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Understanding the Effects of Parents’ Strokes on their Adult Children’s Lives

Jaclyn Weit

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Understanding the Effects of Parents’ Strokes on their Adult Children’s Lives

Jaclyn Weit

Messiah College
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## Table of Contents

Abstract .......................................................................................................................... 4

Introduction ..................................................................................................................... 5

Literature Review .......................................................................................................... 6

Method ........................................................................................................................... 14

Results ............................................................................................................................ 17

Discussion ...................................................................................................................... 25

References ...................................................................................................................... 29
Abstract
Anyone, especially those over 64 years of age, is at risk of a stroke. When a stroke victim has adult children, his or her children often need to step in as caregivers to aid in recovery. Adult children in these positions often face the risks of role strain, unequal division of responsibilities between siblings, and lack of adequate resources available to them. Resources such as stress management techniques, caregiving relief, and valuable educational resources can combat these stressors. Currently, most research focuses on the experiences of stroke survivors during recovery. While this is important, understanding the effects strokes have on survivors’ family members, specifically adult children, can help to minimize the outlined risk factors and maximize the outlined protective factors. This paper explains a qualitative research study in which the focus is understanding how seven adult children’s lives are changed following their parents’ strokes in attempt to answer the question: What is the overall effect of a parent’s stroke on his or her adult child? Analysis of the interviews suggests that adult children often experience the most changes in their relationships with their family, use of their time, and view of their parents. These changes were often attributed to the adult children’s support from others, understanding of their parents’ strokes, and importance of their faiths. This knowledge is beneficial to stroke survivors, family members, and professionals in health care settings on how adult children can best adapt to their parents’ strokes to make the smoothest transition possible into caregiving roles.
Understanding the Effects of Parents’ Strokes on Their Adult Children’s Lives

According to the Centers for Disease Control and Prevention, 66% of the 800,000 people in the United States who find themselves victims of a stroke are over 64 years of age (“Stroke Facts,” 2015). These survivors are often left with many debilitating physical and mental complications such as dysphagia, pneumonia, urinary incontinence, and depression among many others (Kumar, Selim, & Caplan, 2010). As a result, many of these survivors rely on family members, specifically adult children, to care for them post-stroke. Filial responsibility is described as the inclination to protect and help parents due to a sense of personal obligation and respect for them. It is present in both attitudes and behaviors; adult children hold beliefs about what they should do for their parents, but they also actually engage in certain behaviors in an effort to display care for their parents (Hamon & Whitney, 2003). Adult children often care for their elderly parents, just as those parents had taken care of them when they were younger, in order to fulfill their filial obligation (Lashewicz & Keating, 2009). As a result, the sense of filial responsibility often increases the desire adult children have to care for their parents post-stroke. However, the sense of filial obligation alone fails to adequately prepare adult children to care for their parents. When these adult children find themselves in these types of caregiving roles, they must cope with stress and adapt to lifestyle changes (Smith & Hamon, 2012).

Theoretical Framework

Family Stress Theory

Family stress theory helps to explain the process with which families adjust to stress and crisis in their lives. Originally, Rubin Hill (as cited in Smith & Hamon, 2012) developed the ABC-X model to explain this process, outlining the key elements: A: stressors, B: resources, C: definition of the situation, and X: stress and crisis. From this, McCubbin and Patterson (as cited
in Smith & Hamon, 2012) developed the double ABC-X model to more accurately describe the complexity of each of the factors and the concept of pile-up in the ABC-X model during the adjustment process when a family faces crisis, incorporating the dimension of time.

After an adult’s stroke, adult children often need to step into a caregiving role. As a result, they must face the initial crisis, in this case a stroke, as well as other stressors that come along with it, such as increased responsibilities. To cope with these stressors, the families must continuously identify new resources and develop new skills in order to build upon existing or replace expiring resources. Throughout the process, family members will not only evaluate how they feel about the situation but also their abilities to cope and adjust to the new roles each must adopt following a stroke. Finally, a family’s ability to develop a new level of functioning post-stroke determines how positively or negatively the stroke affected the family system (Smith & Hamon, 2012). Family stress theory, specifically the double ABC-X model, can help adult children as they seek to understand a typical family’s adaptation process following a parent’s stroke.

**Risk Factors**

Adult children who act as caregivers following a parent’s stroke must adapt to the increased responsibilities they face. These stressors can negatively impact adult children and family units when risk factors are not properly identified or acknowledged. Adaptation difficulties often lead to role strain from the inability to reduce and/or properly manage demands. Failing to properly distribute and manage tasks between siblings can also cause stress for those who end up with more responsibilities. In addition, not having the proper resources to understand the individual recovery process or meet the needs of different family members also provides unnecessary stress that threatens the family’s ability to cope with the crisis.
Role Strain

Adult children often find it difficult to provide care for their parents in the midst of all of their other daily responsibilities. Gordon, Pruchno, Wilson-Genderson, Murphy, and Rose (2012) studied how providing care to an older person affected the lives of 583 working women. The women reported their individual levels of caregiving demands and support, work demands and support, and role conflict and strain. Based on the women’s feedback, Gordon and colleagues concluded that having too many additional responsibilities often leads to role strain because adults do not have enough time or energy to adequately fulfill all of their competing roles. Examples of some causes of role strain on adult children caring for their parents include: marriage, children, employment, and community involvement. Adult children can remove some sources of role strain, such as community involvement and in some cases employment, from their lives while they assist their parents in recovering from their strokes. However, reducing sources of role strain is not always possible.

For example, role strain increases when adult children have children of their own. Borchers (as cited in Perrig-Chiello and Höpflinger, 2005) used the term “sandwich situation” to refine the broader term “sandwich generation” and describe adult children who need to meet the demands of dependent children and dependent parents. Role strain for those caught in the “sandwich situation” increases with younger children who demand more attention from parents. Teenage children often tend to have a greater awareness of the increased demands their parents face. As a result, they can minimize the demands they place on their parents, which helps to reduce role strain (Bastawrous, Gignac, Kapral, & Cameron, 2015). However, because children need to have their needs met regardless of their age, reducing role strain related to parenting is often difficult, if not impossible.
Sibling Involvement

Logically, one might think that dividing responsibilities among siblings would make the process of caring for a parent post-stroke easier and reduce role strain. However, most research shows an opposite effect as a result of multiple sibling involvement in caregiving. Strawbridge and Wallhagen (1991) stated that adult caregivers expressed that siblings were the cause of most of their stress. Issues often arise from having unequal levels of power and participation between siblings. For example, Lashewicz and Keating (2009) described “dominating siblings” as siblings who try to reduce the amount of contact that occurs between the parents and other siblings. Limiting those relationships increases the amount of power a “dominating sibling” has when it comes to making decisions throughout recovery. This unequal power distribution often causes tensions among siblings and family members (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003).

Ingersoll-Dayton et al. (2003) conducted a research study in which 43 sibling caregiver relationships were analyzed and labelled as equitable or inequitable based on the subjective responses of the participants related to various caregiving experiences they had recently faced. They labelled two-thirds of the sibling relationships as inequitable and one-third as equitable. The researchers also sought to identify the factors that influence siblings’ feelings of equal or unequal caregiving responsibility. This study identified many factors influencing a sibling’s involvement in caregiving including: personality, employment status, other family responsibilities, and proximity. These factors agree with those identified by other researchers.

Many of the identified factors influence adult children’s filial responsibility, which in turn influences their ability, or perceived ability, to aid in caregiving (Hamon, 1992; Ingersoll-Dayton et al., 2003; Lashewicz & Keating, 2009). Work obligations inhibit busy siblings from
participating in caregiving. Siblings with more demanding jobs often rely on siblings who work as stay-at-home parents, at part-time jobs, or at less demanding jobs to complete most of the caregiving responsibilities (Ingersoll-Dayton et al., 2003). Gender also contributes to an unequal distribution of responsibility among siblings. Daughters tend to have greater convictions towards filial responsibility than sons. As a result, they naturally take on more responsibilities (Bastawrous et al., 2015; Ingersoll-Dayton et al., 2003). In addition, unequal participation in caregiving often gets attributed to distance. Living farther away from parents makes it more difficult for siblings to get or stay involved in caregiving (Ingersoll-Dayton et al., 2003; Lashewicz & Keating, 2009). Adult children, particularly adult daughters, who live closer to parents and work less hours, often take on many of the caregiving responsibilities (van der Pers, Mulder, & Steverink, 2015). Many factors influence siblings’ abilities to help take care of a parent after a stroke occurs.

While it seems logical that multiple siblings would reduce individual stress related to caregiving, this does not always hold true. Instead, unequal responsibility levels between siblings often create tension and stress within these relationships due to the increased amounts of stress faced by the sibling providing the greatest amount of care. As a result, multiple siblings’ involvement is not always an “obvious asset” in providing care to an older parent. Instead, in some cases, family systems with multiple siblings face more stress throughout a parent’s recovery (Lashewicz & Keating, 2009).

**Insufficient Resources**

Lack of sufficient resources challenges adult children’s abilities to cope with their newfound responsibilities and manage stress (Lin, Chen, & Li, 2013). Educational resources provide information on various types of assistance and therapy; however, these resources are
difficult to obtain due to limitations in quantity and accessibility (Jaracz et al., 2015; Yeung, Szeto, Richardson, Lai, Lim, & Cameron, 2015). Without having these resources readily available, adult children need to find them on their own. Researching this information individually takes time, another resource many adult children do not have (Bastawrous et al., 2015).

LeDorze, Tremblay and Croteau (2009) studied the experience of an adult daughter whose father had recently had a stroke. She reported having an understanding of and access to the Internet to do her own research, a valuable resource to which not all adult children have access. However, she also reported that taking the time to research took time away from her relationships, causing some to end as a result (Le Dorze et al., 2009). Similarly, other adult daughters also reported not having enough time to fulfill all of their responsibilities. Lack of time and informational resources led them to neglect other relationships, activities and personal care causing increased feelings of role strain and stress (Bastawrous et al., 2015).

**Protective Factors**

While an older parent having a stroke creates a stressful situation for an entire family, especially the adult children, proper adaptation and use of resources can affect the degree to which families might encounter crisis. Adult children undeniably encounter a great deal of stress while coping with adjusting to new roles and responsibilities. Developing healthy stress management techniques can make the adjustment process less difficult. In addition, seeking caregiving relief through other family members and friends allows adult children to maintain a positive perspective while caring for parents post-stroke. Adult children also need to identify and use available educational resources, which can aid them throughout the process of caregiving.
These resources can increase adult children’s knowledge and confidence related to caregiving, which also impacts their attitude towards their situations.

**Stress Management**

The close relationship between physical health and stress makes the development of proper stress management imperative for adult children to stay healthy (Long et al., 2004). The first few months following a parent’s stroke tend to be the most difficult for adult children. Jaracz et al. (2015) define “caregiver burden” as the experience of negative effects on a caregiver’s physical and emotional health, social life, spiritual and financial wellbeing during the caregiving process. In their study, 88 caregivers rated their levels of caregiver burden six months and five years after the occurrence of a parent’s stroke. Responses showed a 14% decrease in rates of caregiver burden from the first to second evaluation. This decrease is partially credited to the development of proper stress management techniques to manage the symptoms of caregiver stress (Jaracz et al., 2015).

Some adult children choose to quit their jobs, eliminate negative relationships, and/or stop participating in various activities to create more free time and reduce role strain in order to care for their parents (Bastawrous et al., 2015; Le Dorze et al., 2009). Cruess et al. (2015) conducted a study in which 120 adults took part in challenge tasks after completion of a 20-minute session using stress management techniques. The results of this research showed that utilizing brief stress management techniques, such as relaxation techniques, can aid in reducing stress (Cruess et al.). Similarly, in another study, 91 caregivers were split into three groups. Each group took part in various levels of stress management therapy. The group that took part in the most frequent programs met once a week. These participants showed the greatest reduction in symptoms of depression and anxiety than the caregivers in the other groups (López, Crespo, &
Zarit, 2007). As the mentioned studies show, stress management is imperative for adult children to achieve successful adaptation.

**Caregiving Relief**

Adult daughters reported that having caregiving relief throughout the caregiving process made it a less stressful and frustrating time (Bastawrous et al., 2015). “Caregiver respite”, or relief, is defined as a brief period of time that a caregiver is relieved of his or her caregiving duties (Rose, Noelker, & Kagan, 2015). This relief can come in a variety of ways from both family members and friends. Adult children find some relief when their other parent, who did not have the stroke, is healthy. In these situations, this spouse often acts as the primary caregiver to the stroke survivor, allowing the adult children to be less involved in the recovery process and focus more on their other work-related and family responsibilities (Le Dorze et al., 2009). Also, having and maintaining a good, healthy relationship with parents reduces the burden of caregiving (Lin et al., 2013).

Friends also impact adult children’s perceptions of caregiving. Feedback from friends can encourage adult children to keep providing love and care to their parents in times when they might want to give up (Lin et al., 2013). Good social networks positively influence adult children, providing them with outlets to separate themselves from their stressful family situations (Le Dorze et al., 2009). This outlet provides much needed love and support. For males, this often comes from work relationships, whereas for females this comes from social relationships outside of work (Lin et al., 2013). Friends and family members can provide caregiving relief that, in addition to implementation of stress management techniques, can make caring for a parent post-stroke a less daunting task for adult children.
Educational Resources

While not always easily accessible, educational resources provide adult children with helpful and reliable information about caring for parents post-stroke. The Internet offers access to potentially helpful information, as long as adult children have Internet access and the capability of using it properly (Le Dorze et al., 2009). In addition to general educational resources, specific educational resources also help adult children adjust to caring for a stroke victim. A research study in Taiwan implemented a discharge program for stroke victims and their family caregivers to see if it would increase their caregiving abilities. Seventy-two participants took part in educational programs and individualized home visits. Compared to the 86 participants in the control group, the experimental group reported higher rates of self-satisfaction related to their caregiving abilities after completion of the programs. (Shyu, Chen, Chen, Wang, & Shao, 2008). Family caregivers also improved the quality of care they gave to parental stroke victims when they had individualized programs preparing them for what to expect the first year after the parent was discharged from the hospital (Shyu, Kuo, Chen, & Chen, 2010). While most research highlights the importance of educational resources and programs in Asian cultures, Western cultures benefit from these resources as well (Shyu et al., 2008).

The purpose of this research is to identify lifestyle changes, stressors, and coping mechanisms most commonly experienced by adult children caring for a parent post-stroke with the attempt to answer the question: what is the overall effect of a parent’s stroke on his or her adult child? Previous research highlights this as a stressful time for a family system but mostly focuses on the effects a stroke has on the survivor. However, this can often be a difficult and stressful time for adult children adjusting to caregiving roles. Researching the experiences of
adult children in these situations will reveal the accuracy and prevalence of the suggested risk and protective factors. This knowledge will help stroke survivors, family members, and those that work with caregivers and victims, particularly within mental and physical health care, to understand how they can help adult children make the smoothest transition to the caregiving role.

Methods

Participants

Using convenience sampling methods, participants were recruited through announcements sent to 20 local nursing homes and other community organizations. These locations were primarily those with which the researcher has personal connections; however, other community organizations with which the researcher has no personal connections were contacted as well. In addition, two electronic mailings to the researcher’s college staff and students and one Facebook announcement were used for recruitment, as well.

For the purpose of this study, the term “caregiver” referred to anyone, over the age of 18, who is currently caring or has cared for a parent who has had a stroke in the past three to four years. The act of caring could include physical assistance with daily activities, rides to and from appointments, emotional support, and/or any other support given to his or her parent post-stroke. The type or severity of a parent’s stroke was not taken into consideration when recruiting participants. Seven people who fit into this description volunteered to participate in this qualitative research.

Participants were asked demographic questions at the start of the interview, and participant characteristics are summarized in Table 1. All of the participants were female ranging from 18 to 52 years old. Four were married and three were single. Three of the participants had no children of their own, three had three children of their own, and one participant had four
children of her own. Six of the participants’ parents were married, and the other one was widowed. All of the stroke survivors were the participants’ biological parents. The participants’ distances from their parent ranged from about 5 minutes to 2 hours apart. The time since the strokes ranged from within the past few months to almost 4 years. None of the participants were only children, but only two had siblings that were able to offer substantial assistance in caregiving. The other siblings were reported to be either too much younger or too far away to help with caregiving.

Table 1. Participant Characteristics (n=7)

<table>
<thead>
<tr>
<th>Sex</th>
<th>Number of Children</th>
<th>None</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>0</td>
<td>None</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>1</td>
<td>0</td>
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<td></td>
<td></td>
<td>2</td>
<td>0</td>
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</table>

<table>
<thead>
<tr>
<th>Age (Years)</th>
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<th>3</th>
<th>4+</th>
<th>1</th>
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</thead>
<tbody>
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<td>18-22</td>
<td>3</td>
<td>3</td>
<td>4+</td>
<td>1</td>
</tr>
<tr>
<td>23-27</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28-32</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33-37</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>38-42</td>
<td>1</td>
<td>31-60</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>43-47</td>
<td>2</td>
<td>61-90</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>48-52</td>
<td>1</td>
<td>&gt; 90</td>
<td>2</td>
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</table>

<table>
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<th>Distance from Parents (Minutes)</th>
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</tr>
</thead>
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<tr>
<td>&lt; 30</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>31-60</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>61-90</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>&gt; 90</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Time Since Stroke (Years)</th>
<th>&lt; 1</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td></td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td></td>
<td>1-2</td>
<td>1</td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
<td>2-3</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>&gt; 4</td>
<td>1</td>
</tr>
</tbody>
</table>

**Materials**

Each participant took part in a face-to-face, semi-structured interview that was used to identify themes related to lifestyle changes and stressors they encountered as well as stress management techniques they employed while caring for a parent post-stroke. The interview instrument was four pages in length and consisted of a variety of questions that were broken down into three sections (sample questions in Table 2). The first section of the interview
consisted of questions to collect general demographic information, such as the participant’s
gender, marital status, and geographical distance (in time) from the parent who had the stroke. In
the second section, participants were asked about the ways in which their parents’ strokes
affected their employment statuses, family relationships, friendships, and other activities. Each
of these categories included opened-ended questions relating specifically to that category. When
necessary, the interviewer asked additional, relevant questions to gain more information and/or
to clarify a question. The interviewer had printed copies of the interview outline and took notes
throughout the interview.

Table 2. Sample Interview Questions from Sections 2 and 3 of the Interview Outline

1. How was your employment changed by the stroke?
2. In what ways were these [family relationships] helpful resources after the stroke?
3. Please describe the social activities you took part in before/at the time of the stroke.
4. What were your general thoughts and feeling regarding your parent’s stroke? In other
   words, how did you make sense of the stroke?
5. What part(s) of the adjustment to caregiving do you feel you handled well? Please
   explain.
6. What coping mechanisms do/did you find to be the most helpful throughout the
   adjustment/caregiving process? In other words, how do/did you manage stress related to
caregiving?

Procedure

After obtaining IRB approval to carry out this research, data were collected in the form of
one face-to-face interview with each participant that averaged about 25 minutes in length. Each
interview took place in a private location at a time most convenient for the participant. In one
instance, a phone interview was conducted in lieu of an in-person interview due to a 6-hour
distance between the participant and interviewer. Before each interview the participant was
asked to read and sign an informed consent form that explained his or her right to refuse to
answer any questions and/or stop the interview at any time. Participants were also assured that all
of their answers would be completely confidential. Confidentiality was ensured by assigning each participant a number (1-7). At this time the interviewer asked for permission to record the audio of the interview with her cell phone. If permission to do so was given, the tape was marked with the number assigned to the participant, rather than his or her name, in order to further maintain confidentiality. Each interview was recorded with the exception of the phone interview. Once all of this was complete, the interview began. Each interview consisted of asking the specified questions and noting the responses on an interview outline for that participant. After answering all of the questions, the participants were thanked for their time and willingness to do the interview with a ‘thank you’ card.

After the interviews were completed, notes taken throughout the interviews were reviewed in order to identify initial themes. Portions of the recorded interviews were also transcribed in order to further analyze the data. After the transcriptions were completed, the corresponding sections from each interview were put together. These sections were then read over a few times in order to identify more common themes. Once themes became more apparent, a coding system was used to highlight data based on the category with which it best corresponded. This information was then compiled into an outline which began with the general identified themes. From there, more specific data from each part of every transcription were added to the outline to further substantiate the findings of this research.

**Results**

The data offer insight on the areas of adult children’s lives that are most greatly impacted when adapting to the caregiving role post-stroke. The data also highlight suggested factors which influence the identified areas of impact. In general, participants expressed the greatest changes in their relationships with their families, use of their time, and view of their parents.
In addition, they attributed these changes to their expressed support from others, understanding of the strokes, and importance of their faiths. Table 3 summarizes the data collected.

<table>
<thead>
<tr>
<th>Areas of Greatest Impact</th>
<th>Relations with Family</th>
<th>Use of Time</th>
<th>View of Parents</th>
<th>Support from Others</th>
<th>Understanding the Stroke</th>
<th>Importance of Faith</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Some initial tensions between siblings over communication</td>
<td>• Experienced more role strain</td>
<td>• Realization of parent’s morality</td>
<td>• Meals, rides, Internet, exercise</td>
<td>• Helpful to know/understand the physical cause of the stroke</td>
<td>• Faith considerable part of the adjustment process</td>
</tr>
<tr>
<td></td>
<td>• Overall increased feelings of closeness with family, immediate and extended</td>
<td>• Less present in children’s lives during caregiving</td>
<td>• Huge shift in roles as they transitioned into being a caregiver</td>
<td>• Emotional support, presence of friends and family, occasionally stepping back from caregiving</td>
<td>• When there was no known physical cause, attributed to being part of God’s plan</td>
<td>• In some cases, going to church became a burden</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Both busier and less busy participants felt the need and desire to reorganize their time and priorities to spend more time with their parents</td>
<td>• Time of becoming “adult-child” from “child-child”</td>
<td></td>
<td></td>
<td>• Overall, praying individually and having a church community to pray for them was considered a valuable resource</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• See role of filial obligation in response to stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Summary of Findings
Areas of Greatest Impact

Throughout the interviews, participants identified the ways in which each area of their lives was impacted by their parents’ strokes and the need to step into a caregiving role. Participants identified similar ways in which their lives were impacted despite differences in the levels of severity of the strokes, caregiving duties, and their other responsibilities.

Relations with family. All participants expressed that their family relationships experienced the greatest impact as a result of the stroke. In general, participants stated the stroke and caregiving process ultimately brought their family closer together in the long run. Some participants expressed initial tensions between family members following the event. These tensions commonly arose between siblings who needed to be in constant communication with one another about issues related to caregiving, or because one sibling did not want to talk about the stroke as much as the other one did. Ultimately, however, the adult children interviewed expressed that their relationships with their, spouses, siblings, parents, and/or extended family members were strengthened following the stroke. Participant 2 summarized her experience in the following: “I think it brings you closer [to your family] because you’re going through a hard time together.”

Use of time. Whether the extra time came from their work, friendships, or other activities, five of the participants expressed a shift in the organization of their time in order to fulfill their necessary caregiving duties. One participant expressed: “So much of your life is your schedule. How am I going to fit everything in? To have that interrupted is stressful… You know somethings always gonna get pushed down. To figure out how to balance all of that is difficult.” Regardless of what they had going on in their lives, most participants expressed an increased desire to spend time with their parents, specifically the stroke survivor. During this time adult
children completed caregiving needs, but would also incorporate one-on-one time with their parent(s). As a result, these participants acknowledged their absence in other areas of their lives to have the time to be with their parents.

Busier participants, for example those who worked more hours and/or had children of their own, expressed difficulty finding time to adequately maintain each of their roles. As a result, they most often expressed being absent in their family’s lives, specifically their children, during the caregiving process. Participant 4 stated, “I found myself not taking a break for myself because I was spending so much quality time with my mom. I was spending one-on-one time with her and letting other things go.” The three college-aged participants acknowledged feeling distant from their parents, the primary caregivers, because they needed to take care of their other parents, the stroke survivors. Participants who had fewer responsibilities at work found themselves seeing their friends less in order to spend more time with their parents. For example, Participant 3 expressed: “I spent less time with them [her friends], because I wanted to be home with my dad.” Another college-age participant showed similar feelings: “My dad was really bored, so I felt like I wanted to spend more time with him.” Overall, participants expressed the need to restructure their lives and reorganize their time following their parent’s stroke regardless of their individual circumstances.

**View of parents.** Six participants acknowledged a realization of their parent’s mortality as a result of the stroke. This remained consistent regardless of the participants’ ages. Participant 1 described this experience as a transition from her role as a “child-child” to “adult-child.” She also stated later in her interview, “Maybe for people who are older adult children, they’ve already had this realization. But for me it was like, my dad’s gonna die someday.” While talking about her view of her father after his stroke, Participant 5 stated, “I view him as more fragile
now. He doesn’t seem as invincible as I once thought.” Participants also described difficulty coping with the need to help their parents with tasks such as bathing, feeding, eating, and using the restroom. At one point, the stroke survivors helped the participants with these tasks, but following a stroke the roles switched. Participant 2 summarizes this in the following:

    Things that had to do with the health part [were the most challenging], like actually having to do things for your parent that you did for your children, but now it’s for your parent. You know, like bathing, helping in the bathroom, feeding, and all of those things that it’s just this huge shift in your role. And that’s really difficult.

Participant 1 expressed a similar viewpoint, but as a younger caregiver:

    It’s weird because they [your parents] have taken care of you your whole life. And how do you even conceptualize that now it’s the reversed? I am the caretaker of this person who changed my diapers, fed me, got me dressed, sent me to school, and now they are dependent on me.

This role reversal causes participants to see their parents in a different light, which they expressed as one of the most significant impacts of the stroke.

**Reasons for Significant Impact**

In addition to identifying aspects of their lives that were impacted by their parents’ strokes, participants indicated possible explanations for why these areas were impacted as they were. Participants identified similar reasons for why their lives changed as they did following the stroke despite differences among their specific situations.

**Support from others.** When participants had access to sufficient resources, they all described the caregiving process as much less strenuous than if they did not have access to the resources. Resources were tangible and intangible. In the form of tangible resources, four
participants expressed thankfulness for people who brought them meals. Three participants with children expressed gratitude for being able to have their kids carpool to practices and other events. In her interview Participant 2 stated, “My friends knew what was going on, and they were helpful and supportive. At times they brought meals or helped with the kids.” Participants valued the Internet as a helpful resource available for them to research and learn more about their parents’ recovery processes. Exercise was the last tangible resource most commonly expressed as valuable. Participants valued this time to clear their minds, think, pray, and/or relieve some of the stress related to caregiving. One participant stated, “I did start exercising a lot. I would use that is a time to pray.” Overall, participants expressed gratitude for many of the tangible resources their extended family members, communities, and church families offered.

In addition to tangible resources, five participants stated they also valued intangible resources from those around them. The first of these resources most commonly expressed includes emotional support. Participants said they coped more successfully with the adjustment to caregiving processes when they were surrounded with people to offer encouragement and empathy. Friends, spouses, siblings, and/or mentors also became good distractions for participants in order to help them get their minds off of their situations. Participant 3 expressed: “I would say my church mentor was really helpful…she would take me out to get my mind off things. People being there to do this with for distractions was really beneficial”. Simply having other people there appeared to benefit the caregivers.

Three participants also acknowledged the necessity to know when it was time to back off from caring for their parents, to take breaks for themselves and give their parents space as another intangible resource. For example, a few participants found it beneficial to realize that, while they wanted to help in every way they could, they sometimes needed to step back and
allow their parents to do activities on their own in order to help regain their independence. In other instances, it was also beneficial for the participants to have the knowledge of when it was a good idea for them to step back in order to avoid conflicts between them and their parents. Participant 4 stated, “I wasn’t stressed having my mom, I wanted to do everything I could. She actually had to tell me to stop. And I had to give her space. I think I was stressing her.” Similarly, another participant expressed a similar idea stating, “You have to step away when you need a break, even if it’s short. You have to not get upset with your parent when they’re frustrated or it’s difficult for you because they can’t help it.” In summary, having numerous tangible and intangible resources available helped the participants with the adjustment and caregiving processes they faced.

**Understanding the stroke.** In terms of making sense of their parents’ strokes, participants most commonly expressed at least one of two explanations. Three participants made sense of their parents’ strokes by understanding the medical causes behind the strokes, such as hypertension or a side effect of a specific medication. A few of these participants expressed that they found it helpful to research the causes, complications, short-term, and/or long-term recovery for their parents’ specific situations. For example, “I really focused on the medical standpoint, and I did research it a lot. I kind of processed it by knowing as much as I could about it.” When the participants did not know the medical explanation of the stroke, they commonly used their faith to make sense of the stroke, attributing it to being part of God’s greater plan and acknowledging that everything happens for a reason. Participant 4 expressed her feelings towards her mom’s stroke in the following:
To make sense of it, it’s just like, everyone has a time to live and a time to die. We can do all our things to help prevent things from happening, but I don’t know. It’s just sometimes no matter what you do, things still happen.

In some cases, participants made sense of their parents’ strokes by understanding the medical reasons, as well as calling upon their God.

**Importance of faith.** Every participant considered her faith to be a considerable part of her adjustment process to caregiving. A few participants expressed frustrations over going to church for a few reasons. In some cases, this frustration was due to the added stress of getting their parents to church following the stroke. In other cases, it was attributed to the burden of providing updates on a parent’s condition each Sunday. One participant summarized this in her statement, “People would flock to us…I didn’t want to go to church because I didn’t want to have to tell 10 different people the same thing I already told 25 other people.” However, in each case, participants expressed that praying and having a church community to pray for them was a valuable resource even when the medical cause of the stroke was known. Participant 4 stated, “My faith tells me that the Lord has a plan and wouldn’t forsake me or my mom or my other family members.” Similarly, Participant 3 expressed the following: “My faith kept me strong, and the encouragement from my church kept reminding me, too.”

**Summary**

To summarize, in response to the interview questions, participants identified a variety of ways in which their parents’ strokes impacted their lives. Three common ways arose from the data showing that the strokes most greatly influenced the adult children’s relationships with their family, use of their time, and view of their parents. With this, participants attributed changes
within these areas to their support from others, understanding of their parents’ strokes, and the importance of their faith.

**Discussion**

The findings of this study offer a glimpse into the lives of adult children’s lives who are affected by a parent’s stroke. Family stress theory, specifically the double ABC-X model, offers an excellent framework to analyze these findings. For example, the participants’ explanations of their adaptation processes consistently align with the outlined double ABC-X model. As outlined by the model, the families faced compound stressors (Aa) as a result of one’s stroke. They expressed needing to continuously identify resources (Bb) to use throughout the caregiving process. Their perception of the situation (Cc) ultimately affected their ability to manage the situation. And finally, even when a parent recovered without deficits, the family needed to regain a new level of normal (X) in order to achieve bonadapation rather than maladaptation. In order to do this, the family members involved, specifically the adult children, needed to adjust their roles within the family.

The data also address the original research question: What is the overall effect of a parent’s stroke on his or her adult child? Participants’ responses about the effects of their parents’ strokes on their lives support many of the ideas discussed in the introduction regarding risk and protective factors. For example, these results indicate that adult children caring for a parent post-stroke often experience role strain in trying to take on responsibility. As research suggests and the participants discussed, adult children find themselves with little to no time to adequately fulfill their various roles, especially for participants with their own children. In this study, sibling involvement did not appear to be the source of as much stress as initially suspected. No one described situations with dominating siblings, which could be due to a variety
of factors such as, the participants’ work schedules, relationships with their siblings, and/or caregiving demands. Consistent with the introductory research, however, a few participants did express some tensions among their siblings for whom distance prevented helping with caregiving. From their statements, participants appeared to benefit from avoiding these potential risk factors.

In addition to identifying the need to acknowledge and address certain risk factors, participants also expressed the need for certain protective factors the original research suggests. For example, participants identified various stress management techniques, such as exercise and prayer. These activities appeared to help participants manage stress related to caregiving in order to avoid caregiver burnout. Similar to this and another protective factor, participants identified the need to take breaks to obtain caregiving relief. This time allowed them to avoid unwanted conflicts with their parent(s). It also gave them the opportunity to seek encouragement from friends, spouses, and siblings. As participants expressed, having another parent act as the primary caregiver made it easier to get this respite than when the adult child bears a majority of the caregiving responsibilities. The participants also identified benefitting from educational resources, most commonly the Internet, to help them better understand strokes. Taking advantage of one or more of these protective factors appeared to help participants manage caregiving more successfully.

This study is not without limitations. As a qualitative research, the sample size was small; the research would have benefitted from more participants, as well as more varied participants. For instance, all of the participants were female, only offering insight into the effects of a parent’s stroke on female adult children. In future research the perspective of male adult children should also be obtained. In addition, the participants were all in some way
affiliated with Messiah College, a faith-based institution. While the interview did not necessarily prompt participants to discuss faith, the topic arose on numerous occasions. This may not be a representative within a larger population. Moving forward, researchers should seek information and experiences from those with a variety of different backgrounds and beliefs, not just that of a Christian faith. Addressing these limitations would help to more successfully identify how adult children’s lives are affected by their parents’ strokes.

While this research is not perfect, it does benefit this area of study in several ways. Two subdivisions of age formed within the participants. The first group consisted of three college-age adult children and the second group consisted of four older adult children with families and children of their own. Despite this difference in life stages that coincide with the participants’ ages, participants in both groups identified very similar changes in their lives before and after their parents’ strokes. Women in these groups also expressed similar ideas of filial responsibility as a motivating factor for them to care for their parents. Even younger adult children appear to recognize and respond to attitudes about the ways in which they should care for their parents. Also, in response to general, open-ended questions participants identified similar areas of impact following their parents’ strokes. These responses supported many of the risk and protective factors discussed from the original research. The consistency in responses, as well as with previous research, suggests a likelihood that other adult children would respond in similar ways when asked about their individual caregiving experiences.

This research is significant due to the prevalence and potentially devastating effects of strokes on victims and their families. This study emphasizes the importance of identifying the impact strokes have on the victim’s loved ones, particularly his or her adult children. As previously discussed, attitudes of filial responsibility are not enough for adult children to
successfully adapt to new roles and expectations as caregivers. Expanding research to address the needs of caregivers, too, will help adult children know what to expect during their parents’ recovery processes. It will also help medical staff and other professionals know how to best offer support to patients in these situations. In combination, caregivers and professionals can work together to successfully minimize the effect of an already stressful situation, one stroke at a time.
References


