

**HIDDEN CAREGIVERS: A LITERATURE REVIEW OF YOUNG CAREGIVERS IN  
THE UNITED STATES**

by

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# **HIDDEN CAREGIVERS: A LITERATURE REVIEW OF YOUNG CAREGIVERS IN THE UNITED STATES**

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Young caregivers are a hidden subgroup among the caregiving population. Young caregivers provide significant assistance (often on a regular basis) to relatives or household members requiring help due to illness, disability, or substance misuse. There is no consensus at this time on the specific age range at which one can be considered a “young caregiver” versus an adult caregiver. Commonly, the age range used to define young caregivers is 18 years and younger or 25 years and younger. The prevalence of young caregivers in the United States is estimated to be 1.3-1.4 million child caregivers (age 8-18 years) as of 2005 and represented approximately 12-18 percent of the total caregiver population. Studies suggest that young caregiving is associated with increased risk for depression or anxiety, poor academic performance, poor socialization or lack of opportunity and more barriers to achieving future goals such as higher education. This paper used a critical review of the literature on young caregivers in the United States, specifically focused on a discussion of the challenges and benefits experienced by young caregivers. The literature review found barriers to services and future goals at various levels of the Social Ecological Model: individual, interpersonal, community, institutional, and policy. Within the literature, the common barriers of positive outcomes typically include: mental health status (rates of depression or anxiety), academic performance, caregiver burden, and developmental issues (or coping skills). Facilitators of positive outcomes most often researched include: self-esteem or pride, perceived familial relationships, and coping skills. The young caregiver population is likely to increase as time goes on and we are only seeing a glimpse of what is likely to increase in a unique caregiver population. Due smaller family sizes and childbearing in later years,

children still in their formative years will be called upon their aging parents for care. The public health significance of identifying the challenges faced by young caregivers (and how their emotional and physical health is impacted) will assist in identifying ways to mitigate the negative impacts via interventions and make appropriate policy changes.

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## 1.0 INTRODUCTION

Young caregivers are a hidden subgroup among the caregiving population. According to the American Association for Caregiving Youth (2012), young caregivers are defined as:

“children and adolescents who are 18 years of age or younger and who provide significant or substantial assistance, often on a regular basis, to relatives or household members who need help because of physical or mental illness, disability or frailty associated with aging, substance misuse, or another condition.”

The prevalence of young caregivers in the United States is estimated to be 1.3-1.4 million child caregivers (age 8-18 years), representing approximately 12-18 percent of the total caregiver population (Levine, Gibson Hunt, Halper, Hart, Lautz, and Gould, 2005). The accuracy of the prevalence statistics is difficult to determine as no consensus on a definition of “young caregiver” exists and the age ranges included in studies on young caregivers varies from 8-18 years, 18-25 years, and at times, even include adults up to the age of 40 (National Alliance for Caregiving and United Hospital Fund [NAC & UHF], 2005). While the experiences of adult caregivers are well documented, there is little information about young caregivers. The United Kingdom was the first country to research the prevalence and implications of caregiving on young caregivers followed by implementation of changes in legislation and initiatives focused on young caregivers as a result of increased awareness and identification of young caregivers (or

“young carers,” the British terminology for young caregivers) <sup>1</sup>(Princess Royal Trust for Carers and The Children’s Society, 2010).

Following the United Kingdom, Australia and the United States are the two other emerging centers of research on young caregivers. With respect to definitions, researchers in the United Kingdom include only caregivers age 18 and younger as “young caregivers” while other countries (e.g. Australia and the United States) may use a broader age range extending to age 25 (Becker, 2007; Burns, LeBlanc, Abernathy, and Currow, 2010). While the many challenges associated with caregiving among adults are documented in the literature, there is little information available on young caregivers, especially within the United States. Research on young caregivers is limited as this caregiver group tends to be a secondary, smaller focus. Research on young caregivers frequently occurs within studies of the general caregiving population such as spouses caring for spouses or adult children caring for elderly parents. Studies suggest that young caregiving is associated with increased risk for depression or anxiety, poor academic performance, poor socialization or lack of opportunity and more barriers to achieving future goals such as higher education (Siskowski, 2006; Lackey and Gates, 2001; Parkenham, Chiu, Bursnall, and Cannon, 2007; East, 2010 ).

While current caregiving programs are typically open to all caregivers, these programs are focused on serving the needs of spousal caregivers or adult children caring for aging parents (Bledsoe, Moore and Lott Collins, 2010; Greensberg, Stacy and Penzo, 2008; Schumacher, Beck

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<sup>1</sup> The Carers (Recognition and Services) Act 1995 provides an assessment to any caregivers (regardless of age), assessing their ability to provide and continue to provide care. In 2000, the Carers and Disabled Children Act was passed and allows family carers (over the age of 16) to request an assessment of their own needs and receive services and support such as counseling. The Carers (Equal Opportunities) Act 2004 requires local authorities to inform carers of their rights to an assessment (The Princess Royal Trust for Carers & the Children’s Society, 2010).

and Marren, 2006; Bookman and Harrington, 2007). Other caregiving programs may offer supports specific to kingship caregivers (e.g. grandparents raising grandchildren). There are very few programs designed specifically to address the needs of young caregivers.

This paper presents a critical review of the literature describing the challenges and negative health effects encountered by young caregivers. While the (mostly negative) effects associated among adult caregivers are more thoroughly researched and known, such effects are likely applicable to children and adolescents (under 18 years) and young adults (18-25 years). The stressors of caregiving form another layer of complexity on the typical formation of developmental milestones among young caregivers. The additional stress of providing care could prove to be more harmful to children, adolescents and young adults who have yet to develop adequate coping skills. The public health significance of identifying the challenges faced by young caregivers (and how their emotional and physical health is impacted) will assist in identifying ways to mitigate the negative impacts via interventions and make appropriate policy changes.

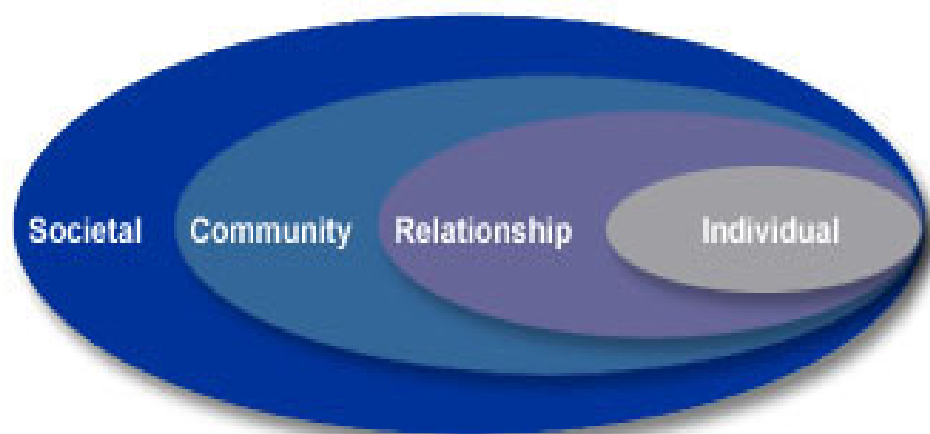


Figure 1. Social Ecological Model (Source: [www.cdc.gov](http://www.cdc.gov))

This paper seeks to answer the following questions: what are the challenges faced by young caregivers, how do the challenges faced by young caregivers impact their emotional and physical health, and what are the possible interventions and policy changes that could be implemented? The Social Ecological Model (SEM) is used as it recognizes the interwoven relationship between an individual and his or her environment. This review found challenges at each level of the SEM: individual (intrapersonal), interpersonal, community, institutional and policy. Chapter 2 discusses the search methods used in studies investigating caregiving in general and young caregiving in particular. Chapter 3 the background of family caregiving is discussed as it much richer and established with known challenges among adult caregivers. This discussion leads into a discussion about challenges faced by young caregivers as well as the impact of caregiving on their emotional and physical health. Chapter 4 covers the literature search findings of young caregivers, specifically the challenges experienced by young caregivers. The discussion in Chapter 5 describes implications for policy interventions, recommendations and research. Chapter 6 will present conclusions.

## 2.0 METHODOLOGY

This paper is a critical review of the literature on young caregivers in the United States, specifically focused on a discussion of the challenges and benefits experienced by young caregivers. This chapter will focus on methods used to select articles for the literature review.

Information and peer-reviewed articles were collected using the EBSCO, Pub Med and Ovid Medline databases at the University of Pittsburgh. Four searches were completed. The first search in PubMed included the search terms “young” and “caregiving” as the author wanted to focus solely on young adults or youth providing care. This search yielded 365 results as it included articles citing care for youth. The author found that with the wording used, it was difficult to direct search engines to process the specific “youth providing care” relationship when searching articles. Abstracts were reviewed and 48 articles were selected as containing a focus on youth or young adults providing care to a family member. After the 48 articles were designated, limits were placed to receive only “Free Linked Text” articles. This option was chosen because it allowed the author access to the articles at no cost. Upon review, limits were also placed to receive only articles in “English” as the author is fluent only in the English language and this resulted in 39 articles. The second search used the terms “young caregivers” and “United States.” This search yielded 5 articles. Limits were placed to include only “Full Text.” The 5 articles were then eliminated as they were already part of the first literature search. Going through search results, articles which addressed only young caregivers were included for

this literature review. Article selection was based on these criteria: (a) articles were published between 1996 to 2012, (b) articles that addressed stressors and rewards of young caregiving, (c) articles discussed policy implications for young caregivers, (d) articles that analyzed and proposed interventions for young caregivers, (e) articles that were focused mostly on the United States and (f) articles that were written in English. Articles that did not meet these criteria were not selected for review. While most literature reviews contains literature published during a ten-year period, due to the scant amount of research available on the topic (especially in the United States) the author chose to expand the timeframe to include the influential work of the United Kingdom as it will be useful in the formation of research in the United States on the issue.

The third search was completed in the EBSCO database. The third search used the terms, “caregiving” and “young.” Restrictions were placed on “Links to Full Text” and English-only articles. This search yielded 583 results. In the fourth search, the terms that were used include “young caregiver.” Restrictions were placed on “Links to Full Text” and English-only articles. This search yielded 29 results. Other inclusion criteria for the articles were that they did not replicate what the previous searches found, and that they articles specifically focused on the relationship of youth or a young adult providing care. Under these restrictions, this search resulted in 15 articles.

The fourth and final search was in the Ovid Medline database. The fourth search used “young caregiver” and “young carer.” Restrictions were placed on “Full Text” articles, “Human” subjects only, and “English language.” This search yielded 72 results. Other inclusion criteria were that it did not replicate what previous searches found and that the articles specifically focused on the relationship of youth or a young adult providing care. Under these

restrictions, this search yielded 4 results. Upon review of the articles, the author eliminated duplicate articles and articles containing information irrelevant to the author's research questions. The author used 27 articles from the literature searches for this review.

Upon completion of the initial review, websites were reviewed to locate relevant work. Both the results for scholarly articles and available information via the internet were used to generate the bibliographic information in this literature review. The author used this approach as an attempt to locate any research available that might include pertinent information to young caregivers. The author also reviewed specialized websites such as: <http://static.carers.org> (The Princess Royal Trust for Carers and The Children's Society), <http://caregiving.org> (National Alliance for Caregiving), [www.thefmailycaregiver.org](http://www.thefmailycaregiver.org) (the National Family Caregivers Association), [www.caps4caregivers.org](http://www.caps4caregivers.org) (Children of Aging Parents), and [www.aacy.org](http://www.aacy.org) (American Association of Caregiving Youth).



### **3.0 FINDINGS**

Anyone could serve as a caregiver and the range of tasks vary from less intense tasks such as financial management (bill paying) to more involved, hands-on tasks such as bathing or dressing. It is also socially acceptable as there is an underlying social expectation to provide assistance to others in one's family (Fruhauf and Orel, 2008; Greenberg, Stacy, and Penzo, 2002; Shifren and Chong, 2012). In this chapter, caregiving is discussed with beginning with the history of family caregiving and a review of the known caregiving stressors among adult caregivers. A description of young caregivers is discussed followed by the stressors of young caregiving.

### **3.1 CAREGIVING**

There are approximately 44.4 million people in the United States providing unpaid care to another adult age 18 or older (National Alliance for Caregiving and the American Association of Retired Persons [NAC & AARP], 2004). Unpaid caregiving within a family is rarely viewed or described as “care work” but is most often viewed as informal care. At the heart of informal caregiving relationships is the mutual understanding that care is provided at no cost as compared to professional care arrangements (e.g. home health agencies). Informal care typically occurs under the private domain of the family, based upon love, attachment and reciprocity instead of monetary gain (Becker and Silburn, 1999; Bookman and Harrington, 2007; Shifren, 2008).

Although many of the factors associated with caregiving have been studied, most research has focused on specific factors related to the challenges of being an adult caregiver.

### **3.1.1 Challenges of Caregiving**

The SEM theory is an ecological theory model used to understand how factors at different levels influence health issues, more specifically health behaviors. The SEM theory was created by Dr. Urie Bronfenbrenner in 1979 and examines the influence of various environments. Social ecological models incorporate five levels: (1) Intrapersonal, (2) Interpersonal, (3) Organizational, (4) Community, and (5) Policy.

Social ecological models use a multi-level approach in designating barriers and facilitators at every level. The SEM assumes interventions, programs and solutions that focus on only one part of an issue ignore the interconnected components across multiple levels and thus, will not be fully effective and/or sustainable. In order to have a wide, effective scope on health issues and for the interventions to be sustainable, factors facilitating the acceptance of an intervention or preventing effectiveness of interventions are active at each level. These factors include sociocultural issues and the physical environment; both of which can influence areas in a variety of ways. The SEM will be used to identify social barriers which influence challenges faced by young caregivers in the United States in the various stages of the model (Glanz et al., 2008) (see TABLE 2: The Social Ecological Model of Challenges Among Young Caregivers).

Much of the available research on caregiving effects discussed negative impacts. Specifically, many caregivers had a tendency to neglect their own health needs, became socially isolated, and experienced higher rates of anxiety & depression (Greenberg, Stacy and Penzo, 2002). It was also common for caregivers to experience anticipatory grief as the illness

progressed (Huston, 1990; Barusch and Spaid, 1996). Research documented the high levels of stress, stress-related illnesses (e.g. stomach ulcers), and noted family caregivers often suffer from fatigue (NAC & AARP, 2009; Schumacher, Beck and Marren, 2006). Caregivers who lacked respite care were at risk of endangering their well-being and may have experienced a limited ability to provide care. These difficulties proved to have an even greater impact on employed caregivers, as caregivers must balance multiple roles with little flexibility (Bookman and Harrington, 2007; Schumacher et al., 2006).

### **3.1.2 Description of Young Caregivers**

Young caregivers faced many of the same challenges their adult caregiving counterparts but may experience increased difficulties in service access and navigation of the complex social service systems (e.g. Social Security benefits, Medicare or Medicaid). Adult caregivers sought early retirement, flexible work shifts or utilized the Family Medical Leave Act (FMLA). Among caregivers age 18 and over, seven in ten caregivers reported making a change in work accommodations such as reducing hours, taking a leave of absence, or leaving the workforce (NAC & AARP, 2009). At this time, it is unclear what proportion of young caregivers serve as primary caregivers or secondary caregivers. A primary caregiver is defined as, “the one person most responsible for providing care,” (Dellmann-Jenkins, Blankemeyer and Pinkard, 2000; p. 177) and provides most of the daily care such as bathing, dressing, grooming (Schumacher et al., 2006). A secondary caregiver is defined as a person who provides, supplementary care, meaning that the care “is done collaboratively with adults present,” (East, 2010) and provides assistance intermittently. A secondary caregiver typically provides more indirect care tasks such as shopping or home repairs and supports the primary caregiver (Schumacher et al., 2006).

Similar to adult caregivers, young caregivers tend to place their caregiving role as a higher priority than other life goals. Caregivers tend to place the needs of others before their own and need to be educated about the importance of preventive self-care (e.g. pneumonia and influenza shots) in order to maintain health and continue providing care to others. This proves to have the potential for the development of negative health behaviors for a young population to practice over the course of their lifetime (Shifren, 2008; East, 2010).

The activities typically asked of young caregivers include (East, 2010; NAC and AARP, 2004):

- Personal care (bathing, dressing, grooming)
- Medical care (wound care management, glucose monitoring)
- Household care (vacuuming, dusting)
- Companionship care

The young caregiver's duties should be critically assessed to determine if the tasks are age appropriate. In addition to determining what tasks are appropriate based upon a young caregiver's ability (and age), the type of caregiver training or health education (e.g. transfer or lifting techniques) need to be assessed (Becker, 2007). If there are no other feasible options, health providers and social service agencies will need to collaborate to provide support. A majority of young caregivers studied came from single-parent households and low socioeconomic statuses. The lack of resources (financially and in terms of physical assistance) is the main catalyst for youth becoming caregivers (Shifren, 2008). Young caregivers were noted to be more likely to be called upon to provide care for longer than the average 4.3 years as care receivers (likely parents) are living longer with diseases and/ or disabilities (NAC & UHF, 2005; NAC & AARP, 2004). If the young caregiver receives the proper support, ideally he or she can

continue to provide age appropriate tasks. This additional care period would supplement any formal services the care receiver obtained and would allow the caregiver to remain primarily a student, thus successfully navigating his or her developmental path. Young caregivers are forced to balance multiple roles and experience greater risk of developing anxiety and depression as well as caregiver burn out (Siskowski, 2006; East, 2010; Shifren and Kachorek, 2003). Due to the increased risk for depression and anxiety, young caregivers experienced difficulty transitioning through the critical developmental stages (e.g. Erik Erikson's Eight Stages of Development<sup>2</sup>). Young caregivers also had difficulty achieving his or her educational desires and develop healthy coping skills (Fruhauf and Orel, 2008).

Childhood has been (and continues to be) viewed as a period requiring protection provided by adults, state agencies and social welfare systems until children enter adulthood (typically age 18) (Dearden and Becker, 2000). Considering the age range of young caregivers, the layers of complexity associated with the caregiving role among this vulnerable group needs to be examined further. Historically, it is far more acceptable for adults to serve as caregivers as they are viewed to be more developmentally appropriate to care for another person and more likely to provide care voluntarily. Adults are typically viewed as the "protectors" or "decision makers" compared to youth. (Dellman-Jenkins et al., 2000; Becker, 2007; East, 2010).

The United Kingdom, Australia and the United States represent three of the more developed nations that have started to pay attention to the issue of young caregivers within their respective countries. At this time, the countries are at different stages of progress in terms of

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<sup>2</sup> Erik Erikson identified eight stages of psychosocial development which each individual experiences during his or her life. Each stage contains specific tasks which must be completed before advancing onto the next stage. If the tasks are not completed, the individual experiences difficulty overcoming life challenges. If tasks are completed at each stage, the individual continues to progress toward a healthy development and ultimately, a satisfying life (Walker and Brokaw, 2004).

research and practice around young caregivers. A bulk of the research on and programs for young caregivers (or “young carers”) began in the 1990s. The average age of a “young carer” in England is 12 years as compared to 13 years in Australia. In the United Kingdom, approximately one-fifth of the young carers (young caregivers) surveyed were found to have provided care for more than six years, which is quite significant when considering the average age of the group was 12 years (Becker, 2007). Research in Australia described children who served as caregivers for as long as 14 years. At this time, the data collected in Australia among caregivers has not determined an average length of a care relationship (Becker, 2007). Within the United States, the average is estimated to be about 13 years old (among youth surveyed 8-18 years) and about 21 years old (among young adults surveyed age 18-25 years). In a study of twenty-one Young caregivers in the United States were found to have provided care from less than a year to 22 years (Shifren and Kachorek, 2003).

In the *2001 U.K. Census*, data revealed about 175,000 children and young people under the age of 18 provide some level of unpaid caregiving to other family members. This figure represented about 6 percent of children who lived with families with illness and or disabilities and provided care to a family member (ONS, 2003). The *2001 U.K. Census* measure also stated the total number of children who provided care was more than three times higher than the previous estimate of 19,000-51,000 young carers (young caregivers). However, it is important to note that Census figures likely underrepresented the prevalence of children as caregivers as parents self-reported their children’s caring roles. Parents with drug or alcohol issues, mental health issues or fear of legal issues would be less likely to fully disclose the extent of caregiving their children provided (Becker, 2007). Australia began to examine their young caregiver population about two decades ago and continues to explore ways to improve identification and

support of young caregivers. Approximately two million young caregivers in Australia (as of 2010) cared for a parent with a physical disability, intellectual disability or substance abuse problem. A majority of the youth performed direct care tasks (e.g. bathing, dressing) and reported adverse impacts related to caregiving (Ireland & Pakenham, 2010). Upon examining global trends, as people age and the number of chronic diseases increase, more young people will be needed to assume caregiving responsibilities. Amidst a review of more than forty-five studies of European and American adolescents, the average young caregiver spends about forty minutes each day caring for a family member. This amount of time varies among the intensity of care required as well as if the young caregiver is the primary or secondary caregiver. While most of the young caregivers in the United States perform instrumental activities of daily living (IADLs) such as medication management, meal preparation and grocery shopping; more than half of the young caregivers also perform more activities daily living (ADL) such as bathing, dressing or grooming (National Alliance for Caregiving, 2005)

In 2005, the National Alliance for Caregiving collaborated with the United Hospital Fund to conduct the first domestic research on young caregivers. The study was a national prevalence survey of 213 young caregivers and 250 non-caregiver (ages 8 to 18 years) who were actively providing care. The first part of the study focused on the prevalence of young caregivers and conducted a random sample of 2,000 households via mail surveys. The surveys inquired if any child in the home (age 8-18 years) provided unpaid help or care to any person. There was an equal representation of male and female young caregivers. The second part of the study inquired about the responsibilities and impacts of caregiving via a brief questionnaire to 80,000 members of a consumer mail panel. The responses were confirmed via a follow up telephone call with young caregivers and non-young caregivers. Similar to research from the United Kingdom,

young caregivers were found to spend more time doing household chores, providing personal care, and babysitting siblings than non-caregiving peers. More significantly, young caregivers were found more likely to develop depression or anxiety. Young caregivers tended to show a higher incidence of antisocial behaviors, especially at school (e.g. truancy, fighting, and poor academic performance). From the study, researchers discovered 31 percent of young caregivers are ages 8 to 11 years and 38 percent are ages 12 to 15 years (NAC & UHF, 2005).

Young caregivers resided more frequently in lower income homes than non-caregivers, and they were more likely to reside in a one-parent household (Ireland & Pakenham, 2010). Seven in ten child caregivers provided care for a parent or grandparents (72 percent), and the care receiver was usually a mother or grandmother. Alzheimer's disease or dementia was the most common reason why a care recipient required care (18 percent) followed by: cardiovascular, respiratory or renal disease (16 percent), arthritis (14 percent) and diabetes (14 percent). At this time, no estimates are available on the specific cost of services provided only by young caregivers nor are there information distinguishing young caregivers who are primary caregivers versus those serving as secondary caregivers. In addition, the presence of a young caregiver in the home was likely underreported if there were issues such as drug and alcohol abuse or suspicion of child abuse accusations (NAC & UHF, 2005).

Among the limited studies on young caregivers conducted in the United States, the two most often cited in research are: the Harvard School of Public Health, United Hospital Fund and Visiting Nurse Services of New York (Harvard/UHF/VNS) study and the National Alliance for Caregivers and AARP (NAC & AARP) study. In a comparison of the two studies, researchers discovered young caregivers make up approximately 12-18 percent of the overall caregiver population within the United States and the average age is 21 years. The age range used in the



studies was 18 to 25 years due to participants' ability to provide their own consent and yielded a higher average age than that of the United Kingdom and Australia. Researchers discovered young males provided care almost as frequently as young female caregivers. Of these young male caregivers, most of them are caring for a female relative. Very few caregivers in either study reported the presence of paid or formal home assistance and most caregivers did not provide most of the care, leading to the assumption there were other individuals assisting with care (formal and informal) (Levine et al., 2005; NAC & AARP, 2004).

### **3.1.3 Care Gaps**

Young caregivers are often placed into the role due to circumstances out of their control, which also brings about a certain level of controversy regarding the voluntary nature of caregiving and the intensity of care performed by youth during critical developmental years. Young caregivers typically became a caregiver when a family member (often a parent) is in need of assistance but unable to access a caregiver, known as a "care gap." A "care gap" occurs when there is a family member in need of care but is unable to either acquire formal services (hire a home health aide) or find a relative to provide care. The caregiving responsibility then shifts to younger family members to fulfill the caregiver role (East, 2010). A few of the issues leading to the caregiver responsibility shifting to younger generations include (1) reduced home health care coverage (Bookman and Harrington, 2007; Schumacher et al., 2006), (2) emphasis on community based care rather than institutionalized care (Bookman and Harrington, 2007; Schumacher et al., 2006), (3) smaller family size/higher divorce rates (Bledsoe, Moore and Lott Collins, 2010), (4) increase among single female headed households (Shifren, 2008), and (5) people with chronic illnesses and or disabilities are living longer (Levine et al., 2005; NAC & UHF, 2005; East, 2010).

In an effort to reduce health care costs, health insurance companies provide limited coverage for in home health care services, such as a nurse to visit the patient and provide medication management or wound care management. After the coverage ends, the patient is forced to either provide the care to himself or herself, pay for formal care services or to find a relative to provide the care. As an additional cost containment measure, community based care is emphasized rather than institutionalized care (e.g. nursing home placement) (Bookman and Harrington, 2007; Schumacher et al., 2006). Family sizes have declined over the last several decades with the average family having one or two children as well as a result of divorce. When a family caregiving need arises, the caregiving burden then falls upon a smaller number of family members, noted to cause an increased burden among caregivers (Bledsoe et al., 2010). At the same time, the increase in single, female-headed households increased the likelihood that the single parent worked outside of the home and the caregiving responsibility then shifted to her child or children (Shifren, 2008). If there are other children in the home, the young caregiver was noted to be very likely to have a dual caregiving role to the ill adult family member(s) as well as to his or her siblings. Lastly, individuals with chronic diseases and/or disabilities are living longer (Levine et al., 2005; NAC & UHF, 2005; East, 2010).

#### **3.1.4 Challenges of Young Caregivers**

The known caregiving stressors among adult caregivers were found to be relevant among the youth caregiver population. Among the young caregivers, the positive aspects (as in the adult caregiver population) are often outnumbered by the more negative aspects (Aldridge & Becker, 1996). Young caregivers must manage the lack of flexibility associated with care giving, similar to adult caregivers. Over the course of providing care, young caregivers often experienced an

increase in the intensity of care and were forced to reduce the amount of time spent on childhood activities and opportunities to further their development of social competency (Schumacher et al., 2006).

Parentification was noted to be a common stressor among young caregivers and occurred when,

“...children prematurely assume extensive family care responsibilities and essentially “replace” a parent in overseeing the family’s nurturing needs,” (East, 2010; p. 58).

In this circumstance, the caregiving tasks often exceed the young caregiver’s ability at his or her current developmental stage and ignore the developmental needs of the young caregiver. Typically, parentification occurred when there was a form of family dysfunction present such as: parental alcohol or drug abuse, extreme poverty, or parental death (or abandonment). It also occurred if there was a severe chronic illness limiting the ability to care of the adult(s), a divorce, or if there were siblings with a chronic illness or disability (East, 2010). If young siblings were present, young caregivers often became caregivers for the siblings as well. A young caregiver “must sacrifice his or her own needs for attention, comfort and guidance in order to accommodate and care for the needs of the parent” (Bellow et al., 2005; p. 44). In a mild form, parentification or “role reversal” may have assisted children in the development of appropriate relational skills such as responsibility; nurturing and assisted children in the formation of a healthy self-identity. Role reversal was noted to potentially yield negative consequences when the relationship between the care receiver and young caregiver lacked reciprocity such as emotional exchange or when the expectations or care demands exceeded the abilities of the young caregiver. When this event occurred, it became even more critical for the young caregiver to have some form of coping skill in place (Bellow, Boris, Larrieu, Lewis, and Elliot, 2005; East, 2010).

Negative consequences of the parentification included: depression, social isolation psychosomatic symptoms (persistence stomachaches or headaches), or suicidal ideation as the young caregiver may have lacked strong coping skills as he or she is was developing and forming a self-identity as well as lack of social support from caregiving agencies, school personnel, and other family members.. Some participants were noted to feel overwhelmed, had too much responsibility, lacked of knowledge or felt unprepared for the deterioration and death of loved one and/or felt unprepared for crisis and emergency visits. Young caregivers stated there was less time for friends and activities and a reluctance to share their role as caregiver with others out of fear of negative stigma. Part of this stigmatization resulted from the assumption the parent would be viewed as “inadequate,” if the youth revealed their role as caregiver or fear of youth being removed from the home due to “exploitation” (East, 2010). The parent(s) were also noted to have reluctance in sharing the extent of caregiving involvement with health care and social service providers, fearing the involvement of child protective services. While child protective services represent a governmental entity charged with advocating and protecting youth 18 years and younger, removing a young caregiver from a caregiving situation was noted to have the potential of harm for the care receiver if there were no caregiving alternatives. Appropriate and supportive services were noted to have the potential to mitigate risks to the young caregiver and the care receiver (Aldridge and Becker, 1996).

“Negative feelings are more evident among caregivers who help with ADLs. For example, 49 percent of child caregivers who help with ADLs feel, at least *sometimes*, they cannot depend on anyone else, compared to 31percent of child caregivers who help only with non-ADL tasks. Further, the ADL caregivers are twice as likely to feel a lot of that people expect too much of them (16 percent vs.7 percent) and that it is no use letting their feelings show

(23 percent vs. 12 percent),” (Levine et al., 2005; p.33). Of the ADL tasks performed, young caregivers find bathing to be the most difficult. Perhaps due to this task being closely associated to a role reversal and the young caregiver may have difficulty adjusting emotionally to this level of responsibility he or she must provide (Lackey and Gates, 2001; Levine et al., 2005). There is also an issue of boundaries in the case of a young caregiver bathing a nude parent (or family member) of the opposite sex. The author was unable to locate discussion of this issue within the research available.

There are benefits to parentification as noted by the American Association for Caregiving Youth (AACY). Parentification was noted to help child gain a sense of responsibility and help the child to develop a sense of purpose. The benefits of parentification were noted to only outweigh the negative consequences if there was a shared responsibility among other siblings (or family members), tasks did not exceed the youth’s ability nor interfere with his or her education (academic and social) and there was positive recognition or feedback from the care receiver (AACY, 2012).

Participants reported caregiving taught responsibility and enabled the participants to be “a part of the family,” “appreciated,” “important,” and “useful.” The acquisition of skills such as medication management and financial management were cited as helpful and participants expressed pride in learning these skills at a young age. Caregiving roles were believed to assist the young caregivers in developing enhanced coping skills, development of social skills, a purpose of life and close attachment to loved ones. Family dynamics were noted to change as a role reversal occurred with the child caring for his or her parent. The full ramifications of being a young caregiver are not fully understood in the United States, especially among those youth from low income and or minority families. While the negative consequences of young

caregiving (especially parentification) outnumber the benefits, the long term impact on the lives of young caregivers as they enter adulthood remain unknown at this time (Aldridge and Becker, 1993; Dearden and Becker, 2000; Lackey and Gates, 2001; East, 2010).

#### **4.0 THE SOCIAL ECOLOGICAL MODEL AND YOUNG CAREGIVERS**

In this chapter, the application of the SEM to young caregiving issues is discussed.

##### **At the Individual Level:**

Similar to adult caregivers, religion played an important factor in the coping skills of young caregivers (Gates and Lackey, 1998). Among the young caregivers in the NAC & AARP study (2004), participants cited their coping strategies as follows: prayer (57.4 percent), talking with family and friends (53.1 percent) and using the internet (34.5 percent). About 40 percent of the young caregivers exercised regularly, 2.8 percent reported taking medications but did not specify for what conditions, and 13.2 percent utilized professional or spiritual counseling. Prayer was the most common coping strategy (Lackey and Gates, 2001). The Young Carers Research Group in the United Kingdom found young caregivers caring for family members with chronic illnesses, mental illnesses, or substance abuse were at a greater risk of stress, anxiety and depression (Dearden and Becker, 2000). The first survey on young caregivers based in the United States revealed that 56 percent of 8-11 year olds who provided care for a family member in the same household were more likely to be depressed compared to the 19 percent of young caregivers not residing with their care receiver (Levine et al., 2005).

Young caregivers were found to be more likely than non-caregiving peers to be restricted in their pursuit of social and recreational activities as well as pursuing higher education due to caregiving responsibilities. Young caregivers were also noted to be more likely to identify

barriers preventing them from fulfilling future goals than non-caregiving peers (NAC & UHF, 2005; Shifren, 2008). Among adult caregivers, many may not self-identify as caregivers and therefore do not access (if available) caregiving resources (e.g. support groups); this likely occurs among young caregivers as well (Roberto and Jarrot, 2008).

**At the Interpersonal Level:**

The ability to build social skills and networks outside of the family unit was found to be difficult for those who began caregiving at a young age (under age 18). Young caregivers were noted to be at a greater risk of isolation than their non-caregiving peers. Difficulty with building social skills was attributed mostly to the lack of time young caregivers have to develop and maintain relationships. More than half of young caregivers cared for their mothers and this care relationship may have negatively influenced the manner in which the mother was able to respond and provide care to the caregiver (her child). The experience of this mother-child relationship could have led to the child's future ability to form healthy relationships with others (Shifren, 2008).

Socialization (specifically dating) was examined among young caregivers and researchers found those who were of age either did not date or dated early to "get out of the home." These two dating extremes often occurred if caregiving occurred over an extended period of time. Among young caregivers providing twenty hours or more per week of care and or providing more than a year or two of caregiving, there was an increase for dropping out of school, developing depression and increased sexual activity (among early adolescent girls) found in literature from the United States, United Kingdom, and Australia (Lackey and Gates, 2001; East, 2010).



### At the **Organizational Level:**

Health and social service providers need to ask more questions about who is involved with caregiving as well as be more attentive to the needs of children serving as caregivers. Providing training and information to caregivers will assist in preparation of caregiving duties. Untrained caregivers pose a risk to themselves as well as the care receivers. Only 12.2 percent of young caregivers (age 8-25 years) reported a physician providing information directly about how to provide care; 1.8 percent reported another health professional (nursing staff, health educator) provided information (Levine et al., 2005). This is a critical piece of transferring formal (or professional) care to informal caregivers as everyday skills may not be as straightforward (e.g. transferring an amputee from a wheelchair to a bathtub). If a young caregiver is not taught proper lifting mechanics during transfers for his or her care receiver, there is a dual risk of injury for both the care receiver (falling or muscle strain) and the care giver (strained back, herniated disc). Abuse and neglect may occur unintentionally via means of inadequate care, unsafe or unhealthy environment, and poor management of finances. A young caregiver may not fully understand a complex medication regimen if he or she does not receive training from a medical professional such as a physician or in-home visiting nurse. This leads to the risk of under or over medication of the care receiver. If the young caregiver is not trained in home safety measures, the care receiver is at risk of falls and other injuries due to hazards such as lack of shower bars in the bathroom and exposed extension cords stretched across walking areas (Schumacher et al., 2006).

### At the **Community Level:**

Given the prevalence of adult caregivers and the general acceptability of caregiving among society, youth providing caregiving is rarely publically discussed. The avoidance of

publically discussing “young caregivers” could be the result of negative stigma attached as if the young caregivers are being “exploited” or conducting “child labor.” Young caregivers provide care to family members as it is often viewed as “being part of the family.” If society acknowledges the act of caregiving as unpaid labor, this could be considered child abuse; especially if emotional (or physical) harm occurs or the young caregiver is forced to perform care duties beyond their abilities. To view a young caregiver’s duties in this context would also be reminiscent of the era prior to Child Labor Laws enacted when children were forced to work with little to no pay, in less than ideal conditions and at times, against their will (Becker, 2007).

Schools can play an important role in the identification and support of young caregivers. Dearden and Becker (1995b) assessed academic performance and found one in four young caregivers (or “young carers”) of mandated school age in the United Kingdom missed school regularly due to caregiving responsibilities. In the NAC and UHF study (2005), young caregivers who provided assistance with ADLs were found to be more likely than caregivers who only provided IADL assistance to be absent from school (38 percent versus 24 percent). If the care responsibility requires much of the young caregiver’s time, caregivers report there is less time for homework and extra-curricular activities; this typically increased as the caregiver progressed in school (Lackey and Gates, 2001). Among young caregivers aged 8 to 15 years, young caregivers did not submit homework assignments more often than non-caregiving peers (43 percent versus 33 percent). One in five young caregivers stated caregiving made them miss school or an after-school activity (NAC and UHF, 2005). During the high school years, caregivers noted missing out on social events such as dances or classes became more upsetting (Lackey and Gates, 2001; Siskowski, 2006).

Caregivers provide a valuable service not only to the care receiver but also to medical and social service professionals. Poor coordination among physicians and service agencies was noted to increase the difficulty in accessing information about available services and receiving the services when needed. Caregivers are forced to monitor a variety of services, find reliable personnel and track deadlines for documentation required by agencies (Bookman and Harrington, 2007; Shifren, 2008). Caregivers serve as an additional resource for physicians and service agencies as the caregivers can supplement the care receiver's medical history (e.g. medication allergies or preexisting conditions). A physician visit may last only a short term (under 30 minutes) but care givers are able to provide a detailed account of concerns and updates on the care receiver functioning. Caregivers can provide information such as subtle changes in the care receiver's cognitive status to reporting adverse side effects experienced. This is an integral role as care receivers may be reluctant to share or unaware of their decline. With multiple providers who may or may not use electronic records, care givers can supplement information to ensure all records are up to date (Bookman and Harrington, 2007).

#### At the **Policy** level

Caregiver experts and organizations need to be involved in policy discussions, especially those pertaining to reforming long-term care programs, caregiver legislation (e.g. Family Caregiver Support Program), and financing long-term care programs. Currently, the Family Caregiver Support Program (FCSP) reimburses informal caregivers for specific, approved care expenses (e.g. incontinence supplies) (White House, 2005). Given the economic climate and strain on financial resources, waiting lists for reimbursement for the state and federal Family Caregiver Support Programs are common. The FCSP prevents caregivers under age 18 from reimbursement for services provided. This limitation on reimbursement may place an additional

financial strain on an ineligible caregiver and limit the care receiving in the services or medical items the care receiver may need if no eligible family member lives nearby to register for the FCSP ([www.aoa.gov](http://www.aoa.gov)).

Young caregivers should be included in discussions to determine if young caregivers wish to be a part of the caregiving experience or simply are because of circumstance (lack of resources and or is the only other family member residing in the household). Obviously, cultural values and familial expectations must be considered as these factors are influential in the young caregiver's willingness to participate in care as well as their ability to cope with the stresses of caregiving (Shifren, 2008). Furthermore, policy will help to determine (along with research) to what extent the involvement of youth and caregiving is acceptable versus when is too much involvement at risk of being harmful to the youth? Policy can assist to allocate funding for training for professionals, which could be provided via online or through continuing education credits to health and social service providers of how best to identify and support this population. Professionals should be trained to ask questions about who is involved, make referrals and provide education as needed. It is important to know who is providing care and how the caregiving relationship is impacting the young caregivers as well as to consider the developmental age of the caregiver. Often times, nurses, hospice staff, home health aides or social workers have more contact with those in need of ongoing care services and may be the ideal population to begin education. School nurses and guidance counselors would also be ideal professionals to provide education or training to assist in the identification of young caregivers. These professionals could also be provided with a resource guide of referral sources for young caregivers (Lackey and Gates, 2001; Siskowski, 2004; Moore, 2005; East, 2010).

Young caregivers are often unaware of how to advocate for themselves or unaware of what questions to ask of health care and social service professionals. Unlike the lobbying in the United States of various National Caregiving organizations and disease specific organizations (e.g. Alzheimer's Association), young caregivers are often not included in the population of caregivers to express their views and needs (Aldridge and Becker, 1996; Levine et al., 2005).

#### **4.1 LIMITATIONS OF LITERATURE**

The lack of consensus for the term “young caregiver” leads to a wide age range used by studies; 8-25 years or 18-25 years. The difference in age ranges used by the studies also makes it difficult to complete accurate comparisons of experiences based on age range. Studies tend to be point-in-time capturing a snapshot of the experience rather than longitudinal studies which would provide a greater knowledge of caregiving challenges over a period of time. The sample sizes are typically small and recruited via online advertisements (support group, disease specific websites or local clinics).

Within the literature, the common barriers of positive outcomes typically include: mental health status (rates of depression or anxiety), academic performance, caregiver burden, and developmental issues (or coping skills). Facilitators of positive outcomes most often researched include: self-esteem, or pride, perceived familial relationships, and coping skills. Additional factors which need to be focused on include: duration of caregiving (and associated perceived burden or strain), long term mental and physical health impact, career trajectory, impact of

caregiving support groups or resources, and awareness of young caregivers among health care and social service professionals.

The research does not distinguish between who is considered a “primary” versus “secondary” caregiver in the data presented, nor does the research fully discuss a policy position in terms how to determine if tasks are age and developmentally appropriate for the young caregiver. It’s misleading to attempt to utilize the same surveys for 8 year old caregivers as well as 40 year old caregivers, thus reinforcing the need to clearly determine what age range one is considered to be a young caregiver. Considering 18 is the age to be an adult in the United States, it would likely be easiest to follow in the path of the United Kingdom and use 18 years and younger as the age range. There is also discussion regarding a “cut-off” age for beginning caregiving such as age 8 or 9 (Levine et al., 2005).

Very few studies considered inclusion of academic performance assessment or attendance record nor does the current research consistently ask if others know about caregiving experience (if person asked or if young caregivers volunteered the information) (Lackey and Gates, 2001). The impact of academic performance and attendance would be more powerful to be data form rather than via self-reports as participants may underreport absences or not disclose poor grades.

## **4.2 STRENGTHS OF LITERATURE**

Due to the mostly qualitative nature of the available literature on young caregivers, the research provides a more descriptive presentation. Within the United States, literature pertaining to

young caregivers began in the early 2000's and builds upon prior work based in the United Kingdom and Australia. Considering the work on young caregivers is still in infancy stage overall, the potential (and need) for partnerships domestically and internationally exists. The Young Carers Research Group (YCRG) in the United Kingdom could provide a great deal of guidance as to establishing a comparable research group in the United States. The YCRG has a network of dedicated support projects (e.g. young caregiver specific support groups and proposed standardized assessments) as a systematic response to the needs of young caregivers. The YCRG could also become a valued research partner as the results of young caregiver studies in the United States are similar to the findings of the United Kingdom and Australia. The United Kingdom and Australia implemented policy and programs in their respective countries aimed at young caregivers. The United States could benefit from collaboration with both countries and consider establish similar models domestically.

## 5.0 DISCUSSION

A majority of the literature focused on young caregivers is rooted in international sources, specifically the United Kingdom and Australia. The United States remains several years behind in terms of data collection, research and policy formation regarding young caregivers.

As a result of the lag time within the United States, young caregivers remain underrepresented in research, and not included in caregiving policies. Young caregivers remain underserved as there is a severe lack of resources tailored to their caregiving needs. Young caregiver contributions are unpaid and perhaps an age inappropriate activity, which are rarely recognized by organizations and medical professionals. Given the lack of research available, there is some degree of difficulty in making concrete assertions as a range of factors complicates an already murky area of caregiving. Caregivers may be reluctant to share their role with others, especially the intensity (e.g. providing toileting assistance or bathing his or his parent). This could be due in part to they do not wish for their parents to be viewed as inadequate. Family members may be reluctant to reveal the intensity of care provided by the young caregivers for fear of negative consequences such as the child could be removed from the home or current formal home health assistance would be removed and further caregiving burden placed upon the young caregiver. The young caregivers may worry about being viewed as “different” or “weird” by their peers. From the general caregiving literature regarding adult caregivers, it is evident that caregiving is very stressful and the increased intensity of caregiving impacts yields mostly



negative effects on the caregiver's health. While the informal caregiving may save health care costs for the care receiver, there is an increased cost associated with the strain of caregiving on the caregiver. In addition, young caregivers are still developing and beginning to pursue goals outside of the mandated schooling. The intensity of caregiving may force young caregivers to postpone or discard their own pursuit of higher education or social activities to provide care to a loved one. This act of sacrifice can later lead to greater levels of social isolation and depression, higher anxiety levels, and poorer physical health.

## **5.1 IMPLICATIONS FOR POLICY**

The Third International Conference on Family Care occurred in October 2002 for the first time in the United States and was held in Washington, D.C. At this conference, young caregivers from Australia and New Zealand shared their stories, how services were designed for young caregivers with their input and provided support during their time of need. This conference stimulated great interest in the topic and by the following year (September 2003) the United States' Administration on Aging awarded a grant to the National Alliance on Caregiving and the United Hospital Fund to conduct the first national survey of young caregivers in the United States. This study was also quite significant as it, unlike many other studies, included caregivers as young as 8 years old. The study found many similarities to the United Kingdom and Australian literature, specifically a call for further research to explore the positive and negative impacts of caregiving

as well as to understand how the experience distinguishes young caregivers from their non-caregiving peers.

Participation of young caregivers (and care receivers) in an international conference is highly recommended as it will provide an opportunity for meaningful exchanges among the countries with varying levels of policies and programs in place. While not all data and programs based in international settings may be applicable to the needs of young caregivers in the United States, the exchange of ideas, research findings and policy development can be powerful in addressing the needs of young caregivers. At this time, young caregivers do not have a sophisticated or well-established level of organization to lobby for inclusion in legislation. Young caregivers need a strong voice to advocate for their needs and inclusion at the policy level would help to ensure their needs are discussed. Organizations such as the National Alliance for Caregiving and the American Cancer Society have the ability to organize on a national level as well as to lobby legislators to bring attention to important issues. Incorporation of caregivers (especially young caregivers) into legislation will help to secure funding for research on this underserved population. Increased visibility would provide an opportunity for increased discussion about the economic value and importance of family caregiving as it relates to the domestic long term care system (Bookman and Harrington, 2007).

## 5.2 IMPLICATIONS FOR INTERVENTIONS

The involvement of stakeholders such as school officials, local caregiver support groups specific for young caregivers, and the family would be ideal. Allowing all the stakeholders to discuss ways to support the caregiver could mitigate the caregiving stress. During school hours, young caregivers could use study halls, lunch periods, or recess hours to speak with a counselor, nurse or to manage some of the caregiving responsibilities (e.g. calling to check on care receiver, scheduling appointments for transportation or medical appointments). To promote academic success, tutors (online or in person) for the caregivers would be useful to assist caregivers with assignments (Siskowski, 2004).

While the caregiver and care receiver have the right to accept or refuse services, health care or social service professionals could assist in making referrals to support groups or other social service agencies. Ideally, health care or social service professionals involved with families will also be able to monitor the safety of the caregiving relationship. Monitoring could include regular depression or caregiver burden screenings and referrals could be made for counseling or respite services. More often than not, caregivers are not aware of the resources available (e.g. prescription drug delivery, companionship services, and case management from an Area Agency on Aging). Caregivers must learn the various systems (medical and non-medical) and coordinate services for their loved one (Bookman and Harrington, 2007).

The internet is likely to be one of the most effective outreach tools for young caregivers as the population is part of a computer savvy generation. Young caregivers should be included in discussions at multi-levels and focus groups would be useful in determining the best methods of supporting young caregivers (Levine et al., 2005).

There are pockets of acknowledgement for the care young caregivers provided by organizations such as the Alzheimer's Association of the Greater Delaware Valley), but the efforts are small and area specific. Examples include the Alzheimer's Association chapter of the Delaware Valley County based in Marlton, NJ and New York City provide support groups for young adult caregivers caring for a parent with early onset Alzheimer's. Perhaps this would be an ideal starting point to inquire how to begin to establish and recruit for a more generalized young caregiver support group. The American Association for Young Caregivers, based in Florida, has been a pioneer in the area of youth caregiving services in the United States. The American Association for Young Caregivers has programs which could be used as models for other organizations nationwide. However, due to the high proportion of adults requiring care in the area, there is a higher known rate of young caregivers which makes the program more effective in terms of offering face to face support, receiving funding as well as tracking/researching the needs of young caregivers (AAYC, 2012). In more rural areas or areas with a higher rate of immigrants, this could prove to be more difficult to implement and to justify funding for.

### **5.3 IMPLICATIONS FOR FUTURE RESEARCH**

Research domestically on young caregivers has been very scant and needs to be increased. It is difficult to generalize all young caregiver experiences when there are national variations to account for such as: culture, health care systems, types of physical illnesses studies, varying age range and recruitment methods. Research would allow stakeholders to gain more accurate

insight of the caregiving experience among this population as well as to better identify the needs of young caregivers (Schumacher et al., 2006).

The Young Carers Research Group in the United Kingdom was founded in 1992 at Loughborough University and conducts research, evaluation and consultancy on issues related to young caregivers. The YCRG could serve as a model for a domestic research agency or serve as a partner agency. Researchers could also implement some of the research methods used by the YCRG to further the research among young caregivers in the United States. The work of the YCRG has had a direct influence on the development of policy and program development (Dearden and Becker, 2000).

Longitudinal studies are needed to determine the long term effects of caregiving on young caregivers. The amount of studies available in the United States is limited to a very small amount which interviewed young caregivers during a period of active caregiving (Shifren, 2008; East, 2010). Other studies available interviewed caregivers 18 years and over or surveyed adults who were family caregivers several years ago during their teenage years. The limited information restricts the ability to gain more insight as to what the caregiving experience is like and how it impacts youth who are still developing coping mechanisms. While the cost saving benefit of family caregiving is obvious for the care recipient and data states the cost savings of unpaid caregiving, it is unknown if the caregiver sees an increase in his or her health care costs for caregiving related issues (e.g. depression, bodily injuries due to heavy lifting) and could lead to increased strain on the health care system (White House, 2005).

As the young caregivers become adults and exercise more autonomy, it would be valuable to observe if the caregiving experience influences future health behaviors as well as to investigate potential increased use of the health care system as a result of caregiving such as

treatment for depression or anxiety (Shifren, 2008). To date, most studies do not include the amount of actual time spent on caregiving. The frequency and continued inquiry of the duration of caregiving would provide additional insight into the challenges faced by young caregivers (East, 2010).

Current research has focused on using qualitative methodologies to gather data about the caregiving experience. In 2009, the Manual for Measures of Caring Activities and Outcomes for Children and Young People was released in the United Kingdom. The manual contains outcome instruments health care and social service providers can use to assess young caregivers (“young carers”). The two instruments within the manual include: the Multidimensional Assessment of Caring Activities (MACA-18) and the Positive and Negative Outcomes of Caring (PANOC-YC20). The MACA-18 contains 18 self-report items and used to assess the total amount of caregiving activities performed by a young caregiver (“young carer”). Items inquire about household management, personal care, sibling care and domestic tasks. The MACA-18 can be used as a pre- or post-test measure to determine if any changes occurred post-intervention or treatment. The PANOC-YC20 is a 20-item self-report measure used to identify positive and negative outcomes of caring. The PANOC-YC20 can also be used as a pre- or post-test measure to identify any changes following an intervention or treatment. The PANOC-YC20 is believed to be particularly useful in assessing if interventions lead to a result of negative outcomes or an increase in positive outcomes. The authors emphasize in the manual that findings of positive outcomes should not be viewed as justification for young caregivers (“young carers”) to remain underserved or under supported by society (Joseph, Becker and Becker, 2009).

In Australia, the “Youth Activities of Caregiving Scale” (YACS) is a tool recently developed and proposed to serve as a standardized assessment tool for young caregivers. The

measurement covers topics such as the type of caregiving provided, age of the caregiver and care recipient, disability type, prognosis, etc. While the YACS has been tested on a small sample size, further research is required to establish test-retest reliability. At this time, there remains no measure to assess tasks performed by young caregivers under the age of 10 years (Ireland and Pakenham, 2010). A standardized assessment for the United States would be useful in providing quantitative data and should be separated in to age specific groups and used as part of a mixed methods survey to again, collect more data about the caregiving experience. Data is especially limited among minority young caregivers; collecting data from this sub population would be quite useful in also examining the cultural influences which may add another dimension to the young caregiving experience (Schumacher et al., 2006).

Areas with high incidences of HIV/AIDS, disability and substance abuse issues could be optimal locations to begin further identification of young caregivers. For example, in 2001 Palm Beach County, Florida, was noted to have a large population of older adults (23.2 percent versus 12.4 percent nationally), ranked fourth in the nation with new AIDS cases (44 percent versus 14.3 percent nationally) and a large population of young adults with disabilities aged 18-64 years (18 percent with specific regions of the county to be as high as 22 percent versus 12.4 percent nationally). Prior research informs the presence of grandchildren caring for grandparents, children caring for parents with HIV/AIDS as well as children caring for family members with disabilities. A 2003 self-administered study was offered to youth in grades six-twelve within Palm Beach County, Florida's public school system. The survey was completed by 12,677 students to gain insight of the young caregiver experience. More than half of the students stated they provided care to someone in need of medical care. However, the high rate of young

caregivers in this study is likely atypical given the larger representation of older adults, individuals with HIV/AIDS and individuals with disabilities (Siskowski, 2004).

#### **5.4 LIMITATIONS**

Since this analysis was a literature review, no new data was generated and the author was only able to read articles that were published in English. The articles selected for this review were limited to those with online access at no cost and available through the University of Pittsburgh's library system.



## 6.0 CONCLUSION

In this chapter, the conclusion will focus on the main parts of the historical perspective with emphasis on the important findings from the literature review.

The increase of family caregivers, especially the emerging knowledge of young caregivers has been a national issue for many decades. One of the most effective ways noted to mitigate the negative impact of caregiving stress is to focus on identification and support for young caregivers. With proper intervention, the risk of emotional and physical strain on young caregivers could be reduced and assist in promotion of a positive, caregiving period or duration while supporting the educational and developmental needs of the youth. Barriers to services have been outlined in this thesis and include: intrapersonal (knowledge about caregiving, knowledge of caregiving resources, fear and beliefs), interpersonal (involvement of other family members, health care professionals, social service professionals, and social support), organizational (programs and resources tailored for young caregivers), and policy (caregiving research and legislation including young caregivers). If these challenges were decreased or eliminated, the adverse impact of caregiving stress would be reduced and both the young caregiver and care receiver could continue the caregiving relationship without harm to either party.

The young caregiver population is likely to increase as time goes on and we are only seeing the beginning of what is likely to increase in a unique caregiver population. While the

documentation of young caregivers may be small in numbers now, we are only seeing the beginning of a trend. We should use this as an opportunity to begin tracking the population to learn how to craft the policies and services. Due smaller family sizes and childbearing in later years, children still in their formative years will be called upon their aging parents for care. The duration of caregiving may also extend beyond the 4.3 years among adult caregivers as more people are living longer and with chronic diseases or disabilities (Shifren, 2008; Levine et al., 2005). As of 2007, family caregiving saved an average of \$257 billion per year in institutional care and governmental spending (Nguyen, 2009). As more cost containment measures are implemented, including delayed institutional placement, it is imperative to implement measures supporting caregivers and care receivers.

**APPENDIX A**

**TABLE 1: LITERATURE SEARCH**

<p><b>Literature Search 1: PubMed</b></p> <p>Search Terms: “young” and “caregiving”</p> <p>Results: 48</p>	<p><b>Literature Search 2: PubMed</b></p> <p>Search Terms: “young caregivers” and “United States”</p> <p>Results: 5</p>
<p><b>Literature Search 3: EBSCO</b></p> <p>Search Terms: “caregiving” and “young”</p> <p>Results: 15</p>	<p><b>Literature Search 4: Ovid Medline</b></p> <p>Search Terms: “young adult caregivers” and “young carers”</p> <p>Results: 4</p>

## APPENDIX B

**TABLE 2: THE SOCIAL ECOLOGICAL MODEL AND YOUNG CAREGIVING**

<b>Intrapersonal level</b>
Knowledge, beliefs, and fear
<b>Interpersonal level</b>
Familial support, health care and social service professionals, social support (peers)
<b>Organization level</b>
Support groups, community agencies, programs designed with and for young caregivers
<b>Community level</b>
Stigma, Schools
<b>Policy level</b>
Caregiving legislation, caregiving research

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