Investigation of Sandwich Generation Caregiver Perceptions and Factors of Caregiving Strain

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Eastern Illinois University
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Samantha Marie Young

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Investigation of Sandwich Generation Caregiver Perceptions and
Factors of Caregiving Strain

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Eastern Illinois University
Dedication

This thesis is dedicated to all of the Sandwich Generation caregivers, for their devotion to their parent(s), children, and other role responsibilities.
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Abstract

The Sandwich Generation caregiver is responsible for caring for their children and parents simultaneously (Miller, 1981). In this study, stressors, burdens, and strains were analyzed in relation to caregiver demographics and the following variables: caregiving relationship quality, caregiving roles, communication, and resources (time and finances). The purpose of this study is to investigate the factors that contribute to perceived strains in Sandwich Generation caregivers. The Sandwich Generation Caregiver Survey was distributed through social media (Facebook, Instagram, Twitter, and LinkedIn), email, listservs, and word of mouth through a nonprobability snowball approach (Creswell, 2012). The researcher used frequency counts, percentages, and mean scores to analyze descriptive data through the use of path analysis (charts and graphs).

Caregiving relationship quality displayed high levels of interconnection among caregiving roles, communication, and resources (time and finances). For caregiving roles, caregiver participants indicated feeling a low level of support from their siblings. Moderate levels of strain were perceived by caregivers in their communication patterns with siblings. Caregiver participants’ perceptions of resources (time and finances) ranged from moderate to high levels of lacking resource availability and stress related to resources. Future research on caregiver strain will improve programs and support networks that provide resources, as well as self-care techniques, for Sandwich Generation caregivers.

Keywords: Sandwich Generation, Sandwich Generation caregiver, caregiver, caregiver strain, caregiving relationship quality, caregiving roles, caregiver communication, caregiver resources, caregiver self-care
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Chapter 1

INTRODUCTION

There are approximately 43.5 million individuals known as caregivers in the United States who have provided unpaid care for children and/or adults over the course of one year (Family Caregiver Alliance, 2016). With a growing aging population, there is an increasing need for caregiving as “the older population – persons 65 years or older – numbered 46.2 million in 2014” (Administration On Aging, 2016, para. 1). Caregivers are finding that their roles span longer periods of time due to increased longevity of older adults (Abramson, 2015). The generation of individuals who are simultaneously caring for their parents and children are known as the Sandwich Generation (Miller, 1981).

The United States is a fast-paced culture with demanding schedules as the norm. There is a growing concern for the “well-being of the ‘Sandwich Generation’” (Ward & Spitze, 1998, p. 647). The perceived lack of resources is affecting the well-being of caregivers and research has emphasized the importance of coping mechanisms, along with self-care (Miller, 1981). As the aging segment of the population increases, the number of caregivers within the United States is projected to increase. With more caregiving responsibilities, location, time, finances, and communication patterns will influence the quality and availability of care for older adults (Wassel & Cutler, 2016).

Need for Study

Research on the Sandwich Generation is limited in the field of gerontology. The Sandwich Generation is not a new phenomenon, but it is not heavily researched. With an increasing aging population, there is a greater need to understand available resources for Sandwich Generation caregivers.
Statement of the Problem

The purpose of this study is to investigate the factors that contribute to perceived strains in Sandwich Generation caregivers. Caregivers in the Sandwich Generation experience varying degrees of stress and associated strains in their roles. This study examines four variables in relation to Sandwich Generation caregivers: caregiving relationship quality, caregiving roles, communication, and resources (time and finances). It is essential to explore and understand the perceived levels of strain, especially for women in the Sandwich Generation, as women account for “upwards of 75 percent of all caregivers” (Institute on Aging, n.d., para. 10; Dautzenberg, Diederiks, Philipsen, & Stevens, 1998; Family Caregiver Alliance, 2016; Miller, 1981).

Research Objectives

1. To determine the extent to which the Sandwich Generation caregiver identifies sibling support as a factor in caregiver strain.

2. To determine the extent to which the Sandwich Generation caregiver identifies multiple obligations as a factor in caregiver strain.

3. To determine the extent to which the Sandwich Generation caregiver identifies lack of role clarity about care expectations as a factor in caregiver strain.

4. To determine the extent to which the Sandwich Generation caregiver identifies sibling communication as a factor in caregiver strain.

5. To determine the extent to which the Sandwich Generation caregiver identifies resource levels as a factor in caregiver strain.
Definition of Terms

Activities of Daily Living. Care that assists older adults with everyday living tasks that include walking, dressing, bathing, toileting, and eating (ADLs) (Family Caregiver Alliance, 2016).

Caregiver. A caregiver is an individual that provides varying degrees of support with instrumental or non-instrumental activities of daily living to older adults (Family Caregiver Alliance, 2016).

Caregiver Burden. “The alterations in caregiver’s emotional and physical health that can occur when care demands outweigh available resources” (Garber-Weider, 2014, p. 5).

Caregiver Burnout. “Caregiver burnout is caused by too much long-term stress. It occurs when you feel overwhelmed and can’t meet constant demands. As the stress continues, you begin to lose the interest or motivation that led you to take on a certain role” (American Heart Association, 2015, p. 1).

Caregiver Strain. “Perception or feeling of difficulty with duties and responsibilities associated with the caregiver role” (Garber-Weider, 2014, p.5).

Caregiver Stress. Consequence “when care provision is constant for the caregiver” and overwhelmingy challenging (Garber-Weider, 2014, p.5).

Caregiver Support. Readily available resources for caregivers to foster and enhance coping skills, such as online websites/forums, support groups, classes, or books (Butler, 2004).

Formal Services. Professionally employed or experienced volunteer caregivers for older adults (Family Caregiver Alliance, 2016).
Informal Services. Family or friends who help care for an older adult (Family Caregiver Alliance, 2016).

Instrumental Activities of Daily Living. Tasks that are supportive of an independent lifestyle (e.g., cooking, cleaning, shopping, or driving) (IADLs) (Family Caregiver Alliance, 2016).

Older Adult. An individual over the age of 65 (Administration on Aging, 2016).

Sibling. “One of two or more individuals having one common parent” (Merriam-Webster, n.d., para. 1).

The Sandwich Generation. Individuals who simultaneously care for their aging parents and dependent children (Miller, 1981).
Chapter 2

LITERATURE REVIEW

The Sandwich Generation Primary Caregiver

The definition of Sandwich Generation was first credited to Miller (1981) and describes the generation of individuals concurrently caring for their children and parents. Miller (1981) defined the age range of the Sandwich Generation as falling between 45 and 65 years of age; however, some caregivers may be younger than 45, while some may be older than 65. Since the initial formal recognition of the Sandwich Generation, additional literature has highlighted the evolving and changing parameters of caregiver demographics. Caregiving responsibilities are dependent on the health, daily activity, and living environment needs of the care recipient. Furthermore, caregiving literature highlights gender influences in family networks, as the majority of caregivers are women (Institute on Aging, n.d.; Ward & Spitze, 1998). However, it is not uncommon to find men who are assuming more caregiving responsibilities within family structures (Kowk, 2006). Likewise, Rosenthal (1999) supported the need to expand the current definition of the Sandwich Generation to better align with the shifting demographic patterns.

Caregiver Demographics

According to the Center for Disease Control, approximately 21% of families in the United States have caregiving responsibilities (2011). Additionally, it has been found the majority of caregivers are white/Caucasian (62%), married, women (75%) who are 49 years of age (Family Caregiver Alliance, 2016). Sandwich Generation caregivers most often have one parent over 65 years of age and at least one dependent child. Forty two percent of the overall caregiver population is part of the Generation X cohort (born
between 1965-1980) and 33% as the Baby Boomers cohort (born between 1946-1964) (Parker & Patten, 2013).

**Geographical location.** As stated by the Family Caregiver Alliance (2016), “the vast majority of caregivers (75%) reside within 20 minutes of their care recipient (para. 13). While there are caregivers in both rural/nonmetropolitan and urban areas, the availability of resources depends on the proximity of the caregiver to the care recipient. Furthermore, the living environment for both the caregiver and the care recipient is imperative in determining the type and level of care (Keith, Wacker, & Collins, 2009). Geographical location is a factor to consider when analyzing the amount of money caregivers spend, as expenditures occur in relation to (e.g., transportation, food) (Center for Disease Control, 2011).

**Daughters as caregivers.** Globally, women more often assume (by choice or by necessity) the role of being a caregiver. As a gender, women tend to be associated with nurturing and helping roles and caregiving aligns with such characteristics (Dautzenberg et al., 1998). Women in the Sandwich Generation have diverse roles, which include but are not limited to: mother, daughter, wife, grandmother, friend, and co-worker (Boyczuk & Fletcher, 2016). When an individual has diversity within and among roles, the likelihood of role strain and role conflict increases (Ward & Spitze, 1998). Through the application of the theories, caregiving roles will be examined.

**Applying Theory to Understand Caregiving**

When studying Sandwich Generation caregivers, there are elements and characteristics related to theory, specifically Symbolic Interaction Theory, Family Stress Theory, and Attachment Theory. Through a greater understanding of each theory and the
relation to caregivers, application of theories provides a foundation to understanding caregiver perceptions and factors.

**Applying Symbolic Interaction Theory to caregiving.** Symbolic Interaction Theory has been long-respected and applicable when analyzing family structures, especially with regard to understanding roles within the family. The development of the Symbolic Interaction Theory is credited to scholars Herbert Blumer (1969), George Herbert Mead (1934/1956), Charles Horton Cooley (1956), and William Isaac Thomas (1918-1920) (Smith & Hamon, 2012). One component of this theory is to view the world as a changing dynamic rather than a constant entity. The recognized assumptions of the theory include human development, self-concept, and society. Through a combination of these elements, environmental interactions develop and shape each individual. In other words, a sense of self is established through environmental interactions, as well as motivational experiences.

There are a combination of various terms and concepts that are connected to Symbolic Interaction Theory. The following terms and concepts including “symbols, interaction, gestures, social norms, rituals, roles, salience, identities, social act, and definition of the situation” are critical to understanding the theory (Smith & Hamon, 2012, p. 17). When analyzing caregivers and family dynamics, there are interactions, roles, and identities to be considered. In other words, interactions among family, friends, and community shape the way in which the family interacts. Each caregiver has a variety of roles. With each role, there are varied identities and perceptions aligned with the role. As caregivers develop more responsibility, there is a growing need to analyze the caregiving resources (Smith & Hamon, 2012).
Figure 1 illustrates the structure of the Sandwich Generation caregiver. The levels within the caregivers’ structure include community, family, children, and parents. Outside of this structure, there are resources, communication, caregiving roles, and caregiving relationship quality. Each level within the caregivers’ structure plays an essential role in the overall caregiver perceptions and factors of caregiving strain.

Figure 1
Symbolic Interaction Theory - Family Role(s) Structure Model

Applying Family Stress Theory to caregiving. There are a variety of definitions of the term, family stress. According to Boss (1992), “with change comes disturbance, pressure –what we call stress” (p. 114). Caregivers and care recipients experience stress
related to role strain, role clarity, and role expectations. Role strain may evolve with increased role expectations of caregivers. As caregivers seek role clarity, there is increased risk for caregivers to experience overload or emotional exhaustion. Role clarity is more evident for the caregiver when the perceived equilibrium of the familial relationships is achieved (Boss, Doherty, LaRossa, Schumm, & Steinmetz, 1993; Price, Price, & McKenry, 2010).

Positive communication interactions are essential among caregivers and care recipients (Boss, 1992). Resources of, time, money, and communication, or lack thereof, influence caregiving relationship quality (Boss et al., 1993). As families experience disruptions or pressures in life, stress increases. Stress occurs when an individual or group of individuals experience change and transition. Specifically, caregivers experience stress with life transitions. The presence and degree of stress are influenced by an individual’s perception of circumstances and roles. Stress can be perceived somewhere on a continuum of positive to negative (Price et al., 2010).

Applying the ABC-X/double ABC-X model to caregiving. Family Stress Theory was first studied and developed by Reuben Hill (1949). The model to understand family stress was constructed through analyzing the familial impacts of the Great Depression, World War II, and the Vietnam War (Boss, 1992). Family Stress Theory incorporates the ABC-X/Double ABC-X models, which analyze pre- and post-crisis stages. Family Stress Theory sequentially analyzes stressor events, resources, perceptions, pile-up stressors, and adaptation levels through the ABC-X model (Boss et al., 1993; Price et al., 2010).

ABC-X Model. As described below, the ABC-X model analyzes A: Event or situation, B: Resources, C: Perceptions, and X: Crisis/degree of stress (see Figure 2).
A: Stressor event. As stressful events occur within the family system, such as “boundaries, structures, goals, processes, roles, or values” (Price et al., 2010, p. 7), there is evidence of stress among the family members. Often, the stress is escalated due to a change that occurs within the family lifestyle. The stressors can be both positive and negative, however it is dependent on the perceptions of family. Specifically, family caregivers and care recipients often experience an event that changes their life, thus it is essential to learn how to adapt to the given changes (Price et al., 2010). The stress levels of individual caregivers and families will rise as normative and nonnormative events continue to impact the family (Price et al., 2010).

Stressors and everyday hassles impact family interactions, which affects the quality of family relationships. When faced with stressors, families who maintain hope allow more room for effective coping strategies. For caregivers, a variety of stressors may occur, including but not limited to, finances, time, and communication within the family system (Price et al., 2010).

B: Resources. A combination of cohesion and adaptability is essential to successfully coping with stressors. Individuals and families have advantages when they are able to depend on each other for emotional, esteem-related, and network support. Furthermore, community resources offer an added critical layer of support through individual and family services and programs (Price et al., 2010; Wujcik, 2008).

With continuous demands that are placed on caregivers, it is imperative that available resources are utilized. Resources are most beneficial when caregivers take a proactive approach to seeking out available resources. When caregivers perceive and actually have a strong sense of support, they are more likely to utilize and accept outside
resources, especially those related to time management, financial sustainability, and effective communication (Riley & Bowen, 2005).

C: Perceptions. Individuals, families, and communities perceive and react to stress differently. While one event may be perceived as minimally stressful, other events may be considered a full crisis (Price et al., 2010). Perceived and actual stress is often accompanied by feelings of lacking control. Feeling a lack of control is a barrier to adapting to and recovering from stress (Keith et al., 2009).

X: Crisis/degree of stress. As the degree of stress builds to a “breaking point”, the individual or family crisis occurs. For caregivers, examples of crises may include, but are not limited to: job loss due to missed time at work; illness or point of increased dependency for care recipient; strain on caregiver’s marriage to the point of separation or divorce; and abuse or neglect of care recipient (Price et al., 2010).

The ABC-X model provides a visual overview of the pre- and post-crisis stages.

*Figure 2*

Family Stress Theory: ABC-X Model adapted from (Witt, 2013) Pre-Crisis/Crisis
Double ABC-X Model. As described below, the Double ABC-X model analyzes AA: Pile-up, BB: Existing and new resources, CC: Perceptions, and XX: Adaptation (McCubbin, Carble, & Patterson, 1982) (see Figure 3).

**AA: Pile-up.** A variety of factors occur that cause the caregiver to experience stress within their role responsibilities. As the stressors pile-up the caregiver and their support system (family) must deal with the unresolved stressor, the associated changes, and the resulting hardships (Price et al., 2010).

**BB: Existing and new resources.** The resources the caregiver has access to are essential in analyzing the resources that are pre-existing as well as the resources that are new and readily available. Through strengthened resource network(s) “(personal, family, social)” (Price et al., 2010, p. 16) there are strengthened coping mechanisms (Price et al., 2010).

**CC: Perceptions.** The perception of the stressor event(s) play a role in the how the caregiver responds to the AA: Pile-up and BB: Existing and new resources, which also affects how the caregiver develops meaning to achieve XX: Adaptation (Price et al., 2010).

**XX: Adaptation.** Involves the original response to the perceived stressor and how the caregiver has adapted. The caregiver started on one end of the spectrum and used BB: Existing and new resources and CC: Perceptions to achieve XX: Adaptation (Price et al., 2010).
**Family Stress Theory: Double ABC-X Model adapted from (McCubbin et al., 1982).**

**Resiliency and coping.** While stressors and strains occur in caregiving situations, there are positive aspects of caregiving. Sandwich Generation caregivers benefit from high levels of resiliency and coping skills (Abramson, 2015). Family protective factors aid in resiliency and coping. Resiliency literature emphasizes four main concepts: vulnerability, crisis, adjustment, and adaptation. Resiliency factors that help to support the caregivers are family problem solving, communication, equality, spirituality, flexibility, truthfulness, hope, family hardiness, family routine, social support, and health. When analyzing successful coping mechanisms, it is evident that more support networks (if time permits caregivers to access) and presence of resiliency factors allow families to experience the benefits of caregiving (O’Rourke, 2016).
When applying Family Stress Theory to better understand the Sandwich Generation caregiver, there is a transitional process that occurs with each stressor, strain, or burden. Furthermore, the concept of perceptions leads to greater understanding that individuals and families will react to stressful events in different ways. There are a variety of supports available to the Sandwich Generation caregiver in the forms of family, friend, and workplace support networks (O’Rourke, 2016). Despite taking on different roles and assuming new by simultaneously caring for aging parents and dependent children, support networks help Sandwich Generation caregivers’ levels of resiliency (Dautzenberg et al., 1998).

As the Sandwich Generation caregiver builds resiliency and utilizes coping mechanisms, there are benefits related to aging readiness. In other words, as caregivers see the risks and benefits to aging, preventative and proactive measures for self-care are increased. Adult children who experience their parents’ lives more closely and intimately are more aware of factors, such as lifestyle choices, that complement successful and healthful aging (Hogstel, Curry, & Walker, 2005).

Applying Attachment Theory to the relationship between caregiver and care recipient. The family relationships among Sandwich Generation caregivers are complex and multifaceted. An important factor in relationship quality is perceived degree of closeness between the caregiver and care recipient. Furthermore, a secure attachment is essential for older adults in a stage of increased dependence on their caregivers. Developed by John Bowlby (1958), Attachment Theory recognizes the relationship bond between caregiver and child. Attachment Theory is often used to analyze children’s relationships with their caregiver. As adults live longer and caregiving roles increasingly
become reversed between parent and child, Attachment Theory offers a useful lens to better understand caregiver and care recipient relationships (De Carli, Tagini, Sarracino, Santona, & Parolin, 2015). Within family caregiving situations, communication patterns change to varying degrees for family systems (Mancini & Blieszner, 1989; Nussbaum, Pecchioni, Robinson, & Thompson, 2000). More frequent contact among family members naturally leads to an increased need for communication. That being said, the type and extent of care recipient deficit or ailment impacts communication abilities, such as comprehension and ability to retain information.

Figure 4 illustrates the fluidity of attachment between the caregiver and care recipient in a mid-range theoretical model created for the current study. It is important to note that this changes throughout the lifespan as caregiver and care recipient roles shift.

Figure 4
Attachment Theory - Caregivers and Care Recipients
Siblings Relationships

Communication is essential among family members, especially siblings, involved in caregiving for an aging parent. As siblings age, there is a greater likelihood for a decrease in sibling contact due to new responsibilities and distance. Furthermore, sibling interactions are based on the perceived level of contact, closeness, and feelings of friendship. There are different functions among siblings and there are noticeable differences between female and male siblings, male siblings only, and female siblings only. Levels of support, communication, and affection are critical components to understanding the perceived degree of closeness in sibling relationships. Each family has diverse dynamics and such diversity is an imperative consideration in recognizing relationship quality among siblings (Nussbaum et al., 2000).

Caregiving Resources

According to Riley & Bowen (2005), over 80% of care for older adults is handled by family members - spouses, children, or other close relatives. With an increased need for caregiver support, current American trends need to shift to allow for comprehensive care for older adults. “By 2050, there will be as many individuals 65+ as children 0-18, for the first time in the history of the world” (Angelis, 2012, p. 6). With a growing need for familial caregiver support, there are many responsibilities that have to be managed (Seaward, 1999). As stated by Boyczuk & Fletcher (2016), the number of people in the business of caregiving is decreasing, while the number of older adults is rapidly increasing.

Time. Caregiving duties for family caregivers are assumed at a starting point and most often continue until the care recipient’s death. Subsequently, caregiving may range
from days to years. Increased longevity of the aging population is resulting in larger numbers of older adults. This trend is referred to as the “graying” of America (Kwok, 2006; Ward & Spitze, 1998; Wassel & Cutler, 2016). The vast majority of caregivers are unpaid family members who spend an average of 20 hours a week on caregiving duties (Center for Disease Control, 2011; O’Sullivan, 2015). When caregivers have an added burden of financial stress, there is a need to have full-time or part-time employment. However, with the amount of time associated with caregiving duties and taking care of children/family, it is often challenging for caregivers to balance employment (O’Sullivan, 2015; Pierret, 2006).

**Finances.** It is important to note that the majority of caregivers are unpaid, as it is seen as a familial responsibility (Keith et al., 2009). Knowing this, individuals who are “caught” in the Sandwich Generation may experience increased financial burdens (Dautzenberg et al., 1998; Raphael & Schlesinger, 1994). Expenditures (e.g., transportation, food, prescriptions, household supplies, gifts) that are accrued during caregiving vary and financially affect caregivers, especially those in low – to middle-income brackets (Keith et al., 2009). One estimate reports that at least $5,531 is spent annually out of pocket by caregivers on care recipients and this is the lower end of the spectrum (Evercare, 2007). Concurrently supporting children and parents often results in a financial burden to caregivers (O’Sullivan, 2015; Pierret, 2006).

**Familial and Societal Caregiving Trends and Attitudes**

There are different stereotypes, as well as positive and negative connotations, associated with caregivers and care recipients. Ageism and stereotyping can be influenced by lack of intergenerational understanding, as well as interactions stemming
from individual perceptions. As more positive intergenerational interactions are generated, a greater level of understanding and appreciation can be reached in familial relationships (Pecchioni & Croghan, 2002). In other words, as ageism and stereotypes are exploited and conquered in the realm of caregiving, then complex familial and caregiving relationships positively shift (Hummert, Garstka, Shaner, & Strahm, 1995). Empathy and understanding for caregivers in the Sandwich Generation are valuable while turning away from negative ageism and stereotyping (Butler, 2004). Diverse traits of openness, self-reflection, and flexibility are beneficial for caregivers to possess because families experience a variety of burdens that influence caregiving. It is important to recognize that family dynamics change due to shifts in relationships within caregiving (Cohen, 2012).

**Caregiver Exhaustion and Fatigue**

Caregivers can experience a variety of diverse stressors, caregiver strains, and caregiver burdens. It is critical to understand the factors of caregiver stress, which include denial, anger, exhaustion, irritability, lack of concentration, sleeplessness, social isolation, health problems, and depression. Furthermore, caregiver strain is recognized as difficulties in caregiver roles (Garber-Weider, 2014). Caregiving burden can lead to feelings of manipulation and/or oppression, which can lead to emotional distress of caregivers (Waller Snyder, 1993). Each and every individual is different in their perceptions of stress, which can lead to exhaustion, burnout, and/or fatigue. It is essential that caregivers find effective ways to stay positive and practice self-care (Garber-Weider, 2014).
Caregiver Stress and Self-Care

With new or changing roles and responsibilities, female caregivers in the Sandwich Generation experience greater risk for burdens and strains (Ward & Spitze, 1998). Often, caregivers become consumed by caring for their children and aging parents, which can result in self-care negligence (Abramson, 2015). Strain from added responsibility occur and those related to work, marriage, and finance are among the top (Cohen, 2012). As supported by Butler (2004), caregivers would be best served to avoid the “coulda-shoulda-woulda” mentality. As a caregiver with diverse roles, self-care becomes more critical. For example, learning to say “no” and developing a comfort level with saying “no” benefits caregivers. Caregivers feel a real or perceived need to perform every task and, consequently, there is an elevated importance for setting clear boundaries (Butler, 2004).

With role reversal in caregiving relationships between a parent and an adult child, there can be an increased level of stress and difficulty in coping (Miller, 1981). Caregivers benefit from accepting help when offered because of the new challenges associated with transition in roles. Although not all caregivers receive formal help, it is valuable for caregivers to be aware of available resources. Every caregiver and caregiving situation is unique and what works for one caregiver may not work for another. Through an understanding of diverse family and caregiving dynamics, three prominent and effective coping mechanism traits include self-determination, forgiveness, and wisdom (Petrovich, 2008). Effective stress management and devoting time to oneself are critical to maintaining the physical, mental, and social health of caregivers (Cohen, 2012).
Mistakes and missteps are going to occur in caregiving situations. Feelings of shame, distress, and isolation result can lead to reluctance of caregivers accepting assistance; however, outside support and help are essential to manage stress and self-care (Butler, 2004). Through the application of Family Stress Theory, greater understanding of stressors in relation to family dynamics becomes evident.

**Summary**

This literature review provides a comprehensive portrayal to answer the question of—“Who is the Sandwich Generation caregiver?” Through analyzing and applying Symbolic Interaction Theory, Family Stress Theory, and Attachment Theory, an increased holistic understanding emerges of Sandwich Generation caregivers. Symbolic Interaction Theory emphasizes the importance of looking at the world as a changing dynamic and allows in-depth exploration of caregivers’ sense of self. Family Stress Theory serves as the umbrella for two applicable and distinct models: the ABC-X model and the Double ABC-X model. The former provides a model for understanding pre-crisis time periods and the latter provides a model for understanding post-crisis time periods. Both allow for greater understanding of Sandwich Generation caregiver strain. Last, Attachment Theory explains the changing complex and multi-faceted parent-child relationship as role reversals occur between the caregiver and care recipient (De Carli et al., 2015).

As individual perceptions and family dynamics change during caregiving, the family structure as a whole is experiencing changes. The quality of the caregiver and care recipient relationship and sibling relationships becomes even more important as family and life dynamics shift (Perrig-Chiello & Hopflinger, 2005). Family structure is fluid, as
relationships either strengthen or weaken over time (George & Binstock, 1998). To maintain or achieve close and supportive family relationships, caregivers must holistically assess the aspects of their lives for higher levels of overall satisfaction to be present. Sandwich Generation caregivers need supportive networks, consisting of primarily family (Ward & Spitze, 1998) or close, trusted resource persons. A cohesive family unit, which offers help and guidance, allows for manageability in caregiving.
Chapter Three

METHODOLOGY

The purpose of this study is to investigate the factors that contribute to perceived strains in Sandwich Generation caregivers. Caregiver strains will be analyzed through self-reporting on items in checklists and Likert scales. Geographical location, caregiving relationship quality, caregiving roles, communication, and resources (time and finances) will be included to analyze data.

Design of the Study

The design of this study is quantitative and descriptive.

Sample

The sample was obtained from social media (Facebook, Instagram, Twitter, and LinkedIn), email, listservs, and word of mouth through a nonprobability snowball approach (Creswell, 2012). Respondents included 50 qualifying participants and 21 non-qualifying participants. Only the responses of the 50 qualifying participants were analyzed and the 21 non-qualifying participants were omitted. Of the qualifying participants, 100% (N = 50) identified as female, had at least one child under the age of 18 living with them (at least part of the time), and acted as a primary caregiver for their parent(s) for at least 6 consecutive months.

Selection and description of the sample. After recruiting the sample, participants were provided with an electronic-based informed consent form. Participant criteria included: female, ages 36-71 (Baby Boomers and Generation X), 1 or more living siblings, current primary caregiver of parent(s) for at least 6 consecutive months, and at least 1 dependent (<18 years) child(ren) living in the home at least part of the time.
Instrumentation

Data were collected through a non-identifiable online quantitative survey (see Appendix A for Sandwich Generation Caregiver Survey) that was developed and administered by the researcher through the survey platform, Qualtrics. The survey consisted of 38 items, including a demographic section, checklists, and 10-point Likert scales. Prior to participation, respondents provided consent (see Appendix B for Consent to Participate in Research) and participants were directed to the survey.

Measurement

The four main variables of the study and their alignment with survey items were as follows:

- Caregiving relationship quality (Items # 23, 24, 25, 31)
- Caregiving roles (clarity, expectations, and strain) (Items # 20, 21, 26, 27, 28, 29, 32, 33, 34, 35)
- Communication (Items # 36, 37)
- Resources (time and finances) (Items # 22, 30, 38)

The survey items have been adapted from the Caregiver Strain Index (CSI) (Robinson, 1983) and Caregiver Burden Scale (Zarit, Reever, & Bach-Peterson, 1980), both of which have been established as reliable and valid instruments. Since this was the first time implementing the survey in its current format, reliability has not been fully established. Additional items were formulated using theoretical concepts as a foundation, which establish construct validity. The concepts of Symbolic Interaction Theory were integrated within the instrument items. Concepts of Symbolic Interaction Theory (see Figure 1)
included the variables of: caregiving relationship quality, caregiving roles, communication, and resources (time and finances) (see Appendix D).

**Procedure for Data Collection**

Approval was secured from the University’s Institutional Review Board. All participants agreed to complete the survey were notified that the data are anonymous. Additionally, if any participants wished to withdraw from the study, then they could do so at any time without penalty.

The survey website link was shared with participants. Social media contacts were encouraged to share the survey link with others to recruit additional participants. Once participants consented to the online survey, they were directed to the survey link. Survey data collection lasted for 4 weeks.

**Data Analysis**

The researcher analyzed the quantitative data using Microsoft Excel Software (2011). Frequency counts, percentages, and mean scores were used to analyze descriptive data. Path analysis (charts and graphs) described patterns of demographics, caregiving, relationship quality, caregiving roles, communication, and resources (time and finances). Path analysis, including charts and graphs, illustrate patterns and themes evidenced by the data.
Chapter 4

RESULTS AND DISCUSSION

The purpose of this research study was to investigate the factors that contribute to perceived strains in Sandwich Generation caregivers. Demographics were analyzed to establish a caregiver profile and compare to benchmark demographics. The four main variables that were analyzed within the study include: caregiving relationship quality, caregiving roles, communication, and resources (time and finances).

Sample Demographics

Demographic questions focused on age, marital status, employment status, highest education level, and race/ethnicity. Each demographic component allowed for analyzing the Sandwich Generation caregiver data. For a comprehensive overview of the demographic data described below, see Appendix C (Figures 5-16).

In relation to age, 24% \((n = 12)\) were 40-44, 24% \((n = 12)\) were 50-54, and 22% \((n = 11)\) were 55-59. Baby Boomers and Generation X (ages 36-71) were included, which corresponds with Miller’s (1981), research indicating the most commonly identified female caregivers fall between the ages of 45 and 65, a statistic that remains current (Parker & Patten, 2013; Rosenthal, 1999).

In relation to marital status, 68% \((n = 34)\) were married and 20% \((n = 10)\) were divorced. Caregiving literature indicates that the typical caregiver is a married woman who is employed full time (Caregiver Action Network, n.d.).

In terms of employment status, 50% \((n = 25)\) were employed full time, 24% \((n = 12)\) were not employed for more than one year, 20% \((n = 10)\) were employed part-time, 4% \((n = 2)\) were other, and 2% \((n = 1)\) were not employed for less than one year.
Often, employment status is affected as caregivers in the Sandwich Generation have multiple roles to fulfill as they balance work-family demands. The task of caregiving commonly becomes an intensified responsibility with added resource (e.g., time, money) constraints. Consequently, full-time employment may shift to part-time employment or unemployment (depending on the level of caregiving involvement) (Scommegna, 2016).

Education level showed 18% \((n = 9)\) with an Associate’s degree or the equivalent, 28\% \((n = 14)\) with a Bachelor’s degree, 8% \((n = 4)\) with a High School diploma or GED, 26% \((n = 13)\) with a Master’s, Doctorate, or other advanced degree, and 20% \((n = 10)\) were attending college.

For race and ethnicity, 78% \((n = 39)\) identified as White or Caucasian, 12% \((n = 6)\) as Black or African American, 8% \((n = 4)\) as Hispanic and Latino, and 2% \((n = 1)\) as Other. Despite having the option to select more than one, each participant selected only one race/ethnicity category. The results from this study align with the current demographics of caregivers. Nationally, over 60% of current caregivers are recognized as White or Caucasian (National Alliance for Caregiving and the AARP Public Policy Institute, 2015).

Furthermore, survey items focused on total household income, geographical locations of caregivers and parents, parent(s)’ current living situation, gender of siblings, siblings’ location in proximity to caregiver, parents’ location in proximity to caregiver, and siblings’ location in proximity to parents.

In relation to household income, earnings ranged from $10,000 through $19,999 to $150,000 or more. The largest categories included: 28% \((n = 14)\) earned $100,000-$149,000 and 14% \((n = 7)\) more than $150,000. Household income influences the level of
support that can be offered by the caregiver. If the caregiver is the main source of income for their family, then paid employment is essential. Caregivers commonly maintain full-time paid career status and a “second career” as a caregiver. If the caregiver is not the sole source of income, then it may be feasible for them to maintain a part-time status or no employment.

The top three caregiver-reported types of geographical locations included: 54% (n = 27) suburban, 28% (n = 14) small town, and 14% (n = 7) rural. Knowing where the caregiver lives provides insight into the proximity to the parent and, possibility, to the type and amount of available and accessible resources offered within the community.

Next, the reports of the parents’ geographical location are similar to the caregivers’ geographical location. As yielded in the survey, 54% (n = 27) of parents live in a suburban setting, 30% (n = 15) in a small town, 10% (n = 5) in an urban area, and 6% (n = 3) in a rural environment.

Twenty percent (n = 10) of participants indicated that their parent lives in a residential care site, 32% (n = 16) live alone in their own home, 10% (n = 5) live with another person in their own home, 32% (n = 16) live with the caregiver, and 6% (n = 3) live elsewhere in an unspecified type of residence.

The type of living situation is important to examine, as living environment influences longevity of older adults. With changing family dynamics, there will continue to be a variety of living arrangements/environments for older adults. With a high percentage of older adults able to perform the necessary Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs), families have greater comfort with parents aging “in place” in their own homes. However, if the older adult is
unable to perform ADLs and IADLs, then families need to consider residential care or another type of long-term care (Scommegna, 2016).

The number of children under the age of 18 in the caregiver’s household included: 60% ($n = 30$) with 1 child, 32% ($n = 16$) with 2 children, 6% ($n = 3$) with 3 children, and 2% ($n = 1$) with 4 children. As originally stated by Miller (1981), the key determining factor for a caregiver to be classified in the Sandwich Generation is having a child under the age of 18. However, in more recent years, there has been greater recognition of adult children over the age of 18 still living in the home. With a changing economy, it is not uncommon to find older children who are college graduates living at home (Parker & Patten, 2013). However, for the purpose of this study, the parameters included the original definition of the Sandwich Generation caregiver who has a child(ren) under the age of 18.

Looking at mileage proximity of caregivers to parents, parents to siblings, and caregivers to siblings helps to further analyze the care recipient to caregiver relationships and sibling relationships. When analyzing location between the caregivers and their siblings, 52% ($n = 26$) having their sibling(s) 100 or more miles away. Geographical distance between siblings and care recipient explain how much potential exists for the primary caregiver to receive instrumental and emotional assistance and support. The distance that the caregiver lives from the care recipient can influence employment status and strain, income expenditures, and in some cases, marital relationship time and quality.

On average, participants had two siblings: one sister and one brother. Siblings ranged in age from under 20 through age 64, with the most common sibling age range as 50-54 ($n = 23$).
For the Likert scale portion of the instrument, four variables were analyzed: caregiving relationship quality, caregiving roles, communication, and resources (time and finances). For a comprehensive item-by-item analysis of all four variables, see Appendix D (Table 5).

**Caregiving Relationship Quality**

For caregiving relationship quality Items # 23-25, and 31, each item mean score (based on a Likert scale of 1 to 10), and the standard deviation will be included.

Table 1

*Mean and standard deviation scores for caregiving relationship quality (N = 50)*

<table>
<thead>
<tr>
<th>Caregiving Relationship Quality Question</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>25. I am afraid about what the future holds for my parent.</td>
<td>6.78</td>
<td>2.95</td>
</tr>
<tr>
<td>24. Caring for my parent affects my relationship with other family members in a negative way.</td>
<td>5.18</td>
<td>2.99</td>
</tr>
<tr>
<td>23. I feel frustrated when I am around my parent.</td>
<td>5.14</td>
<td>2.79</td>
</tr>
<tr>
<td>31. I wish that I could leave the care of my parent to my sibling(s).</td>
<td>4.12</td>
<td>2.97</td>
</tr>
</tbody>
</table>

In Item # 25, the mean was 6.78, which indicates a higher level of strain the caregivers feel regarding their parent and the uncertainty of the future. Through a continued study of the stress of Sandwich Generation caregivers (Miller, 1981), associated caregiving-related fears can be better understood. As caregivers experience different strains and stressors, fear can manifest within and outside of the family environment (e.g., parental living environment, parental health conditions, parental income source(s), parental healthcare).

The levels of perceived stressors contributing to caregiver strain paired with multiple caregiver role obligations were reported. Current research literature describes
the importance of self-care and the need for solitary time of the caregiver. This research literature relates to Item # 23 - I feel frustrated when I am around my parent ($M = 5.14$, $SD = 2.79$). Too often, caregivers neglect self-care. Through understanding the stressors of Sandwich Generation caregivers and their perceived level of available time, there can be a greater level of support in aiding caregiver’s self-care techniques (Miller, 1981).

When caregivers perceive support within the family structure, then relationship quality is likely to experience lower levels of perceived strain (Riley & Bowen, 2005). In relation to resiliency and coping, increased levels of support network allow for greater levels of satisfaction within caregiving (O’Rourke, 2016). Specifically, caregiving relationship quality relates to Objective 1: To determine the extent to which the Sandwich Generation caregiver identifies sibling support as a factor in caregiver strain. If siblings have a minimal or non-existent role as caregivers, then how much – if, at all – are those siblings contributing to satisfaction levels and well-being for caregivers?

Each family has unique dynamics and, subsequently, the associated perceptions of caregiver strain(s) are different. The participants in this study provided information about siblings in Item # 24 - Caring for my parent affects my relationship with other family members in a negative way. A mean score of 5.18 indicated a moderate level of perceived strain by caregivers (see Table 1). With further understanding of sibling relationships in the context of caregiving and sibling relationships, there can be a greater understanding of the continuum of positive or negative sibling perceptions. In some cases, multiple siblings may self-identify as a “primary” Sandwich Generation caregiver, which can either elevate or lessen the degree of role confusion.
Caregiving Roles

In relation to caregiving roles (clarity, expectations, and strain), Items # 20-21, 26-29, and 32-35 are listed below and include the mean (based on a Likert scale of 1 to 10) and the standard deviation.

Table 2

Mean and standard deviation scores for caregiving roles (N = 50)

<table>
<thead>
<tr>
<th>Caregiving Roles Question</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>26. My parent is dependent on me.</td>
<td>6.74</td>
<td>2.67</td>
</tr>
<tr>
<td>21. Because of the time I spend with my parent, I do not have enough time for myself.</td>
<td>6.02</td>
<td>3.03</td>
</tr>
<tr>
<td>29. My social life has suffered because of caring for my parent.</td>
<td>5.78</td>
<td>3.28</td>
</tr>
<tr>
<td>33. I feel that I should be doing more for my parent.</td>
<td>5.78</td>
<td>2.76</td>
</tr>
<tr>
<td>28. My health/well-being has suffered because of caring for my parent.</td>
<td>5.72</td>
<td>3.03</td>
</tr>
<tr>
<td>27. I feel strained when I am around my parent.</td>
<td>5.32</td>
<td>2.64</td>
</tr>
<tr>
<td>32. I feel uncertain of what to do about my parent.</td>
<td>5.30</td>
<td>3.32</td>
</tr>
<tr>
<td>34. I feel that I could be doing a better job in caring for my parent.</td>
<td>5.14</td>
<td>2.51</td>
</tr>
<tr>
<td>20. My parent asks for more help than is actually needed.</td>
<td>4.68</td>
<td>3.29</td>
</tr>
<tr>
<td>35. I feel supported by my siblings in my caregiving role</td>
<td>3.54</td>
<td>2.67</td>
</tr>
</tbody>
</table>

Item # 35 yields a mean of 3.54, which indicates a low level of support felt by caregivers within the sibling relationships. Relationships between and among sibling(s) are influenced by communication patterns. As family dynamics are unique and communication patterns differ, lack of communication can have a detrimental effect on the relationship quality (Boss et al., 1993).
Caregiving roles relate to Objective 2: To determine the extent to which the Sandwich Generation caregiver identifies multiple obligations as a factor in caregiver strain. As indicated by Boyczuk and Fletcher (2016), the increased responsibility perceived by the Sandwich Generation caregiver plays a role in negatively affecting their well-being. Knowing this, the number of perceived roles can influence the caregiver in negative ways. The higher number of roles, the greater the risk to self-care. As reported by Stephens, Franks, and Townsend (1994), the top three roles of a caregiver—wife, mother, and caregiver influence perceived and actual stressors. There are a variety of other stressors that can influence caregiver well-being.

From a theoretical application approach, the ABC-X/Double ABC-X model adapted from the Family Stress Theory can analyze caregiver stress as: caregiving need occurs (A factor - stressor); caregivers have varying types and degrees of resources (B factor); caregivers perceive the situation in multiple ways (C factor); and crisis points may manifest (X factor). Crisis can be largely precipitated by a lack of available/accessible resources to fulfill the caregiving role. The Double ABC-X model can be applied to better understand the post-crisis period of pile-up of stressors (AA factor) (e.g., caregiver exhaustion or fatigue); utilization of existing/new resources (BB factor); constant or changed perceptions (CC factor); and caregiver adaptation (XX factor).

When care recipients display high levels of dependence on the caregiver, there is more often a level of associated strain, which can be explained through Attachment Theory by John Bowlby (De Carli et al., 2015) (see Figure 4). The level of care recipient dependence, Item # 26, yielded a mean of 6.74, which indicated a higher level of
perceived stress on the caregiver due to the care recipient needs (e.g., assuming responsibility for assisting with ADLs and/or IADLs). When applying Attachment Theory, the relationship between the caregiver and care recipient is framed by reversal and shifting of roles. The adult child becomes the caregiver and the aging parent becomes the care recipient. As this study analyzed Item #26, lack of role clarity may be influenced by a misconception of the expectations held by both the caregiver and care recipient.

Caregiving roles relate to Objective 3: To determine the extent to which the Sandwich Generation caregiver identifies lack of role clarity about care expectations as a factor in caregiver strain. Through a greater understanding of the perceived level of role stressors and role clarity, enhanced levels of support can aid Sandwich Generation caregivers. Specifically, when role clarity (how well role is understood and defined) is present for a Sandwich Generation caregiver, then levels of stress may be lower. As displayed in Items #20-21, 26-29, and 32-35, there are no reports of perceived level of strain over a mean score of 6.74. When role clarity is present and role expectations are understood, the perceived levels of caregiver strain tend to remain at moderate levels, as indicated by the mean scores for all items specifically focused on caregiver relationship quality.

Communication

The items focused on communication included #36-37. Each item is listed below and includes the mean score (based on a Likert scale of 1 to 10) and the standard deviation.
Table 3

*Mean and standard deviation scores for communication (N = 50)*

<table>
<thead>
<tr>
<th>Communication Question</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>36. There is a strain in communication among my siblings and me</td>
<td>5.14</td>
<td>3.35</td>
</tr>
<tr>
<td>37. The communication among my siblings and me has declined as care of our parents has increased.</td>
<td>4.96</td>
<td>3.34</td>
</tr>
</tbody>
</table>

Item # 36 and # 37 both display a moderate level of perceived communication strain. It should be noted that sibling communication is particularly interconnected with other variables, as well: caregiving relationship quality and caregiving roles. The variable of communication aligns with Objective 4: To determine the extent to which the Sandwich Generation caregiver identifies sibling communication as a factor in caregiver strain. With communication barriers, families encounter communication difficulties; associated strains, burdens, and conflicts arise in siblings relationships, specifically females assuming the caregiving role (Scommegna, 2016). However, if sibling(s) are able to work together and strengthen the degree/type of communication, there is greater likelihood for higher levels of sibling satisfaction (Smith & Hamon, 2012).

**Resources (Time and Finances)**

Last, the items focused on resources (time and finances) included Items # 22, 30, and 38. Each item is listed below and includes the mean score (based on a Likert scale of 1 to 10), and standard deviation.
Table 4

Mean and standard deviation scores for resources (time and finances) (N = 50)

<table>
<thead>
<tr>
<th>Resources (time and finances) Question</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. I feel stress trying to balance my obligations to my parent with my other obligations (e.g., family, work).</td>
<td>7.54</td>
<td>2.60</td>
</tr>
<tr>
<td>38. I do not have enough time to complete everyday tasks.</td>
<td>6.84</td>
<td>3.24</td>
</tr>
<tr>
<td>30. I do not have enough money to spend on both my parent and my other expenses.</td>
<td>5.52</td>
<td>3.38</td>
</tr>
</tbody>
</table>

The level of resources, as perceived by caregivers, is essential to aid in caregiving responsibilities. Specifically, resources (time and finances) relates to Objective 5: To determine the extent to which the Sandwich Generation caregiver identifies resource levels as a factor in caregiver strain. Often, caregiver(s) assume the responsibility over other sibling(s) because they view caregiving as their familial duty (Keith et al., 2009). It is essential to note that this will change from family to family, but in situations like assuming the role as primary caregiver, there are a variety of perceived stressors (Cohen, 2012). When looking at Item # 22 - I feel stress trying to balance my obligations to my parent with my other obligations (e.g., family, work) - a mean of 7.54 is yielded, indicating higher overall levels of perceived stress. When caregivers understand their responsibilities and have time to fulfill caregiving roles, stress can be lessened (Ward & Spitze, 1998). Time is valuable, especially in relation to Item # 38 - I do not have enough time to complete everyday tasks - which yielded a mean of 6.84. Knowing that time is important to caregivers and the participants perceive not having enough time, specifically Sandwich Generation caregivers, it is essential that their time and schedule are respected.
With increased time, the multiple responsibilities (stressors, strains, burdens) can be better managed and aid in lowering levels of stress (Stephens et al., 1994).

**Application of Symbolic Interaction Theory to Research Findings**

When analyzing the perceived level of caregiving relationship quality, caregiving roles, communication, and resources (time and finances), Symbolic Interaction Theory is applicable to better understand caregiver behavior. As indicated in (Figure 1), each of these factors are concepts of the theory and changing dynamics occur within each unique caregiving role. Sandwich Generation caregivers will experience changes over time, as they may shift in or out of or vary the degrees of their roles and responsibilities. Symbolic Interaction Theory includes the focus on different interactions within the family/parent(s), child(ren), and community and the constant evolving of changes at each level. As Sandwich Generation caregivers assume the role of caregiver, their roles may shift and change as family dynamics do (Smith & Hamon, 2012).

The perceived level of stressors, strains, and burdens can continue to be analyzed, as the body of caregiving research grows. Furthermore, if programming and resources for Sandwich Generation caregivers are based on the constructs of theoretical models (e.g., Symbolic Interaction Theory) there exists the greater potential for effective models of caregiver support networks.

**Summary**

Findings from this study aid in understanding and navigating caregiver strain for current caregivers, specifically Sandwich Generation caregivers, their families, and professionals with whom they come in contact. The Sandwich Generation caregiver has a variety of roles to fill (e.g., mother, daughter, sister, wife, friend, colleague) and there are
perceived levels of strain within different variables (e.g., caregiving relationship quality, caregiver roles, communication, and resources). Through continued research to assist Sandwich Generation caregivers, feelings of caregiver exhaustion and fatigue have the potential to be effectively managed or reduced through increased resiliency and coping mechanisms (e.g., caregiver support networks). The caregiver demographics and the variables of caregiving relationship quality, caregiving roles, communication, and resources (time and finances) aligned with the study’s objectives and data provided in-depth illustrations of each objective.
Chapter 5

SUMMARY, RECOMMENDATIONS, AND CONCLUSIONS

Through an understanding of the previous, current, and future research in the realm of caregiving, specifically Sandwich Generation caregivers, more resources and support can aid in relieving strain, stress, and burdens. Upon careful consideration of limitations, recommendations for professionals, and recommendations for future research, there will be continued and improved resources and support for Sandwich Generation caregivers.

Limitations

One limitation of this study included having only one family caregiver completing the survey. Consequently, findings reflect one caregiver’s perceptions, as opposed to a holistic perception of multiple family members involved in caregiving. Second, the sole focus on females is a limitation, as males do fulfill caregiving roles. Third, there was an underrepresentation of caregivers in low-income brackets, so further investigation is needed of this cohort. Fourth, within the research, data analysis techniques allowed for description of data, but not inferences about the data (e.g., correlations).

Interconnections among Caregiving Relationship Quality, Caregiving Roles, Communication, and Resources (Time and Finances)

One overarching theme from the Sandwich Generation Caregiver Survey results was interconnectedness among the study’s four variables. Through analyzing each variable independently, interconnectedness emerged and was apparent. In other words, caregiving roles, communication, and resources (time and finances) all depict how the Sandwich Generation caregiver more broadly perceives caregiving relationship quality.
The caregiving relationship quality will be different for each Sandwich Generation caregiver, as some will feel higher levels of stress within caregiving roles (e.g., mother, daughter, sister, wife, friend, colleague), communication (e.g., sibling communication, care recipient communication, family communication), and resources (time and finances) (e.g., personal funds, personal time, family time). Understanding that caregiving roles, communication, and resources (time and finances) all play a role in caregiving relationship quality helps build a comprehensive picture of the Sandwich Generation caregivers and their perceptions and factors in relation to caregiving strain.

**Caregiving: Now and in the Future**

Current research paints a picture of “the typical caregiver”. As population and other societal demographics shift, the “typical” caregiver may not be so “typical”. As indicated by the Family Caregiver Alliance (2016), the majority of caregivers are white/Caucasian (62%), married, women (75%) who are 49 years of age. The current study found commonalities (race/ethnicity, marital status, and age) in the sample demographic results compared to demographics benchmarks in the research literature. However, the current study only included female caregivers. Research literature suggests that roughly 40% of caregivers are males (National Alliance for Caregiving and the AARP Public Policy Institute, 2015). Knowing that more males are assuming the roles of caregiving, the traditional definition of the Sandwich Generation caregiver, as coined by Miller (1981), is expanding, shifting, and molding into a new definition of what it means to be a Sandwich Generation caregiver.
Recommenda tions for Professionals

As the Sandwich Generation caregiver profile evolves with shifting demographics, it is essential to remain current on these trends. Through continued knowledge and awareness, new trends in caregiver networks and support will follow. Current programs may not be successful in aiding Sandwich Generation caregivers and a need exists for broader aspects and strategies for caregivers. As implementation of programs are continued online or face-to-face, it is essential to target different levels and degrees of caregiving. Some Sandwich Generation caregivers feel alone and isolated due to the lack of specific support.

Upon speaking with professionals in the field and caregivers’, there were a variety of discussion topics on how to help caregivers in the future. The perceived level of support is often low, as many caregivers experience multiple role obligations. For Sandwich Generation caregivers, there is a lack of support in general. With online-specific support groups to aid Sandwich Generation caregivers, this will be one step towards allowing caregivers to have more support. As more awareness occurs within the realm of caregiving, there can also be more advanced face-to-face availability. However, this may be more feasible in larger cities, as there are more resources. Still, smaller geographic locations would allow for closer and more conveniently accessible options. The diverse trends will allow for future research to adapt to the needs of the different types and degrees of caregivers.

Recommendations for Future Research

Through continued understanding of the perceptions and factors of caregiving strain, future research will reflect the changing demographics and caregiver need.
However, as indicated by Smith and Hamon (2012), more research is needed on caregiving resources. By further study of caregiving resources, there can be a greater understanding of effective strategies to reduce and provide support for caregiver strain. With caregiving strain, there are often associated feelings of guilt, burden (Garber-Weider, 2014), and emotional distress (Waller Snyder, 1993). An escalation of such stress-related emotions often results in a risk or decline of caregiver health. Knowing how to aid caregivers reduce strain, stress, and burdens will allow for more support, which can promote self-care and self-help techniques (Garber-Weider, 2014). To adhere to the current demographics of Sandwich Generation caregivers, further research should be conducted on Sandwich Generation caregivers who have children over the age of 18 living in the home full-time or part of the time.

**Recommendations on Revising the Sandwich Generation Caregiver Survey**

In creating and implementing a new Sandwich Generation Caregiver Survey, as adapted by the Caregiver Strain Index (CSI) (Robinson, 1983) and the Caregiver Burden Scale (Zarit et al., 1980), integration of theoretical concepts as a foundation helped to establish construct validity. The current study was kept to a minimal time frame for completion (10-15 minutes) to respect caregivers’ time constraints. Knowing that Sandwich Generation caregiver study participants are busy and fulfilling numerous roles, it was important to keep the survey completion time minimal to maximize the number of willing sample participants. A larger sample would represent a larger and more diverse caregiver sample, especially in relation to race/ethnicity, education, and income levels. For future research, building upon the existing survey and including a qualitative section are encouraged. By doing so, future research could elaborate on and achieve a better
understanding of perceptions and factors of associated caregiving strain. Furthermore, this survey can be adapted for other types of caregivers beyond Sandwich Generation caregivers.

Conclusions

This study focused on the perceptions and factors of caregiving strain in relation to the Sandwich Generation caregiver. The results of this study increase the understanding of the perceived strains on the Sandwich Generation caregiver regarding demographics, caregiving relationship quality, caregiving roles, communication, and resources (time and finances). By applying family-specific theories (e.g., Symbolic Interaction Theory, Family Stress Theory, and Attachment Theory) to caregiving relationship quality, a foundation is established for greater construct validity and further examination of theoretical concepts in relation to caregiving. Within future research of the perceived strains on caregivers, then programs and support networks can aid in resources, as well as self-care techniques for caregivers who identify as the Sandwich Generation.
Appendix A: Sandwich Generation Caregiver Survey

1. What is your gender?
   a. Female  
   b. Other

2. What is your age group?
   a. 36-39  
   b. 40-44  
   c. 45-49  
   d. 50-54  
   e. 55-59  
   f. 60-64  
   g. 65-71

3. Do you have at least one child under the age of 18 living with you (at least part of the time)?
   a. Yes  
   b. No

4. Have you been primary caregiver for your parent(s) for at least 6 consecutive months?
   a. Yes  
   b. No

5. What is your current marital status?
   a. Married  
   b. Living with partner but not married  
   c. Widowed  
   d. Divorced  
   e. Separated  
   f. Single/Never married  
   g. Other

6. What is your employment status?
   a. Employed full-time  
   b. Employed part-time  
   c. Unemployed for more than one year  
   d. Unemployed for less than one year  
   e. Other

7. What is your highest level of education?
   a. Some high school (no diploma)  
   b. High school diploma or completed GED  
   c. Some college  
   d. Associate’s degree or the equivalent  
   e. Bachelor’s degree  
   f. Master’s, Doctorate, or other advanced degree
8. Please specify your race/ethnicity (select all that apply).
   a. White or Caucasian
   b. Hispanic or Latino
   c. Black or African American
   d. Native American or American Indian
   e. Asian /Pacific Islander
   f. Other

9. What is your total household income?
   a. Less than $10,000
   b. $10,000 to $19,999
   c. $20,000 to $29,999
   d. $30,000 to $39,999
   e. $40,000 to $49,999
   f. $50,000 to $59,999
   g. $60,000 to $69,999
   h. $70,000 to $79,999
   i. $80,000 to $89,999
   j. $90,000 to $99,999
   k. $100,000 to $149,999
   l. More than $150,000

10. What type of area do you live in?
    a. Rural
    b. Small town
    c. Suburban
    d. Urban

11. What type of area does your parent live in?
    a. Rural
    b. Small town
    c. Suburban
    d. Urban

12. What is your parent’s current living situation?
    a. Lives in own home alone
    b. Lives in own home with another person(s)
    c. Lives with you
    d. Lives with another adult child
    e. Lives with another family relative (not an adult child)
    f. Lives in a residential care site (e.g., assisted living)
    g. Other
13. How many children under the age of 18 do you have living with you (at least part of the time)?
   a. 1
   b. 2
   c. 3
   d. 4
   e. 5 or more

14. How many female sibling(s) do you have?
   a. 0
   b. 1
   c. 2
   d. 3
   e. 4 or more

15. How many male sibling(s) do you have?
   a. 0
   b. 1
   c. 2
   d. 3
   e. 4 or more

16. What are the ages of your sibling(s) (select all that apply)?
   a. Under 20
   b. 20-25
   c. 26-29
   d. 30-34
   e. 35-39
   f. 40-44
   g. 45-49
   h. 50-54
   i. 55-59
   j. 60-64
   k. 65 or older
17. Where do sibling(s) live in proximity to you (select all that apply)?
   a. 0-9 miles
   b. 10-19 miles
   c. 20-29 miles
   d. 30-39 miles
   e. 40-49 miles
   f. 50-59 miles
   g. 60-69 miles
   h. 70-79 miles
   i. 80-89 miles
   j. 90-99 miles
   k. 100 or more miles

18. Where do your parent(s) live in proximity to you?
   a. 0-9 miles
   b. 10-19 miles
   c. 20-29 miles
   d. 30-39 miles
   e. 40-49 miles
   f. 50-59 miles
   g. 60-69 miles
   h. 70-79 miles
   i. 80-89 miles
   j. 90-99 miles
   k. 100 or more miles

19. Where do your sibling(s) live in proximity to your parent(s)?
   a. 0-9 miles
   b. 10-19 miles
   c. 20-29 miles
   d. 30-39 miles
   e. 40-49 miles
   f. 50-59 miles
   g. 60-69 miles
   h. 70-79 miles
   i. 80-89 miles
   j. 90-99 miles
   k. 100 or more miles

Please select the rating below that best describes your caregiving relationships. The scale is as follows:
Strongly Disagree (1) and Strongly Agree (10).

20. My parent asks for more help than is actually needed.

21. Because of the time I spend with my parent, I do not have enough time for myself.
22. I feel stress trying to balance my obligations to my parent with my other obligations (e.g., family, work).

23. I feel frustrated when I am around my parent.

24. Caring for my parent affects my relationship with other family members in a negative way.

25. I am afraid about what the future holds for my parent.

26. My parent is dependent on me.

27. I feel strained when I am around my parent.

28. My health/well-being has suffered because of caring for my parent.

29. My social life has suffered because of caring for my parent.

30. I do not have enough money to spend on both my parent and my other expenses.

31. I wish that I could leave the care of my parent to my siblings.

32. I feel uncertain of what to do about my parent.

33. I feel that I should be doing more for my parent.

34. I feel that I could be doing a better job in caring for my parent.

35. I feel supported by my siblings in my caregiving role.

36. There is a strain in communication among my siblings and me.

37. The communication among my siblings and me has declined as care of our parents has increased.

38. I do not have enough time to complete everyday tasks.
Appendix B: Informed Consent Form

CONSENT TO PARTICIPATE IN RESEARCH

Investigation of Sandwich Generation Caregiver Perceptions and Factors of Caregiving Strain

You are invited to participate in a research study conducted by Samantha Young, M.A. in Aging Studies graduate student (and faculty sponsor, Dr. Kathleen O’Rourke) at Eastern Illinois University. Your participation in this study is entirely voluntary.

You have been asked to participate in this study because the researcher is investigating the experiences of Sandwich Generation primary caregivers and caregiver strain. You must meet the following criteria: female, ages 36-71, 1 to 3 living siblings, be a primary, current caregiver of parent(s) for at least 6 consecutive months, and have at least 1 dependent (<18 years) child(ren) living in the home at least part of the time.

The purpose of this study is to investigate the factors that contribute to strains in Sandwich Generation caregivers. Caregiver perceptions will be analyzed through items in checklists and scales. Location, time, finances, and communication patterns related to caregiving will be reported within this study.

If you volunteer to participate in this study, you will be asked to complete an online survey. Once you provide consent, you will be directed to fill out the survey. The estimated time for the survey is 15 minutes. You may withdraw from the study and stop the survey at any time without penalty.

Definition of terms:

Caregiver- A caregiver is an individual that provides varying degrees of support to older adults with activities of daily living (Family Caregiver Alliance, 2016).

The Sandwich Generation- Individuals who care for their parents and dependent children at the same time (Miller, 1981).

Sibling. “One of two or more individuals having one common parent” (Merriam-Webster, n.d.).

The survey has minimal to no risks to the participant. The potential discomforts that may result include recalling stressful caregiving-related events or occurrences. There is the slight possibility of the survey causing psychological discomfort, however the probability is considered to be low or minimal.

The benefits of the study to society include new knowledge to add to the literature in Gerontology/Aging Studies regarding Sandwich Generation primary caregivers.
Any information that is obtained in connection with this study will not have any identifying information tied to the participant. Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University.

The researcher may withdraw you from this research if circumstances arise which warrant doing so. If you do not qualify by the identified criteria of participation, then the researcher will withdraw your participation.

If you have any questions or concerns about this research, please contact: Dr. Kathleen O’Rourke, Co-Investigator, kaorourke@eiu.edu, and Samantha Young, Primary Investigator, smyoung2@eiu.edu.

If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board
Eastern Illinois University
600 Lincoln Ave.
Charleston, IL 61920
Telephone: (217) 581-8576
E-mail: euirb@www.eiu.edu

You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.

I voluntarily agree to participate in this study. I understand that I am free to discontinue my participation at any time.
Appendix C: Demographic Figures of Sandwich Generation Caregivers

Age of Caregivers

![Age of Caregivers](image)

*Figure 5*

Age Range of Caregivers (*N* = 50)

Marital Status

![Marital Status](image)

*Figure 6*

Marital Status of Caregivers (*N* = 50)
Employment Status

![Bar chart showing employment status](chart)

Figure 7

Employment Status of Caregivers ($N = 50$)

Education Level

![Bar chart showing education level](chart)

Figure 8

Education Level of Caregivers ($N = 50$)
Figure 9

Race/Ethnicity of Caregivers (N = 50)

Figure 10

Total Household Income (N = 50)
Figure 11

Caregiver Geographical Location ($N = 50$)

Figure 12

Parent (Care Recipient) Geographical Location ($N = 50$)
Parent (Care Recipient) Living Situation

Figure 13
Parent (Care Recipient) Living Situation \((N = 50)\)

Children Living with Caregiver
(Under the Age of 18)

Figure 14
Children Living with Caregiver (Under the Age of 18) \((N = 50)\)
Caregivers Geographical Location from Sibling(s) (N = 50)

Figure 15

Ages of Sibling(s) (N = 50)

Figure 16
### Appendix D: Variables of Study

#### Table 5

*Four Variables of Study: Item-by-Item Analysis (N = 50)*

<table>
<thead>
<tr>
<th>Four Variables of Study Questions</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>22. I feel stress trying to balance my obligations to my parent with my other obligations (e.g., family, work).</td>
<td>7.54</td>
<td>2.60</td>
</tr>
<tr>
<td>38. I do not have enough time to complete everyday tasks.</td>
<td>6.84</td>
<td>3.24</td>
</tr>
<tr>
<td>25. I am afraid about what the future holds for my parent.</td>
<td>6.78</td>
<td>2.95</td>
</tr>
<tr>
<td>26. My parent is dependent on me.</td>
<td>6.74</td>
<td>2.67</td>
</tr>
<tr>
<td>21. Because of the time I spend with my parent, I do not have enough time for myself.</td>
<td>6.02</td>
<td>3.03</td>
</tr>
<tr>
<td>29. My social life has suffered because of caring for my parent.</td>
<td>5.78</td>
<td>3.28</td>
</tr>
<tr>
<td>33. I feel that I should be doing more for my parent.</td>
<td>5.78</td>
<td>2.76</td>
</tr>
<tr>
<td>28. My health/well-being has suffered because of caring for my parent.</td>
<td>5.72</td>
<td>3.03</td>
</tr>
<tr>
<td>30. I do not have enough money to spend on both my parent and my other expenses.</td>
<td>5.52</td>
<td>3.38</td>
</tr>
<tr>
<td>27. I feel strained when I am around my parent.</td>
<td>5.32</td>
<td>2.64</td>
</tr>
<tr>
<td>32. I feel uncertain of what to do about my parent.</td>
<td>5.30</td>
<td>3.32</td>
</tr>
<tr>
<td>24. Caring for my parent affects my relationship with other family members in a negative way.</td>
<td>5.18</td>
<td>2.99</td>
</tr>
<tr>
<td>36. There is a strain in communication among my sibling(s) and me.</td>
<td>5.14</td>
<td>3.35</td>
</tr>
<tr>
<td>23. I feel frustrated when I am around my parent.</td>
<td>5.14</td>
<td>2.79</td>
</tr>
<tr>
<td>34. I feel that I could be doing a better job in caring for my parent.</td>
<td>5.14</td>
<td>2.51</td>
</tr>
<tr>
<td>37. The communication among my siblings and me has declined as care of our parents has increased.</td>
<td>4.96</td>
<td>3.34</td>
</tr>
<tr>
<td>20. My parent asks for more help than is actually needed.</td>
<td>4.68</td>
<td>3.29</td>
</tr>
<tr>
<td>31. I wish I could leave the care of my parent to my sibling(s).</td>
<td>4.12</td>
<td>2.97</td>
</tr>
<tr>
<td>35. I feel supported by my siblings in my caregiving role.</td>
<td>3.54</td>
<td>2.67</td>
</tr>
</tbody>
</table>
References


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