

YOUTHFUL CAREGIVING: A BITTERSWEET REALITY

by

Brenda A. Donovan

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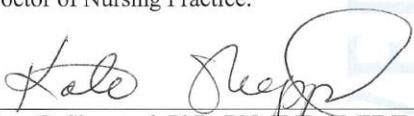
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As members of the DNP Project Committee, we certify that we have read the DNP project prepared by Brenda A. Donovan entitled "Youthful Caregiving: A Bittersweet Reality" and recommend that it be accepted as fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.



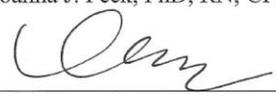
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Final approval and acceptance of this DNP project is contingent upon the candidate's submission of the final copies of the DNP project to the Graduate College.

I hereby certify that I have read this DNP project prepared under my direction and recommend that it be accepted as fulfilling the DNP project requirement.



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## DEDICATION

To the loving memory of my mother

Words cannot express just how blessed I am to have you for my mother. You are and will always be my hero; the strongest woman I have ever known. I remember thinking as I watched you fight your battle with Lou Gehrig's Disease just how strong of a woman you were, and I could only hope to be half as strong as you someday. Your strength influenced my decision to become a nurse, to pursue higher education as a nurse practitioner, but most importantly to complete my DNP project on the lived experiences of being a young caregiver.

Throughout this project, there is a lot that I have learned about myself. I am determined; I am driven, but most importantly I am strong. Although I was too young to realize it then, my experiences as your caregiver was preparing me for something better; something of a higher purpose. Those experiences made me who I am today. Without even realizing it, you bestowed in me one of the best gifts; your strength to carry forward no matter what life throws at you and for that I will be forever thankful.

*"All that I am or hope to be, I owe to my angel mother."*

*Abraham Lincoln*

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## ABSTRACT

*Purpose:* The purpose of this study was to describe the psychological effects on adult mental health of former young caregivers who provided primary care in youth; specifically, the positive and negative aspects of caregiving in youth and how childhood memories and experiences of caregiving affect the former child caregiver's adult mental health.

*Background:* Caregiving is a rapidly emerging public health concern and the incidence of being a young caregiver is on the rise. Research shows the caregiver role effects both the physical and mental well-being of the caregiver; however, there is a paucity of information on the long-term effects of youthful caregiving on adult mental health and its impact on their psychological, social, and emotional development. Research suggests that providing primary care has both positive and negative consequences on children. `

*Method:* To gain a further understanding into the experiences of former young caregivers, three nurses, a Telemetry nurse, a Nephrology nurse, and a Nurse Practitioner were interviewed to form the case study. A content analysis of the interview data was performed to identify commonalities, emotional memories, past and current triggers, and reflections to provide a deeper insight into the perspectives of each participant as they shared their views on the positives and challenges experienced as a young caregiver, in addition to the impact caregiving has had on their adult mental health.

*Findings:* Common positive experiences shared between participants included benefit finding, social support, and influence of self-identity and career choice. Common challenges experienced involved lack of education and resources, impact on school performance, impact on friendships, impact on physical health, unresolved anger, and depression. Their experiences were dependent

on several factors such as their age and gender, school status, gender of the care recipient, progression or severity of the illness/disability, and family closeness; however, the three common variables having the greatest influence on mental health was parentification, social support, and becoming a wounded healer.

*Implications and Conclusion:* The data from this qualitative descriptive study broadens our awareness into the importance of identifying this hidden population and the need for development of effective services aimed and preventing and treating depression.

## INTRODUCTION

Caregiving is a bittersweet phenomenon that is rapidly emerging as a public health concern. It is estimated that approximately 65 million people in the United States (US) provide care for a chronically ill, disabled, or elderly family member (National Alliance for Caregiving [NAC] & American Association of Retired Persons [AARP] Public Policy Institute, 2015). Of these caregivers, approximately 1.3 to 1.4 million are child caregivers ranging in age from 8 to 18 (National Alliance for Caregiving (NAC) & United Hospital Fund, 2005). This number is likely to be underestimated as this is often a “hidden” population as many young individuals do not identify themselves as “caregivers” (Aldridge & Becker, 1993) thus allowing their contributions to go unrecognized.

Unfortunately, the incidence of young caregiving is on the rise (Beach, 1997; Gates & Lackey, 1998). There are a few noteworthy reasons behind this increase. First, many women are waiting longer to bear children which may lead to an early onset of the caregiver experience. According to the CDC (2014), approximately 40% of all babies born in the US are born to mothers over 30 years of age. Individuals who have children later in life often develop chronic or debilitating illnesses during their parenting years as most long-standing illnesses increase as a person ages. Second, diseases common to the aged are being diagnosed in younger individuals. Alzheimer’s, once thought to be a disease of the old, is now impacting those in their 40’s and 50’s (Roach, Drummon, & Keady, 2016). In fact, the estimated population growth of Early Onset Alzheimer’s Disease is 5.5% (Zhu et. al., 2015) and the incidence of the disease is higher in women than men (Vina & Lloret, 2010). Women who begin childbearing after the age of 30 are at an increased risk of chronic illness, placing their children in line for early caregiving

experiences. Third, not only is the US population aging, but healthcare costs are rising. To reduce healthcare costs, changes in the healthcare system are leading to shorter hospitalizations, increased nursing home costs, and decreased home health benefits resulting in a majority of the care to be provided in the home setting with children and adolescents assuming this position along with the caregiving responsibilities.

Physical, mental, and emotional problems often arise from complex caregiving situations especially for those who provide care to individuals with chronic or debilitating diseases. There is a multitude of research showing the implications of the caregiver role on the effects of both the physical and mental well-being of the caregiver; however, there is a paucity of information on the long-term effects of youthful caregiving on adult mental health. This problem is very relevant to clinical practice as families are and continue to be the foundation for providing informal care at home; often impacting the caregivers' health. As an advanced practice nurse working in primary care, it is imperative not only to identify this hidden population but to address those at risk for mental illness. The clinical significance would be to lay the foundation for development of future policies and practices related to improved levels of service. This project answers the question, "In former young caregivers, what is the effect of caregiving on adulthood mental health?"

Young caregivers are often defined as a young person under the age of 21 whose life is impacted or restricted by providing primary care responsibilities to a sick or disabled parent or relative in the home (Aldridge & Becker, 1993). Nationwide, the approximation of young caregivers is 1.3 to 1.4 million who are between 8 and 18 years of age; more than the total number of combined students in third thru twelfth grade in New York, Chicago, and the District

of Columbia (American Association of Caregiving Youth, 2017). Although there is a vast amount of research on the psychological effects of caregiving on mental health, there is limited information on the long-term effects of youthful caregiving.

### **Background Knowledge**

There is a substantial amount of early caregiving research in the United Kingdom (UK) but little attention has been given to this hidden population in the US. In the UK, approximately 19,000 to 51,000 individuals age 18 years and younger provide primary care to parents or grandparents (Dearden & Becker, 1999). In several national surveys conducted between 1995-1997, the average age of the early caregivers was between 11-15 years old, in secondary school, and more than half were female. Unfortunately, there is limited research that has been conducted in the US on the prevalence of early caregiving; however, studies by Gates and Lackey (1998; Lackey & Gates, 1997) reported children as young as 10 years of age providing care to a parent. A New York City survey of family caregivers discovered 28 young caregivers between 18-21 years old comprising 6.7% of the total sample (United Hospital Fund, 2000). Although the above information provides some evidence on early caregiving, there is much to learn about the early caregiving experience.

Research consistently shows depression and depression related symptoms are associated with caregiving. Between 20 to 33% of individuals with depression report its onset before 21 years of age (Arya, Montero-Marin, Barroilhet, Fritsch, & Montgomery, 2013) and if one includes caregiver experiences from childhood or adolescence it is assumed this would exacerbate the presence of depressive symptoms. Evidence also suggests that as many as 75% of young caregivers develop psychological disorders in adulthood (Frank, Tatum, & Tucker, 1999)

especially if the care recipient had mental health issues or substance abuse problems.

Unfortunately, limited evidence remains regarding the impact of youthful caregiving on the long-term effects on their adult mental health.

### **Significance**

Caring for a dependent family member with a chronic illness or disability is a normative developmental challenge for families in the US and worldwide. The findings of this study will add to the limited body of evidence regarding the experiences of former young caregivers and the impact it has on their adult mental health. The new knowledge that is developed will provide insight to both primary care providers and policymakers on the importance of identifying this hidden and underserved population.

An absence of public awareness and a paucity of available resources about youthful caregiving often lead to challenges that could be addressed by the Advanced Practice Registered Nurse (APRN) as they are frequently the young caregivers point of contact. Nurses have often been referred to as wounded healers because they are someone who understands pain; pain from wounds and trauma experienced in their own lives. APRNs are in an important position to help these often-forgotten caregivers because they aim to prevent pain, relieve pain, and cure pain.

### **Purpose and Aims**

The purpose of this study was to describe the psychological effects on adult mental health of former young caregivers who provided primary care. The aims of this project were to:

- 1) Describe the positive aspects of caregiving in youth.
- 2) Describe the negative aspects of caregiving in youth.

- 3) Describe how childhood memories and experiences of caregiving affect the former child caregiver's adult mental health.

### **Theoretical Foundation**

The theoretical foundation for this research was the middle-range theory of Caregiver Stress. This theory was developed from the 1984 conceptualization of the Roy adaptation model (RAM) to lay the groundwork for understanding the correlation between an individual and the stress they face when caring for a chronically ill or disabled family member. Many factors contribute to caregiver's stress. These reasons are as different as the caregivers themselves. One's attitudes and perceptions of how they view the world around them or certain circumstances can determine whether it causes stress. The Theory of Caregiver Stress was developed to predict the stress of the caregiver and its outcomes of chronic or long-term caregiving responsibilities based on a variety of different perspectives such as demographic characteristics, the burden and strain of providing care, stressful life events, presence of social support, and the impact of social roles (Tsai, 2003).

The RAM was originally developed in 1970 by Sister Callista Roy describing individuals as holistic, interrelated systems that constantly adapt while interacting with their environment (Roy, 1970). RAM uses the concept of adaptation to explain how individuals use innate and acquired mechanisms to adapt to internal and external environmental stimuli. The individual's adaptation is a function of the stimulus they are exposed to and are determined by the combined effects of three types of stimuli: focal, conceptual, and residual. Focal stimuli are internal or external factors that present themselves and demand prompt attention (Roy, 1984). Contextual stimuli are the stimuli that guide the situation and contribute to the effect of the focal stimuli

(Andrews & Roy, 1991; Tsai, 2003) and residual stimuli are the individual's beliefs, thoughts, or attitudes that may influence a situation (Andrews & Roy, 1991). These types of stimuli impact an individual's ability to cope with the environment and are considered input into the adaptive system.

### **Focal Stimuli**

#### **Objective Burden**

The focal stimulus in the Theory of Caregiver Stress is the objective burden as perceived by the caregiver (Tsai, 2003). Objective burden is the duties or responsibilities associated with caring for a person with a chronic disease, such as hours of care and management of care arrangements. These tasks initiate the coping mechanism and often interfere or overlap with other facets of the caregiver's life such as finances and interpersonal relationships (Thompson & Doll, 1982).

### **Contextual Stimuli**

#### **Stressful Life Events**

Stressful life events are defined as situations that alter life circumstances, challenging the individual and causing despair (Rabkin, 1993). These events correspond to both physical and mental health implications, but its impact varies depending on one's perception. Is it a threat or a problem? This implies that residual stimuli have a greater influence on the perception of caregiver burden than the task itself (Litzelman et al., 2014; Tosevski & Milovancevic, 2006). Caregivers with unresolved stressful life events will undergo higher levels of stress resulting in negative health related outcomes and maladaptive responses (Tsai, 2003).

## **Social Support**

Social support is an important construct of the stress process. Lin, Simeone, Ensel, and Kuo (1979) defined social support as “support accessible to an individual through social ties to other individuals, groups, and the larger community” (p. 109). It has often been conceptualized as a mediator between the effects of the caregiving stressors and the perceived level of stress (Pearlin, Mullan, Semple & Skaff, 1990). The quality of social support from the caregiver’s network of family and friends has been shown to lower caregiver stress while enhancing resiliency to stress (Shiba, Kondo & Kondo, 2016). The Theory of Caregiver Stress suggests that a caregiver’s social support; 1) helps reduce the objective burden by changing their perception of caregiving, 2) increases their ability to cope in an effective manner, and 3) enhances the caregiver’s overall wellbeing (Tsai, 2003).

## **Social Role**

The final construct contained within in the contextual stimuli is the social role. The Theory of Caregiver Stress defines social role as the function a caregiver has toward other people in their life such as mother, sister, or worker. This theory postulates that the higher the number of roles a caregiver has, the better their mental and physical well-being (Tsai, 2003); however, according to Skaff and Pearlin (1992) this does not hold true if the caregiver is unmarried, unemployed, and without children. Having multiple social roles provides a means for the caregiver to express their feelings; however, the lack of social roles apart from being a caregiver limits their ability to handle stress as they are unable to redirect and focus their attention elsewhere.

### **Residual Stimuli**

Residual stimuli include the caregiver's demographics such as age, gender, and race, all of which alter an individual's ability to cope and impacts their resiliency to stress (Tsai, 2003). Residual stimuli assert its effects on the objective burden through the individual's perception of stress as influenced by cultural beliefs and values (Tsai, 2003). Race is defined as a group of people affiliated by common culture or history (Merriam-Webster, 2017) often influencing personal beliefs and values. Cultures differ in the way they perceive and cope with stress (Boyle, 2003). In a study by Lawton, Rajagopal, Brody, and Kleban (1992), black caregivers were found to experience less stress and less depression. This theory hypothesizes that race affects caregiver's stress and black caregiver's experience less stress than whites (Tsai, 2003).

#### **Age**

Age is another aspect of residual stimuli and describes the caregiver's chronological and developmental stage. Age influences how individuals view objects and situations. Evidence shows that age has an indirect effect on depression by altering one's perception of stress, the ability to cope, and its perceived effectiveness (Aldwin, 1991). The Theory of Caregiver Stress speculates that younger caregivers will experience higher levels of stress than older caregivers as older caregivers may adapt more to adversity because of various life experiences, providing them opportunities to learn and refine their coping skills (Tsai, 2003; Tsai & Jirovec, 2005). Gender also plays a significant role in the perception of caregiver stress. This theory conceives that women will experience escalated levels stress than men as they are most likely to become primary caregivers and are more involved with the caregiving responsibilities (Tsai, 2003). The last component composing the residual stimuli is the relationship between the caregiver and the

care recipient. Some studies have shown no correlation between the type of relationship (i.e. mother–daughter, husband-wife) and caregiver burden (Rankin, Haut & Keefover, 1992) while others have stated otherwise (Young & Kahana, 1989; George & Gwyther, 1986). Therefore, this theory proposes that the caregiver and care recipient’s relationship may influence caregiver stress.

The control process of the Theory of Caregiver Stress is the main component of the coping mechanism held by the caregiver. It is the link that encompasses the caregiver’s coping mechanism through perceived stress and depression. The Theory of Caregiver Stress speculates that environmental stimuli such as objective caregiver burden (focal stimuli), stressful life events, social support, and social roles (contextual stimuli), and residual stimuli (age, race, gender) elicit adaptation responses (Tsai, 2003). Without caregiver stress, focal, contextual, and residual stimuli, there would be no impact on the caregiver’s adaptive responses. The key point is caregiver stress is a perception of the individual’s coping skills that include activities from innate mechanisms known as the cognator and regulator subsystems. The cognator responses are used primarily to cope with psychological stimuli whereas the regulator responses are used to cope with physiological stimuli (Roy, 1970). These responses are demonstrated as behaviors that fall into four adaptive modes; physiological, self-concept, role function, and interdependence (Tsai, 2003). These behaviors or effectors contribute to the four adaptive modes and are considered the output components in RAM.

The physiological mode manifests itself with adaptation in physical integrity and survival such as activity, rest, nutrition, and neurological and endocrine function. In the Theory of Caregiver Stress, physical and physiological function are synonymous; physical impairment

represents a maladaptive coping response whereas high physical functioning indicates an adaptive coping response (Tsai, 2003).

Self-esteem and mastery are used in the Theory of Caregiver Stress to represent self-concept. According to Skaff and Pearlin (1992), caregivers exhibit lower self-esteem and mastery when compared to non-caregivers; placing them at a higher risk of depression and increased burden (Clair, Fitzpatrick & La Gory, 1995). This theory refers to self-esteem as the caregiver's belief of their value or self-worth and mastery as one's perception of their ability to handle or manage life events (Tsai, 2003). Reports of low self-esteem and/or low mastery represents a maladaptive response whereas high self-esteem and/or high mastery are indicative of adaptive responses.

Role enjoyment is another output component in the Theory of Caregiver Stress. Role enjoyment, as defined by Tsai, is "the caregiver's expressive behavior displayed in their major social role, that may be used to represent role mastery and function" (2003, p.142). Role enjoyment is impacted by the perception of caregiver burden (Gold et al., 1995). A decrease in role enjoyment indicates maladaptive coping whereas high role enjoyment is associated with adaptive coping.

The Theory of Caregiver Stress is a middle range theory derived from Roy's Adaptation Model to lay the groundwork for understanding the correlation between an individual and the stress they face when caring for a chronically ill relative. This theory proposes that objective burden is the most important condition leading to caregiver stress and if the perceived stress is high, the caregiver will experience maladaptive responses with the most common maladaptive response being depression. This theory identifies depression as the mediator between the

perceived stress and other outcomes associated with long-term caregiving; therefore, interventions should target caregiver's who are experiencing depressive symptomatology or those at a greater risk for depression.

### **SYNTHESIS OF EVIDENCE**

To gain a better understanding into the experiences of young caregivers a comprehensive literature review was performed using PubMed, CINHAL, PsycARTICLES, PsychINFO, and Google Scholar. A combination of the following key terms was used to identify appropriate articles: former young caregivers, hidden carers, young caregiver experience, identity, adolescents, children, adults with chronic illness, disabilities, lived experiences, mental health, resilience, coping, depressive symptoms, and psychosocial impact. This initial search yielded 546 articles. These were further narrowed by: English language, birth to 18 years, and articles published within the past 10 years. Articles were excluded if age at the time of caregiving onset exceeded the age of 18 and irrelevance to this project. Another strategy used due to the limited availability of research was the ancestry approach to locate recent studies. Also, because of the paucity of evidence in this neglected group, it was necessary to utilize research greater than 10 years; thus, a total of 26 articles were retrieved.

There has been a variety of definitions regarding who a young caregiver is. For this literature review, 'young caregiver' is defined as a young person under the age of 21 whose life is impacted or restricted by providing primary care responsibilities to a sick or disabled parent or relative in the home (Aldridge & Becker, 1993).

The caregiver role can occur at any time during a person's lifetime and the impact on their mental health is important to understand. Of the 65 million caregivers in the US (National

Alliance for Caregiving & AARP, 2015), research has shown factors such as age, personality, support systems, life stressors, coping strategies, and disease severity impact a caregiver's mental well-being (Schulz & Sherwood, 2008).

Of these caregivers, approximately 1.3 to 1.4 million are children, ages 8 to 18, (National Alliance for Caregiving (NAC) & United Hospital Fund, 2005) who are experiencing this role. There is a multitude of evidence that shows how the caregiving role can impact both the mental and physical health of the caregiver; however, little evidence exists on youthful caregiving in the US and the impact it has on their adult mental health. Understanding the long-term effects caregiving has on former young caregivers is imperative; there is still much to learn about their lived experiences and its impact on their psychological, social, and emotional development.

Although there has been discussion in the literature about what it is like to be a young caregiver, little is known about the effects it has on their adult mental health. Research suggests that providing primary care has both positive and negative consequences on children. Some studies reveal that young caregiving has positive psychological effects such as perceived maturity, independence, optimism, enhanced self-efficacy, and feelings of appreciation and importance (Iezzoni, Wint, Kuhlthau & Bourdreau, 2016; Lackey & Gates, 2001; Shifren, Hillman & Rowe, 2014) whereas others reveal negative psychological effects such as decreased life satisfaction, lack of social support, change in roles, and increased stress and burden lead to anxiety and depression (Bjorgvinsdottir & Halldorsdottir, 2013; Iezzoni, Wint, Kuhlthau & Bourdreau, 2016; Pakenham, Bursnall, Chiu, Cannon & Okochi, 2007).

### **Positive Psychological Effects**

According to the National Opinion Research Center (2014), 83% of caregivers viewed their position as a positive experience; often finding benefits in their role and actions. These positive experiences lead to a sense of increased compassion, empathy, and personal growth, along with an enhanced sense in meaning and purpose of one's life.

### **Benefit Finding**

Several studies have found that beginning primary care in early childhood may not be associated with long-term negative consequences for all individuals (Shifren, 2001; Shifren & Kachorek, 2003; Lackey & Gates, 2000). These studies examined the experiences, needs, and lives of youngsters caring for adults with an acute/chronic illness or disability. Types of caregiving assistance included basic activities of daily living (ADL) that included feeding, bathing, dressing, toileting, and ambulating in addition to instrumental activities of daily living (IADL) that consisted of household care such as cooking, cleaning, laundry, and paying bills. Although these tasks may be numerous and time-consuming, young caregivers often described their experience as 'hard yet gratifying' (Lackey & Gates, 2001). Studies suggest that former caregivers felt a sense of maturity and pride as caregiving taught them responsibility, helped them 'to be part of the family', provided opportunities to feel valued and needed, while teaching them independence and life skills (Bjorgvinsdottir & Halldorsdottir, 2013; Iezzoni, Wint, Kuhlthau & Bourdreau, 2016; Pakenham, Bursnall, Chiu, Cannon & Okochi, 2007).

A study conducted by Cassidy, Giles, and McLaughlin (2013), found that benefit finding is directly associated with increased positive outcomes such as resilience, increased support, and greater adaptive stress responses. These findings correlate with previous research indicating that

caregivers experience benefit finding when the burden of care is low thus mediating the negative impact and predicting positive outcomes (Bower, Moskowitz & Epel, 2009; Helgeson, Reynolds & Tomich, 2006). Cassidy et al. (2013) concluded that benefit finding may be the boundary between beneficial and harmful burden. It is recognized as a potential way to identify when the level of care exceeds the beneficial capacity and becomes damaging thus preventing benefit finding from occurring (Cassidy, Giles & McLaughlin, 2013).

### **Resiliency**

Findings thus far suggest a correlation between positive adult mental health and resiliency. Resilience is what provides individuals with the psychological strength to cope with stress and rebuild their lives after facing adversity. The study by Cassidy et al. (2013) supports the findings of Pakenham et al. (2007) that caregiver stress is mediated by social support, role recognition, resiliency, and benefit finding; serving as an effective remedy for depression (Bjorgvinsdottir & Halldorsdottir, 2013) while leading to a state of positive mental health.

In a study by Shifren, Hillman, and Rowe (2014), 40% of the study participants had depressive symptomatology; however, most of the young caregivers did not show poor mental health. Although research has shown caregiving for adults with mental illness or drug addiction has been associated with poorer mental health in caregivers (Frank et al., 1999), the study by Shifren et al. (2014) does not consistently show this correlation.

Resilience is a dynamic process; a constant balance of risk factors and protective factors. Caring for someone who is chronically ill is a risk factor that is characterized by the physical, psychosocial, emotional, and financial stressors associated with caregiving (Dumont, Fillion, Gagnon & Bernier, 2008). Research shows that protective factors such as positive perceptions

can enhance resilience by minimizing the effects of the risk factors, boost positive mental health, and increase one's capacity to effectively manage the stress of daily activities (Bekhet, Johnson & Zauszniewski, 2012; Zauszniewski, Bekhet & Suresky, 2010; Zauszniewski et al., 2002). For example, in a study by Zauszniewski et al. (2002), positive perceptions have been shown to decrease the severity of depressive symptoms in women with type 2 diabetes.

### **Negative Psychological Effects**

Caregiving is often associated with poor mental and physical health (Torres et al, 2015; Tsai & Jirovec, 2005). While numerous studies have shown that providing care to someone with a chronic illness or disability is linked to negative mental health outcomes in adults, little research exists on the long-term effects of youthful caregiving on adult mental health development. The constructs that contribute to these negative effects in children are often academic difficulties, lack of identity or role recognition, and the development of anxiety and depression (Cree, 2003; Dearden & Becker, 2004; Hounsell, 2013; National Alliance for Caregiving & United Hospital Fund, 2005).

### **Academic Difficulties**

One of the most significant negative effects of youthful caregiving is its impact on academic performance (Cree, 2003; Dearden & Becker, 2004; Hounsell, 2013). According to a 2006 study of U.S. high school dropouts, 22% left school to care for a family member (Bridgeland, DiJulio & Morison, 2006). In Hounsell's 2013 survey of young caregivers in the UK the levels of caring responsibilities varied substantially; ranging from a few hours per week to over 100 hours per week. This demonstrates that caring can occupy a large amount of a young caregiver's time often requiring them to miss school (Hounsell, 2013). This is consistent with

other surveys of young caregivers in the UK where one fifth of the participants reported similar academic difficulties (Dearden & Becker, 2004).

A study by Thomas et al. (2003) reported that 50% of the study participants were struggling academically, mostly with keeping current on homework assignments. These findings were supported by Siskowski (2006) indicating that 38.5% of students surveyed agreed or strongly agreed that living with a care recipient often hinders their learning, of which 69% reported their caregiver role impacted their academic performance. There could be a few reasons that contribute to this academic difficulty; 1) Role reversal which includes caregiving responsibilities that may interfere with homework (Cree, 2003; Dearden & Becker, 1998; Thomas et al., 2003), 2) Lack of parental support, encouragement, or assistance with homework assignments (Siskowski, 2006), and 3) Lack of school nurse recognition of students who are also caregivers remains problematic (Hutchinson, Roberts, Daly, Bulsara & Kurrle, 2015; Siskowski, 2006).

According to Cree (2003), there is a strong link between the length of time caring and the deterioration in academic performance. Some 75% of those who cared for 'as long as I remember' reported school problems compared to 33% of those who 'just recently' became carers. Even though some evidence shows a school as a protective factor for young caregivers (Cree, 2003), a majority of studies report poor academic outcomes (Bridgeland, DiIulio & Morison, 2006; Siskowski, 2006).

### **Anxiety and Depression**

Evidence shows that depression is a common occurrence of caregiving in emerging young adults and older adults but there is little evidence on the long-term effects of primary

caregiving in youth. Results from a landmark study in the US indicate that young caregivers were more likely to exhibit depression and anxiety than their non-caregiver counterparts (National Alliance for Caregiving & United Hospital Fund, 2005). Researchers have examined the effect of parental illness or disability on children citing elevated distress, social isolation, lack of support and knowledge all contribute to the anxiety and depression young caregivers experience (Banks et al., 2002; Bjorgvinsdottir & Halldorsdottir, 2013; Lackey & Gates, 2001). They also found the longer the duration of caring responsibilities, the more damaging the effects to a child's emotional and mental well-being (Dearden & Becker, 1999; Shifren & Kachorek, 2003).

In a study conducted by Bjorgvinsdottir and Halldorsdottir (2013), young caregivers often experienced fear and anxiety regarding the uncertainty of how their parent's illness will disrupt their lives. These caregivers reported receiving little or no information about the illness from healthcare providers which directly influenced the lack of communication and decreased information exchange within their homes. This sparse knowledge and decreased communication added to their anxiety regarding the uncertainty of their reality and gave rise to a 'state of silence' to never discuss the illness or their experience either at home or in social settings (Bjorgvinsdottir & Halldorsdottir, 2013). Other reasons given for this 'state of silence' include a fear of being ridiculed, the experience is too difficult to talk about, and not having someone they felt comfortable confiding in (Aldridge & Becker, 1993; Turpin, Leech & Hackenberg, 2008).

### **Mediating Factors to the Psychological Effects**

The positive or negative psychological impact on adult mental health may be mediated by numerous factors which should be identified and considered when planning how to support

young caregivers. These mediating factors include but are not limited to the sociodemographics of the caregiver, the amount of social support received by a young caregiver, and self-identity and role recognition (Rose & Cohen, 2010; Savage & Baily, 2004; Smyth, Blaxland & Cass, 2011).

### **Sociodemographic Factors**

Evidence shows that financial burden in addition to the caregiving role may be associated with a negative impact on a caregiver's mental health. Although many studies have demonstrated the financial burden of caregiving in the adult population; there is limited information on the financial strain experienced by young carers. It has been reported, however, that young caregivers often live in poverty (Dearden & Becker, 2000).

According to Lazarus and Folkman (1984), practical resources such as money are valuable mediators between stress and coping as they provide a significant increase in accessible coping options. In a study of young carers in Western Kenya, Skovdal, Ogutu, Aoro, and Campbell (2009) found that coping strategies in young caregivers consisted of engaging in work and income producing activities. This increased self-efficacy helped build a positive social identity around their caregiver role (Skovdal et al., 2009).

Additional factors that may contribute to the negative psychological effects include age and gender. Age has been shown to have an indirect effect on depression with young caregivers often experiencing more strain than older caregivers (Tsai & Jirovec, 2005). Cree (2003) supports these conclusions indicating that older young people were more likely to report more problems and worries than young people.

Gender also plays a significant role with regard to mental health. There is an abundance of research that shows females are more likely to occupy a caregiver role; however, according to the 2005 U.S survey on young caregivers it is equally balanced (males 49%, females 51%) (Hunt, Levine & Naiditch, 2005). Although there is a balance of boys and girls in the young caregiver role, girls are still more likely to experience more problems and worries than boys (Cree, 2003). Girls were more likely to report sleeping and eating difficulties, problems at school and higher absenteeism, and worried more about their academic performance than boys. Some 72% of girls reported discord with friends (vs. 52% of boys), 58% of girls were concerned about not having any friends (vs. 20% of boys), 50% of girls reported some type of self-harm (vs. 20% of boys), and 50% of girls contemplated suicide (vs. 26% of boys) (Cree, 2003). Nevertheless, these findings may be explained by females being more open and willing to share their experiences.

### **Social Support**

Social support is the physical and emotional comfort received from a network of family, friends, and community members and is an essential part for sustaining physical and psychological health. Numerous studies indicate that social support is an important component to adaptive coping and is associated with an increase in positive mental health (Pakenham, 2001; Turpin, Leech & Hackenberg, 2008) and buffering of stress on young caregivers (Kotchick et al., 1997).

In young caregivers, the availability of social support is a vital resource as most services focus on the care receiver. Although evidence supports the correlation between social support and positive mental health, many young caregivers identify the lack of an informal or formal

support network leading them to feel unsupported, unacknowledged, and isolated often leading to psychological distress and maladjustment (Aldridge & Becker, 1993; Armistead, Klein, & Forehand, 1995; Bjorgvinsdottir & Halldorsdottir, 2014).

In a study conducted by Pakenham, Chiu, Bursnall, Cannon, and Okochi (2007), it was found that social support availability was correlated with increases in life satisfaction, positive affect, and decreases in psychological distress, emerging as the strongest predictor of adjustment outcomes. Given the fact that most services focus on the well-being of the care receiver, many young caregivers rely on the physical and emotional support from family and friends making the presence of a strong social support structure essential for this vulnerable population.

Social support is a crucial variable that contributes to the positive aspects of caring; however, young caregivers often have an inadequate or ineffective social support system. Unfortunately, those with limited social support systems, such as young caregivers, are vulnerable to depressive symptomatology placing their adult health in jeopardy. There appears to be strong evidence linking the lack of a social support system to depression in family caregivers (Thompson, Futterman, Gallagher-Thompson, Rose & Lovett, 1993). Other findings also suggest that lower social support predicted higher perceived burden and lack of social contact lead to isolation and increased stress (Clyburn, Stones, Hadjistavropoulos & Tuokko, 2000; Spaid & Bruschi, 1992).

In their study of 11 child caregivers, Aldridge and Becker (1993) identified the theme of 'self-inflicted silence.' Most of the young caregivers had not discussed their caring situation or experiences with friends or healthcare professionals because of fear or pride (Aldridge & Becker, 1993). Youngsters have also distanced themselves from their caregiving role while at school

citing they did not want to discuss caregiving with others (Gates & Lackey, 1998). This isolation and lack of social support can have serious consequences for young caregivers; affecting academic performance, career or employment opportunities, future earning capacity, but mostly physical and mental well-being (Smyth, Blaxland & Cass, 2011).

### **Identity and Role Recognition**

Although there is a significant amount of survey data from Australia, the UK, and the US on the prevalence of youthful caregiving, these national surveys do not uncover the full extent of this ‘hidden’ population. Numerous research studies have identified a vital component of why this population remains hidden; many do not identify themselves as a caregiver but rather a son, daughter, sibling, or grandchild (Morrow, 2005; Smyth, Blaxland & Cass, 2011) and often consider their increased responsibilities as normal, everyday tasks.

However, further studies illustrate that young caregivers often felt silent, invisible, and unacknowledged not only by their family but also by friends and community members (Bjorgvinsdottir & Halldorsdottir, 2012; Hutchinson et al., 2015). They described how they felt isolated and different from their peers; nevertheless, Smyth et al., (2010) found that 68 young caregivers welcomed the revelation of their experiences and the value of their contribution in the social context of identity formation. This mirrors the research by O’Connor (2007), re-counting the ‘extrinsic rewards’ of the caregiver identity and the opportunities it affords for self-development.

### **Gaps in Literature**

Research to date is very limited on the experiences of young caregivers. Based on the literature search, there appears to be one prominent gap in the literature; a lack of consensus

when defining young caregivers. Because of this inconsistency, the term “young caregiver” leads to a wide variety of age ranges used by studies; under 21, 8-25, or 18-25. The variability among the age ranges makes it difficult to accurately compare experiences based on age. Most studies also tend to capture experiences at a specific point-in-time versus using longitudinal studies that would provide a better understanding of the long-term effects of caregiving.

## **METHODS**

Research methods are as unique as the researchers themselves. They are techniques used to structure a study and to gather and analyze data pertaining to the research question (Polit & Beck, 2012). Researchers who use quantitative designs use empirical evidence that is gathered by using structured methods; whereas qualitative researchers use flexible procedures to capitalize on the meanings that emerge from the phenomenon being studied. A descriptive qualitative study design was chosen to obtain a deeper insight into the physiological effects of youthful caregiving on adult mental health.

A qualitative study is aimed at gaining a deeper understanding of a specific phenomenon of interest and the ability to which the findings can be generalized to a larger population (Polit & Beck, 2010; 2012). It seeks to acquire a clearer insight into a specific research problem from the perspective of the population involved. It does not introduce treatments or alter variables, but rather generates data about a group’s behavior within a social setting (Qu & Dumay, 2011).

Using a case study approach allows researchers insight into the why; why a person thinks, behaves, and develops a certain way (Polit & Beck, 2012). Case studies are particularly valuable when a need arises to obtain in-depth knowledge and understanding of a specific event or phenomenon within its real-life context (Crowe et al., 2011). To examine the long-term

psychological effects of youthful caregiving on adult mental health, a case study not only enables the researcher to obtain a wealth of descriptive information but also assists with establishing trends in one's mental health over time.

### **Ethical Considerations**

Prior to the recruitment of study participants, approval by The University of Arizona and College of Nursing Institute Review Board (IRB) was obtained and both the demographic and interview questions were reviewed by a clinical expert. Disclosures were used in lieu of consent forms. The disclosures helped to ascertain voluntary participation, notify participants of potential risks and benefits, safeguard the participants right to decline participation or withdraw from the study once it began, and outlined who to contact with study related questions. In the unlikely event the interview caused emotional distress, I reminded the participants of their right to decline answering or withdraw from the study. I also offered a list of local mental health providers to each participant in the event any discussions caused emotional distress. To ensure confidentiality and anonymity throughout the study, pseudonyms were used in all documents and in this manuscript. Study materials such as audio recordings, transcripts, and field notes were securely maintained, encrypted, and kept in an area with limited access and were destroyed at the completion of the study project.

### **Recruitment and Participants**

Recruitment for this project included seeking potential participants from the Phoenix Metropolitan Area and Southern Arizona. Project fliers were posted on community bulletin boards to aid in identifying interested participants. Once a key informant was identified, snowball sampling was used to locate additional participants from early sample members (Polit

& Beck, 2012). The setting for each interview session was at a location of the participants choosing. To gain a further understanding into the experiences of former young caregivers, three interviews were used to form the case study; interviews were conducted using open-ended questions organized in a semi-structured format. Potential participants were invited to contact me if they were a registered nurse and as a child or young adult (younger than age 21) they had assumed the role of primary care assistant (i.e. bathing, dressing, feeding, toileting) to a parent or adult relative. No interested participants were excluded due to ethnicity gender, background, or reason care was needed.

### **Data Collection and Analysis**

Case studies are an approach to understand an individual's everyday experiences and are especially useful when a phenomenon has been poorly conceptualized (Crowe et al., 2011). To assist in acquiring the knowledge to comprehend the phenomena, one must look at multiple perspectives of the same situation to generalize what the meaning of an experience is from an insider's perspective. To obtain this perspective, three participants were interviewed to gain a better awareness of the experiences of previous young caregivers. To strengthen trustworthiness of the findings, each interview included identical semi-structured, open-ended questions allowing the study participants to elaborate and answer the questions from their perspective; additional questions were guided by the participant's responses. Each interview began with simple demographic questions that were followed by questions inquiring about their experience as a young caregiver. Each participant was asked the following standard questions:

- 1) What age were you when you began caregiving?
- 2) Whom did you care for?

- 3) How old was the family member?
- 4) What type of illness did your family member have?
- 5) How long did you provide care to the family member?
- 6) What birth order are you? Oldest, middle, youngest?
- 7) Describe your caregiving experience.
- 8) Describe the positive experiences of being a young caregiver both then and now.
- 9) Describe the challenges you experienced as a young caregiver both then and now.
- 10) What was the biggest challenge you experienced?
- 11) How has your experience as a young caregiver impacted your physical health?
- 12) How has your experience as a young caregiver impacted your relationships / friendships as a child? As an adult?
- 13) How did being a young caregiver affect your school performance?
- 14) How do you feel your experiences as a young caregiver has impacted your adult mental health?
- 15) How has your experience as a caregiver influenced your career choice?
- 16) Looking back on your experience, what do you believe would have been helpful to you as a young caregiver?

Each interview was conducted in a private location chosen by the study participant. Each interview was audiotaped, lasting approximately 30 minutes, and I conducted all interviews.

During each interview, close attention was given to not only to the participants' words but also to their body language, tone of voice, emotions, and gestures. Observations of the participants' non-

verbal cues were documented in a notebook during the interview for later assessment and reflection.

Data analysis is a dynamic and collaborative process. Researchers examine the data carefully while scrutinizing the information in search of meaning and understanding of the phenomenon being studied (Polit & Beck, 2012). Analysis of the data began with transcription of the audiotaped discussions. To ensure the best possible quality data and accuracy of transcripts, voice recognition software was used to transcribe the digital audio recordings into word format. Once the recordings were transcribed, I listened to all three recordings to verify accuracy of the transcripts. Once accuracy was verified, the recordings were destroyed.

Content analysis began with the origination of text from each of the participants interviews. As each transcript was studied, shared terms and phrases that were used repeatedly or appeared to be central to perceptions described by the participants were identified. Next, all transcripts were reviewed collectively to identify commonalities of experiences, events, and emotions to ensure their reliability. Cross case conclusions were drawn to determine related themes.

## **FINDINGS**

The purpose of this study was to describe the psychological effects on adult mental health of former young caregivers who provided primary care in youth; specifically, the positive and negative aspects of caregiving in youth and how childhood memories and experiences of caregiving affect the former child caregiver's adult mental health. Findings were analyzed for commonalities such as events occurring during childhood-adolescence, emotional memories, past and current triggers, and reflections. Analysis of the interview data provided a deeper insight

into the perspectives of each participant as they shared their views on the positives and challenges they experienced as a young caregiver, in addition to the impact caregiving has had on their adult mental health.

### **Participant Demographics**

There were a total of three study participants: A Telemetry nurse, a Nephrology nurse, and a Nurse Practitioner. All study participants were female, mean age was 43 years old with an average nursing career of 13 years, the mean age at the onset of caregiving was 14 years old with the duration of caregiving lasting an average of 4 years; birth order consisted of a first born, a middle child, and a baby (Table 1). Common tasks included both ADLs (medication administration, ambulating, lifting, repositioning, wound care, and transporting to appointments) and IADLs (cooking, cleaning, and laundry). Two of the participants provided a majority of the caregiving tasks while their mother was providing financially for the family. The third study participant was married and caring for her widowed grandfather. All three participants met the inclusion criteria. The care recipients consisted of (2) fathers and (1) grandfather averaging 51 years old at the onset of caregiving. Conditions of the care recipient included alcoholism with Hepatitis C, terminal colon cancer, and an industrial accident resulting in bilateral crush injuries to the lower extremities subsequently rendering immobility (Table 2).

TABLE 1. *Study Participant Demographics*

<b>Study Participant</b>	<b>Type of Nurse</b>	<b>Gender</b>	<b>Age</b>	<b>Years of Nursing</b>	<b>Age at Caregiving Onset</b>	<b>Duration of Caregiving (Years)</b>	<b>Birth Order</b>
#1	Telemetry Nurse	Female	26	0.58	12	6	Baby
#2	Nephrology Nurse	Female	50	18	19	0.42	Middle
#3	Nurse Practitioner	Female	53	21	12	6	First Born

TABLE 2. *Care Recipient Demographics*

<b>Care Recipient</b>	<b>Family Role</b>	<b>Gender</b>	<b>Age</b>	<b>Medical Condition</b>
#1	Father	Male	43	Alcoholism with Hepatitis C
#2	Grandfather	Male	68	Terminal colon cancer
#3	Father	Male	42	Crush injury to bilateral lower extremities

### **Description of the Caregiving Experience**

When asked to describe their experiences as a young caregiver, the study participants defined their experience as ‘new,’ ‘challenging,’ or ‘fun,’ with much of their description focusing around the caregiving tasks. Common tasks associated with their experience included ADLs such as medication administration, lifting, ambulating, repositioning, feeding, dressing, and personal care. Two of the participants who cared for their father excluded bathing and toileting as part of personal care as these tasks were attended to by their mother. Additional responsibilities included IADLs of laundry, cooking, cleaning, and transporting the care recipient to doctor’s appointments. One participant whose father suffered from alcoholism and Hepatitis C, initially describes her involvement as minimal. At a young age, she recalls trying to encourage her dad to stop drinking and to make better choices with his diet and social habits, but as she grew older and began driving her role started to change.

*“It felt a lot like a parenting role you know... It really escalated throughout the years and the level of care I had to provide; it was very reversed. I kinda considered myself in a parenting role towards the end.”*

### **Positive Experiences of Being a Young Caregiver: Then**

Participants were asked to describe the positive experiences of being a caregiver during their adolescent years. All participants agreed of feeling accomplished in terms of helping those who cannot help themselves.

### **Benefit Finding**

The participants reflected on positive situations they encountered, but each shared in a common theme of being a young caregiver; the importance of benefit finding. Benefits included

being present through a loved one's end of life, feeling a close family bond, or helping the family. As one participant described,

*“I got to spend the end of life with my grandfather. So, I felt worthy. I felt like it was something I could give that nobody could ever take away from me... “Taking care of him gave me pride and satisfaction”.*

Although not universal, one participant specifically stated that she did not experience many positives while caring for her father; however, the assistance she gave her mother to help reduce the caregiving burden was viewed as the only positive aspect.

*“I felt positive helping my mom. She had to provide financially for us so I guess through my caregiving, I knew that I was helping my mom and taking stress off of her.”*

### **Social Support**

A further attribute associated with the positive experiences of being a young caregiver centered around the concept of social support. For the three participants, social support held similar meanings; the reassurance of having assistance available from others when needed. The type of support the participants received was emotional, financial, informational, spiritual, and personal mostly found through family and friends. One participant reflected on her social network and the impact it made on her coping.

*“My very close friends understood me and really supported me... being present and not being afraid to be with me when stuff was going on. They weren't afraid to come over to my house or allow me to come over to their house even at the last minute if my dad was like really drunk and I didn't feel safe. They would allow me and families would allow me to come over and stay if I needed. Being present was a big thing, but also being patient with me on my bad days. Just understanding if I had an outburst, if I was really angry, or if I was just really frustrated. They didn't make me feel bad for feeling that way. I just felt really like I could be myself with them, like they weren't expecting me to put on a happy face and that was a relief; a huge relief.”*

For all the participants, having a strong social support system helped mediate the negative effects of caregiver stress.

### **Positive Experiences of Being a Young Caregiver: Now**

Participants were then asked how they viewed the effects of their caregiving experience on their present adult life. All participants agreed their experience helped them become more caring and compassionate while molding them into who they are.

### **Influence of Self-Identity and Career Choice**

One of the major commonalities between all participants was the amount of influence caregiving had on establishing their self-identity and career choice. Common words and phrases used to describe themselves include ‘empathetic,’ ‘caring and compassionate,’ ‘proud,’ ‘worthy,’ ‘inspirational,’ and ‘a caregiver.’ All the participants described their ability to connect with family members caring for loved ones.

*“I can associate with my patients caring for family members or a child.”*

*“I look back on caregiving in a different light because I know it taught me how it can feel good to take care of someone and meet their needs.”*

*“I had a natural knack to be a caregiver.”*

For one specific participant, she reflects on her resiliency.

*“I never in a million years would have thought at 14-15 years old, looked forward and saw myself as a nurse... Being able to turn a childhood tragedy into something positive.”*

Another participant commented on how being a young caregiver has influenced her nursing career.

*“It was just fascinating the way the body heals; the way it works around itself and anything you do to it... That curiosity, I guess, is kind of what got me started.”*

The consensus among all the participants was pursuing a nursing career was a ‘calling’.

### **Challenges Experienced as a Young Caregiver: Then**

There are often many challenges of being a caregiver, but when age is a barrier the challenges are more prevalent. The challenges most commonly mentioned among the

participants was; 1) the lack of education or resources available to provide competent care, 2) impact on school performance, and 3) impact on friendships.

### **Lack of Education or Resources**

Although many of the participants reported experiencing difficulties while caring for their loved one, the main concept was the lack of education or resources available to providing competent care. All the participants agreed having resources that provided the knowledge and skill needed were nonexistent or often lacking. One participant reflects on the care she provided her father who had external fixation of his bilateral lower extremities.

*“The providers at the time... were not as interested in educating me on why and what we were trying to accomplish. If they had the internet 40 years ago it would have been so much easier because I could have looked up the way the structure was going and where the rods were; trying to look at how the rods go through his tissue. Not knowing what they were doing inside... It was hard to know where to move things.”*

Another participant details the challenges faced not only with understanding the normal progression to end of life but the entire grieving process.

*“The challenges that I had as a young caregiver is not knowing. Not knowing the grieving process; not knowing how to handle the end of life; not knowing the different stages my grandfather would through coming to the end of life; not knowing the sickness, the illness; not knowing the knowledge I have today.”*

### **Impact on School Performance**

An important contributing factor to the challenges experienced as a young caregiver was the impact on one's school performance. One respondent described the stress and difficulty of balancing school life and home life.

*“...Being in school was hard. I was very involved in sports in high school and I wanted to do well with my grades and my team, but I didn't have a lot of time to do both very well... I always felt the stress that I needed to get home because I didn't know what condition I would find my dad.”*

She continued to reflect on her how her caregiving impacted her ability to complete homework.

*“I really cared about my grades, but I felt like I didn’t have the focus or energy at that time to dedicate everything I needed. I held a decent GPA... but I was capable of more than what I was doing. I just didn’t have the time... because I’d sit down at home, tried to do my homework, and then I’d have to wrestle my dad for his keys... or he wouldn’t take his medication. There was always something to interrupt. I was always up until past midnight.”*

Although not universal, the remaining two participants reported no impact on school performance. Of these participants, one was not in school while caring for her grandfather and the other reported an improvement in her academics because she was always home.

### **Impact on Friendships**

A common finding between all participants was the impact caregiving had on their friendships. The notion of caregiving being a priority limited their ability to spend time with friends or to make friends due to their increased responsibility. Each participant shared having a limited number of friendships. One participant commented on the emotional toll experienced by her friends.

*“I had, ummm, two close friends... in high school. They don’t exist anymore... The decision to not pursue those friendships anymore is not my own. I would love to be friends still but honestly, it took a lot out of those people. I understand for their mental health and their sanity, ... needing to maybe move on and mature... Friendships grow and develop throughout the years... we want the best for one another but we’re just not at a point to be very close anymore.”*

Others revealed how being a young caregiving has influenced their adult relationships. A shared concept amongst the participants was having a small circle of close friends. Factors contributing to the limited friendships include increased maturity, reserved emotions, and being an introvert.

### **Challenges Experienced as a Young Caregiver: Now**

Participants were asked if they experienced any challenges as a young caregiver in their present adult life, three themes emerged; 1) impact of caregiving on physical health, 2) unresolved anger, and 3) adult depression.

#### **Impact on Physical Health**

When asked if being a young caregiver had impacted their adult physical health, two out of the three participants denied any physical health issues. Although not confident in her response, the third participant stated her lower back pain may be associated with the caregiving tasks during her father's end of life. She describes her caregiving role becoming more "physical" as her father could not "function on his own." The physical aspects of these tasks included "helping him out of chairs," "helping him walk," "helping him down the stairs," and "turning him in bed." Although she claims no physical injury occurred, she started seeing a chiropractor at the age of 17.

#### **Unresolved Anger**

Two of the three respondents reported unresolved anger adding to the challenges experienced in their present adult life. When asked to describe their feelings, one respondent reflected on her feelings of anger; lashing out at family because they did not assist in caring for their loved one or wanting to see him in his final days. She describes their behavior as "inhumane".

The second respondent reflected on being angry in relation to her father's declining health, peer isolation, and feelings of unimportance.

*"Seeing him decline through the years... he still felt like my dad but towards the end... I used to say my dad died a long time ago."*

She describes her high school experience as anything but “super positive.” Although she maintained a small group of friends that supported her, she remembers feeling isolated by most of her peers; often hearing them refer to her as “mean” and “nasty.” She acknowledged her current struggle with anger often revolving around her early caregiver experience and her feelings of unimportance.

*“Why didn’t my mom protect me?... Why didn’t she just divorce him?... Why didn’t she remove us from the equation and protect me?”*

*“I was never truly anyone’s priority at that time in my life.”*

*“I felt my mom didn’t really always make the choice with me in mind.”*

Even though this participant shared her feelings of being unimportant, she did, however, acknowledge that her mother was doing the best she could give in the current situation. She also remembered the time her mother took them to a hotel for a week to escape. She recognized being taken care of and receiving everything she needed; from being fed to receiving a great education at a private school.

## **Depression**

When asked how being a young caregiver impacted their adult mental health, two of the three participants acknowledged experiencing periods of depression. One participant explained:

*“I did have depression without my grandfather... I think it resurfaces when I have unhealthy relationships or I’m in a stressful time...Once you get depression, you can come out of it and swing back into it at any given time”.*

She also reports that out of depression became strength; pushing her to go to school to be a nurse.

The second participant affirms she has never been specifically diagnosed with depression; however, she endorses having a strong family history of mental health issues on her father’s side that include bipolar and depression.

*“I found...starting at the age of 23-24, I was showing some symptoms of depression. I have personally never been diagnosed with anything, but I would say going into my adult years... it would be fair to say that I have bouts of depression”.*

Both knowing and recognizing the symptoms of depression affords her the ability to ask for help and allows her to seek support from her husband, family, and her faith.

Although the overall consensus was experiencing adulthood depression while providing caregiving in youth, one participant denied challenges or evolving manifestations of depression. She characterized her overall experience as a young caregiver as “positive;” attributing her positive association to healthy coping strategies she learned while providing care to her father. Because of the immense pain associated with her father’s crush injuries, she witnessed techniques of distraction he used to divert his attention. As an adult, she employs these same techniques to combat both physical and psychological distress.

Although each of the study participants were interviewed separately and in different locations, they all shared in normalizing their early caregiving experience. During their interview, each participant provided their story as ‘matter-of-fact’ and without emotion. It was interesting to see that even though each participant had their own unique caregiving experiences, they all responded with an emotional strength that did not allow for their past experiences to influence them from moving forward.

## **DISCUSSION**

The purpose of this project was to describe the psychological effects on adult mental health of former young caregivers who provided primary care in youth; specifically, the positive and negative aspects and how childhood memories and experiences of caregiving affect their adult mental health. The participants provided their perceptions into the positive and negative

effects associated with caregiving in youth: a bittersweet reality. Their experiences were dependent on several factors such as their age and gender, school status, gender of the care recipient, progression or severity of the illness/disability, and family closeness; however, the three common variables having the greatest influence on mental health was parentification, social support, and becoming a wounded healer. Although these variables contribute to altering one's experience, it is ultimately one's perception of the experience that helps or hinders their mental health.

The findings of this project align with existing evidence from Pakenham et al. (2007) that caregiving has both positive and negative influences on the young caregiver. Positive influences are identified in terms of life satisfaction and positive mental health which can be explained by the caregiver's perception of the caregiving burden, social support, benefit finding, and resilience

### **Parentification**

A common theme throughout the project was the notion of parentification giving rise to an increase in adult responsibilities and a change of family dynamics for the participants. These responsibilities consisted of cooking, cleaning, feeding, dressing, and administering medications; caring for an adult family member who otherwise could not care for themselves. The duration of these adult responsibilities often encompassed multiple hours of the day and occasionally extending into the night. The implications of being a young caregiver on their adjustment and development are not well understood. Evidence shows that family caregiving and assistance with adult-like tasks during adolescence inspires a sense of maturity, self-sufficiency, and empathy while fostering a positive self-identity (Brubaker & Wright, 2006; Goodnow & Lawrence, 2001); all of which have a positive influence on one's mental health.

However, others have voiced a concern about excessive caregiving amongst adolescents and the harm it inflicts on their developmental experiences, mental and physical health, and overall well-being (Dodson & Dickert, 2004; Lareau, 2003; Meyer, 2000). Multiple studies have shown that numerous hours of caregiving (20 hours or more per week) and care extending over several years are associated with increased stress, academic difficulties (Dodson & Dickert, 2004), and depression in children (Shifren & Kachorek, 2003). Evidence from two major studies in the US and the UK, indicate that child caregivers experience higher levels of anxiety and maladaptive behavior than non-caregivers of similar age and race (Becker, Aldridge, & Dearden, 1998; National Alliance for Caregiving and United Hospital Fund, 2005). This could be in relation to the role reversal being experienced by the young caregiver or the lack of preparation to take on the increased responsibility. Participants in this project reported that caregiving consumed much of their time, often taking time away from friendships and school activities.

### **Social Support**

The second commonality amongst the participants was the impact of social support. Numerous studies indicate that social support is an important component to adaptive coping and is associated with an increase in positive mental health (Pakenham, 2001; Turpin, Leech & Hackenberg, 2008) and buffering of stress on young caregivers (Kotchick et al., 1997). According to Tsai's Theory of Caregiver Stress (2003), a caregiver's social support helps reduce the objective burden by changing their perception of caregiving which increases their ability to cope while enhancing the caregiver's well-being. All participants conveyed the positive impact social support had on their ability to cope by helping to alleviate the negative aspects of caregiving such as emotional distress. This support was generally found in friends, family, and

their faith. All participants referred to greater life satisfaction and positive effects on mental health thus making strong support networks critical to this population.

Social support is a crucial variable that contributes to the positive aspects of caring; yet, young caregivers have restricted access to social support networks. Given that most services focus on the well-being of the care receiver, many young caregivers rely on the physical and emotional support from family and friends; but when their caregiving role consumes their time and energy, friendships are usually sacrificed. During the interviews, each participant reflected on their lack of friendships which often lead to substituting the friendship role with that of a caregiver. This substitution of role frequently led to social isolation and higher caregiver burden. Because young caregivers often have inadequate or ineffective social support networks, they are vulnerable to depressive symptomatology placing their adult mental health in jeopardy.

Many studies have been conducted on how social support is associated with health and burden. In a study by Rodakowski, Skidmore, Rogers, and Schultz (2012) it was found that social support strongly influences burden; the higher the social support the lower the perceived burden. Because of the lack of social support networks, one participant recommended the practice of self-advocacy by using the internet to get involved in chat rooms for caregivers. This notion of self-advocacy is not only a beneficial way to express their needs but to spread awareness about young caregivers.

### **Wounded Healers**

The last commonality between all participants was the sense of being a wounded healer and how being a former young caregiver impacted their career choice. Conti-O'Hare (2002) describes a wounded healer as;

*“Those who, through self-reflection and spiritual growth, achieve expanded consciousness, through which the trauma is processed, converted, and healed. The scar remains, giving the person a greater ability to understand others’ pain.”*

Findings of this study correlate with previous research indicating that women are more likely to assume the caregiving role and participation in caregiving may influence one’s career choice (Beach, 1997; Frank et al., 1999; Lackey & Gates, 2001).

“Caring,” “compassionate,” and “empathetic,” are all common qualities shared amongst those in the nursing profession and words use by the participants to describe themselves. Nurses often share in common tendencies of altruistic behaviors and a desire to care for others but often the reason why one becomes a nurse is due to specific innate and developmental traits (Eley, Eley, Bertello & Rogers, 2012). However, others believe individuals are often lead to such careers like nursing, to help relieve the pain and suffering of others after experiencing their own traumatic event (Conti-O’Hare, 2002). It has been said that in helping others they are in turn helping themselves.

Research shows that nursing and codependency often share a similar foundation; deriving a sense of purpose from the caring of others and the priority of others’ needs over one’s own (Sherman, Cardea, Gaskill & Tynan, 1989; Snow & Willard, 1989). Similar findings in this project are demonstrated as participants reflected on their experience as a young caregiver and how they used this experience to overcome the challenges of adversity. All participants in this project matured both personally and professionally despite the challenges faced in youth. The coping mechanisms used to survive as a young caregiver became their foundation of strength and professional growth.

### **Trustworthiness and Study Limitations**

Using a case-study approach allowed for multiple perspectives of the same phenomenon; the positive and negative psychological effects of youthful caregiving on adult mental health. The purpose of trustworthiness in qualitative research is to establish reliability and validity to support the argument that the study's findings are important and worthy of attention. As a means of achieving trustworthiness, Lincoln and Guba (1985) state that credibility, dependability, transferability, and confirmability should be considered in qualitative inquiries. Therefore, specific strategies were utilized to address these four criteria and highlight the overall rigor of this study.

Credibility was achieved through: 1) evaluation of the transcripts from each individual interview; observing for likenesses both within and across the participants; and 2) member checking of emerging interpretations with the participants to confirm accuracy of their experiences. Member checking was accomplished by inviting the participants to the final presentation of this study. Date, time, and web-link were provided for virtual attendance. Dependability was ensured by clearly describing the project's purpose, describing the recruitment and selection of the participants, describing the data collection and analysis methods, and by incorporating multiple interviews offering various insights into the specific phenomenon (Lincoln & Guba, 1985; Thomas & Magilvy, 2011). Confirmability was ensured when I sought clarification of the participant's meanings when needed which permitting data interpretation to be impartial and representative of the participant's voice (Thomas & Magilvy, 2011).

To ensure confirmability, reflexivity was utilized to maintain openness and self-awareness of one's preconceptions. Reflexivity involved the use of written or recorded field

notes regarding my personal feelings, insights, or biases and occurred immediately following each individual interview (Thomas & Magilvy, 2011). Being a novice interviewer, I was astounded by the study participants' lack of emotion when discussing traumatic situations; it was almost as if these experiences were considered a normal part of childhood.

There are multiple limitations to this project. First, an effort was made to obtain multiple participants; however, a limitation to this descriptive qualitative study included a small sample size within one region of Arizona. This limits transferability of the findings to a larger population and other regions. Another limitation was that I am a novice at conducting interviews and performing data analysis of the transcripts. This was my first project of this magnitude.

### **Dissemination and Direction of Future Research**

All efforts will be made to disseminate these findings locally and nationally as research on this topic is lacking. The participants have also expressed an interest to hear about the findings. I have invited the participants to attend the public portion of my DNP Project defense, and I have provided the participants with the date, time, and location of the defense. For those unable to attend locally, information regarding virtual attendance thru a web-link address was provided. Furthermore, a manuscript will be submitted to an appropriate nursing journal to assist with the dissemination of the study findings in hopes of bringing forth awareness of young caregivers.

Further research using longitudinal studies is needed to provide a more in depth understanding of the long-term effects of youthful caregiving on adult mental health. Qualitative studies exploring the impact of caregiving support groups, awareness of young caregivers among healthcare professionals- especially nurses, and identification of when the level of caregiving

becomes damaging is essential for future development of policies specific to youthful caregiving. Additional research should also include culturally diverse samples, specific chronic diseases such as mental illness, and a deeper focus on how resiliency reduces the vulnerability to stress in young caregivers.

### **Implications for Practice**

The findings of this project are intended to add to the limited body of evidence regarding the experiences of former young caregivers and the impact it has on their adult mental health. The new knowledge developed will provide insight to both primary care providers, such as APRNs, and policymakers on the importance of identifying this hidden and underserved population. In the primary care setting, APRNs may not be aware they are interacting with young caregivers; therefore, a thorough assessment should include a detailed family and social history in which caregiving relationships can be identified. Once identified, APRNs can focus health promotion on assisting the child and family with available resources. Findings from this project suggest that providing caregiving at a young-age has both positive and negative consequences on adult mental health; but interventions for young caregivers should focus on those at risk for depression and target the advancement of effective and useful services aimed at preventing and treating depression.

Doctoral essentials of advanced nursing practice consist of organizational and systems leadership, healthcare policy advocacy, and clinical scholarship which is crucial to improving patient and healthcare outcomes (American Association of Colleges of Nursing [AACN], 2006). The findings of this study address organizational, policy, and practice implications that impact the health disparities associated with being a young caregiver. The findings identified

insufficiencies in healthcare policy to protect the legal rights of young caregivers and a lack of specific public services aimed at this vulnerable population. A doctorally prepared advanced practice nurse can influence these issues by helping to bridge the gap between healthcare and social services. This can be accomplished by improving communication between policymakers and healthcare providers.

### **Conclusion**

Young caregiving is on the rise in the US and its long-term effects on adult mental health remain a neglected area of research. Findings from this project help to illustrate that former young caregivers experience both positive and negative psychological effects but the mediating factor of the negative effects remains a strong social network. Primary care providers such as APRNs are in an excellent position to identify young caregivers and assist with their specific needs. The new knowledge derived from this project may help to fill the gap in literature while also illustrating the importance of childhood caregivers as a potentially vulnerable population.

APPENDIX A:  
INTERVIEW QUESTIONS

### Interview Questions

- 1.) What age were you when you began caregiving?
- 2.) Whom did you care for?
- 3.) How old was the family member?
- 4.) What type of illness did your family member have?
- 5.) How long did you provide care to the family member?
- 6.) What birth order are you? Oldest, middle, youngest?
- 7.) Describe your caregiving experience.
- 8.) Describe the positive experiences of being a young caregiver both then and now.
- 9.) Describe the challenges you experienced as a young caregiver both then and now.
- 10.) What was the biggest challenge you experienced?
- 11.) How has your experience as a young caregiver impacted your physical health?
- 12.) How has your experience as a young caregiver impacted your relationships/friendships as a child? As an adult?
- 13.) How did being a young caregiver affect your school performance?
- 14.) How do you feel your experiences as a young caregiver has impacted your adult mental health?
- 15.) How has your experience as a caregiver influenced your career choice?
- 16.) Looking back on your experience, what do you believe would have been helpful to you as a young caregiver?

\*Further questions guided by participant's responses

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