make interventions available to caregivers and to all interdisciplinary team members.

Mores et al. (2013) suggested that timely programs with optimum durationwill benefit the caregiver and finallypolicy makers should encourage research and provide funding for caregiver intervention programs.

Implications for Future Research and Recommendations

This narrative synthesis identified attributes of interventions/programs that could contribute to program development/ planning in order to promote resilience in caregivers of stroke survivors. Stroke happens suddenly and informal caregivers may be flung into the caregiving role unprepared. Caregivers of stroke survivors play a vital role in rehabilitation and caregiving, there is therefore the need to plan and involve them in interventions that will increase their resilience. There is limited research evidence on timing of interventions for caregivers of stroke patient. There is therefore the need to examine the best time that formal social support can be incorporated to help caregivers achieve resilience.

Conclusion

Based on the findings of this review additional knowledge on attributes for interventions of formal social support has been identified. The synthesis highlighted the intervention attributes that facilitate easy delivery of intervention and thus potentially enhance resilience. Outcomes call for careful choice of attributes for intervention. No definite conclusion can be drawn on the most effective attributes of interventions for caregivers of stroke survivors, it however helps identify most helpful attributes used, peculiar to specific interventions that will be beneficial when planning interventions that lead to resilience for caregivers of stroke survivors.

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Appendix 1

Critical Appraisal Skills Programme (CASP)

No	**Questions**	**Yes**	**Can't tell**	**No**	**Comments**
Screening questions 1&2					
1	Was there a clear statement of aims? • What was the goal of the research? • Why it was thought important? • Its relevance				
2	Is a qualitative methodology appropriate? • If the research seeks to interpret or illuminate the actions and/ subjective experience of research participant. • Is qualitative research the best methodology for addressing the research goal				
Detailed questions					
3	*Appropriate research design* Was the research design appropriate to address the aims of the research? • If the researcher has justified the research design (e.g have they discussed how they decided which method to use				
4	*Sampling* Was the recruitment strategy appropriate to the aims of the research? • if the researcher has explained how the participants were selected • if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • if there are any discussions around recruitment (e.g. why some people chose not to take part)				
5	*Data collection* Were the data collected in a way that Write comments here addressed the research issue? • if the setting for data collection was justified if it is clear how data were collected (e.g. focus group, semi-structure interview) • if the researcher has justified the methods chosen • if the researcher has made the methods explicit(e.g. for interview method, is there an indication of how interviews were conducted, did they used a topic guide?) • if methods were modified during the study. If so, has the researcher explained how and why? • if the form of data is clear (e.g. tape recordings, video material, notes etc.) • if the researcher has discussed saturation of data				
6	*Reflexivity* Has the relationship between researcher and participants been adequately considered? • if the researcher critically examined their own role, potential bias and influence during: • formulation of research questions • data collection, including sample recruitment and choice of location				

	• how the researcher responded to events during the study and whether they considered the implications of any changes in the research design				
7	*Ethical issues* Have ethical issues been taken into consideration? • if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • if approval has been sought from the ethics committee				
8	*Data Analysis* Was the data analysis sufficiently rigorous? • if there is an in-depth description of the analysis process • if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? • whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • if sufficient data are presented to support the findings • to what extent contradictory data are taken into account • whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation				
9	*Findings* Is there a clear statement of findings? • if the findings are explicit • if there is adequate discussion of the evidence both for and against the researcher’s arguments • if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.) • if the findings are discussed in relation to the original research questions				
10	*Value of the research* How valuable is the research? • if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?) • if they identify new areas where research is necessary • if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used				

Appendix 2 - Summary of Characteristics of Included Studies

Study	**Purpose**	**Design**	**Sampling strategy**	**Methods yielding qualitative evidence**	**Program/ Intervention**	**Results of study**	**CASP**
First author**:** **Bertilsson, A** Country: **Sweden**	To explore and describe if and how CADL intervention was integrated in everyday life during the first year after stroke, based on significant others' experiences.	Qualitative longitudinal design, with a grounded theory approach	Participants primary caregivers of stroke survivors who received the CADL intervention. Recruitment was ongoing over a period of four months.	Recorded interviews at 6 and 12 months after recruitment. Verbatim transcription of tapes. Open coding followed by focus coding.	**A client-centred ADL intervention** (CADL)	The awareness of the availability of support it gave caregivers a sense of security and encouraged them to engage in everyday life activities and in the rehabilitation.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author**:** **Buckley, K.M.** **Country: USA**	To identify factors that influence the receptiveness, use, and acceptance of telehealth technologies by care givers of stroke patients in the home setting.	Explorative descriptive study	75 participants contacted by phone and only 21(28%) agreed to participate in study.	Reading of notes of the videophone and exits interviews, coding and themes derived.	**Telehealth** .	Telehealth decreased caregiver isolation and stress related to the caregiver role. Almost all caregivers found equipment easy to use. It provided a reliable method of communication and exchange of information.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author**:** **Cobley, C.S** **Country: U. K**	To investigate patients' and carers' experiences of Early Supported Discharge services and inform future Early Supported Discharge service development and provision.	Qualitative studies	Participants who met the early supported discharge services criteria were recruited from two stroke units in the Nottinghamshire region in partnership with the hospital staff.	Audio taped interviews transcribed verbatim and analysed in Nvivo **9**	**Early discharge services**	Greater number of caregivers reported being deprived of their own life style to take up new responsibilities of caring for stroke survivor	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes

First author:**Danzl, M.** Country: **U.S.A**	To examine rural Appalachian Kentucky stroke survivors' and caregivers' experiences of receiving education from health care providers with the long-term goal of optimizing educational interactions and interventions for an underserved population	Descriptive study	In recruiting participants, fliers were circulated and letters sent to 200 + stroke survivors. 31 individuals were interested. 25 individuals were eligible and 6 ineligibles when inclusion criteria were applied.	Interviews audiotaped, transcribed data derived coding	**Health Education**	Stroke survivors and caregivers rely on health care providers to proactively initiate education and provide needed information. Alternate sources of education, such as support groups and health system navigators in rural communities, are needed. Receivers of Education. Survivors and caregivers express the need to provide education to extended family and community social support networks. Participants expressed the need for information about the health care continuum (eg. expectations in each setting)	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author**:** **Dowswell, G** Country**: United Kingdom**	To identify whether the nurses' intervention may have influenced the process of stroke recovery	Qualitative study	A subsample of patients from the larger randomized trial participated in the qualitative evaluation following completion of the final quantitative assessments at 12 months after recruitment to the trial.	Audio taped interviews transcribed	**Specialist home visits**	Advice and information was valued and the specialist nurses were often the only source of reliable advice against which other sources compared unfavourably	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author**:** **Keaton, L** Country**: U.S.A**	To present the findings from a secondary analysis of email questions from adult caregivers of persons with stroke directed to a nurse specialist and members of an electronic (E)-rehabilitation team	Qualitative secondary analysis	13 First time caregivers were recruited and enrol from the rehabilitation centre from metropolitan Ohio and Michigan when care recipients were discharged.	Data collected from questions that caregivers asked nurses a qualitative data management program (QSR N 5) was used to enter, track, explore, code, and search narrative data	**Electronic (E) rehabilitation**	Caregivers were seeking new knowledge and learn caregiving by exploring facts about stroke and discussing experiences with family other caregivers and specialist nurse. Care givers were also interested in community resources and government services available to them.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes

First author: **Low, J.T.S** Country: **U.K**	To explore the impact of two methods of post-hospital stroke rehabilitation on both carers' perceptions of the health services offered and their quality of life	Qualitative study	27 caregivers were identified and recruited from the 140 stroke patients participating in the Dorset Stroke Study for this qualitative study at baseline, as another 13 were recruited at the six-month stage. Thus a total of 40 caregivers. .	Interviews were transcribed and content analysis carried out on transcripts using a coding frame and themes identified	**Domiciliary and day hospital**	Day hospitals provided carers with respite opportunities, the attendance of the stroke survivor at the day hospital provided opportunities for these carers to have time for themselves Domiciliary stroke teams provided carers with better educational opportunities to be involved in therapy, thereby increasing carers' confidence in supporting and encouraging stroke survivors with their rehabilitation. This supported findings that suggested that domiciliary therapists saw one of their functions as educating carers in the rehabilitation process. Domiciliary care was also perceived as being convenient to both carers and survivors. few carers felt that the day hospital provided better accessibility to a wider range of equipment and more space for therapy than was available with the domiciliary teams. One carer in particular felt that medical care in the day hospital would be better co-ordinated as all the doctors, nurses and therapists were based in the same building and so would have better communication with each other.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author: **Marzial, E** Country: **Canada**	To provide primary evidence for the efficacy of an Internet-based psychosocial/ educational intervention for family caregivers	Qualitative	Geriatrician from two participating hospitals identified and recruited 66 caregivers of relatives with moderate level disability from three forms of neurodegenerative disease	Internet-based video-conferencing group sessions analyzed todetermine reliable adherence to the treatment strategies, and also qualitative analyses of group-	**Caring for Others**	Most participant indicated that the Web site was easy to use. Most caregivers felt that sharing their experiences with the support group via videoconference was as helpful as meeting people face to face.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes;

			(Alzheimer's, stroke related dementia, and Parkinson's) that is 22 participants per disease group**.**	discussion themes.			10 Yes
First author**:** **Mores, G.** Country**: Canada**	To evaluate the content, format and resource materials of the FICSS program with 10–12 family caregivers of stroke survivors.	Mixed methods study	Program recruited 11 family caregivers of stroke survivors living within Central South Ontario, through advertisement in existing stroke recovery peer support groups and associations, community support agencies, hospital outpatient rehabilitation programs, regional and district stroke centres and the local media. Participants were eligible to be participate when they meet the inclusion criteria.	Focus groups feedback on all sessions and key themes identified.	**Program: Family Informal Caregiver Stroke Self-Management**	The results of the program evaluation suggest the program provides caregivers with tools, strategies and resources to better manage as caregivers Participants felt more hope and patience since attending the program. They stated that they learned valuable advocacy skills from the workshops and each other. Participants explained that the program informed them of available community services but, more importantly, provided the tools and strategies to self-manage and cope with the struggles of being a caregiver. They indicated that the program provided the opportunity for them to gain an alternative perspective and helped to improve their quality of life, as well as that of the stroke survivor Participants emphasized that the program should be offered earlier on in the caregiving experience, ideally between three and six months post hospital discharge of the stroke survivor,	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes

First author: **Pierce, L.L** Country: **U.S.A**	The purpose of this pilot study was to test the feasibility of providing Internet-based education and support intervention to caregivers living in rural settings, including caregivers' satisfaction with the intervention	Qualitative Studies	A convenience sample of 9 adult caregivers (>21 years of age) of survivors of stroke who had completed rehabilitation treatment, and were discharged to the home with caregivers who provided daily care and care recipient and caregiver lived together in a home setting.		**Caring Web**	Care givers use caring web to find information and receive care maintenance advice. They also use the information for emotional and social support with other care givers and nurse specialist	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes
First author: **Stewart, M. et al** Country: **Canada**	To measure the impact of the peer support intervention on caregivers' perceptions of their social support, burden, stress, and competence and the use of health-care services by stroke survivors	Qualitative studies	A convenience sample of 20 caregivers using the inclusion criteria were recruited from the Nova Scotia and New Brunswick through community sources professional organisations, practitioners, media and Non-governmental organizations. Inclusion criteria.	Transcripts of post intervention interviews coded subthemes and themes identified	**Peer visitors support.**	New caregivers described their demands including providing physical care, managing emotional and behavioural reactions of the stroke survivor as well as coordinating their health care needs. They were also concerned about managing the symptoms Caregivers regarded the peer visitors visits as supportive, bidirectional, appropriate and timely. Caregivers self-esteem increased and felt more capable. They also felt more confident in their role. Peer visiting reduced any doubts about the uncertainties they felt as caregiver.	1.Yes; 2.Yes; 3.Yes; 4.Yes; 5.Yes 6.Yes; 7.Yes; 8. Yes; 9.Yes; 10 Yes