A Thesis

entitled

Problems Reported by Daughters in the First Year of Caring for Parents with Stroke: A Secondary Data Analysis

by

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Submitted to the Graduate Faculty as partial fulfillment of the requirements for the Master of Science Degree in Nursing

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An Abstract of

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Purpose, Background/Significance. Women provide most of the unpaid care to family members within the home throughout the post-stroke recovery and rehabilitation process. Transitioning from the role of adult daughter to caregiver for a parent who recently had a stroke can be very stressful and unsettling. The purpose of this descriptive secondary data analysis is to examine problems reported by adult daughters in the first year of caring for a parent with a stroke.

Theoretical / Conceptual Framework. Guided by Friedemann’s framework of systemic organization, this analysis explores the problems encountered in the caring experience specific to daughters caring for parents. These women are driven by the desire for health and well-being, or congruence, whereas incongruence or poor health can be the result of problems in caring.

Method. With IRB approval, data from a randomized controlled trial were collected from 73 adult caregivers in Ohio and Michigan to examine the experience of caring for someone with stroke. Open-ended questions were included in bimonthly telephone interviews asking the participants to recall their experience of caring in the past two
weeks. For this secondary data analysis and with continued IRB approval, problems reported by only the adult daughters (n=13) were analyzed during two time periods (0-6 and 7-12 months) using Colaizzi’s rigorous method of content analysis.

**Results.** Three major themes emerged. The first theme of witnessing a parent’s condition centered on the adult daughter recognizing changes in her parents’ health condition and behavior and supporting them to retain what they had (Friedemann’s process dimension of *system maintenance*). This theme was consistently apparent throughout 12-months of caring. The second theme, balancing the challenges of the caregiver role, dealt with the struggles and adaption necessary for her new lifestyle as a caregiver (*system maintenance and individuation*). This theme was noticeable throughout the entire year, but more evident in the second 6-months. The final theme, feeling physically, emotionally, and mentally drained, involved problems associated with the overall exhaustion experienced by adult daughters (*system maintenance*). This theme was seen throughout the 1-year period, but more visible in the first 6-months of caring.

**Conclusions.** The findings provide specific, theory-based themes of the adult daughters’ problems during that year of caring that could lead to incongruence in their lives. The information gleaned may offer nurses and other healthcare providers a clearer picture of the problems these daughters experience, leading to more targeted interventions, increased support, and ultimately improved overall health/congruence for daughters.
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Chapter 1

Current research confirms that the high incidence and prevalence of stroke in the United States is leading to more in-home care and support guided by family caregivers. Research also highlights how the experiences of caregivers for stroke survivors ought to be further explored and understood by healthcare professionals to improve in-hospital and discharge education (Haley, Allen, Grant, Clay, Perkins, & Roth, 2009; Pierce, Steiner, Govoni, Thompson, & Friedemann, 2007; Pierce, Steiner, Khuder, Govoni, & Horn, 2009). Eighty-six percent of informal caregiving is for a relative and one-third (36%) of caregivers provide care to their own parent (The National Alliance for Caregiving and AARP, 2009). A majority of informal caregiving is carried out by women in the American society (Saban & Hogan, 2012; The National Alliance for Caregiving and AARP, 2009). Yet, a lack of knowledge related to the specific problems and needs of female caregivers of stroke survivors exists (Saban & Hogan, 2012). This secondary data analysis is aimed towards exploring the experiences of problems encountered by adult daughters caring for parents with stroke during that first year.

The problem statement, the purpose of the study, the theoretical nursing framework chosen to guide this study, and research question are presented in this chapter. The significance of describing adult daughters’ problems in caring for parents with stroke is also discussed. In addition, assumptions and limitations related to the theoretical nursing framework guiding this study are described. This chapter concludes with a summary.
Statement of Problem

Stroke is an acute medical condition affecting the neurological system and is the fourth leading cause of death in the United States (Centers for Disease Control and Prevention, 2014). About 795,000 Americans suffer from new or recurrent stroke each year, which translates into one stroke occurring every 40 seconds (Centers for Disease Control and Prevention, 2014). Over seven million people today in the United States have survived a stroke and these survivors commonly require special care and treatment (National Stroke Association, 2013a). While stroke is sudden and often traumatic, its results often affect both the person suffering a stroke and family members providing care (Lutz & Ellen, 2010). Informal caregivers, such as family members like adult children, are commonly delivering post-stroke treatment and care rather than formal caregivers such as nurses and therapists (The National Alliance for Caregiving and AARP, 2009).

These informal caregivers of survivors of stroke often assume the responsibility abruptly (The National Alliance of Caregiving and AARP, 2009). The shift from the usual parent-child relationship after a parent suffers a stroke can be dramatic and surprising (Heart and Stroke Foundation of Canada, 2010). There are emotional, physical, and psychological ramifications of taking care of a person with a long-term disability (Gaugler, 2010). This new role tends to be overwhelming, and can cause the development of burden, stress, depression and may even affect the physical health of the family caregiver (Lutz & Ellen, 2010). Past literature has been devoted to the exploration of problems accompanying the newly adopted caregiver role by family members (Haley...
et al., 2009; Pierce, Steiner, Hicks, & Holzaepfel, 2006; Pierce et al., 2007; Pierce, Thompson, Govoni, & Steiner, 2012; Saban & Hogan, 2012). Females are responsible for the majority of informal caregiving in the United States (Saban & Hogan, 2012; Saban, Mathews, Bryant, O’Brien, & Janusek, 2012). However, there are a limited selection of nursing research completed and published focusing on gender-specific caregiving experiences, specifically adult daughters (Saban & Hogan, 2012; Saban et al., 2012; Simpson & Carter, 2013).

Authors of recently published research recognize the burden that comes with the task of caregiving (Haley et al., 2013; Pierce et al., 2007; Saban & Hogan, 2012). Caregiver role development for adult daughters is necessary but requires education and influence from a professional with expertise in the area (Pierce et al., 2007). Retrospective evaluation of the adult daughter caregivers’ viewpoints and personal experiences with problems encountered in the first year of caregiving can provide direction for supportive educational interaction by nursing and therapeutic professionals. This secondary data analysis focuses on problems adult daughters face in caring for parents with stroke. The prevalence of women caregivers has been established, yet there is relatively little research focuses on adult daughter caregivers of stroke survivors (Saban & Hogan, 2012).

Further research is needed to help bridge the lack of knowledge regarding gender-specific caregiving experiences. Recognition of the unique problems faced by adult daughters caring for a parent with stroke may help health care professionals better
understand and support caregivers to meet their needs. The information explored in this secondary data analysis will allow healthcare professionals to improve and change their existing methods of intervention and support for adult daughters embracing the new role of the caregiver in the first year.

**Statement of Purpose**

The purpose of this descriptive secondary data analysis is to examine the problems experienced by adult daughters in the first year of caring for parents who recently experienced a stroke.

**Nursing Conceptual/Theoretical Framework**

Friedemann’s framework of systemic organization (1995, 2014) guides this secondary data analysis. This conceptual approach focuses on culture, family health and adaptation to change (Friedemann, 2014). According to Friedemann, human behaviors are driven by the desire of health and well-being, or congruence, while incongruence is the result of dealing with problems and experiencing anxiety that results in poor health (Friedemann, 1995). This framework suggests that the center of systems, such as adult daughter caregivers, pursue four separate targets: stability, growth, control, and spirituality (Friedemann, 1995, 2014).
Stability signifies system survival and is described by Friedemann (1995) as the core and identity of a person. Life patterns, attitudes, and values are a part of stability; followings rules and traditions allows an individual to ward of anxiety and disturbing influences (Friedemann, 1995). Growth is experienced by the new caregiver and although often painful, is believed to be a necessary change or reconsideration of set values and priorities (Friedemann, 1995). When individuals are challenged and halted in their environment, perhaps by quickly falling into the role of caregiver, incongruence results and adjustments must be made as a part of the growth process. Friedemann (1995) describes control as a force influenced by “vulnerability and helplessness” (p. 7), which is a common feeling described by caregivers. In order to reduce anxiety, humans attempt to regulate or control their surroundings, thus producing more comfortable and desirable changes and outcomes (Friedemann, 1995). Spirituality is considered an emotional and intellectual outlet as well as a defense against helplessness by Friedemann (1995). Adjusting and coping with the compromised health state of a parent and the new role of caregiver leads to the caregiver daughter discovering meaning and new purpose. Individuals’ spirituality can reveal inner peace in hopes of leading to a sense of congruence or well-being (Friedemann, 1995, 2014).

Friedemann’s framework of systemic organization (1995, 2014) encompasses the family system process and the human’s behaviors and adaptations when faced with change. This theory is highly applicable to the adult daughter caregiver experiences with problems encountered in caring for their parent with stroke in this secondary data analysis.
Research Question

What are the problems expressed by adult daughters in the first year of caring for parents with stroke?

Definition of Terms

Parent with Stroke.

Conceptual definition. A stroke is a medical condition experienced by the parent survivor, which may necessitate home rehabilitation treatment and care by family members, or in this case, adult daughters (National Stroke Association [NSA], 2013a). This need for care may result in incongruence or poor health (problems, anxiety, unsettling feelings, stress, etc.) in the life of the parents with stroke and their adult daughter caregivers (Friedemann, 1995).

Orientational definition. Stroke is defined in this study as a specific medical condition that occurs when “a blood vessel that carries oxygen and nutrients to the brain is either blocked by a clot or bursts (or ruptures)” (American Heart Association [AHA], 2013, para. 2). Consequently, the brain cannot receive adequate blood and oxygen and results in various sensorimotor deficits (AHA, 2013, p.1). For this secondary data analysis, adult daughter caregivers self-reported that they were caring for a mother and/or father with stroke in the parent study.
Problems.

**Conceptual definition.** The caregiver’s problems are considered to be incongruence from their viewpoint guided by Friedemann’s (1995) framework of systemic organization. Incongruence can lead to well-being or health if it reveals a path toward congruence that results in freedom from life’s problems (Friedemann, 1995).

**Orientational definition.** This secondary data analysis focuses on expressed problems by daughters caring for a mother and/or father with a new stroke. For the parent study, two specific questions were asked bimonthly for a 1-year period to prompt a recall of events: 1) What was the biggest challenge? 2) What were other problems? These caregivers reported these problems over a one-year time frame in the parent study during interviews every two weeks.

**Adult Daughter Caregivers.**

**Conceptual definition.** An adult daughter caregiver is a female who has acquired the role of caregiver and provides care to her parent with stroke in the first year following diagnosis and hospitalization. In her new role as caregiver, the daughter confronts problems or experiences incongruence but aims at reaching congruence or health and well-being identified by Friedemann’s framework (Friedemann, 1995).
**Orientalational definition.** In this secondary data analysis, adult daughter caregivers were females over the age of 18 who have transitioned into the role of informal caregiver in the home environment of a parent who had recently experienced a stroke. Adult daughters were participants in the parent study from which these data were extracted.

**Significance**

Over seven million people in the United States have survived a stroke (NSA, 2013b) and research shows a majority of stroke survivors (80%) return home after initial in-hospital treatment and are cared for by informal caregivers, such as family members including adult children (Washington Hospital Healthcare System, 2010). The acute onset of stroke subsequently results in a rapid role change of family members who provide post-hospital care for the survivor. In 2009, 65.7 million members of the adult population in the United States were providing informal care to someone who was ill, disabled, or aged; 66% of these caregivers were female (The National Alliance for Caregiving and AARP, 2009).

The typical family caregiver is a 49-year-old married and employed woman caring for her widowed 69-year-old mother who does not live with her (The National Alliance for Caregiving and AARP, 2009). More than 37% have children or grandchildren under the age of 18 living with them (The National Alliance for Caregiving and AARP, 2009). Adult daughters experience the effect of the “sandwich generation”
and therefore are caring for both their own children and their parents (Pierret, 2006). Often, adult daughters struggle to adapt to the parent-child role reversal as 36% of women caregivers handle the most difficult tasks of caregiving such as bathing, toileting, and dressing (The National Alliance for Caregiving and AARP, 2009). Weekly, female caregivers spend an average of 21.9 hours on direct care and female caregivers report less use of caregiving assistance (The National Alliance for Caregiving and AARP, 2009).

Female caregivers’ own health is affected by the caregiver role, as well. A recent study stated female caregivers reported their declining health and high stress levels secondary to their strenuous caregiving roles (The National Alliance for Caregiving and AARP, 2009). As previous statistics showed, many adult daughters continue to work and 70% of caregivers suffer from work-related difficulties due to their dual caregiving roles (The National Alliance for Caregiving and AARP, 2009). Specifically, female caregivers are more likely to make work arrangements such as taking a less demanding job, giving up working entirely, and losing job-related benefits (The National Alliance for Caregiving and AARP, 2009). The value of unpaid family caregiving will only continue to grow (Coughlin, 2010) and financial costs associated with caregivers are a significant factor of caregiver burden (Lai, 2013). The National Alliance for Caregiving (2009) reported 47% of working caregivers had to use all or most of their savings secondary to an increase of caregiving expenses and one in five family caregivers had to move into the same home with their loved ones to cut expenses. Female family caregivers are 2.5 times more likely to live in poverty and five times more likely to rely on Supplemental Security Income (Donato & Wakabayashi, 2005).
These statistics highlight how adult daughters caring for a parent after stroke are at risk for experiencing problems in caring and immense caregiver burden. Adult daughters bear the pressure and anxiety of informal caregiving as they struggle to balance their own lives, take care of their own family and self, find a work-life balance, and adapt to the new role and all its accompanying responsibilities. With consideration of the emotional, physical, mental, and financial stress endured by adult daughter caregivers, recognition of the importance of caregiver intervention and education by the healthcare professional is crucial (Gaugler, 2010; Pierce et al., 2007; Saban & Hogan, 2012). Nurses are likely the last individuals to encounter the patient and family prior to discharge from hospitals after a stroke and are valuable resources for the caregivers. Understanding the unique experiences of adult daughter caregivers of stroke survivors is important for nurses to effectively manage care and provide needed support and guidance.

Assumptions

Grove, Burns, and Gray (2013) define assumptions as statements that are taken for granted as true and are accepted as truth although scientific testing has never been conducted. There are several assumptions related to this study on the problems reported by adult daughters caring for a parent with stroke related to Friedemann’s (1995, 2014) framework of systemic organization that guides this study. As cited by Friedemann’s framework (1995), it is an accepted truth that congruence is reflected and detectable in each human, nature, and other systems but cannot be scientifically explained (Friedemann, 2014). During this secondary data analysis, it is assumed the adult daughter
strives for health and well-being (congruence) in her own life while maintaining her role as family caregiver. The state of optimal health and well-being (or congruence) is considered ideal while incongruence or poor health, although less ideal, is an unavoidable reality of life (Friedemann, 2014). With analysis of function of individuals, social, and environmental systems, this conceptual framework emphasizes the interaction between stability, growth, control, and spirituality (Friedemann, 1995, 2014). It is assumed for this secondary data analysis that human behaviors are driven by the desire for health and well-being, or congruence (Friedemann, 1995, 2014). Incongruence caused by caregiving problems can also produce health and well-being as incongruence can lead to problem-solving and subsequent congruence (Friedemann, 1995; Pierce et al., 2007).

**Limitations**

Weaknesses in a study that restrict credibility and transferability of findings are considered limitations (Grove et al., 2013). The main limitation of this study is related to conceptual definitions and relationships. The specific problems and experiences by the adult daughters and the relationship between the daughters and parents have not been directly addressed in Friedemann’s (1995, 2014) theory; therefore, transferability of the findings is reduced. While the caregiver experience is the backdrop for the study, the research question regarding the experiences of problems encountered in caring for parents with stroke by adult daughter caregivers is not directly linked to concepts of Friedemann’s theory. Therefore, this limitation proposes a threat of transferability of findings. Like other nursing frameworks, Friedemann’s (1995, 2014) framework is a
theoretical approach that views the world in only one way, as and such, this view can be narrow.

**Summary**

Stroke is an acute, but common, event that often leads to a dependent need for in-home caregiving. Past research highlighted how women are often the most likely to provide care for the stroke survivor (The National Alliance for Caregiving and AARP, 2009; Saban & Hogan, 2012). The identification and analysis of caregiving problems experienced by adult daughters provides further enlightenment and useful information and will hopefully prompt further research. The importance of nurses and other health care professionals understanding aspects of the caregiver phenomena in undeniably valuable and can lead to better practice and health outcomes for the patient and caregiver.

In this chapter, the domain of inquiry is identified. This current secondary data analysis was guided by using Friedemann’s (1995, 2014) Framework of Systemic Organization. Conceptual and orientational definitions for the key concepts in the research question are linked to this framework. The significance of the study is outlined in this chapter. In Chapter 2, Friedemann’s (1995, 2014) framework is expounded upon and a diagram of the framework is presented. Pertinent research literature is also examined related to this inquiry in Chapter 2
Chapter 2

Literature

In Chapter 1, an introduction to the research topic was presented: problems reported by adult daughters in the first year caring for a parent with stroke. Nursing theory helps explain phenomena among individuals, families, and communities (Grove et al., 2013). Friedemann’s (1995, 2014) framework of systemic organization as the theoretical framework for this study is described in this chapter. Synthesis, clustering, and interrelating ideas from existing research literature in combination with nursing theory allows the investigator to grasp and formulate concepts otherwise unnoticed (Grove et al., 2013). Also in this chapter is an integrated review of previously published, pertinent research studies and their findings that contribute to the body of nursing knowledge about the proposed purpose of this data analysis: to explore the problems reported by adult daughters in the first year of caring for parents with stroke.

Nursing Theoretical Framework

The concept of the family dynamic has been a central theme of nursing since even before the time of Florence Nightingale and still exists in the theoretical world of nursing today (Friedemann, 1995; Pierce et al., 2007). Utilizing concepts from the well-known nursing metaparadigm (environment, person, health), Marie-Luise Friedemann created the Framework of systemic organization to further include the ever-complex dynamics of family and family health in order to better explain the systemic, social, and
environmental functioning of individuals and relationships (Friedemann, 1995). Friedemann (2014) perceives the world in systems: environment, individuals, and family systems. It is important to understand that each system is constantly striving towards health and congruence. “The state of systems being attuned to each other in their rhythms and patterns in a way that energy can flow freely within and between systems is called congruence” (Friedemann, 1995, p. 4). In the event that the energy flow is blocked, incongruence is experienced (Friedemann, 1995). This incongruence known as disharmony and tension is unavoidable between interacting systems. For this reason, congruence is ideal, not reality (Friedemann, 2014).

Friedemann (1995) outlines the many propositions of the environment, person, health, family, family health, and nursing that will be addressed in relationship to the systematic process for this analysis. The environment is comprised of everything outside of the system in focus (Friedemann, 1995). For this analysis, the system in focus is the caregiving role. Friedemann (1995, 2014) propositions about the concept of ‘person’ include that the human body limits human perception, humans have the ability to foresee death, humans experience incongruence or poor health as anxiety, human create an artificial environment in order to decrease their vulnerability, and culture is an ever-changing life pattern. Never fully present or absent, health is the congruence between the individual’s system, subsystems, and the universal order and may or may not occur in the physical presence of disease (Friedemann, 1995). Without health, Friedemann (1995) states anxiety will result from system incongruence; well-being is a sign of health. Friedemann (1995, 2014) propositions that family is a unit with structure and
organization that interacts with its environment. Family includes interpersonal subsystems that have distinct relationships with family members, emotional bonds, and common responsibilities. The term ‘family’ is not limited to those who biologically related or live in single household (Friedemann, 1995, 2014). Family health is the presence of strategies, satisfaction from all members, positive environmental feedback, low anxiety that results in achieving and maintaining congruence in the family in response to changing systems (Friedemann, 1995).

**The system targets.** A balanced state of equilibrium or congruence, within a system is established by the fluid interaction of the four separate targets: stability, growth, control, and spirituality (Friedemann, 1995, 2014).

**Stability.** Stability is described by Friedemann (1995) as the core and identity of a person encompassing patterns, character, attitudes, and values. When stability is accomplished, one is able to challenge his or her own opinions and attitudes as long as the change is aligned under basic values (Friedemann, 1995). For example, a basic underlying value for an adult daughter may be to protect her parent from harm. This core value will be challenged but still followed when advocating for her parent at a doctor’s appointment. Following these rules and traditions but also adjusting his or her current practice allows an individual to ward off anxiety and disturbing influences (Friedemann, 1995).
**Growth.** Growth is the necessary change or reconsideration of set values and priorities that can occur slowly over time or rapidly in a time of crisis (Friedemann, 1995). When an individual is challenged, incongruence is the result. At this time, adjustments must be made and one must reconsider or re-examine their beliefs and develop new behaviors, attitudes, and values (Friedemann, 1995). An adult daughter who is accustomed to her “regular” way of life may run into an abrupt change of lifestyle after embracing the role of caregiver. At this point, her values and behaviors may be re-examined and reprioritized in order to accommodate her new role.

**Control.** Friedemann (1995) describes control as a force influenced by “vulnerability and helplessness” (p. 7) in attempt to regulate or control their surroundings, thus producing comfort and more preferable outcomes (Friedemann, 1995). This force or control facilitates the reduction of anxiety and may be experienced by the adult daughter when faced with fear of safety for her parent. For example, if the daughter’s parent is prone to medication errors secondary to a cognitive deficit post stroke, she may turn to a visiting nurse to help administer medications in a timely and safe manner.

**Spirituality.** Spirituality is a defense against helplessness (Friedemann, 1995). Individuals allow their spirituality to reveal inner peace in hopes of leading to a sense of congruence or well-being (Friedemann, 1995). Friedemann (1995) also refers to spirituality as a sense of belonging, acceptance, unit, and respect with other systems. The
adult daughter may seek out a support group for caregivers of stroke survivors in order to connect and establish relationships with those enduring similar experiences.

**The process dimensions.** There are four process dimensions: system maintenance, coherence, individuation, and system change (Friedemann, 1995). Friedemann (1995) cites how the dimensions include behaviors that are utilized to reach the abstract system targets and strive for congruence. These dimensions are illustrated in the everyday life of the adult daughter caregiver and her family process in this secondary data analysis.

**System maintenance.** System maintenance, directly related to the system targets of stability and control, encompasses actions and behaviors that are grounded in tradition, personal roles, rules, patterns, rituals, decision-making, power structure, and division of labor (Friedemann, 1995). Consideration of the adult daughters’ well-being (rest, sleep, good nutrition, recreation) is also incorporated in system maintenance (Friedemann, 1995).

**System change.** System change is a conscious act and occurs when the caregiver feels pressure from within or from the environment (Friedemann, 1995). Lifestyle behaviors, replacement of old values, behavior patterns, new information integration, and adjustment of established beliefs throughout the caregiving process are all major alterations influenced by system change (Friedemann, 1995). For example, rather than becoming upset with her mother, the adult daughter over time decides to integrate
information from a support group or online interventions on how to encourage her mother to consistently partake in daily exercise. The targets of control and growth are affected when system change occurs (Friedemann, 1995).

**Coherence.** The joining of the caregiver’s subsystem into a whole system secondary to emotional bonding and caring relationships that occur among the caregiver, the stroke survivor and other friends and family members is coherence (Friedemann, 1995). This dimension also incorporates the caregiver’s self-perception and acceptance of self with consideration to self-esteem, personal identity, self-confidence, and sexual identity (Friedemann, 1995). When an adult daughter reaches out and unites with other family members to brainstorm regarding best caregiving techniques, she is experiencing coherence. Stability and spiritually are achieved in the coherent caregiver (Friedemann, 1995).

**Individuation.** Individuation targets spirituality and growth as it focuses on adjustments to personal rhythms and patterns while also encompassing others of similarity (Friedemann, 1995). For example, adult daughter caregivers embrace this process by participation in caregiver support groups, focusing on religion or spirituality, or learning new concepts about stroke caregiving by various methods. Communication among individuals and family leads to examination of new values and thus “individuation leads to growth, but growth cannot happen in isolation” (Friedemann, 2004, p. 13).
**Synthesis of the framework.** Friedemann’s (1995, 2014) framework of systemic organization is a fitting guide for this analysis. The encompassing components of this framework are utilized to illustrate the inner core or meaning stemming from the problems reported by adult daughters caring for a parent with stroke. Problems reported by participants might reveal the daughters’ own growth and adaptation as a new caregiver and show how adult daughters’ lives can be forever influenced and changed. It must be noted that obtaining congruence is a constant balancing act and is never fully obtained. As Friedemann (1995) states, the caregiver is working toward stability, control, growth, and spirituality. In order for these targets to become a reality and in order to find balance, behaviors of the four process dimensions are utilized to reach the system targets (Friedemann, 1995). The caregiver’s need to change both attitude and beliefs to facilitate growth, role development, and new lifestyle patterns is appreciated within Friedemann’s theory.

Whereas health equals well-being and congruence, physical disease or condition of a family member, such as a stroke, presents as a deficiency and causes problems for the caregiver and results in incongruence or poor health (Friedemann, 1995). The caregiver’s ultimate goal is to adjust to inevitable changes while simultaneously trying to maintain the system processes (Friedemann, 1995; Thompson et al., 2004). Figure 1 is the systemic process by Friedemann (1995, 2014). In times of crisis, the adult daughter may experience unsettling feelings and anxiety, making it necessary for adjustments within the system targets to help re-establish balance.
Figure 1. The Systemic Process (Friedemann, 1995, 2014).

**Review of Research Literature**

The research literature related to the topic of adult daughters caring for parents with stroke is sparse and indicates need for further study. A summary of previously published and relevant research literature is organized into two categories: 1) caregivers’ experience related to problems in caring for survivors of stroke 2) experiences related to problems in caring by females.
Caregivers’ experience related to problems in caring for survivors of stroke.

Research studies have addressed the concepts of the caregiver experience and identified problems of caring specifically about stroke. Caregivers of stroke have been recognized as a unique group secondary to the circumstances and challenges that accompany the act of caregiving for members of the stroke population. Eight qualitative and quantitative studies have focused on the post-stroke experience from the caregivers’ point of view.

Pierce et al. (2006) conducted a preliminary study, which examined the problems experienced by new caregivers of persons with stroke guided by Orem's (2001) Self-Care Deficit theory. Researchers investigated the feasibility of a web-based intervention and explored the experiences of caregivers. Adult caregivers were recruited from rehabilitation centers in Ohio and Michigan. Participants ($n=9$) were enrolled in an online Web-based intervention project for three months. Data collection consisted of baseline and bimonthly telephone interviews that prompted the caregivers' recall of problems and experiences related to caregiving. Researchers ensured increased reliability of data collection by asking the same questions for each participant by a trained interviewer. Demographic data were collected during the baseline interview which included gender, age, ethnicity, and employment. Each participant was asked the following question: "Did you have any problems in caring for your loved one during the past two weeks? If yes, please tell me about each problem." Narrative data analysis was completed by strict utilization of participants' answers to questions without bias from of the investigators secondary to eidetic reduction or bracketing. Sixty-eight problems were reported in regards to caregiving and were merged into problem themes. The main
problem themes were 1) having independence issues, 2) dealing with emotions, 3) living with physical limitations, 4) managing co-morbid conditions, 5) balancing it all, 6) participating in physical therapy, and 7) having sleeping issues. Four of Orem's universal self-care requisites were related to the identified general problems. Overall, problems decreased over time except for "balancing it all" which increased over time. Researchers concluded healthcare professionals could apply findings of this study and tailor interventions and support of caregivers, focusing on the self-care needs identified. Limitations of this study included limited transferability. Applicability to specific caregiver populations is subjective and is a decision of the reader (Pierce et al., 2006).

Pierce et al. (2007) completed a descriptive study that identified the problems of caregivers (n=73) of survivors during the first year post stroke which served as the parent study for this secondary data analysis. Participants were recruited from rehabilitation facilities in northern Ohio and southern Michigan from May 2002 to December 2004. Trained interviewers conducted bi-monthly telephone interviews, which consisted of open-ended questions to prompt recall of events and elicit the caregivers’ experiences. Specific questions were: 1) "What was not working well?" 2) "What were other problems?" 3) "What does this mean to you?" Narrative interview data and email data were entered into a qualitative software management program called QSR N 5 (Richard, 2000) and analyzed using Colaizzi's rigorous method of data analysis. Friedemann’s (1995) framework was used for theoretical guidance while data analysis was conducted using content analysis. Results consisted of 2,455 problems. The top three themes for caregivers’ problems were: 1) being frustrated in day-to-day situations, 2)
feeling inadequate and turning to others for help, 3) struggling and looking for “normal” in caring. Timeline progression of problems at 3, 6, 9, and 12 months were also identified. More problems were revealed in the first three months and a sense of the “new normal” way of life by month 12. Researchers noted how understanding problems experienced by caregivers was imperative and facilitated improvement of healthcare professional intervention for the caregiver, which is often ignored (Pierce et al., 2007). Limitations identified by the researchers included transferability of findings secondary to lack of diverse location and cultural groups and lack of qualitative outcome data analysis to confirm applicability of clinical strategies (Pierce et al., 2007).

Later, Pierce et al. (2012) examined the dimensions of new family caregivers’ (n=73) emotional strain secondary to caring for persons with stroke via a secondary data analysis from the above mentioned parent study. Half of the participants for this study were randomly assigned to partake in a Web-based intervention for education and support (n=36) while the other half of participants were the control group or non-Web users (n=37). Basic demographic information was collected from each participant including age, gender, and ethnicity. Data about emotional strain in caring was gathered via e-mail messages and interview data. E-mail messages consisted of discussion between caregivers and the support group facilitator concerning emotional strain. Trained telephone interviewers collected narrative interview data every two weeks using open-ended questions regarding problems in caring, as mentioned above for the parent study. Three themes emerged from these data: 1) being worried, 2) running on empty, 3) losing self. Trustworthiness of the data and interpretations were enhanced by using trained
interviewers who attended presentations by Friedemann on her framework. Additionally, the vast amount of data collected from the telephone interviews and emails added to trustworthiness of overall findings. All researchers/authors participated in the research process and involved in content clarification, refinement, and concurrence enhanced data interpretation. A majority of the caregivers in this study were women and therefore can be applied to the subject of this secondary data analysis regarding the problems of adult daughters caring for parents with stroke. The findings of this study provided information for healthcare professionals involved with family members of stroke patients who are newly taking over the role of caregiver. Understanding the occurrence and significance of emotional strain, or incongruence helps the healthcare provider see the viewpoint of the caregiver and provides further direction for support and education intervention. Researchers claimed many limitations of this study: limited transferability, limited number of participants having access to e-mail, and differences in the structure and format of the two instruments (e-mail and telephone interviews) provided differences in responses and discussion (Pierce et al., 2012).

A longitudinal, mixed method descriptive study guided by a stress and coping model, identified types and frequency of caregiving problems and associated stress and coping effectiveness (King, Rouke Ainsworth, Ronen, & Hartke, 2010). Caregivers participated during the first four months of caregiving during intervention sessions. The sample \( n=58 \) consisted of predominantly Caucasian females and qualitative findings were based on descriptions of problems provided during taped interview sessions with trained interviewers. Data also resulted from caregivers’ numeric ratings of stress and
coping effectiveness ranges which provided quantitative results. The following measures were used: stroke survivor function was measured using the Functional Independence Scale (Granger, Hamilton, Sherwin, 1986); coping variables were rated on a five point Likert scale (Toseland, Rossiter, & Labrecque, 1989); problem-solving coping was measured using the Social Problem Inventory-SPSI-R form (D'Zurilla, Nezu, & Maydeu-Olivares, 1996); depressive symptoms were measured using the CES-D measure (Radloff, 1977); life perception was measured using the Bakas Caregiving Outcomes scale (Bakas & Champion, 1999); anxiety was measured using the Profile of Moods Scale short form (McNair, Lorr, Droppleman, 1992); caregiver preparedness was assessed using the Preparedness for Caregiving Scale (Archbold, Stewart, Greenlick, & Harvath, 1990); family functioning was assessed using the General Functioning Scale of the McMaster Family Assessment Device (Epstein, Baldwin, Bishop, 1983). Content analysis and Pearson correlation coefficients were computed to examine relationships between the stress themes and demographic data and survivor function. Early problems were those reported during the first four interview sessions and later problems were reported during the final six sessions. Three problem-related themes emerged: interpersonal disruptions, sustaining the self and family, and stroke survivor functioning. Emotional distress described as either anxiety or depression was significant (p<0.05) to the stress level of each problem theme. Internal consistency was adequate (0.72-0.85) and validity was supported by correlations with depression and anxiety. This study showed how life disruptions, such as adjusting to the caregiver role, occur instantly and results in problems and stresses. The range of problems themes identified in this study show how family education and discharge preparation focusing exclusively on the needs of informal
caregiving is currently short-sided. Authors identified the main limitation of this study: problem identification took place during a problem-solving intervention session and therefore may have affected problem perception (King et al., 2010).

A prospective epidemiological study was performed from 2005-2008 that analyzed the prevalence and stressfulness of stroke-related problems (Haley et al., 2009). This research addressed the stroke-related problems reported by a convenience sample of community-dwelling stroke family caregivers (n=75) who participated in the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study. Through comprehensive telephone interviews at 8 and 12 months after the stroke, stroke patient problems (ADLs, memory, emotional, communication, and motor and sensory impairments), and caregiver stressfulness appraisal were obtained during the initial study. A 28-item instrument was used during the telephone interview consisting of demographic data, “yes and no” questions, behavior problem checklists, Likert scales, and depression scales. Demographic data and study data were analyzed using mean and standard deviation or frequencies and percentages for nominal values. The most prevalent caregiver problems identified were mood including depression, loneliness, and anxiety, memory, and lack of physical care (bowel control). Conclusively, researchers found health care clinicians should highly prioritize the assessment and intervention of caregivers to help identify lack of knowledge in caregiver education, training, and support. Researcher reported limitations of this study included lack of minority representation, small sample size, reliance on caregiver report, cross-sectional nature of
data, and the measure of stroke patient impairment and problems was a brief composite and some areas of impairment were not sampled (Haley et al., 2009).

A systematic review authored by Gaugler (2010) determined whether duration of family care was a significant predictor of stroke caregiving outcomes (caregiver stress and mental health) and if longitudinal differences occur in stroke caregiving over time. With approval of the IRB, this longitudinal review searched numerous databases (MEDLINE 1966-2009, CINAHL 1982-2009, PsycINFO 1950-2009) to obtain relevant research articles; 117 studies were selected based on eligibility criteria. Data extraction occurred during January and February of 2009. Data synthesis occurred for each of the three study tests (cross-sectional quantitative, longitudinal quantitative, and qualitative). Significance was determined with positive, negative, or non-significant effects (p>0.05). The cross-sectional quantitative studies revealed that the duration of care did not emerge as a significant predictor of stroke caregiving outcomes. Longitudinal quantitative studies revealed that caregiver stress, depression, and subject health measures did not significantly change. A more dynamic stroke caregiving process was revealed in the qualitative studies. Gaugler (2010) concluded more rigorous research regarding the longitudinal ramifications of stroke caregiving needs to be performed. The information gained from this study provided health care practitioners with stronger evidence regarding caregiving experiences and problems to help guide clinical interventions and support. Limitations of this study included a single-author extraction and synthesis of data and multiple reviews would have produced further reliability. There is a possibility that additional stroke and duration of care studies were not included. Additionally,
although this review did include three different types of studies, an in-depth meta-
synthesis of the qualitative studies was not performed and may have provided additional
guidance for longitudinal implications (Gaugler, 2010).

A study performed by Grant, Glandon, Elliot, Giger, and Weaver (2004) identified the problems experienced by caregivers of stroke survivors ($n=22$) during the first month post discharge. This study was part of an original randomized trial that examined the impact of problem-solving telephone partnerships on caregiver outcomes. The intervention consisted of an initial interview followed by three weekly telephone contacts. Trained telephone interviewers inquired about the three most frequent or most stressful caregiving problems. The most common problems identified were safety, difficulty in managing activities of daily living, and cognitive, behavioral and emotional changes of stroke survivors. This study offered valuable information that can be used by healthcare professionals to better understand the most common caregiving problems to allow for better pre-discharge instruction and education. Limitations of this study exist. The majority of participants for this study were Caucasian which limited generalizability secondary to lack of ethnic representation. In addition, the severity of stroke symptoms were not considered for differential comparison of results which could have had an effect on overall reported problems by caregivers (Grant et al., 2004).

In 2013, Gonzales and Bakas conducted a secondary data analysis and explored the demographic and theory-based factors associated with behaviors of the stroke survivor identified by family caregivers. These behaviors were found to be bothersome
and in some cases caused problems for the caregivers. This research study used baseline data from four previous studies and included a combined sample of 96 family caregivers of stroke survivors (Bakas, Champion, Perkins, Farran, & Williams, 2006; Bakas, Ferran, Austin, Given, Johnson, & Williams, 2009a; Bakas, Ferran, Austin, Given, Johnson, & Williams, 2009b; Bakas, Kroenke, Plue, Perkins, & Williams, 2006). Participants were provided with various tools 2 months after their family members’ discharge from the hospital. These previous studies utilized the Demographic Data Form to measure demographic factors and the Revised Memory and Behavior Problems Checklist (RMBPC) to measure survivor behaviors (Teri, Truax, Logsdon, Uomoto, Carit, & Vitaliano, 1992). Other well-validated scales were used to measure theory-based factors such as the 15-item Oberst Caregiving Burden Scale, the Appraisal of Caregiving Scale Threat Subscale and the 9-item PHQ-9 Depressive Symptoms scale (Spitzer, Williams, Kroenke, Homyak, & McMurray, 2000). Associations between demographics and perceived bothersome behaviors were analyzed using t-tests, ANOVA and Pearson r. This secondary data analysis concluded that 35% of the variance in bothersome behaviors described by family caregiver depressive symptoms, task difficulty, life changes, and threat appraisal. Results helped identify the need for nursing intervention to help reduce bothersome behaviors. Limitations of this study included small size and lack of generalizability secondary to limited racial and ethnic representation (Gonzales & Bakas, 2013).

Experiences related to problems in caring by females. Past research has shown the role of the informal caregiver is most likely embraced by women including wives and
adult daughters (Kwak, Ingersoll-Dayton, & Kim, 2012; Saban & Hogan, 2012; The National Alliance for Caregiving and AARP, 2009). However, relatively little gender-specific research regarding problems of caregiving has been conducted in recent literature (Saban & Hogan, 2012). The two studies discussed address the experiences of female caregivers of stroke survivors, gender differences in regards to caregiving, and role comparison between wife and adult daughter. Although minimal in amount, two relevant studies were applicable to the dynamic picture of female-specific caregiver experiences and problems in caring for parents with stroke.

Saban and Hogan (2012) completed a descriptive qualitative study that described the experience of females caring for an adult family member who had experienced a stroke in the previous year. Recruited nationally via recruitment flyers distributed at caregiver support groups, social networking sites, and other neurological outpatient clinics in the Midwest, 48 females were enrolled in this study. Thirty-nine percent females were daughters of the care recipient (n=18). Participants received packets in the mail including a socio-demographic form and a questionnaire containing open-ended questions prompting the exploration of the caregiver experience and coping mechanisms in the first year after the stroke. Analysis of the open-ended questions was conducted by constant comparative methods. Four key categories emerged in this study: 1) losing the life that once was, 2) coping with daily burdens, 3) creating a new normal, 4) interacting with healthcare providers. Other aspects of these three themes included: coping with changed relationship, feeling overwhelmed, missing personal time, facing an uncertain future, financial strain, needing support from friends and family, adapting to new reality,
being dissatisfied with health provider care, and needing coordinated care. The findings of this study emphasized how female caregivers of stroke survivors grieve their previous life routine and truly struggle to cope with family and work life while trying to maintain a relationship with health care providers. Health care professionals must recognize this struggle, appreciate the effort from female caregivers, and provide support and resources to better meet their caregiving needs. This study concluded women caring for stroke survivors have unique needs of which healthcare providers can tailor their interventions, support, and education. Researchers in this study acknowledged the primary limitations of this study including usage of self-report written responses and a limited sample variability as the sample consisted of Caucasian, well-educated participants (Saban & Hogan, 2012).

Based on the stress process model, Kwak et al. (2012) examined the relationships among care recipient impairment, family conflict, and caregiver stress with a focus on the caregivers’ gender. A nationally representative sample of adult child caregivers (n=861) participated in surveys and measures. Results revealed that as care recipients impairment became more severe, caregivers experienced more family conflict and stress. The relationship between care recipient impairment and family conflict was stronger for sons than compared to caregiving daughters. The stress process was found to be similar between sons and daughter caregivers. This study contributed to knowledge regarding gender-specific concerns and reported caregiving problems, such as stress, which allow nurses and healthcare professionals to tailor interventions to alleviate stress that accompanies the role of adult child caregiver. Limitations of this study included using a
cross-sectional design, lack of longitudinal data, and the fact that the survey did not address the role of care receiving parents with respect to family conflict, which usually contributes to diminishing family conflict (Kwak et al., 2012).

**Synthesis of Research Literature**

The research presented in this chapter described problems related to stroke patients and experiences of specifically adult daughters in the caregiving role. Combining these two sections of previous research, a better understanding can be synthesized in regards to the topic of this secondary data analysis.

Eight studies identified the experiences including the problems in caregiving of stroke patients (Gaugler, 2010; Gonzales & Bakas, 2013; Grant et al., 2004; Haley et al., 2009; King et al., 2010; Pierce et al., 2007; Pierce et al., 2006; Pierce et al., 2012). When a family member abruptly transitions into the newfound role of caregiver of a stroke survivor, past literature suggests lifestyle and behaviors change. Several studies examined the impact of problems encountered during caregiving such as stress, depression, anxiety, sleeping issues, several emotional issues, and quality of life (Gonzales & Bakas, 2013; Haley et al., Pierce et al., 2007; Pierce et al., 2006; Pierce et al., 2012). Problems with interpersonal disruptions, sustaining self and family, and stroke survivor functioning were also described (King et al., 2010). As caregiving is a progressive and ever-changing role, several of these research studies conducted serial data collection at specific times in the first year of caregiving and compared and contrasted primary themes (Haley et al., 2009;
King et al., 2010; Pierce et al., 2007; Pierce et al., 2006). However, Gaugler (2010) emphasizes the need for further examination of the longitudinal effects of stroke caregiving past one year. There is a high interest in the correlation between the caregiver experience and perception of health of caregivers (King et al., 2010; Pierce et al., 2007). Additional social support proved a beneficial attribute for the caregiver while decreased social support was associated with depressive symptomology (Gaugler, 2010). Caregivers also expressed concern with safety of their loved one and managing co-morbid conditions (Grant et al., 2004; King et al., 2010; Pierce et al., 2006) while balancing their lives and generating worry secondary to fear of losing themselves and their normal lives (King et al., 2010; Pierce et al., 2007; Pierce et al., 2012). Generally, this literature review has revealed relevant research reporting on the problems endured during the caregiver experience. These studies accentuate the significance of clinicians designing educational and supportive interventions for the caregiver, as well as the stroke victim, to help decrease caregiver-related ramifications and appreciation of successful outcomes. This secondary data analysis contributes the nursing body of knowledge regarding experiences faced by adult daughter caregivers of parents with stroke.

In two studies, specific attention was geared toward the female gender, including adult daughters, and the problems and experiences of caregiving for parents with stroke. As cited by research, a majority of informal caregiving is carried out by women in our society (Saban & Hogan, 2012). Common problems regarding the caregiver experience reported among adult daughter caregivers were symptoms of depression and stress (Kwak et al., 2012). Open-ended questions lead to narrative responses that revealed adult
daughters struggled with “losing a life that once was, coping with daily burdens, creating a new normal, and interacting with healthcare providers” (Saban & Hogan, 2012, p.4). Kwak et al. (2012) compared the family conflict among male and female caregivers. Results showed both genders experienced stress. However, increased time (hours) spent towards caregiving tasks and lack of reaching out for help was more prevalent in the wives and daughter caregivers (Kwak et al. 2012). The above literature provides an overview of the experiences and problems female caregivers. Yet, there is a need for more knowledge related to specific experience related to caregivers’ problems and needs of female caregivers of stroke survivors exists (Saban & Hogan, 2012). This secondary data analysis contributes to the knowledge related specifically to adult daughters caring for a parent with stroke.

Summary

Evidence-based nursing research related to caregiving of chronic conditions is widely available to the individual nurse. Nonetheless, a need exists for recognition of the unique characteristics and experiences related to problems faced by caregivers of stroke survivors (Haley et al., 2009; Pierce et al., 2007; Pierce et al., 2012). Due to the high prevalence of female caregivers, (Kwak et al., 2012; Saban & Hogan, 2012; The National Alliance for Caregiving and AARP, 2009) the experience of female caregiving is a unique category all on its own. Yet, relatively little research focused on the female, specifically the adult daughter, caregivers of stroke survivors. Further research is needed to help bridge the lack of knowledge regarding gender-specific caregiving experiences.
Friedemann’s framework of systemic organization (1995, 2014) guides this study. Friedemann’s framework helps to describe specific problems reported by adult daughter caregivers and enhance understanding of interactions within the family system. This secondary data analysis seeks to unravel the unique problems reported specifically by the adult daughter caring for parents whom recently suffered from a stroke. Findings from this analysis have the potential to help to identify crucial issues related to the caregiving experience. Application of these findings by health care professionals may facilitate more thorough and effective assessment and intervention regarding the needs of the caregiver. The methods for data collection and analysis used in this secondary analysis are discussed in Chapter 3.
Chapter 3

Method

In Chapter 1, the rationale for studying adult daughters in the first year of caring for parents with stroke was presented. The problem statement, conceptual framework, research question and definitions, basic assumptions and limitations related to the framework were identified. A theoretical discussion of Friedemann’s framework (1995, 2014) and a research literature review in Chapter 2 supported the rationale for this secondary data analysis. In this chapter, the methodological processes for this secondary data analysis are discussed in detail including specific information regarding the study’s design, materials, methods of data collection, sample, protection of human rights, assumptions and limitations, and method of data analysis.

Design

The research design for this secondary data analysis is qualitative and descriptive. According to Grove et al. (2013), qualitative research is utilized when the researcher is describing life experiences. Qualitative research allows the exploration of the depth and complexity inherent in the lives of human beings (Grove et al, 2013). Descriptive study designs are crafted to “gain more information about characteristics within a particular field of study” (Grove et al., 2013, p. 215). Descriptive analyses are generally used to portray natural situations and how they occur, develop theory, and identify problems with current practice (Grove et al., 2013). This secondary data analysis focuses on
identification of problems expressed by adult daughters caring for parents with stroke. Data from the parent study, a randomized controlled trial (RCT), conducted from May 2002 to December 2005 and reported elsewhere in publications (Pierce et al., 2007, Pierce et al., 2009) is used.

Materials

The parent study (Pierce et al., 2007), utilized a semi-structured interview format that elicited reports about caring for persons with stroke from the caregivers. Two open-ended questions were asked bimonthly for a 1-year period to prompt a recall of events: 1) What was the biggest challenge? 2) What were other problems? This particular methodological process was used because the researchers were seeking personal and detailed information from the participants. Because the interview was organized around a set of open-ended questions, the researchers remained true to the participants’ responses, which allowed the participants’ perspectives to emerge and tell a story (Grove et al., 2013). Although there is no statistical scoring for an interview format consisting of open-ended questions, there are threats to reliability and validity that exist with utilization of the interview process. For example, “the physical, mental, and emotional condition of the participant may cause difficulties during the interview” (Grove et al., 2013, p. 272). Different personal characteristics among the subjects such as ethnicity, professional background, education level, fatigue, emotional state, and other numerous factors can affect the data being collected (Grove et al., 2013). Additional concepts regarding validity and reliability will be discussed further in the Data Collection section.
Data Collection

**Sample.** In the parent study, 73 family/friend caregivers of stroke survivors from four rehabilitation facilities in northern Ohio and southern Michigan were recruited and followed for 1 year. These caregivers were able to read, write, and understand English; they had a telephone connection for participation in bimonthly interviews. Other inclusion criteria were that the care recipient had a new diagnosis of stroke and was discharged to home following treatment (Pierce et al., 2007; Pierce et al., 2009). For this secondary data analysis, adult daughters (n=13) were responsible for providing day-to-day care for a parent with stroke over the course of that one year period.

**Protection of human rights.** The university Institutional Review Board (IRB) approved the parent RCT study and university IRB approval was also obtained for this secondary data analysis. The respect for anonymity and confidentiality is an issue that researchers must recognize and appreciate. Like most qualitative data, this research is pursuing intimate, personal details of the participants’ lives and may have asked the participants to open old wounds (Fouka & Mantazorou, 2011). In order to protect the participants’ anonymity, investigators in the RCT ensured confidentiality and personal responses could not be linked to the participants’ identity. Informed consent was signed by all participants of the parent study.

**Data collection and recording.** Demographic baseline data, e.g., age, gender, and employment, were obtained for the participants in the RCT study. Participants were
queried every two weeks for a one-year period via a telephone by trained interviewers. Bimonthly telephone contact prompted recall of events by using open-ended questions regarding the caregiver’s experiences of problems in caring. These data were immediately entered into web-based forms by trained interviewers.

Secondary data analysis involves the use of existing data, collected for the purposes of a prior study, in order to pursue a research question which is distinct from that of the original work (Boslaugh, 2007). This new research question for this secondary data analysis of these data was an alternative perspective of the original questions which queried family and friend caregivers for a person with stroke about their challenges/problems, as well as successes in caring, and well-being (perceived depression, life satisfaction) reported elsewhere (Pierce et al., 2007; Pierce et al., 2009). In addition, the care recipients healthcare service use (self-reported provider and emergency department visits, hospital re-admissions, nursing home placement) reported by the caregivers was collected to answer the original research question in the RCT study (Pierce et al., 2009). To recap, this secondary data analysis explores the research question: what are the problems reported by adult daughters in the first year of caring for parents with stroke.

**Controls for threats to internal and external validity.** Reliability and validity of qualitative research are conceptualized as trustworthiness and rigor (Golafshani, 2003). Trustworthiness of the data and interpretation was established in the parent study (Pierce et al., 2007) through credibility, auditability, and transferability. Trained interviewers
were knowledgeable of the recent and relevant literature and attended presentations by these investigators and the theorist, Friedemann. Interviewers were also proficient in the interview process. The biweekly interviews provided a vast amount of data from the caregivers and the interviewers, which added to the trustworthiness. These investigators had graduate education and years of training in qualitative research. All investigators were involved for content clarification, refinement, and concurrence, which enhanced data interpretation. For this secondary data analysis, two former investigators for the parent study were involved in the data collection and in publishing an audit trail to understand the data collection process (Pierce et al., 2007; Pierce et al., 2009). When trustworthiness is maximized, transferability of findings may result (Golafshani, 2003) and is a goal for this secondary data analysis. Transferability means that the data collected have meaning to others in similar situations (Streubert & Carpenter, 2010). Transferability is subjective and is in the hands of the readers to decide if this secondary data analysis is appropriate to their setting.

**Assumptions and limitations.** In addition to the theoretical assumptions discussed in Chapter 1, there are assumptions within the design of this secondary data analysis. First, it was assumed for the parent study that one year was an adequate period for data collection to reveal progression and development of problems reported by caregivers. During the data collection, it was also assumed the participants were telling the truth when answering the open-ended questions. Additionally, it was assumed the caregivers were knowledgeable about the topic at hand and were capable of answering such thought-provoking questions with accuracy and adequate elaboration. For this
secondary data analysis, it is assumed that the aforementioned assumptions for the parent study are in fact true and reliable. It is also assumed the participants in the parent study were truthful in their responses and were open in sharing their intimate thoughts and feelings. Trustworthiness of the data and interpretations were enhanced due to use of trained interviewers, bi-weekly interviews that provided vast data, and involvement by all investigators/authors in content clarification, refinement, and concurrence of data interpretation.

Although data for the parent study were derived from a large number of narrative interview entries, transferability of findings to other populations of caregivers and settings secondary to homogeneity of demographic characteristics is a major limitation of the parent study and for this secondary data analysis. Caregivers were mostly of the same ethnicity and from two Midwestern states, which limits geographical consideration (Pierce et al., 2007; Pierce et al., 2009). As previously mentioned, the caregivers’ specific demographic characteristics related to caregivers’ perceptions of problems may have presented as a limitation as these factors can influence data (Grove et al., 2013). Secondary analyses are limited to the partiality of the parent study; specific and potentially unknowable aspects of context can interfere with the ability to make further analysis fit for this specific topic (Irwin & Winterton, 2011). However, the actual verbatim context collected from the parent RCT study was used during this secondary data analysis, which should eliminate some of “the unknown” related to the possible risk of systematic misinterpretation of data (Irwin & Winterton, 2011).
**Data analysis.** After data collection for the RCT study was complete, the narrative data were cleaned, organized, and then entered as text files into a software management program titled QSR N 5 (Pierce et al., 2007). For this secondary data analysis the data related to problems reported by adult daughters caring for a parent with stroke during that first year were reviewed in the original transcript and analyzed. Using content analysis processes established by Colaizzi (1978), one investigator independently read all verbatim transcripts of the data to establish a baseline impression of the whole dialogue. She then reread the transcripts and extracted significant statements relating to the problems reported by the adult daughter caregiver participants. Colaizzi’s (1978) rigorous method of content analysis is used to make sense in research studies concerning people’s experiences. The following steps are included in Colaizzi’s method of content analysis (1978).

- Read the entire descriptions to obtain a sense for the whole.
- Extract significant statements and phrases pertaining directly to the phenomenon, in this case the experience of *adult daughter caregivers in the first year of caring for parents with stroke*.
- Formulate meanings from the significant statements and phrases.
- Cluster meanings into themes.
- Integrate results into an exhaustive description of the phenomenon.

The statements and explanations of the participants were coded by one investigator for this secondary analysis. Coding characterization were based on
Friedemann’s (1995, 2014) framework of systemic organization. Then, four investigators collaborated and discussed differences in coding and categorizing the data throughout this process until a final agreement was obtained. Only then were the results integrated into an exhaustive description of the phenomenon. With 482 data entries reviewed, these data were saturated and expand the knowledge of the problems experienced by adult daughters in the first year of caring for parents with stroke who reside in the home setting.

**Summary**

Past research suggests that stroke is a family affair and can be accompanied by many uncertainties, especially those family members abruptly embracing the caregiver role (Pierce, et al., 2007; Pierce, et al., 2009). However, problems faced specifically by adult daughter caregivers is lacking in current research. This descriptive secondary data analysis is used to discover the most common problems reported by adult daughters in the first year of caring for a parent with stroke. After receiving university IRB approval, this secondary data analysis uses data collected from a parent study (Pierce et al., 2007; Pierce et al., 2009) and rigorous content analysis of narrative data is applied through Colaizzi’s (1978) method of content analysis. The process of analysis, selected quotations from participants, as well as results of the analysis, is presented in the next chapter.
Chapter 4

Results

In the previous Chapter the research design, data collection procedures, and data analysis were delineated. Results of this secondary data analysis are presented in this Chapter 4. First, the sample is described; then results of this study describing the themes among the problems reported by adult daughters are addressed individually. This chapter concludes with a summary.

Sample

Of the 73 adult caregivers recruited for the parent study (Pierce et al., 2007; Pierce et al., 2009), 13 (18%) were adult daughters. The majority of these adult daughters were 51-60 years old (n=6, 46%), white of non-Hispanic origin (n=8, 62%), had received more than a high school education (n=9, 69%), and were currently working full-time while caregiving (n=7, 54%). In addition, a majority of the adult daughters reported their self-perception of health as “Good” (n=5, 38%) or “Very Good” (n=4, 31%). In Table 1, a complete profile of the demographic information for the participants is presented.
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<th>Characteristics</th>
<th>Sub-Characteristics</th>
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<td></td>
<td>Excellent</td>
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</table>

These adult daughters were caring primarily for their mothers; sixty-nine percent of the care recipients were females \((n=9)\). Sixty-nine percent were also in the age group of 71-90 years old. A majority of the care recipients were white, non-Hispanic origin \((n=8, 62\%)\) and had a left-sided stroke \((n=7, 53\%)\). In Table 2, a complete profile of the demographic information for the care recipients is presented.

**Table 2**

Demographics of Care Recipients

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Sub-Characteristics</th>
<th>(n)</th>
<th>%</th>
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<td>81-90</td>
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</table>

<table>
<thead>
<tr>
<th>Affected Side of Brain (from stroke)</th>
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<tr>
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Findings

The purpose of this secondary data analysis was to describe the problems reported by adult daughter caregivers of parents with stroke within the first year. Among the 13 daughters, a total of 482 statements were reported during telephone interviews when asked about problems over that first year of caring. The focus of qualitative research is on the quality of information obtained from the participants, rather than from the size of the sample (Grove et al., 2013). With the large number of statements, these data are saturated. Qualitative analyses do not allow for statistical comparisons, however, the themes that emerged from the caregiving problems are distinguished and described in this section.

Themes. The mean number of problems reported over the 1-year period by each adult daughter caregiver was 36. Problems reported were analyzed during two periods: 0-6 months, and 7-12 months. An average of 21 and 16 problems per caregiver were reported for those two periods, respectively. Three major themes emerged from the data. The first theme of witnessing a parent’s condition centered on the adult daughters recognizing changes in their parents’ health condition and changes in behavior, as well as supporting them to retain what they had. The second theme, balancing the challenges of the caregiver role, addressed the struggles and adaption necessary for the lifestyle of a new caregiver. The third theme, feeling physically, emotionally, and mentally drained, involved problems related to the overall exhaustion expressed by adult daughters.
**Witnessing a parent’s condition.** Adult daughters expressed many problems in relation to witnessing the new condition of their parents in that first year. Daughters revealed their worry and feelings of insecurity as they stood on the sideline and watched their mothers and fathers abruptly, and other times slowly, change or deteriorate. They tried to help them retain what they had or could regain. Specifically, health changes secondary to the stroke (physical and mental losses/impairment), co-morbid conditions, and behavior and attitude changes, such as lacking motivation, were frequently expressed as problematic. Adult daughters often told of worries about their parents’ disposition, decline in health, and whether or not their parents would improve. Witnessing the condition for their parents caused frustration and feelings of being lost and unable to help struggling or difficult parents. Specific quotes relevant to this theme are listed in Table 3.

Table 3

<table>
<thead>
<tr>
<th>Theme 1 Quotes: Witnessing a parent’s condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Her right arm is still giving her trouble, not able to use it much, so this gets her down at times, she keeps up on therapy but it does not seem to be making any progress at this time...”</td>
</tr>
<tr>
<td>“His disposition is hard to get along with. He was always kind of a bear before the stroke but it has been intensified. I never know from day to day what he will be like. He can be very uncooperative.”</td>
</tr>
<tr>
<td>“My mother has always suffered from SAD [Seasonal Affective Disorder] and it is getting worse with the passing of years and now the cognitive changes she is experiencing...”</td>
</tr>
<tr>
<td>“My biggest challenge is the thought that my mother may never be able to come home again. She was/is my best friend and I really miss having her here. I am finally realizing she may never get to come back here or to her house without a lot of difficulty...”</td>
</tr>
<tr>
<td>“My mother had a number of emotional, rationalizing disturbances such as anxiety and depression before the stroke so all this is complicated now.”</td>
</tr>
<tr>
<td>“I am concerned my mother is giving up. I do not see the ‘spark’ in my mother anymore...”</td>
</tr>
<tr>
<td>“We are now having to probably deal with cataract surgery.”</td>
</tr>
<tr>
<td>“I don’t see a lot of progress in her physical abilities, this concerns me...”</td>
</tr>
</tbody>
</table>
“Her physical health is declining; she does not seem to be getting better but worse...”

“One of my mother’s biggest challenges is her brain damage. She had a number of emotional, rationalizing disturbances such as anxiety and depression before the stroke so all this is complicated now.”

“I am seeing a progressive deterioration of my mother’s cognitive capabilities especially with disorientation...”

**Balancing the challenges of the caregiver role.** Adapting to the changes mentioned in the first theme and learning to provide adequate care transitioned into the second theme of balancing the challenges of the caregiver role. The challenge of strategizing all the issues that accompanied the new role and lifestyle of a caregiver was a problem expressed by adult daughters throughout the first year of caring. A majority of the total problems reported dealt with daughters struggling to adjust to the new caregiver role, time constraint issues, adapting to the new normal, balancing their own life and time for self, coping with a changed parent-child relationship, feeling abandoned by family members, and decision-making regarding parental care. Physical tasks of caregiving, household chores, and trying to make certain parents were safe were also vital aspects of this theme. Health problems of the caregivers also proved problematic as many participants expressed an inability to take care of themselves and their own health needs. Table 4 identifies specific quotes from participants exemplifying this theme.
Table 4

Theme 2 Quotes: Balancing the challenges of the caregiver role

“Every day is a challenge to see that my mom gets the proper care and medications on time, she is not a challenge but all the tasks of daily living and routine can be.”

“Taking care of my mom has really cut into my life. I was used to doing what I wanted, when I wanted. Things used to be on my timetable. It is really hard some days. Some days I just want to stay in my pajamas a little longer.”

“I do not have any time for myself with meal prep & in between other chores along with laundry…”

“This never ending process resulting in change and adaptation for both my mom and me.”

“I am having problems with scheduling appointments for myself since family will not pitch in and help with caregiving…”

“My own mental disposition, trying to maintain a positive outlook at least once during the day is a challenge.”

“Time constraints are an issue because the simplest of tasks (such as walking to the bathroom and that whole process) takes her mother a minimum of thirty minutes. It's (time) a big concern of mine.”

“I am having trouble sleeping as I lay awake at night thinking about the things I did not accomplish during the day and thinking about the things I need to do the next day…”

“I have an increase in asthma symptoms. I have needed to see her doctor twice. I agree with her PT that stress may have something to do with the increase of asthma symptoms…”

“I have been sick over the past couple of weeks. I have not had anyone to take over for my mom, so I have continued caring for my mother instead of taking care of myself. I feel frustrated that other family members have not been more helpful.”

**Feeling emotionally, physically, and mentally drained.** The third and final theme deals with adult daughter caregivers feeling drained. Emotional, physical, and mental exhaustion secondary to the everyday tasks of caregiving was an obvious problem among caregivers. Although this particular theme did not make up a large percentage of the total problems reported, “feeling drained” remained problematic over the first year of caring. Adult daughters often found themselves feeling pulled in multiple directions; taking care of their parent and their own families not only left these women feeling
drained emotionally and physically, but at times, hopeless. Feeling exhausted and mentally drained secondary to a lack of sleep, dealing with burdens and stresses of everyday chores, caregiving responsibilities, and disappointment related to a lack of parental improvement led to many daughters’ feelings of inadequacy and a lack of motivation to continue with caregiving. See Table 5 for quotes from the adult daughters related to this theme.

Table 5

<table>
<thead>
<tr>
<th>Theme 3 Quotes: Feeling emotionally, physically, and mentally drained</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I'm real tired. All I do is run around every day. Even when he's staying with someone else, I run all day long calling doctors, taking him to doctors. It is just too much.”</td>
</tr>
<tr>
<td>“My mother's condition has beaten her down. I am running on empty.”</td>
</tr>
<tr>
<td>“I am feeling fatigued. Some days are worse than others and more stressful.”</td>
</tr>
<tr>
<td>“I am emotionally stressed and exhausted with running back and forth from house to house.”</td>
</tr>
<tr>
<td>“I am having difficulty with having enough energy to keep up.”</td>
</tr>
<tr>
<td>“I am feeling run down. I am busy making arrangements with medications, doctor appointments…”</td>
</tr>
<tr>
<td>“I have been feeling overwhelmed and &quot;stressed out&quot; regarding my mother's health…”</td>
</tr>
<tr>
<td>“I am not sleeping well at night, I feel tired throughout the day.”</td>
</tr>
<tr>
<td>“I am still exhausted…”</td>
</tr>
<tr>
<td>“Mother is always fatigued and I am feeling fatigue as well due to emotional drain of being with my mom 24/7.”</td>
</tr>
</tbody>
</table>

**Themes over time.** The occurrences of the three themes were originally analyzed and compared during three time periods: 0-3 months, 3-6 months, and 7-12 months. Initially, the first six months were divided into two time periods because past literature
showed an increase of problems during the first three months post hospital discharge (Gaugler, 2010; Pierce et al., 2007). However, this assumption was not supported in this data analysis; vast differences regarding problems between 0-3 months and 4-6 months did not exist. The problems reported by adult daughters were then divided into two time periods, 0-6 months and 7-12 months. This division then allowed for better comparisons as time periods were the same length. With over 480 total problem statements reported during telephone interviews with adult daughters, an average of 21 problems per caregiver were reported during the first six months and an average of 16 problems per caregiver were reported during months seven through 12.

Results revealed that as time passed, the first theme of witnessing a parent’s condition remained consistently apparent throughout all 12 months. The second theme of balancing the challenges of the caregiver role was noticeable throughout the entire year, but more evident in the second six months of caring compared to the first six months of caring. The third theme, feeling physically, emotionally, and emotionally drained, was seen throughout the one year period, but more visible during the first six months of caring.

An assumption was that many more problems would be reported in the first six months compared to the second six months. There was a 20% decrease of reported problems in the second six months; 262 problems and 210 problems were reported by adult daughters, respectively. Figure 2 illustrates the problem themes over time.
Summary

The purpose of this secondary data analysis was to describe the problems reported by adult daughters in the first year of caring for their parents who recently suffered a stroke. For the parent study, data were collected from two open-ended questions from participants from northern Ohio and southern Michigan via bimonthly telephone interviews during one year. Thirteen females qualified for this secondary data analysis and the original data were analyzed for these participants only. Participants were strictly females, primarily 41-60 years of age, white of non-Hispanic origin, had at least 12 years of education, worked full time and rated their own health as either “Good” or “Very good.” The majority of the care recipients were female, age 71-90, white of non-Hispanic origin, and the most common type of stroke among care recipients was left-sided.
The open-ended questions asked during the parent study were “What was the biggest challenge?” and “What were other problems?” The mean number of problems reported over the 1-year period by each caregiver was 36. On average, each caregiver reported five more problems during the first six months of caregiving. Problems reported by adult daughters emerged into three distinct themes that included: witnessing a parent’s condition, balancing the challenges of the caregiver role, and feeling emotionally, physically, and mentally drained.

As demonstrated in the previous Tables, the longitudinal analysis of the themes from each period revealed an unchanged presence of the first theme: witnessing a parent’s condition. The second theme, balancing the challenges of the caregiver role was noticeable throughout the entire year but more apparent during the last six months of caregiving while the last theme, feeling physically, emotionally and mentally drained, was more evident in the first six months of caregiving. The number of problems reported during the first six months was 20% higher than the number of problems reported in the second six months. With these findings, the research question was answered. A discussion of these themes linked to the literature and Friedemann’s (1995, 2014) framework that guides this study is presented in Chapter 5.
Chapter 5

Discussion

The findings of this secondary data analysis were delineated in-depth in the previous chapter. The purpose of this study was to conduct a qualitative secondary data analysis to describe the problems reported by adult daughters caring for their parent with stroke in the first year. The secondary data analysis resulted in three themes that conceptualize the most common problems. In this Chapter 5, a synthesis of the findings to describe the meaning of the problems reported by adult daughters caring for their parent with stroke in the first year is examined. Findings from this study will be compared to those in the literature and will also be discussed in relationship to Friedemann’s framework of systemic organization (1995, 2014). Conclusions and limitations of the study are presented. Implications for nursing and recommendations for further research conclude this chapter.

Findings

Research question. The research question for this secondary data analysis was: What are the problems expressed by adult daughters in the first year of caring for parents with stroke? Three problem themes were identified: 1) witnessing a parent’s condition, 2) balancing the challenges of the caregiver role, and 3) feeling emotionally, physically, and mentally drained.
Witnessing a parent’s condition.

Synthesis. It is clear that women bear the burden of informal caregiving (Saban & Hogan, 2012; The National Alliance for Caregiving and AARP, 2009). Not only are the physical and emotional aspects of caregiving challenging, but also simply standing on the sideline and witnessing a parent’s changed, sometimes deteriorated condition, presented a significant problem for these daughters. This theme encompassed adult daughters witnessing all the changes from stroke including physical and mental impairment/losses, behavioral and attitude changes, and co-morbid conditions, as well as supporting them to retain what they had.

Additionally, this theme involved the worry adult daughter caregivers expressed about their parents’ uncertain disposition, decline in health, and whether or not their parent would improve. At times, adult daughters revealed feelings of disbelief and astonishment regarding their parents’ condition. For example, one daughter stated, “I watch my parent walk and now I see just how old and frail she is.” Another daughter expressed, “My mother had a number of emotional, rationalizing disturbances such as anxiety and depression before the stroke so all this is complicated now.” Adult daughter caregivers also reported concerns related to the stroke survivor’s disposition and future. One daughter worried that her parent’s living situation was unsuitable to meet his needs, “I will need to be assessing potential future living arrangements” while another daughter expressed her disappointment and stated “her physical health is declining, she does not seem to be getting better but worse.”
Comparison to the literature. Similar to the results of this secondary analysis, recent studies found that caregivers often report problems in relation to their parents’ condition post stroke and the realization of their parents’ uncertain future (Grant et al., 2004; King et al., 2010; Pierce et al., 2007; Pierce et al., 2006; Saban & Hogan, 2012). Saban and Hogan (2012) looked at female caregivers (nearly 40% of the sample were adult daughters) and their results were very similar to the results of this secondary data analysis. Significant life changes post stroke left parents without capabilities they once had and subsequently left female caregivers feeling uncertain regarding the stroke survivor’s future. They also identified how the consequences of a stroke such as irreversible brain injury and physical impairments caused immense feelings of loss for the caregiver (Saban & Hogan, 2012). Although the study did not focused specifically on female caregivers, Grant et al. (2004) identified emotional and behavioral changes of the stroke survivor as reported problems. Caregivers reported feelings of uncertainty of the care recipient’s future and were identified as an extremely stressful and problematic factor (King et al., 2010; Saban & Hogan, 2012). Pierce et al. (2006) discussed caregivers living with the physical limitations of their parent with stroke and how new health problems in conjunction with established comorbid conditions caused problems in everyday living. Physical, cognitive, and emotional losses or changes were identified as stressors among caregivers and more common in the later months (4 months post discharge from rehabilitation) of caregiving according to King et al. (2010). In contrast, findings from this secondary data analysis revealed that this theme was consistently noticeable throughout the entire first year of caring.
Balancing the challenges of the caregiver role.

Synthesis. In addition to feeling significant loss due to the changed condition of the parent after the stroke, adult daughters often expressed problems with balancing and adjusting to the issues that accompany the new lifestyle of a caregiver. Adjusting to the role and ‘new normal’ way of life, dealing with time constraints, balancing time for self (own health and well-being) and own family, coping with a changed parent-child relationship, feeling abandoned by family members, and decision-making comprised the problems categorized under this theme. Physical tasks of caregiving, household chores, and trying to make certain parents were safe were also problematic issues of adult daughters. Specifically, one daughter was challenged with balancing the routine tasks of caregiving and she stated, “Every day is a challenge to see that my mom gets the proper care and medications on time, she is not a challenge but all the tasks of daily living and routine can be.” Another daughter exemplified the depth of challenge behind trying to balance caregiving and finding time for herself, ”taking care of my mom has really cut into my life. I was used to doing what I wanted, when I wanted. Things used to be on my timetable. It is really hard some days.” Daughters struggled with balancing the caregiver role more in the second six months of caring compared to the first six months.

Comparison to the literature. Caregiver stress and burden of stroke survivors has been well documented in the literature (Gonzales et al., 2013; Grant et al., 2004; King et al., 2010; Pierce et al., 2007; Pierce et al., 2006; Saban & Hogan, 2012). Nearly every study that was reviewed found that the problem associated with a newly adopted
caregiver role identified balancing and adapting to the challenging role. Grant and her colleagues (2004) identified parent safety and difficulty managing activities of daily living as very problematic responsibilities for family caregivers of stroke survivors. Females were noted to have a “sense of duty” and have more problems adjusting to the responsibility of caregiving tasks (Gonzales et al., 2013, p.207). Similar to the results of this secondary data analysis, Saban and Hogan (2012) mention the various problems reported by female caregivers associated with balancing the challenges of the caregiver role. These problems also included missing personal time, losing a life that once was, feeling abandoned by other family members, coping with a changed relationship with the stroke survivor, coping with daily burdens, and needing support from others (Saban & Hogan, 2012).

Similar to this theme, the theme of struggling to balance and adapt to the new role and find a new sense of normalcy was also reported by the Pierce et al. (2007) study. Feeling frustrated with day-to-day situations while trying to decipher if life would ever return to the way it once was a common problem. These researchers also described how many caregivers became overwhelmed and reached out for support (Pierce et al., 2007).

Related to the findings of this secondary data analysis, the themes King et al. (2010) identified in the first months of caring for a person with stroke were interpersonal disruptions and sustaining the self and family. Interpersonal disruptions included caregiver frustration with role reversal and feeling and speaking negatively regarding caregiving. Financial stress, transportation of the stroke survivor, balancing time for
work, lack of time for self, and dealing with the caregivers’ own emotions were problems about sustaining the self and family (King et al., 2010) which were similar components to the findings of this secondary data analysis.

The results of this secondary data analysis regarding the various demands of the caregiver role were slightly dissimilar to the literature as the prevalence of this problem was noticeable throughout the entire year, but more evident in the second six months of caring. Conversely, according to King et al. (2010) and Grant et al. (2004) this theme was more consistently apparent over time. Pierce et al. (2007) found that day-to-day caregiving frustrations were reported more often in the first three months. Gaugler (2010) also recognized how the need to balance and manage the caregiver role was expressed by caregivers as problematic mostly in the early months of the caregiving process.

**Feeling emotionally, physically, and mentally drained.**

**Synthesis.** Adult daughters reported emotional, physical, and mental tolls in the first year of caring for their parent with stroke. A majority of participants reported problems related to feeling drained secondary to their new role as caregiver. Many daughters reported feelings of inadequacy and a lack of motivation to continue with caregiving due to the lack of sleep in combination with the burdens and stresses of everyday chores, caregiving responsibilities, and disappointment. Simple yet meaningful comments by adult daughters exposed the feelings of exhaustion from caregiving. For example, one daughter reported, “I have been feeling overwhelmed and stressed out
regarding my mother's health.” Another daughter expressed similar frustrations when she stated, “my mother is always fatigued and I am feeling fatigue as well due to emotional drain of being with my mom 24/7.” This secondary data analysis found that adult daughters reported feeling drained and exhausted more often in the first six months compared to the second six months. The physical, emotional, and mental exhaustion was a visible problem over the first year, but more evident in the first six months of caring.

**Comparison to the literature.** Most caregivers of stroke patients report feeling drained, overwhelmed, and exhausted in recent literature. Saban and Hogan (2012) found very similar findings among the female caregivers of stroke survivors. Feelings of physical, emotional, and mental exhaustion often presented as conflict when trying to overcome the demands of caregiving (Saban & Hogan, 2012).

Although not all the literature addressed female caregivers, there was a consistency of problems reported by caregivers about inadequate sleep (King et al., 2010; Pierce et al., 2006). Inadequate sleep and feeling fatigued were reported as consistent problems over the months of caregiving (King et al., 2010), which contrasted the findings of this secondary data analysis, as this theme was less visible during the second six months of caregiving. Pierce et al. (2012) identified “running on empty” as a major problematic theme among caregivers (16% adult daughters) of stroke.

Conclusively, the first theme of *witnessing a parent’s condition* was evident during the entire first year of caring; daughters never ceased to report problems regarding
standing on the sideline and witnessing their mothers’ or fathers’ condition change or decline. However, daughters felt more physically, emotionally, and mentally drained during the first six months and struggled to balance all the responsibilities of the caregiver role more in the second six months. It could be surmised that because daughters felt less drained in the second six months of caring, they were attempting to juggle more responsibilities of caregiving and subsequently reported more problems of balancing the caregiving role in the second six months.

**Nursing Theoretical Framework and Findings**

Friedemann’s (1995, 2014) framework of systemic organization (Figure 1) is the nursing theoretical framework for this study. A schematic (Figure 3) depicts the congruence of desired family process compared to the incongruence of the family in crisis (adult daughter caregiving process experienced in the first year of caregiving for a parent with stroke). When systems (adult daughters) do everything in their power to maintain their systems, a full circle with balanced process dimensions results. The full circle on the left depicts the desired process including all four process dimensions. When a system behaves within these process dimensions, balance and congruence can be achieved. Friedemann’s framework is applied to this study with the assumption that the adult daughter strives to achieve balance in her own life. The second, incomplete circle (right-side) will be later explained.
Figure 3. Comparison of the desired family/person process (left-side) and the family/person in crisis: adult daughter caring for a parent with stroke (right-side) using Friedemann’s (1995) framework of systemic organization.

Important to this framework is the understanding that there is a basic order in the universe that all things are connected in a congruent pattern and rhythm (Friedemann, 1995). Congruence is a state of those things in balance and energy flowing freely between them. When there is a block in the balance, incongruence results (Friedemann, 1995). Friedemann (1995) describes how four targets (control, stability, growth, and spirituality) adjust within equilibrium to achieve balance or congruence. To achieve or maintain balance among these targets, a person behaves within the process dimensions: system maintenance, system change, coherence, and individuation (Friedemann, 1995, 2014). The incomplete circle (right-side), the Family/Person in Crisis (Figure 3), represents the adult daughter caregiving for her parent with stroke. The right-sided figure depicts incongruence. Coherence and system change are missing entirely. System
maintenance is enlarged as an attempt to restore balance; individuation is present but only in a reduced form.

*Process dimension: System maintenance.*

The first theme, witnessing a parent’s condition, compelled adult daughters to behave in accordance with *system maintenance.* According to Friedemann’s (1995) framework of systemic organization, when system maintenance is achieved, a controllable order or pattern of life provides one with feeling secure and safe. When adult daughters witness their parent in a vulnerable state, unlike their previous condition prior to a stroke, the sense of security and safety is threatened, and therefore behaviors of system maintenance were in overdrive as represented by the enlarged quarter circle in Figure 3 (right-side).

In Friedemann’s (1995) terms, the theme of balancing the challenges of the caregiver role serves as the adult daughter’s attempt to achieve *system maintenance*, as well. This process dimension involves aspects of adaptation to the caregiver role by the adult daughters. While system maintenance includes simple actions aimed towards maintaining basic needs such as eating, resting, working, and exercising, it also includes any action geared towards maintaining and protecting the system (caregiver’s life) from threat or great change.
Once again, behaviors and strategies of *system maintenance* were exhibited when adult daughters felt drained or exhausted (Friedemann, 1995). Lack of sleep in combination with the burdens and stresses of everyday chores, other caregiving responsibilities, and disappointment related to a lack of parental improvement led to many daughters’ feelings of inadequacy and a lack of motivation to continue with caregiving. Deliberate actions such as sleeping and resting encompassed in this dimension must be fulfilled in order to gain stability and control (Friedemann, 1995). As the demand for system maintenance became stronger, the actions of this dimension are unable to be fulfilled secondary to outside demands and stressors. Consequently, stability and control are lost, value and beliefs are challenged, and physical and mental health are compromised (Friedemann, 1995).

**Process dimension: Individuation.**

Adult daughters reported problems with balancing the challenging caregiver role. These problems would not have existed if adult daughters were not trying to maintain individuation. Friedemann (1995) explained inner security allows for stable interaction and connection with others and in the environment. People are able to develop their talents, gain knowledge and understanding, and eventually grow as individuals. A sense of purpose in life occurs when the dimension of individuation exists. When the process dimension of individuation is used by a new caregiver role, as evidenced by a smaller quarter-circle (right-side) in Figure 3, the target of growth is desired, and the adult daughter must learn an entirely new role and purpose in life. For example, a daughter
reported “This never ending process resulting in change and adaptation for both my mom and me” while another daughter expressed “I need to endure the current situation and recognize it will not likely change.” One daughter reported her problems and then expressed her need and willingness to make changes in order to begin to achieve a positive sense of self, “My own mental disposition, trying to maintain a positive outlook at least once during the day is a challenge.” The frustrations of the caregiver role stemmed from the adult daughter attempting to maintain individuation and often caused anger, disappointment, and sometimes attitude analysis from adult daughters.

**Process dimension: System change.**

Friedemann (1995) states when individuals (caregivers) become flexible and respect diversity, the struggle and pain leads to system change in later months or years. In some circumstances, pressure secondary to the new role of caregiver occurs and this leads to system change. “Tension or unhappiness with a present situation compels to person to test values and set new priorities” (Friedemann, 1995, p.11). Although adult daughters may report experiences that lead to the beginning process of system change, system change usually does not truly occur for years. Due to the length of time of data collection for the parent study (12 months), system change was not a process dimension found among the analysis of problems reported during this secondary data analysis and is not represented in Figure 3 (right-side).
**Process dimension: Coherence.**

Values, attitudes, beliefs, and perceptions originate in childhood and later develop into a sense of security and peace within (Friedemann, 1995). During the first year of caregiving, adult daughters found themselves in a crisis situation and more concerned with their parents’ condition, the new role of caregiving, and the accompanying exhaustion. Indirectly, the dimension of coherence was probably exhibited during the first year; however it was not outwardly apparent in the three themes identified and is not represented in Figure 3 (right-side).

When assessing human system actions, it is important to understand that certain actions may pertain to or involve more than one specific process dimension (Friedemann, 1995). The meaning behind the reported problems determines the correlating systemic process dimension (Friedemann, 1995). This secondary data analysis identified system maintenance and individuation as the main impacted dimensions for adult daughter caregivers during the first year of caring for a parent with stroke. Table 6 illustrates each theme and its correlating process dimensions.
Table 6.
Themes and Correlating Process Dimensions

<table>
<thead>
<tr>
<th>Themes</th>
<th>System Maintenance</th>
<th>System Change</th>
<th>Individuation</th>
<th>Coherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Witnessing a parent’s condition</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balancing the challenges of the caregiver role</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Feeling emotionally, physically, and mentally drained</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Limitations

Several limitations were reported for the parent study (Pierce et al., 2007; Pierce et al., 2009) and are applicable to this secondary data analysis. Although data for the parent study were derived from a large number of narrative interview entries, transferability of findings to other populations of caregivers and settings secondary to homogeneity of demographic characteristics is a major limitation of the parent study and for this secondary data analysis. Adult daughter caregivers were recruited from northern Ohio and southern Michigan and most were of White, not Hispanic origin and between the ages 41-60, which limits demographic and geographic consideration. Although homogenous sampling is used when the goal of the research is to understand and describe a particular group in depth, it can also lead to the inability to transfer findings to groups
of other demographics (Cohen & Crabtree, 2006). Additionally, the caregivers’ specific demographic characteristics related to caregivers’ perceptions of problems may have presented as a limitation as these factors can influence data (Grove et al., 2013).

Secondary analyses are limited to the partiality of the parent study; specific and potentially unknowable aspects of context can interfere with the ability to make further analysis fit for this specific topic (Irwin & Winterton, 2011). For example, the reliability of the parent study in regards to data collection is unknown. “Re-users will have to make do with what is made available to them” (Irwin & Winterton, p.11) and therefore, analysis of secondary data can lead to systematic misinterpretation.

In regards to the theory guiding this secondary data analysis, the main limitation was related to conceptual definitions and relationships. The specific problems and experiences by the adult daughters and the relationship between the daughters and parents have not been directly addressed in Friedemann’s theory (1995, 2014); therefore, transferability of the findings is reduced. While the caregiver experience is the backdrop for the study, the research question regarding the experiences of problems encountered in caring for parents with stroke by adult daughter caregivers is not directly linked to concepts of Friedemann’s theory. Therefore, this limitation proposes a threat of transferability of findings.
Implications for Practice

The findings of this secondary data analysis support the premise that adult daughters caring for a parent with stroke in the first year experience specific problems. Understanding the unique experiences of this middle-aged, female population, baccalaureate-prepared registered nurses and advanced practice registered nurses can adjust their practice to effectively manage care and provide needed support and guidance for adult daughters prior to discharge from the acute care setting and into the community/outpatient setting. Several physical, emotional, social, and mental stressors threaten psychological well-being of these daughters as caregivers. Although this secondary data analysis analyzed problems reported by only small cohort of women, the common problems should be be considered by the nursing professionals; nurses must ask the adult daughter caregiver what she wants and needs to know. Then, nurses can provide individualized, gender-based and age-related interventions.

With the recent changes in healthcare and epidemic lack of access to healthcare for many consumers, Nurse Practitioners (NPs) are filling the gap in the primary care setting as health care providers (HCP) for patients who require quality, effective healthcare. The growing number of elderly patients, increasing complexity of illnesses (such as stroke), and a focus to provide care in the home rather than the hospital requires strategies for affordable, available healthcare in the outpatient setting (Joel, 2009). NPs are often the primary care provider for either the parent who suffered the stroke or the daughter who functions as the caregiver. As a HCP, the NP blends expert clinical
knowledge and nursing philosophical tenets to connect with patients on a mutually respectful and collaborative level. Thus, the NP can form a trusting patient-provider relationship responsible for meeting the adult daughter’s health needs based on evidence-based, patient-centered, cost-effective clinical outcomes.

Caregiver advocacy, education, and community resource outreach are aspects of care for all levels of nursing practice and should be implemented in the care plans of adult daughters caring for the parent with stroke. These broad implications for nursing practice apply to the specific problems identified in this secondary data analysis.

**Advocacy.** The most important implication for nursing practice is caregiver advocacy. Nursing plays many vital roles in the care of patients, especially in the role of the patient advocate. A patient advocate is a person who acts or intercedes on behalf of another, such as daughters caring for parents after a stroke. At the individual and family level of advocacy, nurses use skills to assist consumers (caregivers) identify their own needs, obtain orders for necessary services (respite care), and provide support to meet those needs (Joel, 2009).

Nurses, who serve as HCPs for adult daughters, should inquire about their caregiver status, as some daughters may not offer this information voluntarily during a routine office visit or annual physical examination. The Screen for Caregiver Burden (SCB) is a screening tool that can be easily completed during an office visit and updated as a resource to direct services and support as caregiving duties change. (Vitaliano,
Russo, Young, Becker, Maiuro, 1991). As a patient advocate, nurses can ensure that caregiver daughters do not become the “hidden patient.” Daughters may need to be reminded that their own families and own health condition are important and cannot be ignored. They may have to be persuaded to set time aside for self to minimize caregiver exhaustion and live a healthier lifestyle. For instance, the nurse could recommend preparing a weekly schedule to better anticipate daily responsibilities and to set aside at least 30 minutes each day just for herself (yoga, light reading, gardening, etc.).

Patient advocacy includes tracking and documenting issues of caregiving experiences of adult daughters in their medical record to facilitate ongoing assessment, intervention, and planning for appropriate respite care consultation. Advocating through care plans that individualize interventions creates an atmosphere of respect, empathy and understanding can translate into a secure a patient-nurse relationship.

The healthcare delivery system complicated and many consumers need help navigating their way. Nursing navigators assist daughters overcome barriers to the support and services they need (Joel, 2009). The American Nurses Associated Code of Ethics encourages collaboration between nurses and other disciplines to promote community and national efforts to meet the needs of individuals (ANA, 2001). Nurses have the opportunity to advocate for caregivers at the federal level as either members or leaders in organizations such as the federally funded Family Caregiver Support Program (Administration on Aging, 2013).
**Education.** Nurses are in an idyllic position to teach strategies about balancing the challenges of the caregiver role prior to discharge from acute care and in the outpatient setting. This secondary data analysis revealed that adult daughters often have problems witnessing their parent’s condition and struggle to balance the challenges of the caregiver role. In the neuro-intensive care unit (NICU) inpatient setting, nurses can provide verbal anticipatory guidance regarding what physical and cognitive deficits commonly occur after a stroke. They often have access to numerous ‘what to expect’ and ‘facts about stroke’ patient education literature that can be reviewed with daughters to reduce the shock and some of the ‘unknowns’ about stroke.

In the community or outpatient setting, nurses can gather information about the caregiving experience when the adult daughter accompanies her parent at the HCP appointment. During these appointments, nurses can take time to dialogue about the struggle of balancing caregiver role challenges and offer specific caregiving strategies such as: using pillboxes for medication management or offering tips about adaptable clothing, non-slip flooring, toileting schedule, large-handled silverware. Since adult daughters often report problems about witnessing their parents’ condition, nurses can plan targeted mini education sessions about common post-stroke symptoms, behaviors, and attitudes to prepare these daughters for future problem solving. Knowing what to expect and having a simple plan can reduce frustration in the patient and stress in the daughter caregiver. “The nurse’s ethical responsibility is to transfer as much…knowledge as possible to the patient (and caregiver) support (them) … in making informed decisions” (Joel, 2009, p. 264).
By applying expert knowledge, clinical competence, and personal demeanor to care and treatment plans nurses can provide educational and support resources for their adult daughter caregivers. During outpatient office visits, nurses can take extra time to assess what information is most urgent or anticipated by the daughter and then efficiently provide an education session based on time and attention span. Some common questions that daughter have include: common post-stroke symptoms, complications of comorbid conditions, common behavioral problems and attitude changes, and the possibility of significant health decline of the parent. Although an office visit may not always be long enough for patient/family education by the HCP, office nurses can often provide written educational material (pamphlets, printed handouts) about stroke and co-morbid conditions with the offer to further discuss questions during a scheduled follow-up phone call or use supplemental visual aids, such as educational DVDs or credible online resources. One of the most commonly reported safety problems for caregivers involves medication administration. Common medication errors, medication-medication interactions, and medication-disease interactions must be reviewed at every visit. Educated caregivers make safer caregiving decisions.

**Community resources outreach.** Nurses can recognize the challenges faced by adult daughter caregivers and make recommendation for outside resources. Because behaviors of the process dimension of coherence were not seen in this secondary data analysis, adult daughters may need extra encouragement from nursing to identify and verbalize their need for emotional and spiritual support. Caregiver support groups serve as a supplemental shoulder to lean upon and can help caregivers better navigate through
the recovery process and identify solutions for difficult financial and social problems that occur following a stroke. Local and national support groups for stroke caregivers provide online resources and in-person sessions that offer information about: practical tips on symptom management, balancing the caregiver role, legal resources, financial support, and health coverage. Some easily accessible online national support groups include www.strokeassociation.org/ and www.caregiver.org/. The Caring-Web™ is an excellent resource for caregivers and is designed to educate and support caregivers of persons with stroke. This resource is available worldwide through a university website at Caringweb.utoledo.edu/.

**Recommendation for Further Research**

This secondary data analysis could be replicated in another study to include a more heterogeneous sample including a variety of ethnic groups, in other states and/or countries, and participants from multiple settings to enhance transferability. For the parent study (Pierce et al., 2007; Pierce et al., 2009), the problems reported by caregivers were limited to a 12-month period. An extended data collection period in a new study would allow for a more thorough epidemiological data analysis. An extended time may also allow for behaviors of system change and coherence (Friedemann, 1995, 2014) to emerge and be identified. Another recommendation for further research is not only identifying the most common problems experienced by adult daughters caring for parents with stroke, but also taking it another step further and identifying how problems were solved which was beyond the scope of this secondary data analysis. Examining the
experiences of adult daughters beyond one year and evaluating both the problems and successes may allow for the process dimensions of coherence and system change to be exhibited.

Conclusion

This is one of the few analyses to focus on the unique needs of middle-aged adult daughters caring for a parent in the first year after a stroke. Becoming a caregiver is an abrupt process that leaves the caregiver with degrees of cognitive, emotional, and physical challenges. It is clear that women, often adult daughters, bear the burden of informal caregiving in our society, as 66% of informal caregiving is provided by females (The National Alliance for Caregiving and AARP, 2009). Through describing the problems reported by adult daughters caring for a parent with stroke in that first year, more is learned about the caregiving experience. Specifically, adult daughters reported problems associated with witnessing a parent’s condition, balancing the challenges of the caregiver role, and feeling physically, emotionally, and mentally drained. Awareness of commonly reported caregiver problems of adult daughters can better equip healthcare providers identify and initiate with knowledge to intervene. Nurses can design appropriate interventions, e.g. education and community resource outreach, offer anticipatory guidance and advocate for these caregivers, as well as assist/support adult daughter caregivers to adjust, cope, and balance their own lives as a caregiver and thereby restoring congruence.
References


The National Alliance for Caregiving. (2009). *The evercare survey of the economic downturn and its impact on family caregiving.* Retrieved from


To: Linda Pierce, Ph.D., R.N.  
UT College of Nursing

From: Roland Skcel, M.D., Chair  
Deepak Malhotra, M.D., Ph.D., Vice Chair  
Gregory Siegel, R.Ph., J.D., Chair Designee  
UT Biomedical Institutional Review Board

Signed: [Signature]  
Date 4/15/13

Subject: IRB # 103261  
Title: The Caring–Web: Web-based Support for Stroke Caregivers

On 04/11/2013, the Amendment listed below was reviewed and approved by the Chair and Chair Designee of the University of Toledo (UT) Biomedical Institutional Review Board (IRB) via the expedited mechanism. The Chair and Chair Designee noted that enrollment is closed at this site, data collection is complete and the study remains open for data analysis only. Signed and dated Consent/Authorization for Use and Disclosure of Protected Health Information was required prior to an individual taking part in this research. This action will be reported to the committee at its meeting on 04/18/2013.

Items Available for Review:
- IRB Application Requesting Expedited Review of Amendment (UT Reference #8575)
  - Add Lisa Sommer as study personnel.
- Current IRB Approved Protocol (assigned version date 06/27/2005)
- Most Recent IRB Approved Consent/Authorization Form (version date 07/16/2004)

This Amendment is approved until the expiration date listed below, unless the IRB notifies you otherwise. Enrollment is closed at this site.

AMENDMENT APPROVAL DATE: 04/11/2013  
EXPIRATION DATE: 02/18/2014

Please read the following attachment detailing Principal Investigator responsibilities.