MAKING THE INVISIBLE VISIBLE: ADOLESCENT CAREGIVER EXPERIENCES IN MULTIPLE SCLEROSIS

Renee Crizer

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MAKING THE INVISIBLE VISIBLE: ADOLESCENT CAREGIVER EXPERIENCES

IN MULTIPLE SCLEROSIS

A Dissertation Presented

by

RENEE C. CRIZER

Submitted to the Graduate School of the University of Massachusetts Amherst

In partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2019

College of Nursing
DEDICATION

With gratitude to my participants and their families whose stories touched my soul. My hope is that others will hear your words and learn from your experiences. Thank you for bringing your story to light so that other families with MS may benefit from your experience.
ACKNOWLEDGEMENTS

I would like to thank the National Multiple Sclerosis Society and Dr. Ionettie and colleagues, from the MS Clinic at the University of Massachusetts University Campus for their help in reaching my participants. I would not have gained access to the invisible population of adolescent caregivers without their help. I hope this study will benefit you in your work with the MS community.

Next, I would like to thank my academic advisor Dr. Karen Kalmakis for taking me on after all these years; and believing in me and encouraging me throughout the process of my dissertation. You inspired me to continue when things didn’t go as planned and gave me amazing and challenging feedback on my work. I am thankful for your wisdom and guidance in my PhD journey.

I want to thank my entire family for believing in me, supporting me, and encouraging me along the way. To Kevin, my husband, I couldn’t have done it without you. You are my strength and my encouragement from the beginning. Your support and love helped me through these years. To my children Mia and Reece, thank you for understanding mommy’s homework time. I love you both more than you’ll ever know. To my siblings, in-laws, and friends, you were an encouragement and gave me faith along the way. To my parents who have since passed on, you were my inspiration, I hope I made you proud.
Lastly, I want to acknowledge that none of this would have been possible without my faith in my Heavenly Father, Jesus Christ. My trust in him is what gets me through each day and has led me to my calling of serving others in the field of nursing.
Making the Invisible Visible: Adolescent Caregiver Experiences in Multiple Sclerosis

May 2019

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Ph.D., University of Massachusetts Amherst

Directed by: Professor Karen Kalmakis

Multiple Sclerosis, a chronic, debilitating neurological disease is typically diagnosed during the child bearing and child rearing ages of 20-50. Therefore, many people diagnosed with Multiple Sclerosis have children and adolescents living at home. With approximately 400,000 people in the United States currently diagnosed with multiple sclerosis and 10,000 new cases each year, a group of caregivers have emerged that are often unrecognized and potentially at risk: a group of young caregivers.

The aim of this study was to explore the lived experience of individuals who provided care for a family member with Multiple Sclerosis during their adolescence. This qualitative, retrospective, hermeneutic study used interviews with adults who were once adolescent caregivers for a family member with Multiple Sclerosis. A five-step process for data analysis and interpretation was followed, and two common themes were identified: invisibility and support.

Participants identified invisibility in their role, by family, healthcare, and the community. A discussion as to why some adolescents take on the caregiving role, while...
other siblings don’t is included. Participants discussed their support by sharing their pre-
caregiving experiences, role change, daily routines and tasks, future outcomes after
caregiving, and their needs and desires as adolescent caregivers. The results of this study
provide nurses, other health professionals, and the MS community with a better
understanding of adolescent caregiver experiences in MS.

Key Words: Adolescent caregiver, young carer, caregiving, experience, multiple
sclerosis, phenomenology, retrospective, interview method.
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CHAPTER 1
INTRODUCTION

In this chapter, a brief discussion of caregiving, chronic disease, and Multiple Sclerosis will be presented. The emerging prevalence of young caregivers, and the significant needs of this population, particularly related to their health will be described. Additionally, the significance of this issue to the nursing and the purpose of the study will be clearly stated.

Background

Chronic illness is becoming more prevalent, not only in the United States, but worldwide. This is often attributed to advancements in public health which have changed the leading cause of death in the United States from infectious disease to chronic illness (Remington, Brownson, & Wegner, 2010). Chronic illness has a prolonged course, does not resolve spontaneously and is considered incurable. Chronic disease has an effect on functional impairment or disability, and encompasses chronic illnesses, degenerative diseases, and non-communicable diseases (Remington, Brownson and Wegner, 2010). Approximately 125 million people in the United States (half of all Americans) have a chronic illness and this number is projected to increase to 157 million by 2020 (Anderson, Horvath, Knickman, Colby, and Schear, 2002). Currently, seventy-five percent of our national health care budget now goes towards the treatment of chronic illness (Centers for Disease Control and Prevention, 2009).
Advancements in technology and medicine are helping individuals with chronic disease live longer (Health United States, 2007). However, it is causing a greater need for long-term care. The movement of healthcare from institutions to the home setting has become increasingly prevalent due to economic issues, health insurance provisions, or lack thereof, and family preferences. As a result, more and more families are caring for their chronically ill and disabled loved-ones in the home. The projected increase in older Americans will likely further increase the need for home care.

Familial caregiving is not a new concept. Family or friends typically become the primary caregivers of those who have become ill or disabled. There are approximately 9 million caregivers in the United States and 40% of them continue to hold full-time jobs (Anderson, et al., 2002). With many adult caregivers continuing to hold full-time jobs, an unrecognized and understudied group of caregivers is emerging to provide in-home care: the population of young caregivers ranging from 3 to 18 years of age. Young caregivers may spend up to 56 hours a week with caregiving tasks (Svanberg, Stott, and Spector, 2010).

To date, the majority of caregiving research and scholarly articles have focused on adult caregivers over the age of 18 who are providing care for spouse, partner, parent, or child; yet, young caregivers have remained relatively invisible (Aldridge & Becker, 1993; Banks Cogan, Riddell, Deeley, Hill, & Tisdall, 2002; Thomas, Stainton, Jackson, Cheung, Doubtfire, & Webb, 2003). Caregiving can greatly impact young caregivers lives, both positively and negatively (Hunt, Levine, & Naiditch, 2005), and has the
potential to influence developmental, psychological, social, spiritual, and physiological health.

A 2005 survey conducted by the National Alliance for Caregiving, in collaboration with the United Hospital Fund, found approximately 1.4 million young caregivers ages (8-18) in the United States. Of these young caregivers, 72% are caring for an adult family member and 11% for a sibling (Hunt, Levine, & Naiditch, 2005). The increasing population of young caregivers is not exclusive to the United States. According to the 2001 United Kingdom census, there are approximately 175,000 young caregivers between the ages of 5-18 in the United Kingdom (National Office for Statistics, 2001). In Australia, the Young Caregiver Research Project found an estimated 388,800 young people under the age of 26 were caregivers (Carers Australia, 2001).

In light of the significant number of young caregivers, and the growing number of persons living with chronic disease, it is important for nurses and other healthcare professionals to understand experiences of young caregivers. For this study, the experiences of being a young caregiver who provided care for a family member with Multiple Sclerosis was investigated.

Multiple Sclerosis (MS) is the most common, progressive, neurological chronic disease among 20 to 50 year olds (Remington, Brownson, & Wegner, 2010). According to the National Multiple Sclerosis Society (2011), there are approximately 400,000 people living with MS in the United States, and an estimated 2.1 million worldwide.
Every year there are 10,000 new cases reported in the United States (Rumrill, P.D., 2009).

Although the etiology of MS is unclear, this autoimmune neurological disease affects the Central Nervous System (CNS) comprising the brain and spinal cord. In MS, the body targets and destroys its own protective coating (myelin sheath) surrounding the nerves. Without myelin, electrical or chemical signals through the nerve is lost and the body loses its ability to communicate information to (sensory neurons) and from (motor neurons) the CNS (Multiple Sclerosis, 2009).

Approximately one out of four MS patients will need to use a wheelchair 25 years following diagnosis (Paty, Poser, and Schapiro, 1989). Patients with sensory symptoms tend to do better than those with motor symptoms (Paty, Poser, & Schapiro, 1989). The National Multiple Sclerosis Society (2011) reports 1/3 of MS patients’ end up severely disabled (confined to wheelchairs or bed) while the other 2/3 eventually need assistive devices to walk. Ninety-six percent of patients will have bladder problems after ten years of initial onset of disease, and 70% of males with MS will have sexual dysfunction (Hawker & Frohman, 2001). Due to the typical age of onset for MS, there is the likelihood that there are children in the home, children who may assume the role of caregiver.

Significance of the Phenomenon to Nursing

Young caregivers have remained ‘hidden’ or ‘invisible’ to researchers (e.g. Aldridge & Becker, 1993; Banks et al, 2002; Hunt, Levine, & Naiditch, 2005). Health
professionals contribute to young caregiver invisibility by unconsciously overlooking this population, and instead focusing on the needs of adult caregivers, or the disabled family member (Thomas et al, 2002; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Aldridge, 2006). In two studies conducted with young caregivers (Thomas, 2003; Butler & Astbury, 2005), the young caregivers believed the medical community was not recognizing them. Specifically, they felt their role, needs, opinions, and knowledge went unrecognized (Thomas, 2003; Butler & Astbury, 2005). Young caregivers also believe they are getting no support from healthcare professionals (Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood & Chow, 2013).

Contributing to the lack of knowledge about this population of caregivers, young caregivers continue to stay hidden due to their own fears of separation (e.g. Early, Cushway, & Cassidy, 2006; Packenham, Chiu, Burnsnall & Cannon, 2006; Cass, 2007a), ridicule or bullying (e.g. Banks et al., 2002; Butler & Astbury, 2005; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005), “caregiveree’s” disease stigma (Packenham, Chiu, Burnsnall & Cannon, 2006), embarrassment and guilt (Aldridge & Becker, 1993; Dearden, Becker, & Aldridge, 1995), and issues of privacy (Banks et al, 2002; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Moore, 2005). Furthermore, young caregivers simply may not self-identify as a caregiver (George, 1993; Cass, 2007b).

The three countries of the United Kingdom (UK), Australia, and the United States (US) are the main contributors to research on young caregivers. In 2001 the U.K. reported approximately 175,000 young caregivers between the ages of 5-18 (National
Office for Statistics, 2001), while in Australia, the Young Caregiver Research Project found an estimated 388,800 young people under the age of 26 were caregivers (Carers Australia, 2001). The United States estimate surpasses these countries with an unsettling 1.3 to 1.4 million young caregivers between the ages of 8 and 18 (Hunt, Levine, & Naiditch, 2005).

Although the US has the greatest amount of young caregivers, many who may be in need of support and guidance, one would think the US would provide the greatest amount of resources, programs, and research for this population. However, the United States has done less compared to other countries, such as the United Kingdom and Australia to support young caregivers. According to Becker’s (2007) typology of awareness and response to young caregivers, the US is considered to be at the preliminary level, just above Sub-Saharan Africa’s emerging level. The emerging level is viewed as the lowest level in the typology. Sub-Saharan Africa has potentially millions of young caregivers, many of whom are caring for family members affected by the pandemic of AIDS/HIV (Becker, 2007). In sub-Saharan Africa family caregiving by children and adolescents has become the ‘social norm’ (Skovdal, Ogutu, Aoro, & Campbell, 2009). Children in Africa are often sent away to live and care for sick family members (Skovdal, Ogutu, Aoro, & Campbell, 2009). In the US there is “little public or specialist awareness and recognition of young carers…limited research base…no specific legal rights…, and few, if any, dedicated services or interventions at national or local levels” (Becker, 2007, p. 42).
The little research that has been conducted with young caregivers has not drawn much attention. Young caregivers continue to be unrecognized by school officials, community service agencies, and health professionals (Hunt, Levine, & Naiditch, 2005). Educators, social-service agencies, and health care professionals need to be made aware of this growing, at-risk population of young caregivers.

Nurses who are caregivers themselves, should be at the forefront of research and advocacy for young caregivers. Nurses’ multidisciplinary connections, holistic viewpoints, comprehensive assessment skills, plans of care, understanding of disease and disability with emphasis on health and wellness, and case management skills affords them a unique knowledge upon which to identify, assess, manage, and help the young caregiver population. Nurses are uniquely positioned to support young caregivers in many settings including in homes, schools, camps, community health centers, and hospitals. Nurses should be educated about the needs of young caregivers, and become skilled in recognizing, teaching, and supporting this growing population.

**Statement of Purpose**

Considering the lack of knowledge about young caregivers and the growing number of family members in need of long-term home care, the purpose of this study was to explore the lived experience of adolescents who provided care for an adult family member with Multiple Sclerosis.
CHAPTER 2
LITERATURE REVIEW

To provide readers with an understanding of Multiple Sclerosis and why progression of the disease leads to the need for caregiving, a description of the MS disease process will be described prior to an integrative literature review on young caregivers.

**Disease Process of Multiple Sclerosis**

In Multiple Sclerosis (MS), the body’s immune system targets and destroys its own protective coating (myelin sheath) surrounding the nerves of the Central Nervous System (CNS) including the brain and spinal cord. Without myelin, electrical or chemical signals through the nerve are lost and the body loses its ability to communicate information to (sensory neurons) and from (motor neurons) the CNS (Multiple Sclerosis, 2009). The National Multiple Sclerosis Society (2009) compares the demyelination of nerves to an electrical wire, which has lost its insulative coating. The body naturally replaces the damaged myelin with scar tissue (lesions, plaques), a process known as sclerosis (Multiple Sclerosis, 2009). Symptoms of MS are due to the nerves inability to function correctly from the damaging process of demyelination. Signals from the periphery are unable to communicate accurately with the central nervous system due to damaged sensory neurons. Similarly, outgoing signals from the central nervous system via damaged motor neurons can cause problems with muscle function and weakness. Various symptoms of MS include: vision problems, gait disturbances, incoordination,
muscle weakness, paresthesias (numbness, tingling, burning sensations), fatigue, muscle
spasticity, tremors, bowel constipation, bowel incontinence, bladder dysfunction and
incontinence, and sexual and erectile dysfunction (Multiple Sclerosis, 2009). As
symptoms and disease state progress, a person may become partially, or completely
paralyzed, and undergo loss of cognitive function and intellectual deterioration (National
Multiple Sclerosis Society, 2011; Holland, 2002; Paty, Poser, & Schapiro, 1989). The
secondary disorders of depression and anxiety are also relatively common in MS patients

MS is a challenging, chronic disease with no known cause, and no known cure.
The disease interferes with activities of daily living and is highly unpredictable. Acute
relapses can occur at any time and the length of each relapse is unknown. There are four
categories of MS that range from moderate to severe: relapsing-remitting; primary-
progressive; secondary-progressive; and progressive relapsing. A moderate type of MS
can change to a more severe type at any time (Holland, 2002).

Relapsing-remitting MS, the most common type, involves attacks on the CNS
also called relapses, exacerbations, or flare-ups followed by a recovery period
(remissions) in which there is no disease progression (National Multiple Sclerosis
Society, 2011). A relapse typically lasts 24 hours to a few weeks. Approximately 85% of
MS patients have this type (National Multiple Sclerosis Society, 2011). Primary-
progressive MS results in a continuous worsening of the disease (inflammation, scarring,
and neurologic symptoms) and does not involve remissions (Holland, 2002). According
to Tsang & Macdonnell (2011) 20% of MS patients have primary-progressive MS; however, the National Multiple Sclerosis Society (2011) found this type to be more rare, or 10% of all MS cases.

Secondary-progressive MS begins as relapsing-remitting MS, but then changes to the progressive type (continual worsening disability with or without minor relapses or plateaus) (Tsang & Macdonell, 2011; National Multiple Sclerosis Society, 2011; Holland, 2002). Approximately half of all relapsing remitting MS cases will progress to secondary-progressive MS after 10 to 20 years of initial disease onset (National Multiple Sclerosis Society, 2011). Progressive-relapsing MS involves acute relapses from disease onset (which may or may not resolve) followed by worsening progression of the disease (National Multiple Sclerosis Society, 2011; Holland, 2002). Approximately 5% of MS patients have this type (National Multiple Sclerosis Society, 2011).

The prognosis for relapsing-remitting MS is better than that of primary progressive MS (Tsang & Macdonell, 2011; Paty, Poser, & Schapiro, 1989). It is rarely considered fatal unless symptoms shorten life expectancy (National Multiple Sclerosis Society, 2011). A 2005 study conducted on the prognosis of spinal MS, revealed that disease progression differed with age of onset, and disease type (progression was worse in primary progressive than in relapsing remitting), and was less related to the location of the lesion (see Nociti, Cianfoni, Mirabella, Caggiula, Frisullo, Patanella, Sancricca, Angelucci, Tonali, & Batocchi, 2005).
Selecting Hypotheses or Questions for the Review

The integrative review of sources for this report followed the guidelines developed by Ganong (1987). These include the tasks of (1) selecting hypotheses or questions for the review, (2) sampling, (3) characteristics of the primary research, (4) analysis of the findings, (5) interpretation of the results, and (6) reporting the review.

The purpose of this integrative review was to (a) analyze the research on young caregivers of family members with an illness or disability in the home, (b) discuss the methodological studies that have been conducted, (c) discuss the state of young caregiver research in nursing, and (d) identify areas for future nursing research.

Caregiving (n.) is conceptually defined for the purposes of this research study, as the actions of a motivated caregiver (professional, familial, or professional-familial) attending to the needs (physiological, psychological, socio-cultural, spiritual, and developmental) of a dependent recipient that goes above and beyond traditional everyday experiences. For this review, the caregiving action is carried out by a motivated (e.g. obligation, love, fear, guilt) young caregiver (≤ 18 years old) attending to the needs of a dependent family member (e.g. mother, father, grandmother, grandfather, stepmother, stepfather, or sibling) with an illness or disability. Young caregivers can be either primary caregivers (the main caregiver for the family member) or secondary caregivers (assisting and supporting a primary caregiver in caregiving activities). The recipient of adolescent caregiving will be identified as ‘caregivee.’
Sampling

A search was conducted using the literature from nursing, psychology, social science, and medicine. Multiple databases were used: Academic Search Premier, CINAHL, Pre-CINAHL, PsycARTICLES, PsycINFO, Social Science Abstracts, and PubMed. No limit was set on article publication dates. The limit of English language was applied to a title search using the keywords: adolescent OR adolescence OR teen* AND caregiving* OR caregiving OR carer* OR young AND carer* (N=546).

The 546 article abstracts were analyzed and measured against the criteria of (1) caregiver must be under or equal to the age of 18, and (2) caregiving must take place in the home (informal caregiving). Articles were excluded if they did not contain both criteria. Articles depicting the experiences of children or adolescents solely as a family member (not as a caregiver) of an ill or disabled relative were excluded for this review. Forty-eight research articles (see Appendix A) were found to be of relevance.

An organizational chart on the research articles can be found in Appendix A. This organization chart includes the year the study was published, the authors, discipline conducting the research, the location where the study was conducted, the study design, sample size, age of caregivers, and caregiving recipient ailments. The characteristics of the research described below include the disciplines and countries conducting the research on young caregivers, methodologies utilized thus far, and sample characteristics.

Although young caregiving is not a new issue, research in the area has only recently begun. The initial stages of research began in the late 1980’s (Dearden, Becker,
& Aldridge, 1995). To this day, the majority of research has been conducted in the United Kingdom and Australia by the disciplines of social science and psychology. The issues and needs of young caregivers has great implications for nursing, yet the research contributed by the nursing discipline is limited (N=9), with two of these articles (SmithBattle, 2000; 2006) focusing on teens caregiving for their offspring rather than caregiving for an ill or disabled family member.

Methodologies Used in Reviewed Studies

A greater portion of studies have utilized qualitative research (N=34), with relatively few studies using quantitative research (N=10) and mixed methods (N=5). The qualitative studies predominantly applied the method of phenomenology (N=16), followed by grounded theory (N=7), case study (N=1), narrative (N=1), comparative analysis (N=1), and participatory action (N=1). Six studies did not clearly state the method they used in their study (see Appendix A).

The interview method was predominantly used to collect data: hermeneutic style (N=2), retrospective interview (N=2), unstructured interview (N=1), loosely structured (N=2), semi-structured (N=10), structured (N=2), and in-depth interviews (N=5). Ten articles (see Appendix A: under design) did not specify the type of interview used in their study. Focus groups were used in twelve studies, and questionnaires were used in nine. There was limited use of participant observation (N=1), surveys (N=4), checklists (N=1), chart reviews (N=1), scales (N=1), instruments (N=1), tests (N=1), and a demographic data form (N=1). Heyman and Heyman (2013) used constant comparative analysis to
compare experiences of young caregivers and their social workers; data which was
collected by the first author in a previous study.

Sample Characteristics

The sample size of the 27 qualitative studies varied from N=1 (Sisowski, 2007) to
N=253 (SmithBattle, L., 2006). The sample sizes for the quantitative studies ranged from
N = 24 (Shifren & Kachorek, 2003) to N = 2,429 (Cox & Packenham, 2014). Sample
size was the most frequently mentioned limitation of the research studies. The ages of
young caregivers used in all forty-eight studies ranged from 3 to 29. Most of the
caregiving recipients suffered from either an illness (e.g. chronic, mental, behavioral,
substance abuse) or a disability. Two SmithBattle (2000, 2006) studies focused on teens
caregiving for healthy offspring, two studies focused on health professionals’
perspectives of young caregivers (Gray, Robinson, & Seddon, 2008 and Heyman &
Heyma, 2013), and nine studies simply did not delineate the caregiving recipient.

Analysis of the Research Findings

Six major themes, pertaining to young caregivers, were developed from the forty-
eight research articles; invisibility, tasks, negative and positive outcomes, needs, and
ways of coping. Each of these themes will be discussed in more depth in the following
pages.

First it is important to clarify the definition of young caregivers. There has been
some debate as what to call and how to define these young people that are in the position
of caregiving for family members with an illness or disability (Eley, 2004; Butler &
Astbury, 2005; Pakenham, Chiu, Bursnall, Cannon, & Okochi, 2006). The most frequent term used to describe these young people is ‘young carers’. Young carers are mostly described as those under eighteen years of age that take on the caregiving responsibilities and complete tasks for sick or disabled relatives in the home. However, eighteen studies have expanded the top age range for young carers (see Appendix A: Status). Two research studies took care to delineate young carers from young adult carers in their sample (see The Princess Royal Trust, 2009 and Hamilton & Adamson, 2013). For this study, a conscious decision was made to call the interest group “adolescent caregivers” due to the lack of age boundary that lies with the term ‘young carer’ and because of the familiarity with the concise terms ‘care’ and ‘give’. Although, the terms young caregivers and young carers will be used in this chapter to describe the population, according to the terms used in the literature reviewed.

**Young Caregiver Invisibility**

According to the research, there are multiple reasons for the invisibility of young caregivers. These include: not self-identifying as a caregiver (Moore & McArthur, 2007), fear of being taken away from their family (Moore & McArthur, 2007; Gray, Robinson, & Seddon, 2008; Metzing-Blau & Schnepp, 2008; et al.), ridicule or bullying by peers or others (Banks et al., 2002; Butler & Astbury, 2005; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; et al.), unwanted intervention (Moore & McArthur, 2007), being judged, criticized, or scrutinized (Moore & McArthur, 2007), a stigma associated with the caregiving recipients illness (Packenham, Chiu, Bursnall & Cannon, 2006;
Bolas, Wersch, & Flynn, 2007), embarrassment and guilt on behalf of the young
caregiver or caregiving recipient (Aldridge & Becker, 1993; Moore & McArthur, 2007),
a belief that caregiving should stay private within the family (Keigher, et al., 2005; Bolas,
Wersch, & Flynn, 2007; Moore & McArthur, 2007; et al.), and a belief that the caring
role will be a risk to gender identity or masculinity (Bolas, Wersch, & Flynn, 2007). In
their retrospective study with adults who were once young caregivers, Nagl-Cupal,
Metzing, and Mayer (2015) found their participants continued to remain invisible due to
inability to self-identify as a young caregiver, and a fear of rousing painful memories.
Fear is the number one contributing factor to invisibility in the research, followed by the
lack of self-awareness as a “caregiver”.

Professionals also contribute to young caregiver invisibility by unconsciously
overlooking this population and instead focusing on the needs of adult caregivers, or the
ill or disabled family member (Thomas, et al., 2003; Keigher, Zabler, Robinson,
Fernandez, & Stevens, 2005; Aldridge, 2006). Gray, Robinson, and Seddon (2008), found
professionals contribute to young caregiver invisibility because of a fear of having to deal
with family separation and child protection procedures.

Young Caregiver Tasks

Frequently mentioned young caregiver tasks fit into one of 10 categories (see
Table 1). The most frequently mentioned tasks of young caregivers in the literature are
instrumental activities of daily living (IADL) such as cooking, shopping, cleaning,
laundry, fetching items, running errands, and paying bills. Young carers spend more time carrying out domestic tasks than their non-caregiving peers (Warren, 2007).

Table 1: Tasks Performed by Young Caregivers

<table>
<thead>
<tr>
<th>Tasks</th>
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<tbody>
<tr>
<td>Activities of Daily Living: e.g. feeding, walking, transferring</td>
<td>Gates &amp; Lackey (1998)</td>
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<td>Lackey &amp; Gates (2001)</td>
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<td>Shifren &amp; Kachorek (2003)</td>
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<td>Metzing-Blau &amp; Schneppe (2008)</td>
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<td>Svanberg, Stott, &amp; Spector (2010)</td>
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<td>Nichols, et al. (2013)</td>
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<td>Instrumental Activities of Daily Living: e.g. cooking, shopping,</td>
<td>Gates &amp; Lackey (1998)</td>
</tr>
<tr>
<td>cleaning, laundry fetching items, run errands, pay bills.</td>
<td>Lackey &amp; Gates (2001)</td>
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<tr>
<td></td>
<td>Shifren &amp; Kachorek (2003)</td>
</tr>
<tr>
<td></td>
<td>Keigher, et al. (2005)</td>
</tr>
<tr>
<td></td>
<td>Forest Keenan, et al. (2007)</td>
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<tr>
<td></td>
<td>Siskowski, et al. (2007)</td>
</tr>
<tr>
<td></td>
<td>Warren (2007)</td>
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<tr>
<td></td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
</tr>
<tr>
<td></td>
<td>Moore, McArthur, &amp; Noble-Carr (2011)</td>
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<tr>
<td></td>
<td>Nichols, et al. (2013)</td>
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<tr>
<td></td>
<td>Kavanaugh (2014)</td>
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<tr>
<td></td>
<td>Keigher, et al. (2005)</td>
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<tr>
<td></td>
<td>Aldridge (2006)</td>
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<tr>
<td></td>
<td>Warren (2007)</td>
</tr>
<tr>
<td></td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
</tr>
<tr>
<td></td>
<td>Moore, McArthur, &amp; Noble-Carr (2011)</td>
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<tr>
<td></td>
<td>Metzing-Blau &amp; Schneppe (2008)</td>
</tr>
<tr>
<td></td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
</tr>
<tr>
<td></td>
<td>Moore, McArthur, &amp; Noble-Carr (2011)</td>
</tr>
<tr>
<td></td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td></td>
<td>Kavanaugh (2014)</td>
</tr>
<tr>
<td>Medical Care</td>
<td>Lackey &amp; Gates (2001)</td>
</tr>
<tr>
<td></td>
<td>Keigher, et al. (2005)</td>
</tr>
</tbody>
</table>
Personal Care: e.g. bathing toileting, and dressing.

- Lackey & Gates (2001)
- Shifren & Kachorek (2003)
- Siskowski, et al. (2007)
- Warren (2007)
- Svanberg, Stott, & Spector (2010)
- Nichols, et al. (2013)
- Kavanaugh (2014)

Caring for Other Family Members

- Keigher, et al. (2005)
- Moore, McArthur, & Noble-Carr (2011); Kavanaugh (2014)

Employment

- Richardson, Jinks, & Roberts (2009)
- Moore, McArthur, & Noble-Carr (2011)
- Kavanaugh (2014)

Protecting the Care Recipient

- Keigher, et al. (2005)
- Siskowski, et al. (2007)
- Kavanaugh (2014)

Taking Responsibility for Family in the Neighborhood & Community

- Keigher, et al. (2005)

Personal care is a type of Activity of Daily Living but was mentioned separately because of its negative impact on young caregivers. Activities of Daily Living tasks that were discussed include feeding, walking, and transferring. In eight studies, personal care such as bathing, toileting, and dressing were the second most frequently mentioned tasks, and the tasks considered most difficult for young caregivers.
Emotional care and crisis support such as listening, supporting, and encouraging was discussed in six articles (see Table 1). Young carers also have to give medications and injections, change wound dressings, and providing catheter care for the caregiving recipient (Lackey & Gates, 2001; Keigher, et al., 2005; Siskowski, Diaz, Connors & Mize, 2007; et al.). Being present and providing company for the caregivee was a top task for children and adolescents providing care for parents with Huntington’s Disease (Kavanaugh, 2014). The responsibilities of young carers increase for those who have to monitor and assess their caregiving recipient to prevent harm (Metzing-Blau & Schnepp, 2008; Svanberg, Stott, & Spector, 2010; Moore, McArthur, & Noble-Carr, 2011; et al.). This can include observing suicidal relatives and emotional/behavioral monitoring. Svanberg, Stott, & Spector (2010) called this type of caregiving ‘checking in’ while Metzing-Blau & Schnepp (2008) considered their young carer participants to always be on ‘standby.’

Less frequently mentioned tasks included caring for other family members (Keigher, et al., 2005; Moore, McArthur, & Noble-Carr, 2011) such as younger siblings (Moore, McArthur, & Noble-Carr, 2011); protecting the care recipient by being a peacemaker or safeguarding them (Keigher, et al., 2005; Siskowski, Diaz, Connors & Mize, 2007); employment to provide for the entire family (Svodal, Ogutu, Aoro, & Campbell, 2009; Moore, McArthur, & Noble-Carr, 2011); and taking responsibility for the family in the neighborhood and larger community (Keigher, et al., 2005). This may even include speaking for an ill parent in medical situations (Kavanaugh, 2014). As the
young caregiver ages, their caregiving expectations and duties increase (The Princess Royal Trust, 2009). Similarly, as the recipients’ chronic illness progresses, so do the tasks of young caregivers (Metzing-Blau & Schnepp, 2008).

Negative & Positive Outcomes

The effects of caregiving on young caregivers, as obtained from the review of the research literature, were analyzed and placed into two categories. The effects were readily identified as having either a negative or a positive impact on the caregiver. These are presented in following sections.

Negative Outcomes

Researchers have found more negative effects than positive effects of caregiving on young caregivers. The negative effects place young caregivers in the category of an ‘at risk’ population. Young caregivers with a working parent, and those with a single parent, are at greater risk for negative outcomes (Forest Keenan, et al., 2007). The negative effects of each study were analyzed and placed into five categories: physiological, psychological, sociocultural, developmental and spiritual (see Table 2).

Table 2: Negative Effects of Caregiving

<table>
<thead>
<tr>
<th>Category</th>
<th>Negative Effect</th>
<th>Article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological</td>
<td>Physical injury</td>
<td>Aldridge &amp; Becker (1993); Forest Keenan, et al. (2007)</td>
</tr>
<tr>
<td></td>
<td>Impact general well-being</td>
<td>Packenham &amp; Bursnall (2006); Skovdal, et al. (2009); Moore, McArthur, &amp; Noble-Carr (2011)</td>
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<tr>
<td></td>
<td>Physical violence</td>
<td>Aldridge &amp; Becker (1993)</td>
</tr>
<tr>
<td></td>
<td>Inability to concentrate</td>
<td>Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010); Cluver, et al. (2012); Kavanaugh (2014)</td>
</tr>
<tr>
<td></td>
<td>Tired/fatigue</td>
<td>Banks, et al. (2002); Svanberg, Stott, &amp; Spector (2010); Moore, McArthur, &amp; Noble-Carr (2011)</td>
</tr>
<tr>
<td>Psychological</td>
<td>Stress</td>
<td>Aldridge &amp; Becker (1993); Lackey &amp; Gates (2001); Thomas, et al. (2003); Packenham, et al. (2007); Svanberg, Stott, &amp; Spector (2010); Heyman &amp; Heyman (2013); Kavanaugh (2014)</td>
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<tr>
<td></td>
<td>Sleeping problems</td>
<td>Cree (2003)</td>
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<td></td>
<td>Eating problems</td>
<td>Cree (2003)</td>
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<tr>
<td></td>
<td>Self-harm</td>
<td>Cree (2003); Ali, et al. (2012)</td>
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<tr>
<td></td>
<td>Substance abuse</td>
<td>Cree (2003)</td>
</tr>
<tr>
<td></td>
<td>Sad, grief</td>
<td>Banks, et al. (2002); Thomas, et al. (2003); Early, Cushway, &amp; Cassidy (2007); Svanberg, Stott, &amp; Spector (2010); Kavanaugh (2014)</td>
</tr>
<tr>
<td></td>
<td>Conflict within</td>
<td>O'Dell (2010); Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010); Cluver, et al. (2012)</td>
</tr>
<tr>
<td></td>
<td>Conflict with parent</td>
<td>Kavanaugh (2014)</td>
</tr>
<tr>
<td></td>
<td>Feeling of being punished</td>
<td>Aldridge &amp; Becker (1993); O'Dell (2010)</td>
</tr>
<tr>
<td></td>
<td>Feeling uncomfortable or unsafe</td>
<td>Moore, McArthur, &amp; Marrow (2009); Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010)</td>
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<tr>
<td></td>
<td>Unpleasant</td>
<td>Lackey &amp; Gates (2001)</td>
</tr>
<tr>
<td></td>
<td>Helpless feeling</td>
<td>Lackey &amp; Gates (2001); Sahoo &amp; Suar (2010); Kavanaugh (2014)</td>
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<td></td>
<td>Tension</td>
<td>Lackey &amp; Gates (2001); Barry (2011)</td>
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<tr>
<td></td>
<td>Overwhelmed</td>
<td>Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010)</td>
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<td></td>
<td>Anger</td>
<td>Lackey &amp; Gates (2001); Early, Cushway, &amp; Cassidy (2007); Moore, McArthur, &amp; Marrow (2009); Nichols, et al. (2013)</td>
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<tr>
<td></td>
<td>Frustration</td>
<td>Nichols, et al. (2013)</td>
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<tr>
<td></td>
<td>Shame</td>
<td>Metzing-Blau &amp; Schneppe (2008); Richardson, Jinks, &amp; Roberts (2009)</td>
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<td></td>
<td>Embarrassment</td>
<td>Hamilton &amp; Adamson (2013)</td>
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<tr>
<td></td>
<td>Fear</td>
<td>Thomas, et al. (2003); Forest Keenan, et al. (2007); Grant, Repper, &amp; Nolan (2008); Hamilton &amp; Adamson (2013); Kavanaugh (2014)</td>
</tr>
<tr>
<td></td>
<td>Powerless</td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
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<tr>
<td></td>
<td>Mental health</td>
<td>Shifren &amp; Kachorek (2003); Packenham &amp; Bursnall (2006)</td>
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<tr>
<td></td>
<td>Uncertainty</td>
<td>Aldridge &amp; Becker (1993)</td>
</tr>
<tr>
<td></td>
<td>Confusion about illness</td>
<td>Early, Cushway, &amp; Cassidy (2007); Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Theme</td>
<td>References</td>
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<tr>
<td>Low self-esteem</td>
<td>Moore, McArthur, &amp; Noble-Carr (2011)</td>
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<tr>
<td>Depressed</td>
<td>Shifren &amp; Kachorek (2003); Sahoo &amp; Suar (2010); Kavanaugh (2014)</td>
<td></td>
</tr>
<tr>
<td>Negative viewpoint</td>
<td>O'Dell (2010); Sahoo &amp; Suar (2010); Moore, McArthur, &amp; Noble-Carr (2011)</td>
<td></td>
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<tr>
<td>Sociocultural</td>
<td>Isolation</td>
<td></td>
</tr>
<tr>
<td>Exclusion</td>
<td>Eley (2004); Grant, Repper, &amp; Nolan (2008); Metzing-Blau &amp; Schnep (2008); O'Dell (2010)</td>
<td></td>
</tr>
<tr>
<td>Bullying/harassment</td>
<td>Cree (2003); Butler &amp; Astbury (2005); Early, Cushway, &amp; Cassidy (2007); Moore &amp; McArthur (2007); Warren (2007); Grant, Repper, &amp; Nolan (2008); Moore, McArthur, &amp; Marrow (2009); Richardson, Jinks, &amp; Roberts (2009); Heyman &amp; Heyman (2013)</td>
<td></td>
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<tr>
<td>Making sacrifices</td>
<td>Svanberg Stott &amp; Spector (2010)</td>
<td></td>
</tr>
<tr>
<td>Forced choice</td>
<td>Cluver, et al. (2012)</td>
<td></td>
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<tr>
<td>Difficulty with friendships</td>
<td>Aldridge &amp; Becker (1993); Cree (2003); Thomas, et al. (2003); Keigher, et al. (2005); Early, Cushway, &amp; Cassidy (2007); Metzing-Blau &amp; Schnep (2008); Moore, McArthur, &amp; Marrow (2009); Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>Tension in relationships</td>
<td>Early, Cushway, &amp; Cassidy (2007); Svanberg, Stott, &amp; Spector (2010); Moore, McArthur, &amp; Noble-Carr (2011)</td>
<td></td>
</tr>
<tr>
<td>Loss of old relationship with caregiver</td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
<td></td>
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<tr>
<td>Loss of parental figure</td>
<td>Kavanaugh (2014)</td>
<td></td>
</tr>
<tr>
<td>Problems/difficulties with school</td>
<td>Aldridge &amp; Becker (1993); Cree (2003); Thomas, et al. (2003); Butler &amp; Astbury (2005); Packenham, et al. (2006); Metzing-Blau &amp; Schnepp (2008); Moore, McArthur, &amp; Marrow (2009); Skovdal, et al. (2009); Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010); Moore, McArthur, &amp; Noble-Carr (2011); Hamilton &amp; Adamson (2013); Kavanaugh (2014)</td>
<td></td>
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<tr>
<td>Challenges getting to school</td>
<td>Moore, McArthur, &amp; Marrow (2009)</td>
<td></td>
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<tr>
<td>Late to school</td>
<td>Aldridge &amp; Becker (1993); Banks, et al. (2002); Warren (2007)</td>
<td></td>
</tr>
<tr>
<td>See school as respite</td>
<td>Gates &amp; Lackey (1998); Moore, McArthur, &amp; Marrow (2009); Cluver, et al. (2012)</td>
<td></td>
</tr>
<tr>
<td>Being hungry at school</td>
<td>Cluver, et al. (2012)</td>
<td></td>
</tr>
<tr>
<td>Unable to do homework</td>
<td>Gates &amp; Lackey (1998); Lackey &amp; Gates (2001); Banks, et al. (2002)</td>
<td></td>
</tr>
<tr>
<td>Caregiver stress causes teachers to perceive caregiver has a lack of interest in school</td>
<td>Butler &amp; Astbury (2005)</td>
<td></td>
</tr>
<tr>
<td>Difficulty leaving home/ pressure to stay at home</td>
<td>The Princess Royal Trust (2009); Kavanaugh (2014)</td>
<td></td>
</tr>
<tr>
<td>Perceive future restrictions</td>
<td>Early, Cushway, &amp; Cassidy (2007); Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>Behavioral problems</td>
<td>Keigher, et al. (2005)</td>
<td></td>
</tr>
<tr>
<td>Denied access to resources &amp; paid work</td>
<td>Aldridge &amp; Becker (1993)</td>
<td></td>
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<tr>
<td>Difficulty with Trust</td>
<td>Grant, Repper, &amp; Nolan (2008); Barry (2011)</td>
<td></td>
</tr>
<tr>
<td>Poverty</td>
<td>Aldridge &amp; Becker (1993); Moore, McArthur, &amp; Marrow (2009); Skovdal, et al. (2009); Moore, McArthur, &amp; Noble-Carr (2011)</td>
<td></td>
</tr>
<tr>
<td>Developmental Impaired development</td>
<td>Skovdal, et al. (2009); Moore, McArthur, &amp; Noble-Carr (2011)</td>
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<tr>
<td>Increased responsibility</td>
<td>Lackey &amp; Gates (2001); Thomas, et al. (2003); Packenham &amp; Bursnall (2006); Packenham, et al. (2006)</td>
<td></td>
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<tr>
<td>Difficulty turning off responsibilities.</td>
<td>Early, Cushway, &amp; Cassidy (2007); Kavanaugh (2014)</td>
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<tr>
<td>Lack of time for play</td>
<td>Gates &amp; Lackey (1998); Butler &amp; Astbury (2005)</td>
<td></td>
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<tr>
<td>Less time for friends</td>
<td>Svanberg, Stott, &amp; Spector (2010); Hamilton &amp; Adamson (2013)</td>
<td></td>
</tr>
<tr>
<td>Decrease in warmth, empathy, &amp; caring from parents</td>
<td>Shifren &amp; Kachorek (2003)</td>
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</tr>
<tr>
<td>Girls more likely to be or become caregivers</td>
<td>Eley (2004)</td>
<td></td>
</tr>
<tr>
<td>Role change</td>
<td>Aldridge &amp; Becker (1993); Lackey &amp; Gates (2001); Thomas, et al. (2003); Packenham &amp; Bursnall (2006); Packenham, et al. (2006); O'Dell (2010); Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010); Barry (2011)</td>
<td></td>
</tr>
<tr>
<td>Grow up too soon, maturity level</td>
<td>O'Dell, (2010); Svanberg, Stott, &amp; Spector (2010); Barry (2011); Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>May restrict future opportunities</td>
<td>Warren (2007); Barry (2011); Moore, McArthur, &amp; Noble-Carr (2011); Hamilton &amp; Adamson (2013)</td>
<td></td>
</tr>
<tr>
<td>Long-term or disproportionate caring can have adverse effects on young caregivers development or childhood experiences</td>
<td>Aldridge (2006)</td>
<td></td>
</tr>
<tr>
<td>Participation in young caregiving might influence career choice later in life</td>
<td>Lackey &amp; Gates (2001); Early, Cushway, &amp; Cassidy (2007)</td>
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<tr>
<td>Spiritual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of praise</td>
<td>Butler &amp; Astbury (2005)</td>
<td></td>
</tr>
<tr>
<td>Lack of respect</td>
<td>Butler &amp; Astbury (2005)</td>
<td></td>
</tr>
<tr>
<td>Never-ending battle</td>
<td>Skovdal, et al. (2009)</td>
<td></td>
</tr>
<tr>
<td>Bored</td>
<td>Banks, et al. (2002)</td>
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</tbody>
</table>
Young caregivers may provide care for many hours in a day, and can become overly tired or fatigued (Banks et al., 2002), as well as overly stressed (Aldridge & Becker, 1993; Lackey & Gates, 2001; Thomas et al., 2003). It is at these times that the young caregiver is at greater risk for physical injury when carrying out tasks such as lifting or transferring the care recipient (Aldridge & Becker, 1993; Forest Keenan, et al., 2007). Pakensham & Burnshall (2006), Svodal, Ogutu, Aoro, & Campbell (2009), Moore, McArthur, & Noble-Carr (2011), and Ali, et al. (2012) did not go into specifics about young caregivers’ health, but simply made general statements that young caregivers health or well-being is negatively affected. There is also a risk for physical violence, physical self-harm, substance abuse, sleeping problems, eating problems, inability to concentrate, tiredness/fatigue, and stress (see Table 2).

Young caregivers in three studies had a negative viewpoint of caregiving with few to none positive aspects (O’Dell, Crafter, Abreu, & Cline, 2010; Sahoo & Suar, 2010; Moore, McArthur, & Noble-Carr, 2011). According to Moore, McArthur & Noble-Carr (2011) young carers did not feel their caregiving role made them more strong or resilient. Caregiving can negatively affect young people’s psychological health causing depression, anxiety, worry, sadness, burden, anger, guilt, and fear (see Table 2).

Some young carers actually felt uncomfortable or unsafe around the family member they were caring for (see Table 2). Others struggled with an internal conflict such as the duty to themselves and the duty to the careee or the dilemma of high value
of an education versus moral obligation of caring for family (see Table 2). Sahoo & Suar (2010) found this moral conflict was more prevalent in young carers than their non-carer peers. Young carers also felt that they were being punished or felt they were a “tragic victim of circumstance” (O’Dell, Crafter, Abreu, & Cline, 2010; Sahoo & Suar, 2010, p.650). Other less frequently mentioned negative effects include unpleasant feeling, helplessness, tension, overwhelmed, frustration, shame, embarrassment, powerless, less positive mental health, uncertainty, low self-esteem, and confusion (see Table 2).

The sociocultural category contained a large amount of negative caregiving effects. Numerous studies found that caregiving has the potential to greatly impact a young person’s school experience. The problems in school include difficulty participating, lack of concentration, and lower educational attainment (see Table 2). Because of their caregiving activities, many young caregivers frequently miss school, or were tardy. This could be because young caregivers find it difficult leaving home and finding suitable sitters while they are away. For many, it was a challenge to get to school. Despite having difficulty completing homework, some young carers found homework and school to be a respite from their caregiving duties. Compounding their difficulties and problems with school is the lack of recognition by schools and teachers. Many studies found young caregivers’ work, needs, knowledge, and opinions are not acknowledged or validated by teachers and the school system (The Princess Royal Trust, 2009; Svanberg, Stott, & Spector, 2010; Hamilton & Adamson, 2013; et al.). This lack of recognition also extends to the health care personnel particularly nurses and doctors.
According to Earley, Cushway, and Cassidy (2007) young caregivers believed others were trivializing their role and capabilities as caregivers.

Many young caregivers have difficulty starting and keeping friendships because of long hours dedicated to caregiving, from stigmatization by peers, and because they have to make sacrifice and forgo their own socialization and enjoyment (see Table 2). They are frequently excluded from activities and peers which in turn leads to a feeling of isolation. Many are even bullied by their peers. Troubled relationships were also found to be a negative effect of caregiving. Some young carers feel a sense of loss of their ‘old’ relationship with the caregiving recipient while others feel increased tension, arguing, and conflict had ensued. Some young caregivers can develop behavioral problems and become aggressive.

Five studies revealed economic issues with their young caregivers (see Table 2). Young caregivers can live in poverty or suffer from financial hardship. Compounding the poverty, young carers are frequently denied access to resources and may have difficulty obtaining and keeping jobs.

According to Aldridge & Becker (1999) there is a risk for caregiving to negatively influence or damage young persons “development and transition to adulthood” (p. 314). Even long-term or disproportionate caring can have adverse effects on young caregivers’ development or childhood experiences. The research purports young caregivers lose their role as ‘children’ or ‘adolescents’ causing them to grow up too soon. This may be the result of their increased responsibility which decreases their time for
play and activities. The term ‘parentification’ has even been used to reflect this issue (Earley, Cushway, & Cassidy, 2007). In fact, parents were more likely to decrease their warmth, empathy, and caring for young caregivers as compared to non-caregiver parents (Shifren & Kachorek, 2003). Parental focus may have shifted during these times of crisis (i.e. family member disability or illness). As a result, young caregivers may not be receiving the positive attention they so desire.

Caregiving may even restrict future opportunities. In Warren (2007), young carers were ambivalent about moving out of their parents’ house and identified caregiving as a barrier to future ambition. Similarly, in Barry’s (2011) study, young carers also believed caregiving was a barrier to their future. According to Moore, McArthur, & Noble-Carr (2011), these barriers may limit hope for the future. With limited options and hope, young carers are making conservative choices about their future. Hamilton & Adamson (2013) found young caregiver choices about their future education, course load, and university locations are affected by their caregiving obligations.

Little research or literature focused on the spiritual aspect of caregiving. Butler & Astbury (2005) mentioned young caregivers lack praise and respect and Banks et al. (2002) indicated some young caregivers were bored or fed up with caregiving. To some young caregivers, caregiving is a never-ending battle that they cannot win (Skovdal, Ogutu, Aoro & Campbell, 2009). Without recognition from professionals, policies, programs, and young carer services, these negative spiritual effects will not change.
Positive Outcomes

The positive effects of caregiving (see Table 3) were studied far less in the research. Only one study (Beach, 1997) focused entirely on the positive effects of young caregiving. According to past research, caregiving can teach young people the values of caring, being helpful, and responsible, empathy, sympathy and how to become nurturing and enduring. They can also develop a sense of pride and emerging morality. Young caregivers have been found to enjoy the feeling of being appreciated, important, and needed, feel it is rewarding, and makes them an overall a better person.

Table 3: Positive Effects of Caregiving

<table>
<thead>
<tr>
<th>Category</th>
<th>Positive Affect</th>
<th>Article</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physiological</td>
<td>Not at inevitable risk for harm</td>
<td>Aldridge (2006)</td>
</tr>
<tr>
<td></td>
<td>Able to do homework</td>
<td>Banks, et al. (2002); Eley (2004)</td>
</tr>
<tr>
<td></td>
<td>Not at inevitable risk for developmental delay</td>
<td>Aldridge (2006)</td>
</tr>
<tr>
<td></td>
<td>Feeling of importance, appreciated, needed</td>
<td>Lackey &amp; Gates (2001)</td>
</tr>
<tr>
<td>Psychological</td>
<td>Gain acknowledgement</td>
<td>Skovdal, et al. (2009)</td>
</tr>
<tr>
<td></td>
<td>Gain love</td>
<td>Skovdal, et al. (2009)</td>
</tr>
<tr>
<td></td>
<td>Could cope on their own</td>
<td>Moore &amp; McArthur (2007)</td>
</tr>
<tr>
<td></td>
<td>Cope better when they had a choice in caregiving</td>
<td>Packenham, et al. (2007)</td>
</tr>
<tr>
<td></td>
<td>Positive view of caregiving</td>
<td>Packenham &amp; Bursnall (2006); Skovdal, et al. (2009); The Princess Royal Trust (2009); Heyman &amp; Heyman (2013)</td>
</tr>
<tr>
<td></td>
<td>Greater empathy</td>
<td>Beach (1997); Heyman &amp; Heyman (2013)</td>
</tr>
<tr>
<td></td>
<td>Greater sympathy</td>
<td>Sahoo &amp; Suar (2010)</td>
</tr>
<tr>
<td></td>
<td>More nurturing &amp; enduring</td>
<td>Sahoo &amp; Suar (2010)</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
<td>Sources</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Learning to adapt</td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
<td></td>
</tr>
<tr>
<td>Protective of family</td>
<td>Barry (2011)</td>
<td></td>
</tr>
<tr>
<td>Heightened political</td>
<td>Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>awareness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationships</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sociocultural</td>
<td>Increase family interdependence</td>
<td>Lackey &amp; Gates (2001); Skovdal, et al. (2009)</td>
</tr>
<tr>
<td></td>
<td>Improved peer selection &amp; maintenance</td>
<td>Beach (1997); Svanberg, Stott, &amp; Spector (2010)</td>
</tr>
<tr>
<td></td>
<td>Sense of togetherness with family/groups/community</td>
<td>Skovdal, et al. (2009); Svanberg, Stott, &amp; Spector (2010); Nichols, et al. (2013)</td>
</tr>
<tr>
<td></td>
<td>Parents attempted to be supportive</td>
<td>Richardson, Jinks, &amp; Roberts (2009)</td>
</tr>
<tr>
<td></td>
<td>Want to continue caregiving role in future/career</td>
<td>Gates &amp; Lackey (1998); Earley, Cushway, &amp; Cassidy (2007); Svanberg, Stott, &amp; Spector (2010); Heyman &amp; Heyman (2013); Kavanaugh (2014)</td>
</tr>
<tr>
<td></td>
<td>Hope for the future</td>
<td>Hamilton &amp; Adamson (2013)</td>
</tr>
<tr>
<td></td>
<td>School gave them sense of belonging</td>
<td>Moore, McArthur, &amp; Marrow (2009); Cluver, et al. (2012)</td>
</tr>
<tr>
<td></td>
<td>School recognized them and gave them support</td>
<td>Joseph, et al. (2009); Richardson, Jinks, &amp; Roberts (2009); Skovdal, et al. (2009)</td>
</tr>
<tr>
<td></td>
<td>No effect on school</td>
<td>Banks, et al. (2002); Eley (2004)</td>
</tr>
<tr>
<td>Developmental</td>
<td>Values their role as caregiver</td>
<td>Early, Cushway, &amp; Cassidy (2006); Earley, Cushway, &amp; Cassidy (2007); Skovdal, et al. (2009); O'Dell (2010)</td>
</tr>
<tr>
<td></td>
<td>Parent recipient maintains their role</td>
<td>Aldridge (2006)</td>
</tr>
<tr>
<td></td>
<td>More mature</td>
<td>Heyman &amp; Heyman (2013)</td>
</tr>
<tr>
<td></td>
<td>Learn valuable skills</td>
<td>Skovdal, et al. (2009); O'Dell (2010)</td>
</tr>
<tr>
<td>Spiritual</td>
<td>Makes them a better person</td>
<td>Skovdal, et al. (2009)</td>
</tr>
</tbody>
</table>

Young caregiving can positively impact familial relationships and relationships with the surrounding community (see Table 3). The family unit, survival, and interdependence were shown to improve with young caregiving. Familial bonds and
relationships also may improve. For example, young caregivers can develop more friend-like relationships with the other caregiving parent due to shared experiences. Regarding improved relationships with the community, young caregivers felt they received love and respect from the community.

A few research studies found positive aspects of caregiving on young caregivers schooling. In order for the young caregivers to have this positive outlook on school, the schools had to first recognize and support them (Moore, McArthur, & Morrow, 2009; Skovdal, Ogutu, Aoro & Campbell, 2009; The Princess Royal Trust, 2009). School was sometimes seen as respite and gave the young caregivers a sense of belonging. For some, homework was not an issue (see Table 3).

Not only do young caregivers gain valuable experience and skills, but it also prepares them for future leadership. Earley, Cushway, & Cassidy (2007) revealed their participants desired to set up support groups in the future or go into health professions. Similarly, Svanberg, Stott, & Spector (2010) participants wanted to use their experience to help others. In a retrospective study interviewing adults who were once young carers, Lackey & Gates (2001), found many of their participants had gone into caring careers.

**Needs of the Caregiver**

According to Aldridge (2006) the needs of children are typically “overlooked or discounted” by health care and social service professionals (p.84). This was apparent in the reviewed research as well. Twenty articles mentioned a specific young caregiver need (see Table 4), however, no specific needs analysis instruments with reliability
coefficients were used for the caregiver population. Gates & Lackey (1998) used an unstructured needs survey on 11 young participants. Keigher, Zabler, Robinson, Fernandez, & Stevens (2005) attempted to identify the needs of young caregivers, however, only through the perceptions of adult mothers with HIV/AIDS. The identification of young caregiver needs from this study is limited coming from a secondary source reflecting the mothers’ point of view. Moore and McArthur (2007) interview with 50 children in Australia (which already has policy and programs in place for young caregivers), found it was important to recognize the needs of the entire family as well as the young caregiver. They also found these services were not always affordable, flexible, and not available to meet their specific needs. The remaining articles suggest special caregiver needs that resulted from their research; yet, this was not their main purpose.

Table 4: Needs of Young Caregivers

<table>
<thead>
<tr>
<th>Need Categories</th>
<th>Specific Needs</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self/personal Needs</td>
<td>Information/knowledge</td>
<td>Aldridge &amp; Becker (1993); Eley (2004); Metzing-Blau &amp; Schnepp (2008); Sahoo &amp; Suar (2010); Elf, Skarsater, &amp; Krevers (2011)</td>
</tr>
<tr>
<td></td>
<td>Education</td>
<td>Metzing-Blau &amp; Schnepp (2008)</td>
</tr>
<tr>
<td></td>
<td>Desire for caregivee to maintain their adult role.</td>
<td>Aldridge &amp; Becker (1993)</td>
</tr>
<tr>
<td></td>
<td>Assistance with intimate care tasks</td>
<td>Moore &amp; McArthur (2007)</td>
</tr>
<tr>
<td></td>
<td>Socialization with peers</td>
<td>Bolas, Wersch, &amp; Flynn (2007); Svanberg, Stott, &amp; Spector (2010); Elf, Skarsater, &amp; Krevers (2011);</td>
</tr>
<tr>
<td>Topic</td>
<td>References</td>
<td></td>
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<tr>
<td>--------------------------------------</td>
<td>---------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Trusting adult to talk to</td>
<td>Moore, McArthur, &amp; Noble-Carr (2011)</td>
<td></td>
</tr>
<tr>
<td>Advice</td>
<td>Aldridge &amp; Becker (1993); The Princess Royal Trust (2009); Elf, Skarsater, &amp; Krevers (2011)</td>
<td></td>
</tr>
<tr>
<td>Respite/their own time</td>
<td>Aldridge &amp; Becker (1993); Packenham, et al. (2006); Bolas, Wersch, &amp; Flynn (2007); Moore &amp; McArthur (2007); Sahoo &amp; Suar (2010); Svanberg, Stott, &amp; Spector (2010); Barry (2011); Elf, Skarsater, &amp; Krevers (2011); Moore, McArthur, &amp; Noble-Carr (2011)</td>
<td></td>
</tr>
<tr>
<td>Room/space</td>
<td>Aldridge &amp; Becker (1993)</td>
<td></td>
</tr>
<tr>
<td>Cultivate patience</td>
<td>Thomas, et al. (2003)</td>
<td></td>
</tr>
<tr>
<td>Community services/support services</td>
<td>SmithBattle (2000); Packenham, et al. (2006); Bolas, Wersch, &amp; Flynn (2007); Metzing-Blau &amp; Schnep (2008); Richardson, Jinks, &amp; Roberts (2009); The Princess Royal Trust (2009); Svanberg, Stott, &amp; Spector (2010); Barry (2011); Moore, McArthur, &amp; Noble-Carr (2011); Nichols, et al. (2013); Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>Spend time with family &amp; others</td>
<td>Aldridge &amp; Becker (1993)</td>
<td></td>
</tr>
<tr>
<td>More involvement in care process</td>
<td>Elf, Skarsater, &amp; Krevers (2011)</td>
<td></td>
</tr>
<tr>
<td>Sensitivity from Education system</td>
<td>Heyman &amp; Heyman (2013)</td>
<td></td>
</tr>
<tr>
<td>Cope</td>
<td>Packenham, et al. (2006); Bolas, Wersch, &amp; Flynn (2007); Svanberg, Stott, &amp; Spector (2010)</td>
<td></td>
</tr>
<tr>
<td>Make own decisions about caring</td>
<td>Eley (2004)</td>
<td></td>
</tr>
<tr>
<td>Buddying/befriending</td>
<td>Eley (2004); Richardson, Jinks, &amp; Roberts (2009)</td>
<td></td>
</tr>
<tr>
<td>Recognition</td>
<td>Eley (2004); Aldridge (2006); Bolas, Wersch, &amp; Flynn (2007)</td>
<td></td>
</tr>
<tr>
<td>Knowledge on care</td>
<td>Aldridge &amp; Becker (1993); Gates &amp; Lackey (1998)</td>
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</tbody>
</table>
Two themes were found from the young caregiver needs mentioned in the research: self/personal needs and needs to care for the recipient/family (see Table 4). The majority of needs fit into the self/personal needs category. Some of the most frequently mentioned needs of young caregivers are support, respite, community services, information/knowledge, and socialization with peers. The less frequently stated needs from the research included: education; desire for caregivee to maintain their adult role; assistance with intimate care, monitoring, supervising, and keeping the caregivee safe; time for leisure activities and hobbies; a trusting adult to talk to; advice; more room/space; cultivating patience; counseling; spending time with family and others; more involvement in care process; referral; help coping; opportunities and support to develop
as individuals/children; making own decisions about caring; buddying and befriending other young carers; and recognition by professionals and schools.

The needs of the recipient and family were also looked at. Aldridge and Becker (1993) and Gates & Lackey (2001) found the entire family needed education on providing care such as information on medical tasks. They also desired that health care professionals support the entire family and close friends as a whole (Elf, Skarsater, & Krevers, 2011). Home care nurses who are trained in educating their patients are well suited for this task. The family and caregivee also need updated and honest information about the health of the caregivee (see Table 4). A few less common needs of the family include emotional support, family centered activities and respite for the entire family, and financial assistance (see Table 4).

Ways of Coping

Several studies discussed their participant’s ways of coping (see Table 5). For the most part, social supports such as school, church, family, and friends helped support them in their role as young caregivers. Healthcare professionals, activities in the community, and young carer projects were minimally seen as support systems by young caregivers. Ability to cope was dependent on having a choice in caregiving, coming to acceptance, detaching, avoidance, and confiding in someone else. Nichols, et al., (2013) found several coping mechanisms: spending time with recipient and reminiscing; exercising; watching tv/movies; conversations; family vacations; and participating in activities outside the home. Interestingly, in the study by Pakensham & Bursnall (2006), young
caregivers reported less reliance on coping strategies than their non-caregiving counterparts.

Table 5: Ways of Coping Among Young Caregivers

<table>
<thead>
<tr>
<th>Ways of Coping</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>School</td>
<td>Gates &amp; Lackey (1998); Lackey &amp; Gates (2001)</td>
</tr>
<tr>
<td>Church</td>
<td>Gates &amp; Lackey (1998); Skovdal, et al. (2009)</td>
</tr>
<tr>
<td>Friends</td>
<td>Gates &amp; Lackey (1998); Lackey &amp; Gates (2001)</td>
</tr>
<tr>
<td>Activity in the Community</td>
<td>Skovdal, et al. (2009)</td>
</tr>
<tr>
<td>Young carer project</td>
<td>Banks, et al. (2002)</td>
</tr>
<tr>
<td>Social support (in general)</td>
<td>Packenham, et al. (2007); Grant, Repper, &amp; Nolan (2008)</td>
</tr>
<tr>
<td>Knowledge</td>
<td>Forest Keenan, et al. (2007)</td>
</tr>
<tr>
<td>A choice in caregiving</td>
<td>Packenham, et al. (2007)</td>
</tr>
<tr>
<td>Detaching</td>
<td>Svanberg, Stott, &amp; Spector (2010)</td>
</tr>
<tr>
<td>Spending time with recipient and reminisce</td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Exercise</td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Watching TV/Movies</td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Conversations</td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Family Vacations</td>
<td>Nichols, et al. (2013)</td>
</tr>
<tr>
<td>Participating in activities outside the home</td>
<td>Nichols, et al. (2013)</td>
</tr>
</tbody>
</table>

Interpretation of the Results Presented in the Literature

This discussion and interpretation of the findings is based on the analysis of the research conducted thus far. The interpretation of the results is categorized into the following topics: Multiple sclerosis and young caregivers; discipline and setting;
methodologies utilized; limitations of the studies; child versus adolescent caregiver; programs, policies, and services; and researcher recommendations.

Although there has been some discourse as to how young caregivers should be defined, the majority of research indicates this population consists of minors <18 years of age who are providing care for ill or disabled family members in the home. Reasons for their invisibility are influenced by young caregiver fears, family beliefs, and unaware professionals.

Young caregiver tasks are numerous and can range from less difficult instrumental activities of daily living, such as fetching items or cooking, to the more difficult tasks of personal/intimate care. The research and literature have mainly focused on the negative aspects of young caregiving which suggests that this is an at risk population. Research looking at interventions to decrease this risk is warranted. Also, more research is needed focusing on the positive aspects of young caregiving. The needs of young caregivers have been studied; however, no reliable instruments were found.

**Multiple Sclerosis & Young Caregivers**

Only one young caregiver study out of the forty-eight focused on the caregivee disease of Multiple Sclerosis (see Packenham & Bursnall, 2006). This study used quantitative methodology with questionnaire survey data collection methods. A limited number of studies briefly mention including Multiple Sclerosis among many other chronic illnesses. Multiple Sclerosis, however, was not the main focus of these studies. We cannot assume that the symptoms and needs of one disease is comparable to that of
another. With only one study that focused on the caregiving recipient disease of MS, a large gap remains in the research.

**Discipline & Setting**

The disciplines of social science & psychology have conducted the majority of research on young caregivers, whereas only 9 studies have been conducted by nurses (see Appendix A). Twenty-one of the studies reviewed have been conducted in the United Kingdom, therefore may not represent young caregivers elsewhere because of the UK’s advancements in policy and program development. Since research has greatly focused on negative sociocultural outcomes of young caregiving, studies must be conducted in the United States to distinguish if societal, cultural, and environmental differences effect the findings. Excluding the two studies conducted by SmithBattle (2000; 2006), only 7 studies have been conducted in the United States: 3 studies by the discipline of Nursing (Gates & Lackey, 1998; Lackey & Gates, 2001; Siskowski, Diaz, Connors & Mize, 2007), 1 by Psychology (Shifren & Kachorek, 2003), 1 by Public Health (Beach, 1997), and 2 by the Social Sciences (Keigher, 2005; Kavanaugh, 2014).

**Methodology**

There have only been 10 quantitative studies on young caregivers. For the most part, these have been quasi-experimental studies (Early, Cushway, & Cassidy, 2006; Packenham, Chiu, Bursnall, Cannon, & Okochi, 2006). Only three studies were conducted to test reliability of instruments for the young caregiver population. Ireland & Packenham (2010) developed and tested the Youth Activities of Caregiving Scale
(YACS). This instrument with an internal reliability factor of .74-.92 was developed in order to analyze and document tasks of young caregivers. Another study tested two self-report instruments in multiple phases: MACA-YC18 which analyzed caring activities and PANOC-YC20 which analyzed caring outcomes (Joseph, Becker, S., Becker, F., and Regel, 2009). During the initial phase of the study, both instruments were found to be cumbersome and too large for young caregivers. After modifications were made, the instruments were re-tested during the second phase and were found to be more age appropriate. A few modifications to the wording/terms were still needed. Both instruments are promising to be useful in young caregiver research. Cox & Pakenham (2014) used invariance testing and confirmatory factor analysis for the Young Carer of Parents Inventory (YCOPI). The YCOPI allows for valid comparisons between youth with an ill parent vs. peers with a healthy parent and can measure the impact of young caregiver services and interventions.

Besides the necessity for more, reliable young caregiver instruments, research using descriptive, correlational, and longitudinal designs is also needed. Intervention outcomes (e.g. young caregiver groups, camps, internet support sites), and the effect of young caregiving over time, remain important areas for inquiry.

Concerning qualitative research, 15 of the studies used phenomenology to gain an understanding of young caregivers through their descriptive experiences (see Appendix A). Research using the phenomenological method has yet to focus on spiritual, environmental, or cultural effects on young caregivers. Six studies used grounded theory
approach (Beach, 1997; Cree, 2003; Forest Keenan, et al., 2007; Grant, Repper, & Nolan, 2008; Metzing-Blau, & Schneppe, 2008; Svanberg, Stott, & Spector, 2010), two used participatory action research (Moore & McArthur, 2007; Moore, McArthur, & Noble-Carr, 2011), one used case study (Butler & Astbury, 2005), and one used narratives (Keigher, 2005). No studies were found using the methodology of ethnography and thus remain an important area for future inquiry.

Limitations

As frequently mentioned by the researchers, limitations of research to date has been their small sample size. This limitation was equated to the ‘invisibility’ of this population. Additionally, five studies did not specify the chronic illness or disability of the caregiving recipient (see Aldridge & Becker; 1993; Banks, Cogan, Riddell, Deeley, Hill, & Tisdall, 2002; Thomas, Stainton, Jackson, Cheung, Doubtfire, & Webb, 2003; Eley, 2004; Butler & Astbury, 2005). Merely indicating the caregiving recipient had an illness or disability, decreases the generalizability of their research. The symptoms and needs of one illness may be vastly different to that of another.

Child vs. Adolescent Caregiver

To date, the majority of the research conducted with young caregivers has grouped children and adolescents together in their sample under the general term ‘young carers’ (see Aldridge & Becker, 1993; Gates & Lackey, 1998; Lackey & Gates, 2001; Banks et al., 2002; Cree, 2003, Shifren & Kachorek, 2003; Thomas et al., 2002; Eley, 2004; Aldridge, 2006; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005;
Siskowski, Diaz, Connors & Mize, 2007) and four studies grouped adolescents and young adults together. Combining these differing age groups suggests that their caregiving experiences, perceptions, needs, and risk factors are the same.

Adolescents tend to leave behind their childlike ways and seek out a new identity, understanding/knowledge, activities, relationships, and friendships with the ultimate aim of gaining maturity which comes with adulthood. This transition period from childhood to adulthood usually carries with it much turmoil and stress which adolescents learn to overcome. However, questions arise when a secondary stressor such as a family crisis occurs alongside this transition period. Is there a greater risk to this population because of the multiple developmental changes taking place? There is a greater risk, “parental illness is a stressful experience for young people, constituting a potential threat to physical and mental health, and normative development” (Pedersen & Revenson, 2005, p.404). Adolescents are very sensitive to the social world around them and are at risk with any type of crisis (Craig & Dunn, 2010). Any negative influence on the normal development of adolescents may potentially hinder their development to adulthood.

Adolescents put away the childish state of mind and begin to plan for adulthood (Craig & Dunn, 2010). The time of adolescence is “characterized by instability, uncertainty, and challenge” (Craig & Dunn, 2010, p.257). Adolescents go through major developmental changes, these include drastic physical body changes, advancement of their cognitive and intellectual capabilities, emotional growth, enhancement of social interactions, and behavioral adjustments (Craig & Dunn, 2010).
The crisis of a family member becoming ill is stressful and has the potential to interfere with the normal cognitive growth and self-image of the adolescent (Craig & Dunn, 2010). The additional stresses as a caregiver can compound the normal stresses of development. A credible voice in adolescent cognitive development was Jean Piaget (1896-1980). Jean Piaget, a Swiss professor of psychology and a developmental theorist, created the theory of cognitive development which includes four stages: sensorimotor, preoperational, concrete operational, and formal operational (Presnell, 1999). The sensorimotor and preoperational stages deal with children six or seven years of age and under (Presnell, 1999).

The concrete operational stage begins at the age of 6 or 7 and ends at approximately age 11 or 12 (Presnell, 1999). During the concrete operational stage, children are able to understand another person’s viewpoint and integrate multiple perspectives together; however, they lack the ability to think abstractly and consider all of the outcomes that a situation can bring forth (Presnell, 1999). For example, a child may view the parental illness as “daddy’s sick again today” and be able to understand what it is like to be sick; however, they would not understand the possible consequences of being sick or what the future may hold for their parent or their family.

Adolescents are grouped into the formal operations stage which begins at the age of 11 or 12 and continues into adulthood (Presnell, 1999). During this stage, adolescents are able to think abstractly, logically, and reason theoretically (Presnell, 1999). Adolescents can look at a situation and imagine all the possibilities before exploring it. In
the case of caregiving for an adult family member with an illness, adolescents are aware and understand the full severity of their family member’s condition and what the future may bring, whereas a child may not fully grasp the severity. This knowledge can exacerbate the stress or turmoil typically brought on by normal adolescent development (Craig & Dunn, 2010).

Emotionally, adolescents are attempting to establish their identity, seek their independence, and attract a partner (Presnell, 1999). Caregiving may slow the identity formation process because they have less time to explore who they are in relation to the world around them. This would result in what the developmental psychologist, Erik Erickson, termed ‘identity confusion’, which could impede the subsequent stages of development (Balk, 1995). Adolescents seek their independence in preparation for their role as an adult. With a time-consuming caregiving role and a dependent ill parent, adolescents may not attain the independence they so desire. Adolescent caregivers may become resentful of the parents, because they have less freedom and time for activities compared to their peers. With less time for socialization, adolescent caregivers may not develop the skill of attracting a partner, affecting their future relationships. It may also hinder development of close relationships with peers.

In summary, we cannot assume a child is at the same developmental stage, or has the same caregiving needs and experiences as an adolescent or a young adult. Because of this, young caregiver research needs to be delineated into ‘child caregivers’ and ‘adolescent caregivers’ in order to analyze the impact of caregiving during each life
stage. Scholars may delineate adolescent years further into *early adolescence* (ages 10-13) and *later adolescence* (ages 14-18) (Craig & Dunn, 2010). Emerging adults are frequently considered ages 18-25 in that they are still ‘preparing’ for adulthood (Craig & Dunn, 2010).

**Programs, Policy, and Services for Young Caregivers**

In the United Kingdom, young caregivers are recognized by the national caregiving legislation and based on the Carer’s Recognition and Services Act 1995, have the right to be evaluated with a needs assessment along with obtaining support from social services (Department of Health, 1995). The Children’s Society is now a major resource for young caregivers due to funding £60,000 (123,810 U.S. dollars) by the United Kingdom Department of Health (Coombes, 2001). The United Kingdom has already established approximately 300 voluntary, regional young caregiver services (Fox, 2006).

In the United Kingdom, an annual festival is held by the Children’s Society in collaboration with the YMCA Fairthorne Manor, to further policy and practice for young caregivers (Underdown, 2002) and provide them with respite, fun activities, and a chance to make friends who are in similar situations (Coombes, 2001). In 2002, twelve hundred young caregivers came together to share their views on caregiving (Underdown, 2002).

Young caregiver assessment tools are currently being developed in Canada and the United Nations. The Young Carers Initiative Niagra, Canada, is in the process of developing a needs assessment tool for young caregivers to implement in their work with
fourteen community agencies (Baago, 2004). In the United Kingdom, Early, Cushway, & Cassidy (2006) developed an effective Young Carers Perceived Stress Scale (YCPSS) to measure stress in young caregivers.

Sadly, in the United States, we lack research to support legislation that recognizes the rights and needs specific to young caregivers. However, in Florida, a registered nurse named Connie Siskowski, has taken it upon herself to develop the American Association of Caregiving Youth to help local young caregivers in need. Siskowski, who was a child caregiver herself, developed this organization to provide services to caregiving youth in need (Brody, 2016). The organization provides respite care, field trips, tutoring, recreational activities, classes, caregiving demonstrations, etc. (Brody, 2016).

**Recommendations for Future Research**

Professionals from education, social, and health services need to work together in assessing and planning care for young caregivers (Underdown, 2002; Fox, 2006). Based on the United Kingdom’s caregiving legislation, social and health professionals must inform young caregivers and their families of their rights (Department of Health, 1995; Underdown, 2002). These professionals should use a sensitive, non-judgmental (Dearden, Becker, & Aldridge, 1995), and non-threatening approach when dealing with this population (Aldridge & Becker, 1993) and should consider the needs of the entire family (Aldridge & Becker, 1999; Packenham, Chiu, Bursnall, Cannon, & Okochi, 2006; Siskowski, Diaz, Connors & Mize, 2007). Needs assessment instruments specific to this population still need to be developed (Siskowski, Diaz, Connors & Mize, 2007), along
with additional qualitative studies to gain more insight into young caregivers and to build policy (Doran, Drever, & Whitehead, 2007).

Reporting the Review

The findings of this review reveal young caregivers are an understudied population at increased risk for negative effects of caregiving at an early age. In the U.S., services for young caregivers are not standardized as they are in other developed nations, and young caregivers continue to go unrecognized. Nursing has an opportunity to become a leader in recognizing, educating, and providing care and services for this population. Nurses with diverse specialties (e.g. emergency room, primary care, home care, schools, camps) are dispersed throughout communities, giving them unique access to this population.

The authors Dearden, Becker, & Aldridge (1995), social scientists, called on nurses to use their skills in identifying and supporting young caregivers. They stated, “Nurses are extremely well placed to identify and support children who care” (Dearden, Becker, & Aldridge, 1995, p. 700). Not only are nurses needed identifying and supporting this population, they are also needed to be leaders in this research endeavor in the U.S. The wide gap in nursing knowledge about young caregiver health needs, must be filled (Lackey & Gates, 2001).

Conclusion

Research on young caregivers has grouped children, adolescent, and young adults into ‘young carers’. Of the forty-eight studies reviewed here, participants varied in age,
assuming their experiences to be the same. Some studies even include young adults into their sample of young caregivers. Based on the varied phases of development discussed earlier, this suggests the caregiving experiences of children, adolescents, and young adults are the same. It is essential for future research on young caregivers to delineate child, adolescent, and young adult carers if we are to provide age and developmentally appropriate resources to support them.

Only one young-caregiver study focused on the caregiving recipient ailment of Multiple Sclerosis, and this study used quantitative methods. Therefore, a gap of knowledge exists in our understanding of young caregiver experiences of caregiving for family members with MS. Thus, young caregivers remain invisible, in need, and potentially at risk. Multiple young caregiver studies made a call out to nurses with their comprehensive skills to help this understudied population. The discipline of nursing has the potential to become a leader in research for this invisible population because of our practice in homes, in the community, and in hospitals.

**Phenomenology as a Research Method**

Phenomenology is considered both a philosophy and a qualitative method of research. Maurice Merleau-Ponty, a leader in the French phenomenological movement, defines research following a phenomenological approach as, “the study of essences…such as the essence of perception or the essence of consciousness” (2012, p.7). According to phenomenologists, the essence of reality (ontology) is the events or objects as a person understands or perceives it to be (Merleau-Ponte, 2012). Therefore, the
phenomenological methodology involves describing the world as perceived by the individual (Merleau-Ponte, 2012). Each participant may hold varied meaning for an event or object based on their experiences. The researcher then may explore all the possible meanings and different perspectives.

The phenomenologist explores human experiences from a holistic perspective (Speziale & Carpenter, 2007), thereby providing an understanding of individuals’ lived experiences. To accomplish this, a researcher’s a priori assumptions or beliefs about the phenomenon are excluded and a pure description of a participant’s subjective experience is obtained (Speziale & Carpenter, 2007). This bracketing, or ‘epoche’, of a researcher’s assumptions or beliefs permits the researcher to remain neutral as she learns from study participants (Marshall & Rossman, 2006).

History of Phenomenology

Historically, the movement of phenomenology comprised three phases: Preparatory, German, and French. The Preparatory Phase was the earliest phase promoted by Franz Brentano (1838-1917) and Carl Stumpf (1848-1936). These researchers looked at the scientific rigor of phenomenological methods (Speziale & Carpenter, 2007) and focused on clarifying the concept of intentionality, which according to Spinziale & Carpenter (2007) means “consciousness is always conscious of something” (p. 78). In other words, one’s perception of objects or events is based on past and present experiences and a person develops meaning based on those perceptions.
During the German Phase of phenomenology, Edmund Husserl (1859-1938), considered the founder of phenomenology, analyzed people’s experiences of reality as they interpret it in their consciousness (Husserl, 2003). His method required that presuppositions not be involved in the research in order to bring forth a pure description of the phenomenon as experienced by individuals (Phenomenology, 2004). Husserl desired to establish rigor in phenomenology in hopes that it would become the basis for all science and philosophy (Speziale & Carpenter, 2007).

Martin Heidegger (1889-1976), a student and successor of Husserl, eventually expanded upon his method of phenomenology, focusing on understanding ‘being’ and creating meaning (Munhall, 2007). Based on Heidegger’s phenomenology, all phenomenological descriptions can be interpreted (Munhall, 2007). His view is associated with Hermeneutic phenomenology (discussed in more depth later in the paper) which requires the researcher interpret the phenomena after it has been described by the participants (Speziale & Carpenter, 2007). Researcher’s interpretations are followed by examples (e.g. quotes from participants) which uphold the validity and trustworthiness of the findings. Readers gain insight from the researcher’s background, experience with the participants, and immersion in the data.

The French Phase of the phenomenology movement involved Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980), and Maurice Merleau-Ponty (1905-1980). This phase delves deeper into how we make meaning from experiences. According to Speziale & Carpenter (2007), two new concepts emerged during this phase; embodiment
and being-in-the-world. Based on these concepts, a person will act based on their perception or awareness of a phenomenon (Speziale & Carpenter, 2007). A person has ‘experiences’ in the body which develop from touching, seeing, tasting, hearing, feeling, and thinking. Each person’s perception of these experiences is subjective.

Types of Phenomenology

There are two basic approaches to phenomenology commonly used by nursing researchers, descriptive phenomenology and interpretive phenomenology. Researchers choose their approach based on their own personal philosophy and the type of research they will conduct. Interpretive phenomenology was chosen to be the best fit for this research project.

Since interpretive phenomenology evolved from descriptive phenomenology, a brief discussion of descriptive phenomenology is needed here. Descriptive phenomenology was first introduced by Edmund Husserl (1859-1938) (Wojnar & Swanson, 2007). In descriptive phenomenology, the researcher must be in direct contact with the subjects. The researcher’s presumptions must be placed aside through bracketing, and it is suggested that a thorough literature review should take place only after data collection and analysis, so as not to influence the research process. Thus the researcher is (1) open and neutral to the participants reality (aka transcendental subjectivity), (2) able to discover truths (eidetic essences), and (3) may interact with the participants unencumbered by presupposition (Wojnar & Swanson, 2007). The ultimate
test for quality with this approach is use of participant checking (Wojnar & Swanson, 2007).

Descriptive phenomenology was critiqued and further developed into interpretive (Hermeneutic) phenomenology by Husserl’s student, Martin Heidegger (Wojnar & Swanson, 2007). For Heidegger, context was of primary concern, while Husserl believed context was a mere secondary importance. Heidegger believed that in order to understand a person, he/she could not be separated from his/her cultural, societal, and historical context, nor could the researcher be separated from his/her own context (Wojnar & Swanson, 2007). The researcher’s preconceptions and background are acknowledged through bracketing; however, as the researcher gains an understanding of the meaning the participants share, the researcher may use their own understanding of the world to interpret the information given. This process is thought to be cyclical (Wojnar & Swanson, 2007). The objective of interpretive analysis is to “identify the participants’ meanings from the blend of the researcher’s understanding of the phenomenon, participant-generated information, and data obtained from other relevant sources” (Wojnar & Swanson, 2007, p 175).
CHAPTER 3

METHOD

The Research Design

Interpretive phenomenology was used in this retrospective study to explore past adolescent caregiving experiences for a family member with MS. An iterative process of data interpretation was utilized.

Approach

Selection and Sample

The study was advertised through flyers (see Appendix B) hung at a MS Center in Central Massachusetts and postcards (see Appendix C) distributed via email to MS support groups throughout New England via the National Multiple Sclerosis Society. A phone number and email address were provided for questions about the study and for participation. Interviews were conducted until data saturation was reached. Data saturation was determined when no new information was being discovered.

Various recommendations have been made regarding the number of participants needed for a phenomenological study. A very small sample increases the risk to anonymity and confidentiality (Speziale & Carpenter, 2007). Seidman (2013) suggests there are two criteria for “enough” participants: sufficiency and saturation. To achieve sufficiency, there must be a diverse range of participants, so that many viewpoints can be expressed and a person reading the study can relate to the findings. Data saturation is obtained when no new data is obtained from participants (Seidman, 2013). The researcher
may recognize data saturation when participants relate the same information over and over, and nothing new is learned from interviews. For this study, it was estimated a sample of 6-10 participants was needed. This number was based on previous studies conducted with caregivers of family members with varying diagnosis.

Purposive sampling was used to select study participants. Purposive sampling requires that the participants’ experiences fit those targeted by the researcher and that participants have the qualities of a good informant (Munhall, 2007). To experientially fit the study, participants had to be English-speaking (aged 18-49) and had to have provided care (primary or secondary) for at least six months to an adult family member with MS during the ages of 13-17. At least six months of caregiving was required in order to allow participants enough time to experience caregiving. Adolescent caregivers diagnosed mental or physical illness were excluded to decrease any risk for outliers. Based on accessibility, participants were chosen that lived within New England.

Procedure

An initial semi-structured phone interview (see Appendix D) was conducted to screen the participants based on inclusion/exclusion criteria. During this phone interview, the researcher determined if the participant was willing to talk about their experience, assessed their availability for participating, and developed rapport. A general description of the study, its methods and need for informed consent was provided. The preferred method of interview (either in-person or Skype) was chosen by the participant. Skype is a Microsoft internet-based system that provides users with free online video and
audio calls. The internet calls can be done from computer to computer, computer to phone, or phone to phone. For those desiring in-person interviews, a meeting place was chosen by the participants. An interview time was also scheduled. For participants that chose Skype interviews, Skype profile names were exchanged, and the consent form was emailed to the participant. It was required that participants email their signed consent forms to the researcher prior to the start of the first Skype interview. In-person consent was obtained at the first interview meeting, just prior to the interview (see Appendix E).

Data Collection Plan

This study was guided by the five steps process developed by Reinharz (1983). Reinharz (1983) developed five steps that guide researchers through a process to transform a phenomenon, of which little is known, into public knowledge. The first step guides the data collection procedure.

*Step 1. The participants share their experiences through data collection techniques e.g. interviews, focus groups, and journals.* Adults who were adolescent caregivers shared their caregiving experiences through two in-depth interviews. In-depth interviews were chosen to best understand the lived experience of adolescent caregivers and how they made meaning from their experience.

Whether in-person or via Skype, the researcher began the first interview with an inquiry about demographics, family dynamics, type of MS the adult family member had, what they knew about Multiple Sclerosis, their involvement as primary or secondary caregiving, months or years involved in caregiving, and time (daily) involved in
caregiving. These introductory questions were followed by two broad questions based on Seidman’s interview technique (2013): 1. What was life like prior to caregiving?, and 2. What was life like as an adolescent caregiver? Adequate time was allowed for each response, and when necessary, prompts and follow up questions were used (see Appendix D). The interviews were audio recorded and notes were taken. Notes were made on participant emotions, reactions, comments, family presence, and setting as well as reaction, thoughts, and questions generated by the researcher. Interviews were audio recorded.

A second in-depth interview was conducted at a time convenient to the participant, between 1-2 weeks after the first interview. According to Seidman (2013), this timeframe allowed the participant to reflect on the first interview and prevented distancing between participant and researcher. This interview was also audio recorded and handwritten notes were taken. Again, participants were able to choose an in-person or skype interview. To understand the meaning of the adolescent caregiver experience, the researcher asked the third question following Seidman’s interview technique; What does caregiving mean to you and where do you see yourself in the future? (Seidman, 2013). Follow-up questions and prompts were used, as in the first interview, to encourage the participants to fully explore the meaning of their experience (see Appendix D).

Plan for Analysis

The plan for data analysis, and interpretation followed the remaining steps recommended by Reinharz (1983). *Step 2. The collected data is reviewed in an attempt to*
gain an understanding of the phenomenon. Immediately after each interview, the audio recordings and handwritten notes were reviewed to gain an understanding of adolescent caregiver experiences and become immediately familiar with the data. The researcher used a transcription service TranscribeMe! via NVivo Plus, a data analysis program, to transcribe all audio recordings verbatim. Additionally, transcriptions were printed for ease of reading and mark-ups during review.

Step 3. Conceptual categories that are true to the participants’ experiences are developed. Audio recordings of the interviews were played numerous times, while referring to the corresponding notes. The transcripts were read and re-read in order to become familiar with the content and formulate ideas for further analysis: this is known as naïve reading (Speziale & Carpenter, 2007). Structural analysis followed, in which the transcriptions and notes were read and re-read until connections were made between the participants’ responses. These connections are developed into conceptual categories (Reinharz, 1983). In order to develop these conceptual categories, computer assisted qualitative data analysis software NVivo Plus was used in adjunct to the more traditional and creative hands-on analysis (Reinharz, 1983) note taking, marking, and color coding. The process of data analysis was reviewed by a dissertation committee familiar with phenomenological methodology.

Step 4. The conceptual categories and the researcher’s understanding/interpretation are transformed into a written document. Next, the researcher reflected on the entire transcript and interpretations found to ensure an all-inclusive description, a
process called ‘interpretation of the whole’ (Speziale & Carpenter, 2007). Detailed examples and quotes are provided along with interpretations made by this researcher, which provides an audit trail for readers to follow. Comparisons and contrasts of the findings against past research are discussed, implication for practicing nurses are made, as well as suggestions future nursing inquiry.

Step 5. A detailed comprehensive description is provided to clarify the previous four steps. This last step provides an audit trail for the reader to ensure research trustworthiness. In order to establish trustworthiness, an unbiased party reviewed the in-depth interview questions prior to the interview process (peer checking). Member checking was carried out at the beginning of the second interview. A summary of what was discussed in the first interview was presented, and the participant asked to confirm or clarify the researcher’s summary, thus providing assurance that the data from the interview and the researcher’s interpretation remained true to the participants’ meanings.

Ethical Considerations and Protection of Participants

In order to protect confidentiality, only the minimum necessary participant identifiers were collected. Participants were assigned pseudonyms to identify all study related data. Participant identifiers were available only to the researcher and were kept in a secure separate location when not in use. The data with pseudonyms were available to the dissertation chair and committee. Participant identifiers were removed/destroyed upon dissertation completion. The computer used to organize the data was password secured and stored in locked desk when not in use. The tape recordings and handwritten notes
were locked in a desk when not in use. The data was further secured by an alarm system armed when the researcher was away from the storage location.

Participants were informed that the study will provide professionals and the community members affected by MS, gain a greater understanding of the phenomenon and promote visibility of this currently invisible population. This, in turn, will advance research for their population and address their specific concerns and/or needs. Future goals could include nursing guidelines for adolescent caregiver assessment and needs, conditions for outside discipline referral, establishment of online information sites and community support groups.

To protect against any risk for emotional harm to the participants as a result of revealing sensitive issues, participants were offered information on local community counseling services at the end of the first interview (see Appendix F).

**Bracketing**

In qualitative research, bracketing also known as ‘epoche’, involves documenting feelings, experiences, or presuppositions of the researcher in order to be open to the incoming data (Speziale & Carpenter, 2007). This process occurs prior to data collection and continuously during data collection and analysis (Speziale & Carpenter, 2007). This process was employed, by the researcher as a time to reflect upon, and document previous personal experiences as an adolescent caregiver prior to data collection interviews (see Appendix G).
Conclusion

Since only one study was found in the young caregiver research with the recipient illness of multiple sclerosis, in-depth data needed to be obtained to lay the foundation for future study. Therefore, a qualitative phenomenological study was chosen to learn about the lived experience of the participants. Considering the preceding review of the literature and the researchers caregiving experience (see Appendix G), a Hermeneutic interpretive analysis was used; because, the researcher and the participants cannot be separated from their context.

A retrospective study was chosen: adult participants who were once adolescent caregivers for family with MS. Participants learned about the study through flyers and postcards and were purposefully selected based on defined criteria. Initial telephone interviews helped in this selection process. A total of 8 participants were purposefully selected.

The data collection, analysis, and interpretation were guided by the 5 steps of Reinharz (1983). Two in-depth interviews were conducted with each participant. Participants chose either in-person or Skype interviews that were guided by Seidman’s interview technique (2013). Data was audio recorded and notes were taken. The audio was transcribed and analyzed using hands on methods and data analysis software. The findings were then interpreted and compared to previous study.
CHAPTER 4

THE PARTICIPANTS

Participant Profiles

Eight adult participants between the ages of 18-41 (see Figure 1) were interviewed in this study. Two separate interviews one to two weeks apart were conducted with each participant either by skype or in-person. In order to get a better understanding of each participant and their experience, a brief summary of each participant follows. Demographic information along with salient information about each participant can be found in Appendix G. Participants will be discussed in the order they were interviewed starting May 21, 2018 to the last interview on September 4th, 2018.

Adam, a 41-year-old, Caucasian male chose to be interviewed in person at a public location in Central Massachusetts. Adam was expressive and optimistic. He took his time with the interview questions and gave detailed, thoughtful answers. Adam was a primary caregiver for his grandmother with MS. His experience with caregiving started at the age of twelve when his grandmother and grandfather moved in with his family. His grandmother was in a wheelchair and needed 24-hour care. Adams grandfather died shortly after moving in with the family. Adam was the eldest of three siblings. His immediate family of five included himself, Sara [also a participant] who was one year younger, a brother eight years younger, a mom, and a stepfather. His younger brother was viewed as less involved with caregiving due to age at that time. Adam describes his sister, mom, and himself as primary caregivers. His mother and stepfather worked full
time jobs while he and his sister homeschooled themselves. His younger brother was in elementary school. Adams room was on the same floor as his grandmother with a door interconnecting his room to his grandmother’s apartment. Adam was a caregiver during his entire adolescence since he started caregiving at the age of twelve to the age of eighteen when he moved out. These days, Adam is working in Information Technology which allows him to work from home where he is a caregiver to his wife with MS and son with a history of leukemia.

Sara is a 40-year-old, Caucasian woman. She is the sister to Adam [previously discussed] and provided primary care to her grandmother with MS during her entire adolescence. Sara chose to do in-person interviews in Massachusetts. Three interviews were conducted with Sara due to a malfunctioning voice recorder. The first interview was conducted in the participants’ home. The second interview one week later was conducted in the participant’s car at a public place. Notes were taken, however, the recording for this interview malfunctioned and no audio data was recovered. The participant was notified the same day and she was willing to meet again a few days later to re-interview at her home. Sara, like her brother, was very detailed, expressive, and provided insight along with detail into her experience. Very little probing was needed for the participant to expound upon her experience. Sara recalled starting caregiving around eight years of age and continued until she moved out of her family home at the age of eighteen. Sara’s timetable was different than that of her brothers because she recalled frequent visits to her grandparents where she would perform tasks to help her grandmother prior to their move
into the in-law apartment. Currently, Sara is married and has three children. Sara and her husband also provide for two exchange students who live in their home. Sara owns her own cleaning business which allows her to be home for her family when needed.

Emily, a 32-year-old Hispanic/Latino woman moved to Massachusetts from Puerto Rico at the age of twenty-three. Emily agreed to in-person interviews in a private area at her workplace. The interview with Emily was shorter than expected; however, all the interview questions were answered thoughtfully and in detail. A few interruptions by co-workers occurred but did not have any impact on progress of the interviews. Emily is from a family of six which included her mother with MS, a father who worked full time, a grandmother who lived upstairs and two siblings, she was the middle child. Her mother was diagnosed with MS in the mid 1990’s. Emily described herself as a secondary caregiver along with her siblings and her grandmother while her father was the primary caregiver. Emily started caregiving at the age of thirteen and reports she still is caregiving long-distance by providing frequent emotional support, coordinating medical care, and following up with the latest MS research. Emily chose a career in healthcare to help others with Multiple Sclerosis.

James, a 27-year-old Caucasian male from Pennsylvania chose to conduct two Skype interviews from his childhood home; where he resided as a caregiver for his father with MS. James took his time with the interview and was able to describe his experience in detail. James was part of a family of seven which consisted of: his father with MS, his mother, three brothers and one sister. James was the fourth child who described his three
older siblings as significantly older than him and out of the house when he was an adolescent; therefore, they were not involved in his father’s care. James’ younger brother was closer in age to James, but did not help provide care. James was thirteen when he started caregiving; thus, he was caregiving during his entire adolescence. James reported he recently graduated from college and was getting married in a few weeks with plans to move out of his childhood home. His father now requires full time “CNA type” care and his sister has recently moved back home to help James and his mother with caregiving.

Eric, a 20-year-old Caucasian, male college student from New Hampshire chose to Skype for his interviews. During his interviews, Eric was away from home at military school and he reported it was the first time he left his mother and his caregiving responsibilities. Eric was an animated participant, seemed to speak easily about what was on his mind, and recalled caregiving for his mother with MS in detail. Eric was an only child and considered himself a primary caregiver, along with his father who worked full-time. Eric started caregiving at the age of five and provided care during his entire adolescence.

Rachel, a 28-year-old Caucasian school teacher from New Hampshire chose to Skype for both interviews, due to the expected arrival of her first child. Rachel was upbeat, excited about her future and looked back at her experience fondly. Rachel was part of a family of four which included her father, mother and a brother who was three years older than she. When Rachel was an adolescent, her mother rapidly declined in health and for the first three years she went undiagnosed. Rachel became a secondary
caregiver to her mother at the age of sixteen while her father was the primary caregiver. When Rachel turned nineteen, her mother was diagnosed with MS. Rachel provided care until her mom passed away from complications of MS a year prior to the interview. Despite the recent loss of her mother, Rachel has been actively writing a book about her experience as a caregiver.

Tammy was an 18-year-old, Caucasian female from New York who participated in the study via Skype interviews. Tammy had a quiet, shy personality which made it difficult to get lengthy detailed responses. Frequent prompts and follow up questions were required. Tammy’s family consisted of an older sister, Beth, who also participated in the study and a mother with MS. When Tammy was five years old her mother was diagnosed with MS and when she was thirteen, her parents divorced, and her father moved out of the home. Tammy reported she had initially moved out with her father but then moved back when she was 15 years old. Tammy started caregiving at this age and is still living at home and providing care. Tammy appeared conflicted about her future plans. She was taking online classes at the time of the interviews, but was undecided about a major.

Beth, age 22, was a Caucasian female and the older sister to Tammy [previous participant]. Beth also chose to conduct both interviews via Skype. Her interview followed her sisters on both occasions. The sisters were asked to conduct interviews in private and separate from each other to provide privacy and to reduce the likelihood of repetition of answers. Beth was a little more talkative than her sister, but again, frequent
probing was needed to elicit information about her experience. Beth started caregiving for her mother at the age of nine and shared primary caregiving responsibilities with her sister. Beth worked part-time throughout the years to help support her mother and sister. Beth still lived with her mother and sister at the time of the interview and continued to provide care for her mother.

Demographics

A general inquiry into demographics of each participant was conducted in the first interview (see Appendix H). The participants ages ranged between 18-41 years old (see Table 1) with the majority (N=5) in the range of 18-29. One participant was in their thirties and two participants were in their early forties. The age the participants started caregiving ranged from 5 to 16, with the majority starting prior to their adolescent years. Six of the eight participants were caregiving during their entire adolescence. Two participants started caregiving later in their adolescent years, at fifteen and sixteen years of age. There were 5 female participants and 3 male participants. Most participants were white (N=7) with only one identifying as a Hispanic/Latino. The participants were from the northeast (Massachusetts, New York, New Hampshire, and Pennsylvania). Three of the participants were interviewed in-person, and five via Skype.
Figure 1: Age of Participants During Interviews

Five caregiving recipients with MS were mothers, one father, and one grandmother. This is likely due to the increase in incidence of MS in females of child bearing and rearing age. Half of the participants viewed themselves as primary caregivers (the main caregiver) while the other half viewed themselves as secondary caregivers (helping a primary caregiver). Each of the eight participants reported they had family that was working while they were providing care during their adolescent years. Hours per day involved in caregiving ranged from one hour to ten hours with the majority being less than six hours per day (see Appendix H).
CHAPTER 5

FINDINGS

Introduction

Two interviews with each participant yielded 16 interviews. Recordings were transcribed and analyzed over a period of 4 months. The analysis was carried out by the researcher through an iterative process of reading, rereading and grouping responses as per the analysis plan. The following results are intended to describe the adolescent caregiver experience to the reader in order to bring their experiences to light through participants’ own words. Through the process of analysis, two themes emerged: invisibility and support. The theme of invisibility was arrived at after bringing together the following categories: Why Me?; Invisible in My Role; Invisible in Healthcare: the Uninformed; and Invisible in the Community. The second theme of Support was arrived at following the identification of the categories: All the Support I Need; I am Your Support: I am Your Rock; and Support for My Needs.

Invisibility

The theme of invisibility was identified early in the data collection phase of the study. Originally, the study population of interest was to focus on adolescents who were currently caregiving for adult family members with MS. After four months of recruitment efforts, and not one response, a decision was made to change the population of focus. The study remained essentially the same, however, the population of focus shifted to adults who had experienced caregiving of family member with MS when they were adolescents.
Thus, it became a retrospective view of the caregiving experience. The question arose: Why were adolescent caregivers not coming forward? Invisibility continued to resurface and was found to be a theme of the interviews with the adult participants. The categories of invisibility: Why Me?; Invisible in My Role; Invisible in Healthcare: the Uninformed; and Invisible in the Community, formed the theme.

**Why Me?**

During the first interview, participants were asked to describe their families and discuss the roles and relationships with one another. This was an attempt to understand who was at home during those years, who was involved with care and the reasoning behind it. All but one of the participants reported siblings. Some participants viewed their involvement in caregiving was greater than that of their siblings. The question arose as to why some children stepped forward as caregivers while other siblings didn’t. In order to make this population visible, it is first important to understand why some adolescents caregive and others don’t.

The participants gave a few reasons for their increased involvement compared to their siblings. Some of the participants reported a closer bond with the caregiving recipient than that of their siblings. James reported his bond with his father is the reason his brother did not provide care.

He and my dad clashed as he was going through adolescence...my dad and I have always seen eye-to-eye on working outside, doing physical work, attention to detail, doing things right. And I think my willingness to work with my dad...and just that it was easier for him to ask me than to ask my brother. And my brother to gripe and moan and...so he'd just often ask me instead and I would do it. Don’t know why. But I would just
My other brother never really took to it. He was never very comfortable doing it.

During the first interview, Emily could not describe why she took on more responsibility caregiving than that of her siblings. She seemed to ponder the question a bit before replying, “I don’t know, I don’t know”. During the second interview, Emily reported she reflected on the question posed to her during the first interview, and even discussed it with her mother the careevpee. Emily came to the realization her bond with her mother contributed to her taking on this role. She found herself being the primary emotional support for her mother as compared to her father and two other siblings.

All of us pitched in but I was more of an emotional support for her…because I was more close to her in terms of understanding, and her symptoms, and listening to her. She didn't want to complain to my dad all the time in terms of what she was feeling, so I was kind of like her ears. My dad's still her support and my brother and my sister but my brother was younger and my sister gave some support, but again, I'm closer to her.

When facing things that were difficult, some adolescents retreated because they did not want to face reality. Emily reported that stepping back from the caregiving role is a coping mechanism for some siblings.

My sister is more reserve and I think she was fine to-- the way that she coped was kind of being there but staying away, too because, for her, it was also hard to see my mom like that.

Similarly, Rachel described her brothers coping mechanism as distancing.

Yeah, he was definitely away. I wouldn't even consider him a caregiver. He was a distance away, but he also distanced himself a little bit too, I think on purpose, from it.
Rachel also describes distancing as her coping mechanism when her mother first started showing symptoms of MS. She also reported to use friends as a distraction.

My mom and I had always been really close and I always spent a lot of time with her. So as this fatigue started setting in, I kind of distanced myself just because I was so angry about it. And I had focused more on being out of the house and being with my friends and not talking to her much.

Besides close bonds/relationships and distancing as a coping mechanism, for some people, caregiving comes easier than for others. Emily described that for her, caregiving was natural. “It just comes naturally that you don’t even think.” Adam also described that some people are just not equipped to handle caregiving, but for him, it just came naturally.

For people that ended up being caregivers, taking care of someone just brings it up to a whole different level. Cause now your being asked to literally help this person exist and help keep this person in a pleasant state of mind. “Oh, you got to help an adult go to the bathroom, or you got to clean an adult up after they go to the bathroom or get them out of bed when they’ve had accidents at night.” A lot of people would just be like, “That’s not my thing. I can’t do that. No.” As much as it might seem difficult for me as a young person caregiving for someone old like that, it’s also difficult on the person that has the needs. Because at a certain point, they feel like they’ve kind of stepped over a threshold or a boundary that they shouldn’t have to have you be a part of. And for me, it was just natural. It was like, “I don’t mind going there with you.”

When tasks are difficult, adolescent caregivers may do what they are able.

Siblings Adam and Sara found a way to make it work for them. Adam viewed his caregiving activity as primary and equal to that of his sister, Sara. He described that he was able to do things his sister could not and vice versa.
We each were able to help in unique ways some ways that I may not have been comfortable doing something she was able to do those types of things...things that she wasn't able to do or wasn't comfortable doing, I was able to handle. I would say between my sister and I, I think it was equally balanced.

Sara viewed her siblings as cohorts in caregiving for her grandmother and viewed what they did as an act of love. When describing which of her siblings was caregiving for her grandmother, Sara stated: “I would say more so my older brother, but yea, we all did something because we loved my grandmother so.”

Some adolescent caregivers don’t have an option because they have no siblings to help. Eric, an only child, described the caregiving for his mother with MS fell on his father and himself. Eric viewed himself as having a ‘primary’ role in her care. His father worked full-time; therefore, much of the responsibility was left to Eric. Eric started caregiving at the age of five and reported to start working at age of 10 doing ‘odd jobs’ and a part time job as a janitor at this school by the age of 13. During the time of the interview Eric was away from home for the first time at military school but reported to continuously worry about his mother and her caregiving needs.

There are a few reasons as to why some adolescents caregive and others don’t. Close bonds with a family member and a caregiving instinct were reported to increase the chances of taking on this role. Some adolescents do not take on the caregiving role because it is unnatural for them; or they may be unable to handle the situation and use distancing a coping mechanism.
Invisible in My Role

Many of the participants did not view themselves as an adolescent caregiver because they grew up doing what was needed for their family. At that time, they did not know any different lifestyle. Since there has been little recognition of young caregivers in the media, in the healthcare field, or in research, adolescent caregivers continue to provide care, unaware that their experience is not typical. Adam describes his adolescent caregiving as being just a part of his family lifestyle.

It was more of a daily lifestyle, it wasn’t, I didn’t really keep track of...I did it from this year to this year and then took a break and then did it from this year to this year. It was just part of my childhood…I didn’t really see myself as a caregiver. There was never any like real recognition for what we did. We were kind of like ‘behind the scenes’ caregivers [laughs]. I think when people think of caregivers, they think it’s definitely an adult all the time.

Similarly, James didn’t recognize himself as a caregiver when he was an adolescent. He questions whether he would have even known the definition of ‘caregiver’ at that time.

I can’t remember if I would’ve known the definition and the meaning of caregiver at that time. I would, probably, if I were to have thought about it, I probably would have said, “Yeah, I guess that is me.” But I would not have classified myself as my dad’s caregiver. I would’ve classified myself as my dad’s son.

Sara also did not recognize herself as a caregiver.

When I was young, I didn’t ever consider myself a caregiver. I didn’t give myself a label. I considered myself a granddaughter to a grandmother.

Likewise, Eric did not see himself as a caregiver but instead was just trying to be a ‘good son’ to his mother.
I’m with my parents, you know, day in, day out. Even as—especially as a teenager, it’s just your dealing with your parents—this is your parents. You’re kind of—you know, you haven’t branched out, you haven’t gotten outside the house yet. You’re in your family. It’s one of those like—take care of them, it’s part of life. I’m just trying to be a good son at the end of the day. It's almost like— I grew up with it, so it's hard to kind of figure out what is caregiving versus what's normal for people.

Tammy reported that she was unaware that she was a caregiver and she found out because her mother told her.

Probably around 16, when my mom told me that I was caregiving. Yeah. I probably still wouldn’t know if she didn’t tell me.

Interestingly, James did not view the caregiver title as separate from family. He describes a caregiver as being part of the family. Even outsiders coming in to help would become part of the family.

I know last time I said, to me, I never really knew of caregiving, it was just being a son. I think it’s kind of along the same lines of being—as a family member, caregiving really defines a family member. Somebody who’s there for them anytime, all the time. And for somebody outside of the family, being a caregiver is almost, especially if they’re going to be doing it full-time every day, family… So I think caregiving is a lot more than just the action.

Based on these responses by the participants, we are able to see that adolescent caregivers may not view themselves as having the role of caregiver. They grow up thinking their responsibility is typical of other adolescents which contributes to their invisibility and lack of support.

Invisible in Healthcare: The Uninformed

Invisible in Healthcare: The Uninformed looks at participants’ viewpoints on MS, their lack of knowledge about MS as an adolescent, and the lack of involvement in
healthcare. It brings to light how families often don’t talk about their illness and try to keep it secret. This category also reveals limited interaction with healthcare workers which contributes to adolescent caregivers being uninformed.

Participants described what they knew about MS as an adolescent caregiver. Surprisingly, most described their knowledge of MS as lacking and emphasized a strong desire to have known more. Rachel described the way she found out about her mother’s MS was traumatic. She accidently found a pamphlet in her house and proceeded to run away.

I knew absolutely nothing. I remember when I found out she had MS, is was through a goody-bag that the doctor had given her the day she was diagnosed. My parents just left it on the counter, and I found it and I pulled out the pamphlet that said, "All about MS." And I was like, "What is that?" And I figured, "Okay. That must be what they think she has, but what is this?" And so I read the pamphlet, and that was the first time I had ever heard of it, ever read anything about it, and that was like-- the thing that I remember in the pamphlet is seeing the timeline of the progression. And it said, "From the day she's diagnosed-- and then within 5 years she'll probably need a walker. Within 10 years she'll probably be in a wheelchair." So that was my first understanding was, "Okay. She's not going to die from it, but she's probably going to be in a wheelchair in 10 years."

In order to find out more information on MS, Rachel googled it. She reported her parents didn’t provide her with information because they wanted to keep her protected.

Yep, I didn't want to talk to them about it. I ran to my room and I closed the door and I think the whole thing with my mom was like she wanted to keep it a secret from us and wanted to hide it. And even though she was having all these symptoms, she didn't want us to have to be involved with it and to have to take care of her. So she just tried to keep us out of it. It was a lot. One of the first things I tried to do, actually, was find a book that was teenagers going through MS, like, "What does it mean when your mom has MS," you know? And there was nothing out there, but I just
remember Googling it and just whatever I could find. And there wasn't a lot too, I mean, that was 12 years ago. So back in that time, there was really not a lot. So I knew nothing. I really knew nothing.

Eventually, Rachel’s mom, the caregivee, started to talk with her about MS but the information was limited.

My mom and I were always really close, so I felt like I could talk to her about it, but we never had a sit down, "Okay. I've been diagnosed with MS and here's what it means." It was more just like, "Mom, why are you so tired?" She'd tell me, "I have MS. That's what happens." And she told me about the spoon theory. The bloggers use this spoon theory to talk to kids about it. And it's like every day you're given a number of spoons, and it's like your energy supply. And everything that you do requires you to use up your spoons. So eventually you run out of spoons, and in order to get more energy, you have to reset your spoon supply. You have to go to sleep. So that was kind of how she talked to me about it in the beginning was trying to make it a little more understandable.

Sara described her limited knowledge of her grandmother’s MS came from her mother and her own observations of her grandmother’s symptoms.

She never experienced any moments of reprieve, it just gradually got worse and worse and at that time I just knew that she was losing function so when I was really young she could walk. She was a school teacher but then the older I got I noticed she would lose more and more freedoms and mobility so I didn’t know how it worked, I didn't know what it attacked, I didn't know it was an autoimmune disorder or any of that stuff, I just knew it was something that was taking her mobility and freedom from her.

Adam, like his sister Sara, reported a lack of information and discussion by his family which he related to the lack of advancements in healthcare.

The way she had always explained it to me is that it was a disease that they didn’t know anything about, they didn’t have any cures for, the type of treatments…even just the notion of having medications to treat many of the side effects and symptoms, they didn’t have any of that. I don’t even think at that age I realized that it could potentially be the cause of the end of her life….I wouldn’t say that there were any overly deep conversations
that took place ‘here’s MS and here’s the fact about MS.’ Cause again, there wasn’t, I don’t feel like there was a lot known back then, It was an uncertain area. A lot of research had not been done there yet, and doctors seemed pretty limited as to what they could do.

Eric described his experience where his parents didn’t talk with him about the MS and he had to seek information elsewhere. When asked if he felt his parents were open to talking with him about MS, Eric responded.

Not at first. It took them a while. And they’re still not always, but it got to that point. They just don’t want to worry me. I did my own research, too, because I had a biology professor I was really good friends with back in high school. And his specialty was basic neuroscience, so we were always—I’d always be talking about that kind of stuff with him.

When asked if he could recall what type of MS his father had at that time, James could not recall. He went on to describe his desire for knowledge on MS led him to do his own research and ask others outside the family for information.

I don’t know specifically. We never really discussed that much. His diagnosis just, general terms of MS. We’ve kind of moved past the detailed discussion of it. We just came to an understanding that it’s here and we don’t talk about it that much. Thinking back, in middle school whenever he was losing the ability to walk, that's really all I knew it as, was he was losing the ability to walk. I didn't really understand much. In high school is whenever I really got in-- my dad was the science teacher, so I got the science bug from him. So I was very interested in it, and I did a lot of research on my own. And that's when I realized what it was, how it was happening, that there really was no cure for it. There is some things that were helping some people, but not others. And that's kind of when I came to the realization. But when I was younger, I really didn't know that it was anything that serious, really. My best friend, his dad is a chiropractor, and he is an osteopathic doctor now. And I've had discussions with him. I've had discussions with him just about the scientific side of it, but never really got into a deep discussion about it, no.

James continued to describe his family reaction to discussions about MS.
Occasionally there'd be discussions. Not much. We don't discuss things as openly as some families. I mean, if questions arise, we discuss it, but we're not one of those people that come home and say, "Well, okay. This is what happened." That type of family meeting. It was more of a, if somebody asks a question, it's answered. There have been times where I've asked specific questions, like back in 2007 -- 2006, 2007 is when my dad really started to decline because of his steroid treatment. It was supposed to kind of break him down and rebuild him to better than he was before, but as it broke him down, he got an infection and it almost killed him. And ever since then, he hasn't been able to even stand, barely move his legs, and his upper body movement has been declining. And he's to the point now where he's about 98% dependent, so. That's probably the most we've discussed, is whenever that happened, we discussed how things had just-- how that had happened and what had happened and where we were going to go from there, so.

Emily described going to the neurologist with her mother and desiring to know more.

Since I was going to the doctors with her, I try to gather what I could gather. Later on, as we grew up, then we got a little bit of a better understanding and talking to her, but at the beginning, yeah, we actually didn't have that conversation of, "yes, I have this."

In contrast, Beth had a positive experience and reported she was well informed by her mother who was open to talking with her. Beth also mentioned she received a little booklet for kids called “Keep S’myelin”, which gave her information that helped her understand. Beth felt that the booklet helped her understand MS and she felt reassured she could talk with her mother.

She had sat down me as she kissed me goodnight and that she sat down with me and explained to me about that. She's not sure if-- right before she was diagnosed-- before she was diagnosed. She said, "I don't know if it's going to be multiple sclerosis or if it's going to be cancer or--." But she sat me down and explained to me what MS is and so she was the one who told me about it. And then she heard about a thing called “Keep S'myelin”. So that helped a lot too. Plus, too, I knew I wasn't alone.

Beth goes on to describe the “Keep S'myelin” booklet.
It's a little booklet thing for kids. It has sometimes jokes in it. I don't think so much-- maybe some puzzles, I'm not sure. But it has little cartoon strip in it. It has a factual thing like something with MS. What is myelin and all that. It's an informative thing.

The majority of participants found their experience with healthcare professionals was lacking and there were only a couple reasons for it. Many participants stated they were not involved with appointments; therefore, there was no contact with any medical professionals. Another participant felt like he was being ignored because he was not an adult. Only one participant felt the communication between the healthcare team and herself was positive.

Rachel was not involved with taking her mother to appointments; therefore, she was not able to ask healthcare providers questions about MS.

And I never talked to a doctor or anything like that. It was always my dad that took her to appointments, so I never had anyone really explain it to me either.

Adam denied being involved with the doctor’s appointments.

Typically any involvement with any of that with the visits would be to help her get ready to go for the visit: get her cleaned up, make sure she was dressed and just help in any physical way that we could getting her...whether it was from her bed or like finishing up breakfast, helping to clear the dishes and all that stuff. My mom would typically take her to her appointments.

Emily was asked if she felt like she was recognized by medical professionals at her mom’s doctor appointments. Emily responded that at first, she was not recognized, but as she grew older they acknowledged her questions.
Not that much. Because we were kids. Later on, yes, because I was in high school, and I was going to the appointments, and I was interested in medicine, so that’s—later on, yes.

Sara remembered accompanying her grandmother to her appointments but typically did not go into the exam room until they were older. Sara’s viewpoint on her grandmothers’ appointments was different than her brothers. Sara remembered taking their grandmother to the appointments; whereas, Adam remembered getting his grandmother ready for the appointments.

If she had a doctor's appointment, we had the wheelchair van. So we would bring her, usually, as a family, and this sounds funny, but it was always interesting to see how many people were fascinated with the van doors opening and this lift coming down. It's like the Queen of England would be rolling out onto this lift. And we used to pop wheelies [laughter], tease her when she was in her wheelchair. She would laugh, but we thought we were being so funny. But yeah, we would accompany her to doctor's appointments. Not necessarily always going in the room when we were younger, but when we were older, for sure, we would.

Eric’s experience with healthcare workers was negative. He felt like he was more of a nuisance and was not acknowledged as his mom’s caregiver. Eric reports frequent trips driving his mom to her appointments, urgent care, or the hospital emergency room.

I'd walk her in the appointment, and then it was basically, "All right. You can't really be here, so scram, buddy." But that's why I got my license as soon as I could. I started driving when I was like 15 or 15 and a half. That's like all my driving hours, taking her down to the hospital… If person with MS shows up at the neurologist and they have a kid with them, chances are that kid's the caregiver because they're there with them.

Conversely, Beth felt acknowledged by her mom’s healthcare providers. She felt like she was able to ask questions.
If we went with mom to her appointment, we could ask her or the nurse questions like, "What is drop-foot?" Or anything we have questions of. Like, "Can this be reversed?" Like, "Can the drop-foot be reversed?" Or whatever. Does she think my mom will ever not use a rollator if we felt-- does she think mom's at risk of being wheelchair-bound?

Adolescent caregivers are uninformed for a few reasons per the participants responses. They found their parents were trying to protect them and therefore offered limited information on their condition and MS in general. The participants also reported they were less involved with the healthcare appointments contributing to less access to knowledge from medical professionals. Due to the lack of knowledge, participants became frustrated and desired to know more information about what was happening to their family member. They sought other means to gain this information including the internet and adults outside the family who they respected.

Invisible in the Community

Do adolescent caregivers want to be recognized or would they prefer to stay hidden in the community? While all the participants stressed the importance of being acknowledged and being educated, two participants discussed a desire to hide due to unwanted pity, fear, burden, privacy, and embarrassment. Eric had a strong viewpoint and described multiple reasons as to why he wanted to stay hidden when he was an adolescent caregiver. Eric described unwanted pity from his classmates and teachers.

Like you know then they're worried about getting someone else's pity. Or unwanted attention. I mean that was definitely me up to a point, because I didn't want to tell anyone my mom had MS because oh that happens, oh, my mom has MS, all the attention on this guy now. How's your mom? Is everything okay? Because that's-- but by the end of high school people knew, so every day… it was the guidance counselor, it was the teachers, it
was the principals. It was even a school nurse. "How's your mom? Are you okay? How's this?" And it's like, "I'm fine. Leave me alone." It's definitely some unwanted attention comes along a lot when that happens.

Eric also describes a fear of burdening others with his complaints.

I didn't want to almost burden anybody with it. I didn't want to be complaining, like, "My mom has MS. Feel bad for me." See, I didn't want that because I was able to deal with it. It was fine. I mean, I got used to it. It was all right. It was what I grew up with. And I didn't really want to burden anyone.

Eric mentioned a fear of ridicule and bullying by other peers.

I got bullied a lot when I was younger, like really badly, so it was another- I didn't want to tell people what was perceived as weakness, almost.

He also desired to keep his caregiving life private and didn’t want to burden anyone. Eric stated, “I’d try to keep it quiet. I just didn’t think it was anybody’s business.” Eric disliked the typical questions and responses from those that heard of his mother’s MS or his caregiving; and therefore, chose not to tell people.

I'm just like, "My mom has MS," wait for it, "I'm sorry," continue. It's just when you-- this isn't even attention, just when you tell someone, because I've noticed this when I was in high school and stuff, it was like 50-50. You'd tell-- and they'd either give you a ton of pity and be like, "I'm so sorry" or they'd look at you blankly but either way, you'd get a-- I guess one reason people don't really talk about it is because you get a reaction that you don't want. It's either a zombie expression or it's "I'm so sorry" now it's the pity. I don't think I've ever met one person who didn't react with the typical reaction.

James reported the feeling of embarrassment when he had to provide care to his father in front of his friends while at the movies. Despite this embarrassment, James was excited to have some father son time.
One of the last times I remember him driving, he took me and my friends to go see one of the Star Wars prequels. I think it was the Revenge of the Sith. But for some reason, every time somebody asked about my dad and the caretaking and stuff, that pops into my head. And I don't know exactly why. I think part of it was because I was so happy he was able to take us, but I was also a little embarrassed, because I still had to take care of him as we were going into the movie. I wasn't able to just be with my friends. So I think that's kind of why it sticks with me. But a lot of it is just that was the last time it was only my dad and I and my friends going out to do something.

Two participants reported a desire to keep their caregiving experience hidden from others as an adolescent. The fears of being a burden, unwanted pity, bullying, ridicule, and embarrassment as well as the belief that caregiving was a private matter contributed to their invisibility.

Support

The theme of support was drawn from the interviews and based on three categories: All the Support I Need; I am Your Support: I am Your Rock; and Support for My Needs. The category ‘All the Support I Need’ represents participants life prior to caregiving; in which, the participants described having no need for support. The category ‘I am Your Support: I am your Rock’ was developed from the description of participants’ caregiver- transition period and the role change that took place. In this category, participants talked about their adolescent caregiving experiences and their development as ‘a rock’, or support, for their family member with MS, as well as their perceptions of how caregiving has led them to be a support for others. Finally, the category ‘Support for My Needs’ describes the needs of adolescent caregivers and the participants make recommendations to help other adolescent caregivers.
All the Support I Need

During the first interview, participants were asked to recall what their life was like prior to caregiving. Participants recalled their pre-caregiving years as worry-free, less stressful, and looked back on those years fondly. Adam recalls the pre-caregiving years before his grandparents moved in with him and described that time as enjoyable.

I would go over and play the piano at their house. We had bikes there, they had a big tree out in front of the house that we would climb. It was really fun, it was a fun reality, when it was like that.

Sara recalled the pre-caregiving years as memorable.

I do remember before she moved in that we would drive to her house everyday...but I loved it because she had an awesome basement. I remember going to her house and it was more about fun and at that time she had a lot more freedom, mobilities, so we would have sleepovers and my grandfather would be making pancakes. My relationship at that time with them was more grandparent-child as opposed to you know, her being so reliant upon us. So I do remember that... that dynamic with that relationship.

Emily described her pre-caregiving years as carefree.

It's odd because actually, it's like it's part of it. The only thing is, I guess, not to worry about the disease of your parents, and progression of your parents, and seeing your parents struggling. So that actually is how I remember before.

James reflected on his father being active and having more bonding father-son time.

I have very few memories-- my dad was always very active. We grew up fairly poor, so we were constantly doing things to save money. Recycling, doing odd jobs, that sort of thing. And we used to collect aluminum cans from the school that he worked, and we would sort them, and that was one of the few memories I have of him physically being active, is doing that sort of stuff. Or he always had a really big garden, working in the garden. It was oftentimes, because of me not understanding anything back then, it was oftentimes me whining about working and him saying, "Oh, come on.
Let's go out and do it, and we've got to do it." And it was often a lot of that stuff, and now it's-- yeah. So that's probably the biggest thing is, before then it was just constantly doing stuff, always being active, always doing stuff, so.

Rachel recalled her pre-caregiving years as ‘great’ and reflected on her mother’s strength and vitality.

She was really active and really funny and really happy. And she always liked being home, but she also had a lot of friends that she kept in touch with. She ran a marathon in 2001, I want to say, when I was about 12. So like I said, she was a pretty intense runner. She worked a lot, but our family was just like pretty simple. It was a pretty regular family. We didn't really have any issues. Parents worked full time and then my brother now and then would come home from school, and we were just a pretty regular family…It was great, I would say.

Similarly, Tammy recalled having a more active mother during her pre-caregiving years. Tammy stated, “I remember when I was probably, oh my gosh, 10 maybe? And we used to go for walks with our dog, up and down the street.”

Eric could not recall life prior to caregiving since he started caregiving for his mother at the age of five. The participants recollection of their pre-caregiving years was looked at fondly as they recalled increased activity, increased bonding time, and a sense of normalcy.

I am Your Support: I am Your Rock

In order to understand participants’ viewpoint on their caregiving experience, it was important to see how they defined caregiving. Initially participants were asked: What was life like as a caregiver? Participants were then asked the question: What does caregiving mean to you and how has it influenced who you are today? Participants found
meaning in caregiving; emphasized a role change; described a range of caregiving activities; and reported caregiving has influenced who they were and how they viewed others in need.

**Meaning of Caregiving**

Adam, Eric, and Sara described caregiving as a selfless act of service and the importance of setting ones’ feelings, emotions, desires aside for the benefit of the other person in need. This description was seen in Adam response.

The act of setting yourself aside for the sake of somebody else from a physical, emotional, mental health position.

Eric compared the definition of caregiving to core army values.

The closest definition I can compare it to is just one of the Army values of selfless service, them before you. You’re having a bad day? Okay. They have a bad day? You put a smile on your face and go make sure they’re ok.

Sara described caregiving and emphasized the importance of not making the caregiving recipient feel like a burden.

Just meeting somebody’s need or needs, treating them with dignity, with respect. Dignity...not making the person feel like the last thing on Earth you want to be doing is wiping their bum.

With other participants, caregiving was defined as a task related activity. Beth described caregiving as helping with tasks.

Caregiving to me is somebody that helps out somebody that can’t do whatever they need to, like laundry or even reading a book, doing all sorts of different tasks that what an able-bodied person would be able to do.

Tammy gave a simple task related description of caregiving.
Just helping out somebody that needs help. With getting stuff or if they can’t reach to get something up on the top shelf…and need you to do it for them.

Sometimes it’s not the big things one does for others, but the little things that count. Rachel viewed caregiving as helping out with the little things to improve the quality of another’s life.

Caregiving is just doing all those little things that you should be able to do yourself but you can’t because MS sucks and you’re just trying to make them feel like their life is still the same even through it’s not. It mostly comes down to the little things.

James described caregiving as more than just tasks, but being like family, establishing a relationship, knowing each other’s needs, and helping out.

I think it's kind of along the same lines of being-- As a family member, caregiving really defines a family member. Somebody who’s there for them anytime, all the time… So I think caregiving is a lot more than just the action.

Emily defined the meaning of caregiving as improving one’s quality of life.

It’s improving the quality of life of a person…emotional support, being there for somebody, feeling that somebody has their back, that changes their perspective a lot and gives at least purpose to somebody that has this chronic disease.

**Role Change**

The participants did not turn into a caregiver overnight. The development into an adolescent caregiver took time. As symptoms emerged for the family member with MS, they would adjust, and help out. When symptoms progressed, more and more caregiving tasks were needed. The participants described this period as ‘role change’ where roles were reversed between the adults and the children.
Eric reported his mother’s decline in health led him to take on more responsibility. Eric felt he matured fast as he had to take on an adult role.

She kind of just stayed active. She cooked for-- towards the end of sophomore year, it kind of stopped. But she used to walk a lot, go for walks with people. Just freshman year, it was getting to that point when she couldn't drive much anymore. And by sophomore year, it was, "Here's the keys, boy. Go to school." And I was the first kid at my high school was driving. People always tell me I'm older. I don't know. That's what happens when you grow up with a parent who's sick. You just get older faster.

Adam described his role reversal as a common saying.

This expression that when you were a baby I changed your diapers, and then when you are older I’m going to change your diapers. It’s a cyclical thing.

Adam acknowledged he had a right vs wrong decision to make when faced with his grandmother’s MS and her needs. Adam believed caregiving was even more difficult for his grandmother than it was for him.

I had a choice to make, it was to either step up and do what I knew was right or kind of not do what was right. As much as it might seem difficult for me as a young person caregiving for someone old like that, It’s also difficult on the person that has the needs. Because at a certain point, they feel like they’ve kind of stepped over a threshold or a boundary that they shouldn’t have to have you be a part of.

Similarly, James reported his father wished he didn’t have to rely on him for care and wished he had more independence.

I know for a fact my dad wishes he was more independent. There's a lot of times where I'll help him with something, I'll sit down and two minutes later he's like, "Hey. I hate to bother you." And he'll make comments about "Sorry to bother you" or "I wish I could do it myself" or something like that. But I know for a fact that he wishes he could be more independent.
When talking about his role change, James reported he matured quickly and felt more of a connection with adults than with friends his age.

I know I've bonded with older people about caregiving [laughter]. But not anyone my age. I've always gotten along better with my friend's parents than my friends. A lot of times I would find myself, if we'd go over to my friends, I'd find myself talking with their parents out in the kitchen, helping them clean up while they were playing games. But I would eventually go back to them. But I always enjoyed talking with my friend's parents almost more than my friends. I think a lot of that was me searching for something I didn't have at home. I think a lot of it was I was forced to mature a little bit. So I saw myself as more mature than my friends. I know a lot of times I was annoyed by the immaturity of my friends. But, yeah. It screwed me up a little bit. But I think a lot of it was I always enjoyed talking with my friend's parents a lot.

James continued to describe his quick maturity led him to be immature in other ways.

The role change led James to seek out drugs and alcohol for a brief period. He reported a lack of parental guidance from the role reversal.

I matured in some ways, but I didn't have the guidance in other ways. So I was immature in a lot of decision-making and stuff like that. But general actions and interactions with people socially, I think I feel like I matured. But decision-making and making wise choices, I think, suffered because of not having that parental guidance. I got into some trouble just with drugs and alcohol and just made some poor choices, and a lot of that was kind of a resentment for my dad not being able to be a dad. My best friend, his dad and him had the ultimate relationship, and I never acknowledged it, but I was just jealous of them and the relationship that they had. That was probably the biggest impact it had, is kind of build up some resentment from my dad not being able to be the dad I wanted him to be, so to speak. But when I was younger, again, I wasn't mature enough to realize what was going on. I was just being young and dumb. I think anybody who's been a caregiver at that age is going to be forced to mature in some way, whether it's knowledge, social interactions, all of it, or-- I mean, there's going to be some increased maturity. But then there's probably going to be a lot of resentment with that because they have to do things other people their age don't have to.
Rachel’s matured quickly when she compared her problems to that of her mother.

It happened so quick I mean from the time I was 16 to 17 everything just started changing so fast. And yeah, I definitely had to grow up and put things in perspective. So my stupid dramatic problems when you're 16-years-old just didn't matter anymore. I'd see her fall and all of a sudden that stupid thing that happened at school didn't matter anymore. So it puts everything in perspective and definitely made me grow up faster.

Rachel described her role change with her mother and reported a negative effect on their relationship. She was worried that her problems would just be an added burden on her mother.

I would say that in the beginning it wasn't as obvious but it just-- that I became the one taking care of her and I did not feel comfortable having her take care of me anymore. So as a teenager that was really hard because I was used to going to her for advice and telling her everything and talking to her. We were so close. So I would talk to her about everything. I didn't hold back at all. But once she started getting more tired and more sick I felt like my problems were so stupid in comparison to hers. So I didn't want to tell them-- I didn't want to burden her with my own problems. So I kind of kept my own stuff inside and I focused on listening to her and helping her. And in that sense, I felt more like, "Okay, I'm now the mother and you're now the daughter that needs my help." And I felt like I was losing what I had of a mom. She wasn't the same mom anymore because she wasn't able to help me the way she used to. And a lot of hatred started to grow out of that, which wasn't her fault and eventually I sort of stopped wanting to talk to her. And then I just got so mad at her for it even though it wasn't her fault.

Like Rachel, Eric had a similar feeling when comparing his stressor to that of his peers. His increase in tasks, worries, responsibilities led Eric to have anger towards the “trivial” stressors of his peers.

Because I remember some days, people would come in and be complaining that they didn’t get the new iPhone. And I’m like, “I’m sorry, but I had to go grocery shopping for my blind mother. And I had to go get
the tires swapped. And I finished all my homework at one in the morning. And then I got up at four to go work out. So you didn’t get the new iPhone? Sorry. I’m sorry, really. Really, like I care [laughter]. Just like, nope.

Emily reported being torn between her new-found responsibilities as caregiver and that of just being a typical teenager.

At some point, you’re a teenager, and you want to help your mom, but at the same time, sometimes you’re a teenager, and sometimes you’ll be like, “Ugh, do I have to do this today?” There were some days I was like, “Really? Do I have to do it?” But I will do it anyway. But, yeah, there were those days that—still, you want to be a teenager, you’re a teenager, and you’re like, “I don’t want to do it!” But then you’re a caregiver, too.

Similarly, Sara also desired to have the typical teenage life but realized that her role as a caregiver was more important.

As a kid, I just wanted to sleep in late on a Saturday or whatever... I would want to sleep over a friend’s house and I had to worry about who was taking care of grammy. Um, or I want to go to a movie and I know if I am out or like a youth group event like my church and if it's midnight I know my grandmother is still up... and probably exhausted and leaning over to the right side and can't sit herself back up. I'm thinking 'oh my gosh, I can't stay here, I have to go home.'

The change in role from a carefree child to that of a caregiver with increased responsibilities was described by the participants as feeling like they matured too quickly. Some participants felt they didn’t have the freedom of doing what they desired at that time. However, when comparing their needs to that of their family member with MS, their needs seemed trivial. This role change can lead to frustration and resentment, a strain on the relationship with the family member requiring care, and jealousy of other families and peers.
Caregiving Support

During the first interview with each participant, the question was asked, “What was life like as a caregiver?” The participants described their experiences in detail providing stories of their daily lives as they knew it. They described being an emotional and physical support and gave detailed examples of their tasks and daily routines. After listening to their stories, it became evident the participants felt they were ‘a rock’ (metaphorically), for their family member with MS. The participants described themselves as a support for their family with MS: his hands, his feet, her ears, her stick, her eyes…

James described his experience as a secondary caregiver to his father where he reported to be called “his hands and feet” by his father.

But my mom’s always been there for him. She’s been amazing. I was more of the informal care, initially just kind of doing the heavier work. And my mom did the bathing and changing the bed and everything like that, so… My dad jokes that I was always his hands and feet.

James continued to describe his dad’s MS progression and his own daily routine as adolescent caregiver.

Well, when I was a teenager, my dad was still able to teach. And when I was a teenager is when he progressed from using a cane, to using a walker, to using a portable scooter, to then using a scooter anytime he didn't have to transfer, to being in a scooter completely. Or powered chair completely. So as a teenager, I would say waking up before school, would have to help him down the steps. My mom usually helped him get ready, which, at that point, he could do pretty well himself. Mainly just had to help him get down the steps, stand in front of him, be a brace. And then ride with him to school, make sure he could get out of the car, get in his scooter. He stopped teaching my junior year. He worked about a half-year. That's whenever he got pretty sick. And then my senior year, that was when he
retired. So during middle school is whenever it was the daily of helping him in the morning and then getting home and helping him a little bit, and then the biggest thing was at night, helping him up the steps. Because he was-- and really had trouble walking. So I would physically pick up his feet and bend his knee for each step up the steps.

Eric also described his experience providing physical support. Eric’s mother had vision loss which necessitated Eric to read and drive for her. Eric also called himself ‘her stick’ as he was his mother’s balance support.

It's like reading stuff on a menu. Like, "What's that sign say? Where are we? I can't drive. I don't see where we are. What's that say? Why don't you pick that?" It's like I grew up with it. I guess it would be classified as caregiving. But even something as simple as reading. "Hey, can you read this recipe for me? I can't… …She calls me her stick… I’d have to walk her. She’d basically just grab my arm and kind of lean on me and stuff and start walking. So like literal physical support in that sense.

Eric described multiple tasks in his daily routine.

Got to cook and grocery shop, all that. And so by probably when I was teenager, I was cooking a few days a week, doing laundry, if I had to take her, drive her somewhere, I'd drive her there, just you name it. Just cleaning around the house. I want to say basic household chores.

Eric discussed his daily routine, being on call during school, and how a bad day for his mother could change everything, including his mood.

I got to wake up. I got to get my workout in. I got to cook, take out the trash and stuff, make sure Mom's okay, make food, go to school. I was at the point-- yeah, by junior year, or hell, sophomore year, I had a cell phone. So I'd be texting her during the day, be like, "Hey, do you need me to get anything after school, or do you need anything, or--?" It was, I don't want to say constant worry, like crippling I-can't-do-anything kind of worry, but it was always on my mind. A lot of kids-- the school policy was you can't really have your phone on, or whatever. I always had mine on. I'd have mine on in my backpack. I'd check it every hour, basically, to make sure everything was okay. I don't want to say it was-- I don't know. One of the big things was I didn't have much of a social life because of
how focused on academics and taking care of my mom I was. So it was pretty much-- it was wake up, do stuff around the house, school, make sure Mom was okay, come home, stuff around the house for Mom, homework, workout, martial arts, workout, homework, do one last check around the house, bed. And I would-- Dad would be helping with that, too. And it just kind of just-- it just kind of turned into a cycle, just one day after another. Some days was a fluke. "Hey, this is-- I'm not feeling great. We got to go now." I mean, there was a day she just walked outside, fell, broke her arm in two places. I had to-- because she just couldn't walk, I had to run down, pick her up, carry her into the house, call school, tell them I had to take her to the ER, take her to the ER to get a cast, take her back home. She had a flare freshman year when I was 14, so we'd spend the entire week of my February vacation down in Newton Wellesley and getting steroids. So I was driving her down, and my then my grandmother-- and it was getting to the point my grandmother was having to drive her because it was every single day. It was always on my mind. Sometimes if stuff was going bad, I wouldn't say I'd be the happiest of campers sometimes.

Eric mentioned his task of injecting his mom with her medication was uncomfortable due to his fear of needles.

I had to give her shots a few times. I didn't like it. I have a problem with needles. Yeah, she taught me. The reason I did it was because he [Eric’s father] had work. It put holes like this big [hand gestured size of quarter] in her.

Eric reported his mother thought he was a good emotional support for her by staying positive despite the situation.

I just tried to stay positive. She used to say I did this thing called forward motion. She'd go fall down stairs, and I'd just keep pushing her up motion lava. Apparently, I-- I don't know. I always try to stay positive and stuff.

Eric described his mother’s progression and his positive outlook despite MS brutality.

Every day, every year, just get a little worse every day. I mean, you just didn't see something anymore, or you couldn't feel it, or you forgot where we were. Driving same way every year, and then one year, she just goes, "Where are we? Can't see where we are. I can't see this." With recipes, we
used to make strawberry jam all the time, and after two years, she just goes, "What's this recipe say?" We've made this for nine years. "I can't feel this. I dropped this. I dropped that. It's getting worse. I couldn't see that. I walked into that. I fell." Just every day, get worse. It's getting worse. And it sucks because there's nothing I can do about it. So I just try to keep positive. Yeah. Feel my best, try to make sure she's okay. Make sure she's happy and everything's okay. But it sucks.

Emily’s caregiving experience was both emotional and physical. She expressed the caregiving was more emotional than physical and described herself as her mother’s ears.

And she didn't want to complain to my dad all the time in terms of what she was feeling, so I was kind of like her ears.

Emily not only provided emotional support for her mother, she also helped with daily tasks and taking her to appointments.

Yeah, we used to clean up around the house and do the chores. Because my grandmother was the one that cooked, but we used to help around the house and go to the appointments with her. Just companion.

Emily talked about her typical routine providing care after school.

When she was regionally first diagnosed, unfortunately, she had difficulty walking, and she was in bed a lot. So go to school, I'll come back, I will go to her room, see how she was doing, make sure that she had her medications, help her out if she needed to go to the bathroom.

One of the caregiving task Emily spoke of was giving her mother injections. Emily learned how to administer injections from her Aunt who worked in a lab.

Later on, actually, I was the one-- because she doesn't like injections, so my aunt was the person that gave her the injections, the Betaseron and then the Avonex. Then, after that, I was the one that gave her the injections, the Avonex, every week.
Adam also gave a thorough description of his tasks. His caregiving tasks for his grandmother included emotional and physical support; including household chores and more personal tasks. Adam showed emotional support by just being present.

I would kind of just go down and sit with her we would watch her ridiculous shows on tv (laughs) and I'd watch bargathons on the home shopping network and talk about all the great gadgets she wants to buy everybody and at the time it was just fun for me but I realized she just needed somebody there. I would even talk about frustrations I was having upstairs [with other family] with her, we would just, we were there for eachother and we supported each other emotionally.

Physical support of his grandmother was frequent as Adams room was right next door to his grandmother’s in-law apartment. Adam described the physical support as the heavy lifting and transporting of his grandmother, which included the more personal tasks of transferring to the bathroom.

Some more of the intimate tasks would be helping her get from her chair on to the toilet and from the toilet back on to the chair. She was paralyzed pretty much from the torso down, didn't move, she absolutely needed assistance and one of the things I would usually do just because it was a strength type thing was pick her up and put her from the chair onto the toilet and from the toilet onto the chair. Occasionally, I don't know how detailed you want me to get, occasionally, she would have difficulty getting herself cleaned [nervous laugh] and I would help her in that capacity, with her...getting her up in the mornings. She typically would sleep in the bed, regular bed, with the chucks pads...Every single morning we would come down to the smell, the smell of urine and whatever else. So, cleaning that up and helping to put her in a hoyer lift, picking her up and transporting her from there to a chair for the rest of the day. I would say, anything that required pretty much lifting her or helping to transport her from one place to another or any of the heavy lifting...I definitely handled those type of things.

Adam described some household tasks and chores that he would help his grandmother with.
Other tasks would be preparing breakfast, helping her with the breakfast. A lot of times she would have trouble drinking her coffee, we would help her pick her cup up and I would help her drink that. She loved when I made donuts, they had a donut maker so I would make donuts for her. Cleaning dishes, um, she lived off of a card table in her living room, I would say just sometimes organizing and cleaning that.

Sara, like her brother Adam, was heavily involved in caregiving for her grandmother. She described herself as a primary caregiver along with her brother.

Well in the sense of doing the like physical requirements of caregiving, I felt like more of a primary. So if somebody needed to wake up to help my grandmother, my mother was always home but usually that responsibility fell on me or maybe my brother. In my mind I thought 'well oh, if there was ever an emergency my mother is here'. So, I felt like in maybe that sense I was secondary as far as if there was an emergency. Does that make sense?

Her emotional support was like that of her brother, spending time with her grandmother and just being present.

I used to hang out down there cause she was my best friend, so I would just hang out with her even if I wasn't performing caregiving tasks.

Sara was responsible to help with the daily tasks which included physical care and personal care such as catheterizing, hygiene, and dressing. She gave an example of this when discussing her daily routine.

Ok, so I would get up in the morning, I would go downstairs, of course I would have to undo the catheter bag immediately because it had been filling all night...unless I had to go down in the middle of the night, um, and then my grandmother would...she had her schedule so I'd roll her over and she'd do her business on a chucks and I would clean that up, clean her up and then we'd pick her dress. It was always a dress and she always wore knee highs. And of course even though she was not walking anywhere she always had to have shoes because that was proper and so we always had to decide what shoes do you want so we would get her dressed and then ahh, at different points in caregiving there were different
situations so sometimes in the early situations we would sit up on the side of the bed and we'd pivot into her wheelchair and then she ended up having to be lifted and we illegally pushed her down her hallway in the Hoyer lift [laughs] I know its not good and that would be one person...and it wasn't an electric one, it was a hand crank, a hand pump lift and I'd get her in her chair, she had a tray that sat on her, it was like a recliner, so it was an electric recliner she would have a tray and we would get her breakfast, brush her hair, brush her teeth, that kind of thing and get her propped up with pillows so she had a tendency to lean to the right, she always used to say "your the only one who can position these pillows and it stays good the whole day". I'd shove them in there really low down behind her right hip and then honestly I would hang out with her unless I had to do homeschool or whatever I would do that. I would hang out with her because we would watch the price is right the game shows she would watch. Then in the middle of the day I would always be eager to say 'i'll go make her lunch' because I could sneak soap operas [laughs] because she watched soap operas religiously and I wasn't allowed to watch soap operas...mainly General Hospital...and I was like 'this is wonderful!' I would make her gourmet meals so I could watch the whole soap opera [laughs]. And then I would remember doing her bill paying, you know at one point she was able to use a typewriter and as much as she could still do she insisted that she do so I would painstakingly watch her type out self addressed envelopes and everything so yeah, there was a lot of routine.

Sara also felt she was on call 24/7 even in the middle of the night.

My grandma was in the in-law apartment downstairs and my bedroom was directly above her bedroom so if she needed to go to the bathroom or there was something wrong she would call out for me, so it wasn't my mother waking up or my brothers. She would call out for me probably because she knew I could hear her. She would call, 2:00, 3:00 in the morning. And I was so annoyed that I would have to get up, but then when I ever would get to her room and just see her mouth so parched, I thought, "How could I not do this for somebody?" Or she might need to go to the bathroom or her catheter bag might be full and need to be emptied. So those would be kind of things in the middle of the night. Or maybe her hip hurt and she couldn't move. We'd have to rotate her or something like that.
Rachel’s caregiving tasks were less due to her mother’s new-found symptoms at that time. Her mother’s MS was not yet diagnosed when Rachel was an adolescent. Rachel described caring for her mother’s symptoms of vertigo, fatigue, and muscle spasticity.

At that point, her only symptom was really tiredness and getting dizzy, getting vertigo. So just help her sit down and help her pack her lunch every now and then for work. Like cutting up her apple, little things like that. I do remember there being a time when we were shopping and she had a dizzy spell and I had to sort of put my arm around her and escort her to the nearest bench. But at that time she didn't have a cane or anything. So you could say I was a little bit of a mobility help, I guess, at that time. Every now and then. It was really random. It wasn't consistent. It was only whenever she had like a flare up.

Rachel recalled additional task related details of her caregiving experience during the second interview.

I think the biggest ones that I think I skipped on were the really simple things. Things like helping her pack her lunch for work because she was still working full-time. So I just remember helping her pack her-- kind of standing at the counter was too much for her and she always wanted to eat really healthy, especially in the beginning when she thought diet played a really important role. She always wanted to have fresh fruits and veggies but standing at the counter to do that was often way too hard for her. So I remember helping her pack her lunch for work and cutting up all those veggies and all those fruits was a big thing for her. And then just the really little things like she couldn't-- when her fingers weren't working or if they were numb she couldn't tie her shoes. So helping her put her shoes on and tie them was something that I used to help her out with. And then just helping her get settled. So when she would transition somewhere else, her water mug would be just out of reach so just helping her make sure everything was in her reach and getting her settled in the right spots. Especially, once she was in her spot for the night-- she'd settle on the couch at like 7:00 and then once she was there I wanted to make sure everything was in reach for the night, for her nightly activities. So we put the remote and her water and everything she needed kind of right there. So just getting her settled.
Rachel remembered having to take on a task that was once her mother’s. She reported her mother’s inability to then do this task made her upset and frustrated.

The refrigerator was a big one and again, I was still in that really bitchy mode so I would get really upset that there was expired food in the refrigerator because she used to clean it out. So I would find expired food or moldy food and I would shove it in her face and be like, "Look how gross this is. Why is this--." I was such a bitch. So then cleaning out the refrigerator became one of my things that I helped with. And my dad is still terrible at that. So that was definitely my job [laughter]. And just dusting, vacuuming a lot of the chores, I ended up picking up a lot of slack.

Beth gave a few examples of caregiving for her mother out in the community and at home. During caregiving, she tried to promote her mother’s independence as much as possible.

I'd go with her places. Sometimes I'd go into stores because she needs a medication I'll be the one to go inside and go to pharmacy. Let's see. Some days putting away the rollator for her. Some days I'd cook. Mom enjoys cooking for the most part, so, which is good. And I don't want to take away her-- if she can cook-- if she wants to, go for it. I don't want to limit her at all unless it's in the heat, then it's like, "Mom, no. Nice try you're in." I just try to keep an eye out.

Beth gave an example of her constant worry about her mother and how family stressors increased her MS symptoms.

At one point she should have been wheelchair-bound just due to stress because my sister moved out with my father and the stress from it-- she was going down the stairs on her butt basically. She was having a hard time walking and I was scared. I was honestly, truly scared.

Beth described her worry led her to have a cell phone while at school, so she could be on-call in case her mother needed help.
I kept my phone in my pockets so then I could feel if it vibrated or whatever and especially as-- when I got into my senior year I had my senior releases so it's like, "Okay, now I can maybe--," I could text during that time or whatever. So if I needed to talk to mom-- well, she knew the times when I was on break and when I wasn't, so. She's got my schedule better memorized than I probably did [laughter].

Beth described how she and her sister would give their mother injections of a MS medication. Beth explained she learned how to inject her mother by practicing in the doctor’s office.

My mom actually has a lot of my sister and I do injections for her when my mom first did Rebif they had an auto-injector so you didn't see the needle at all or anything. That was pretty cool… I sort of looked at what the doctor did and then my sister and I were playing around in the office with the empty thing and it was sticking into some ball, or whatever.

Tammy, like her sister Beth, gave a brief description of her caregiving, which included fetching items for her mother and cooking.

We would get home and then we would talk. And then I would help her if she needed something from downstairs because we used to live in a raised ranch. And then if she needed something from underneath one of the cabinets or something, I would help her. Or if it was up higher. Usually, she just needed help with grabbing something or cooking or anything like that.

Tammy described a flare-up her mother experienced after she moved back in with her mother. For a brief period Tammy lived with her father after the time of her parent’s divorce.

When she first-- or when I first moved back she was having a problem with walking because she just had a really bad relapse with it-- or with the MS. So I would like-- If she needed help I would support her.
The daily routines of the adolescent caregivers included physical and/or emotional support. Participants described numerous caregiving tasks which included bracing, ambulating, lifting, transferring, pivoting, driving, running errands, reading, fetching, cooking, cleaning, bill paying, bathing, catheter care, incontinence care, comfort care, administering medication, etc. The participants described providing emotional comfort and support through listening, and being a companion.

**Influence of Caregiving**

Does being an adolescent caregiver shape who you become when you are older? According to multiple participants, their development was positively influenced by caregiving for their family member with MS. Many reported they were stronger because of their caregiving as an adolescent. Adolescent caregiving was shown to improve how well one reacts to stressful situations. When Adam’s wife was diagnosed with MS and his son was diagnosed with leukemia, Adam felt better prepared.

I felt like this is no big deal, whereas a lot of people I talked with, they were like, ‘I don’t know if I could handle that. I don’t know if I could..’ I was like, ‘I got this. It’s not a big deal. It definitely helped shape the person that I am today…it prepared me for my adult life. Because my adult life has been kind of nothing but a handful of medical surprises for me as a husband, as a father…I feel like God prepared me to be the man that I am today when I was taking care of my grandmother.

Similarly, Sara believes adolescent caregiving prepares one for adulthood, ultimately bringing fulfillment and better coping mechanisms.

In all honesty, if I had chosen it at the time, I probably...if I had the choice, I probably wouldn’t have chosen it. So it’s not anything to pat myself on the back or to dig on other moms, but they have a really hard time just
doing life. They have all kinds of anxiety and a lot of fear and they just get overwhelmed and they almost kind of shut down and they’re depressed. And I feel like…I feel really sad and I try to wrap my mind around why. And I can just only imagine maybe they haven’t had to do hard things their whole lives…when you step outside yourself, and especially when you step outside yourself and are meeting somebody else’s needs, it definitely brings joy and fulfillment in ways that doing everything just for yourself and your own pleasure will never provide.

For Emily, her adolescent caregiving experience led her to a future of helping others with MS. Emily felt her emotions benefited from continuing to helping others in need.

As I was studying medicine, I started to be interested in neurology…I started to understand how to treat it, and how to help her, and other resources to do. So giving her advice on what things to do. I feel good that I’m helping somebody and I’m helping my mom actually go through this and giving her advice.

Emily felt more connected to others with MS and their families because of her history as an adolescent caregiver.

When I talk to patients and they’re trying to describe a symptom and they’re like, ‘I can not..’ and then I say exactly how they are feeling and they step back and say, ‘How do you know?’ So it gives me a little bit of a better connection. Not a little, a lot better connection with the patients because sometimes they don’t feel like we understand them.

Is caregiving a life skill that everyone should practice, but is lacking today? According to Sara, humans are innately selfish and lack this skill. She believed that helping others in need is an important skill that all humans need but do not want.

When you’re a teenager, you’re selfish and you think about yourself. But I was forced to step out of myself every time I went to my grandmother’s apartment because I didn’t want her to feel like a burden. And so I think it is a life skill that is lacking today where people are willing and able to step
outside themselves and their wants and their desires in order to meet somebody else’s needs.

Multiple participants talked about how they developed a sensitivity of others in need. They described it as “being aware” and they felt they were more apt to notice, step up, and help someone in need where others without the caregiving experience would not. Beth described a work-related experience.

I think it has made me more patient, kinder person because I understand slow-moving people… It’s like, ‘okay. I get that.’ So it’s helped me learn a lot of kindness and patience, where I noted my other co-workers don’t have. And I have a customer who has MS…goes into the grocery store. So when she was saying she’s forgetful and everything. It’s like, ‘Oh, yeah. No, I get it. My mom has MS so I understand.

Similarly, Eric found he is now more sensitive to the feelings of others and when others are insincere towards him. Eric also describes his increased understanding to when someone needs help.

I’m definitely more aware of other people’s feelings. And I’m also, I want to say, generally pretty good about picking up when someone’s BSing me. Even if they’re…you know, not ok. I’m like, ‘Nice try. Talk. Now.’ I just like making sure people are okay. If somebody looks like they are struggling, I’m going to try to help them. I don’t know if that was because of the MS that I grew up with or that’s just me. That’s just kind of who I am.

Eric caregiving experience as an adolescent has trickled into his adult life. He still finds himself counting stairs out loud, which he started as an adolescent caregiver for his mother who was visually impaired from MS.

I count stairs for people who don’t even have—it’s just instinctive. I was walking around with my girlfriend a few weeks ago, we were going up some stairs, I was literally just muttering to myself, I was like “One, two, three, four,” and she’s like, “What?” It was the first—I just noticed like—
because normally I do it in my head, but I was doing it out loud this time and I was like “Oh, sorry.”

James similarly described his increased perception of the needs of others.

It’s given me a much greater appreciation for caregiving [laughter]. I think that’s the biggest thing is a lot of people my age, they’ll walk past somebody who’s in a wheelchair or be annoyed by somebody in a wheelchair blocking the entrance to a restaurant or causing problems at a restaurant. But I have gained an extraordinary appreciation for those situations because I’ve often been that person causing the problem. I think that’s the biggest thing that I realized at a young age is the difference that it is that you have to be aware of a lot more in that situation. And I think it’s made me a lot more appreciative of everything that has to do with that.

Rachel also described being more aware of others in need. Her awareness of the needs of others makes her grateful for what she can accomplish.

I’m definitely more grateful of the things that I can do. The quote that she [mother with MS] used to say was, ‘I run because I can.’ So I like to just keep that in my minds now and remember all the thing that I can do and remember to do them, just embrace the abilities that I have I guess. I’m really aware of other people like when I’m out in public and I don’t know them but I see that they dropped something or they’re walking with a cane and maybe they need the door held, just little things that I probably wouldn’t have paid attention to or notice. But now that I kind of know a little bit more about invisible diseases I pick up on them and I’m more willing to step in and just help, and not stand back and be shy and wonder if they need help. Now, I just kind of go and help them and don’t think twice.

Sara reported she is grateful for her health and the things she can do and uses her experience to help and bless others.

Having had that experience growing up, I feel like I have more empathy or compassion. Empathy in the way that…not that I’ve experienced what people who are suffering or ill have experienced, but just a sensitivity to the fact that they’re going through something and I’m blessed that I’m not and I have the ability to meet needs.
Adolescent caregiving taught Sara to step outside of herself to complete a task for another, even when that task was unpleasant or hard. Sara described two stories of putting her desires aside and being able to complete unpleasant tasks others (lacking the caregiving experience) could not handle.

I’m thankful that, at the time, I would have just like to be able to sleep in every Saturday. And sometimes I could. Sometimes my mother would just tell me, ‘Don’t wake up in the morning. I’ll take care of Grammy.’ So, at the time, it felt like, ‘Ugh,’ but I did it anyways and so now, in my life now, I notice that, If there’s a hard job to be done, something that’s unpleasant, unpleasurable, even within my own family, or my in-laws, I notice people back away. They back down from that task. And I just have this ability to wrap my mind around it and just, one step at a time. I’m just going to do it…we had a sick dog recently and he had diarrhea that I’ve never seen before and it was on the walls and it was everywhere. And my husband couldn’t even…I mean, he couldn’t go into the room without gagging…he wouldn’t have been able to help me at all. And so I just kind of went into the mode in my mind where you just shut down your senses and you just say, ‘I need to clean this diarrhea,’ and I just do it. There was a time that my husband’s mother was in the hospital and she vomited and the nurses were all busy and I was right there, completely capable of helping her. My husband and his sisters ran out of the room because they got nauseous because she vomited and I cleaned her vomit. And so I don’t think I could have had that ability to function in that capacity if I hadn’t been accustomed to dealing with unpleasantries, just of the human body.

Sara’s adolescent caregiving experience helped her develop her ‘moral compass’ which she believes is lacking nowadays in most teenagers.

I don’t know if I would be the same type of…being able to sacrifice. I don’t know if I would be able to do that or willing to do that if I hadn’t had that experience when I was really young, when all my morals and my moral compass and who I was going to be were forming. I was meeting needs in a very tangible way that a lot of kids would find pretty unpleasant…situations that help establish their moral compass to be one of sacrifice and empathy and compassion.
Sara views caregiving as a gift, which she was given.

When I look back on it, during the time of caregiving, it seemed like a little bit of a burden and a bummer and I wished that I could have had a more free schedule. But in retrospect, now, I realize what and honor it was and a privilege it was to be involved in somebody’s life in such an intimate and crucial capacity. And that I think that it was, for me, something that really changed the person that I was and the kind of person that I am today. So when I think about it, I just think the whole experience of caregiving was a gift to me.

James talked about a fine line between positive and negative, and that if you don’t come to an overall understanding of the benefits, the negative aspects can ruin a person.

I think, in general, I think it’s made me a better person. I think I’m only a better person because I’ve come to an understanding of it. I think; however, that was, whether it was the grace of God or whatever, I think if I wouldn’t have come to an understanding it would have ruined me.

Adolescent caregiving has influenced many of this study’s participants to choose career paths in the ‘service’ industry. Some of these career paths include: teaching, cleaning industry, military, medical field, and some of the younger adult participants are still in the career decision-making process (see Appendix H). The participants felt that caregiving during their adolescent years had greatly influenced them to become stronger, sensitive, and helpful individuals.

Support for My Needs

The participants were open and quite willing to divulge their needs as adolescent caregivers. Their needs consisted of knowledge, good communication and support. They made many recommendations to help other adolescents who are currently caregiving for
family with MS. Participants expressed their desire for knowledge and staying informed by both parents and the medical community.

Adam recognized that in order for education to exist for adolescent caregivers, they first must become visible.

But I think educating-- but see that's the whole thing. In order for someone to be able to educate me on how to do something, they have to first of all notice and recognize that I'm actually helping do that.

Similarly, Emily recognized the importance of making the adolescent caregivers visible.

She gives a solution for helping healthcare providers become aware of family members and possible adolescent caregivers.

That is actually hard because a lot of the patients come by themselves and it is hard to identify. At least asking more about the household on to the patients what is contents, and how many children they have, what age, to knowing the people and actually getting the family in. I believe that's important for them to also understand. And I know it is hard, but as I grow up and going into the clinic and seeing I know what to expect with my mom but your mom going back and forth, yeah, she going to the doctors but you don't understand why she's going to the doctor. But having the family come in at least once at the time of-- at least, I'm saying at least because things change. But at time of diagnosis having the full family come in… I think that is a way that we can identify and who's actually-- and give a little bit more perspective on who's actually doing the caregiving.

Emily described the importance of doctors providing information to the adolescent caregiver to decrease their confusion when it comes to exacerbations.

It's more or less-- because I know it's hard to understand when you're an adolescent. Like the pathology, but at least what to expect, and what can happen, what cannot happen, but to get a better sense of an overall what will be the need and what things can make worse. Because, yeah, I know that there were some episodes when my mom could not walk and she was in bed but then I didn't know how long that was going to last. Then as I
grew up and I understood the disease we know, "Okay. Yeah. You need your solumedrol. It's like you need the steroids. We need to get you in. I will go with her but it's confusing to try to say, "Okay. What's going on?" Is that explanation of... "Yes. These episodes can happen. This can get better. This is what you need to--" it's a lot to put in on a kid in a sense but at least you're not that confused.

Emily recommended having pamphlets available with simple explanations about MS and what to expect.

I think that we need to get more, like I said, more simple explanations. So, yeah, there is pamphlets for patients but I think to get it into a more simpler way that we can give that to the kids that will actually be better.

Emily described the importance of having a social worker in the MS centers.

And this is something that actually we don't have and that's there's some centers that do. It's a social worker because there's a lot of social and I can say emotional support trying to see what is the household, yet I don't have to go into the house. But understanding a little bit better who is taking care of who. But yeah, understanding the social aspect and having a social worker in the centers that actually will be really helpful. Unfortunately, the nurses have a lot of work but if we can get that social part and give them resources at least.

James also stressed his greatest need was communication and education on what was happening to his father.

I think the biggest thing that would've helped me would be somebody to kind of walk me through what was happening. Because I don't think I really had a grasp on what the hell was happening. I think it was just kind of like "This is your dad. This is how he's different." And no one really explained why it was happening and where things were going to be going, and. Yeah. That's probably the biggest thing is just, it would've been nice to have him, or somebody sit down with me and explain why he wasn't able to be the dad that everyone else had and kind of go from there. But that's probably the biggest thing.
James continued to describe how to go about educating an adolescent caregiver. He describes adolescent caregivers may not be receptive to direct approach by healthcare providers. Instead he believed an indirect approach through the parents may be the preferred method.

I know for me, my parents were so stressed and emotionally occupied that there was no way that they would be able to do it here, that they had the ability to understand that I needed that. I think it's one of those things where-- I think a lot of teenagers wouldn't be very accepting of it also. I don't know if I would've been accepting of somebody outside of my family coming in and trying to explain to me what was happening. I think a lot of it is people coaching the parents or the person afflicted with MS to be like, "All right. So his is how your child might be affected by it. These are the things that they could very well be needing or be looking for." I think that's probably the best way to do it because I don't think I would've been very receptive to a stranger coming and talking to me about it.

James mentioned the importance of communication and education by healthcare providers to the parents and parents to their children. James felt he did not have either and had no explanation as to why his father was “falling apart before his eyes”.

Communication. Education and communication. I think a lot of it would be-- I don't know the set-up for everything. But I would say if somebody's diagnosed with MS and the MS community is meeting with that person, I think having that person communicating to the parents about how communicating to their children how things are going to be changing and how their responsibilities could be changing. I think a lot of that up-front information would be good. I think a lot of it is just an open and consistent communication about everything. I never had any sort of, "Okay. So dad's going to be sick or dad is sick. And things are going to get worse and eventually he's going to get to this point. And that's whenever we're going to need you to help with everything." It was just kind of like, "Oh. He can't walk now; now you need to help him" or "He's having trouble getting up the steps. You need to help him tonight because it's a lot harder tonight." And then two months later I find every single night I'm helping him. And then two months later we're moving his bed downstairs. And then a couple
months later, he's only in a chair. That sort of stuff. It just happened. I didn't have any sort of information or communication about what was happening.

Rachel stressed the importance of education and support for the adolescent caregiver. She recognized that they are going through a stressful time and with a lack of information and support they may be feeling overwhelmed.

Basically, information and support. Any way that the MS community can be providing teens with information and ways to make them feel less alone is the biggest thing because they already don't know what's going on in their own life. And then they have this huge bomb dropped on them with the person they're taking care of and it's a lot to juggle and if you don't know where to turn and if it's not right in front of your face you can get really lost.

Rachel gave an example of her desire for knowledge about MS and the difficulty asking her parents for information.

I just think the biggest thing like being an adolescent with a parent with MS was just not getting it and not-- like wanting to know more, but also not wanting to sit down and talk to your parent about it. You're still in that, "I'm too cool. I don't want to talk about it. Leave me alone." You kind of brush it off, but you also really do want to know more. So that's just the biggest thing I remember is not understanding it, not knowing what to do, and just wanting more information, but also not wanting to ask for it. Having that typical teenager reaction of you want your parents to love you, but you don't want to tell them that you love them, you know?

Rachel reported her mother thought she was trying to protect her by not talking about MS. However, this was opposite to what Rachel wanted.

Like I wished that she would tell me about it. I wished she would talk to me about it, but she wanted to hide it from me because I was the youngest child and she didn't want me to have to be involved with it. So she thought she was keeping me safe and keeping me protected, but I was just like, "No. Just tell me what's going on. Talk to me about it." So that was hard.
Besides the desire for knowledge and education from adult family members and medical professionals, participants also gave suggestions for other information resources. Rachel suggested one way to educate adolescent caregivers about MS would be to start a MS news feed for kids via Instagram or Facebook. This news feed would update kids on the latest MS research, explained in simple terms.

So one thing that I do like is the Tisch MS Center is on Facebook and they post-- they have something called Research Tuesday and Thursdays where they bring the latest information from their lab. And I love that they do because it shows up right in my newsfeed and I click on those every week and they're really accessible and easy for me. I don't know if I were a teenager if the information would be as easy to digest. It's definitely very medical so it's often hard for me to even understand the terminology and the jargon that they're using. But if there were a way that they could tone that down for kids, that would be awesome. Like an MS News for Kids type of thing and putting it in their Facebook feeds or their Instagram feeds so it's there for them.

Adam desired more knowledge on MS and how it progresses.

Better understanding as a kid like what MS actually was, what types of things to expect. When you're dealing with the disease especially disease like MS that manifest itself in so many different ways, I don't feel like we really had a good understanding or knowledge of what MS actually was. So we didn't really know what kind of things to watch for. I had no idea how the disease was going to progress. So I think just the overall knowledge base of data that was available wasn't that great.

Adam continued to describe a situation where he needed more knowledge about care for his grandmother.

I think for me, a lot of stuff with caregiving for my grandmother was kind of just common sense. But there certain things that I just especially when she was catheterized-- if I remember correctly, a tube came disconnected somewhere. I don't know if it was on her body end or the bag end. But I had no clue what to do. I mean, I realized something had to be reattached,
but I had no idea how to do what needed to be done. And so stuff like that was definitely--it stumped me.

Adams sister, Sara, also gave examples of her need for education and support during two separate incidents caregiving for her grandmother. The first incident was a fall in which her grandmother fractured her hip. Sara was home alone with her grandmother and unsure what to do.

Yeah, I would have appreciated training, just with maybe pivoting skills. I mean, we did it so many times, but one time, my grandmother did kind of gracefully drop to the floor and so that was kind of traumatic for me because I felt helpless. It was just kind of a graceful fall, but she didn't know that her MS had progressed. I didn't know and I didn't even know that that was a potential. And had I maybe known, then I might have checked to make sure she was sure-footed before I pivoted, but it was such a-- just a common practice every day, multiple times a day, to pivot her onto the toilet. And so I--we did the one, two, three, my arms wrapped around her so it's like a big hug every single time, and her legs just were like jelly. And so I slid my arm around her and I unlocked her wheelchair with my free arm and I kicked it backwards and then we just kind of both went slowly, slowly, slowly to the floor. And so I know she didn't want me to feel bad that she was on the floor of her bathroom. And so I just hung out with her there until my parents came home and I was just--I couldn't believe it. I can't believe I--I mean, I didn't really drop her, but I wasn't able to successfully keep her upright. And obviously, I felt awful. And then after that, she had pain and so she had to go and get X-rays and she had a broken hip. So I just felt like the worst granddaughter ever.

Sara gave a recommendation for a 24-hour support hotline for caregivers where if they have any questions about caregiving they could access that support as needed.

No, I wish that--if I think about it now, something that would be beneficial for caregivers is maybe a 24-hour hotline that is not necessarily a life-threatening emergency because that's what 911 is for. And had I known then what I know now, I would have just called 911 because it would be no big deal for paramedics to come and lift her up. I didn't know that at the time. I thought 911 was just if you're dying. But I could have called a 24-hour hotline and just asked them, "This is the situation and
what do you think I should do?" So maybe just staffed by nurses or-- and they can offer advice, suggestions, because they probably would have said, "Call 911. It's not a big deal. And they'll come lift your grandmother." And I mean, thankfully, nothing additional happened to her because she waited for a couple hours on the floor. I mean, we just hung out. But I'm sure there are situations where something like that could happen and there could be devastating consequences of waiting on the floor for a couple hours. So, yeah, it would have been helpful.

Sara gave another example of the need for education regarding care of a catheter. She recommended a 24-hour support hotline would have been useful.

I remember another time that my grandmother called me in the middle of the night and she just had a feeling like her catheter bag was full. And so it really was full. And so I went to clamp-- they didn't have fancy catheter bags when she needed-- when I was taking care of her. And I went to clamp the tube so the urine wouldn't flow out when I emptied the bag and I had grabbed a pair of scissors instead of a clamp. So here I am at like 2:00 AM. I don't know, it was late night, early morning. And my grandmother now had no way to correctly go to the bathroom. And I didn't know how to remove the balloon. I didn't know if it was deflated, how to deflate it. Thankfully, after that, my aunt gave me training. But it would have been awesome to be ahead of the game and have training on that because that's something that could happen. And even if it wasn't just a grabbing scissors instead of a clamp, even if it was just you are transitioning her and you realize, "Oh my gosh, her catheter literally just fell out," or, "The balloon deflated," or just knowing what to do.

Beth recommended education by physical therapists on different moves and workouts in order to help their family member with MS at home.

If I can have the physical therapist either show me or have something actually written out on what I can do to have-- what machines I could have Mom do, like the ones you pull down and something like that, so. I think that would help a lot, especially so I could see the different-- I mean, I've seen some things when I'm there with Mom, occupational therapy and physical therapy, but I don't have the training to do, where I can be like, "Okay. Do bridges. Hey. Why don't you do some bridges?" Or whatever.
Adam discussed a lack of supplies and equipment to help his grandmother during her progressive stage of MS. He believed there should be education on how to work with the caregiving recipients as MS progresses.

I would have loved if I saw more effort being given to like, and she may have been too progressed at this point, but just more effort given to just have her upright somehow. So I think for me, the lack of back then, the lack of supplies, equipment, protocols if you will on how to work with people at different stages of MS.

Besides education and communication, another need that was discussed by the participants was support groups. Adam mentioned the importance of connecting with other adolescent caregivers via support groups.

And I'm even thinking too maybe if there was even support groups for younger caregivers, that could have been useful. Or even if it was just like families that are caregiving for family members or whatever. Just some kind of a community that you could go to like a hospital and meet in a waiting room, or a cafeteria, or something, and just talk about-- that probably would have been useful, too. Especially later in our teen years, it would have been helpful to connect with other people that were kind of seeing and dealing with similar things.

Rachel also recommended support groups but thought it was important to make the support groups more enticing to adolescents, and to decrease the intimidation factor. She recommends making it fun and allowing you to bring a friend.

Yeah, I think support groups are a good idea I just-- for me, I know I never could bring myself to attend them. They're definitely a good idea but I think instead of calling them MS support groups if you could call them something more enticing for teenagers like a bowling night and, "Oh, hey. All the kids that are going bowling this night they happen to have parents with MS too so maybe you'll make a friend." If you frame it in that way kids might be more likely to go. I just think there's a stigma around-- "I don't need support. I don't need to go to a support group. I'm fine," especially as a teenager. But if you say, "Oh, it's like a bowling night with
a bunch of kids who are also in your boat," then I might have gone to
something like that and if you can bring a friend, bring someone that you
feel comfortable with that's your best friend that doesn't have-- not a
caregiver, but you can bring them with you. That would be cool. I
probably would have done something like that.

Emily stressed the importance of starting a support group for adolescent caregivers.

It's because we have a lot of blogs for patients and support groups for
patients. Maybe a support group for caregivers. See what other kids are
doing, how they're coping with stress, understanding that you're not by
yourself. Because sometimes you feel like you're by yourself and you're
having this responsibility that other people don't have.

James recommended support group headed by a ‘big brother’ someone who understands
their situation or has been in the same situation.

Support, I guess, would be the biggest thing. I think a lot of it would have
to be finding that perfect match though. Somebody who really relates to
them. And somebody who they can see as more of a friend and a shoulder
than a counselor or-- I think it's kind of like that big brother thing. But
yeah. I don't think it-- me personally, I don't think that I would've been
receptive to a counselor.

Participants were collective in their view that adolescent caregivers need, and
desire, knowledge from both adult family members and medical professionals. They
desire frequent communication from providers and adult family members and desire that
the caregiving recipient initiate communication. Recommendations were made on how
adolescent caregivers could access additional information from age-appropriate handouts
and online resources to 24hr hotlines and support groups.
CHAPTER 6
INTERPRETATION OF THE FINDINGS

Introduction

In this chapter an interpretation on the findings from participant interviews is presented. The findings are described in the order they were reviewed in Chapter 5; along with discussions of previous research on young caregivers.

Invisibility

Why Me?

It became apparent that an increased bond or close relationship with the caregivee increased the likelihood that they would become a caregiver over that of a sibling. All participants reported a close relationship with the caregivee. However, James, Emily, and Rachel reported their bond with the caregivee was closer than that of their siblings, and that is why they stepped into the caregiving role. In their grounded theory study on young caregivers (age 4-19), Metzin-Blau and Schnepp (2008) found affection for the ill parent as a motive for caregiving, along with additional motives of responsibility, pride, emerging morality, and socialization into caregiving tasks.

When more than one child has a close bond with the caregivee, they will likely share caregiving tasks. Siblings Sara and Adam reported they worked together in their grandmother’s care; when one sibling felt uncomfortable with a task, the other sibling was able to help in that area. Similarly, siblings Beth and Tammy shared responsibilities;
however, they were at different times due to circumstances in the family. This finding was similar to the descriptive, retrospective study by Lackey and Gates (2001), which looked at the future effects of young caregiving for family with a variety of chronic illnesses (see Appendix A). Lackey and Gates (2001) discovered if there was more than one sibling in the home, caregiving tasks would be divided up and agreed upon by the siblings. Despite four siblings sharing responsibilities in the present study, this was not the case for all the participants. Some siblings kept their distance and some adolescent caregivers learned when they needed to distance themselves.

Young caregivers described the use of emotional and physical distancing as a coping mechanism. Emotional distancing included hiding feelings, concerns, or daily events from the caregivee. Examples of physical distancing included moving out of the house, spending less time with the caregivee, focusing on school, friends, sports, and use of drugs and alcohol. Distancing was a coping mechanism for the adolescent caregivers and appeared to coincide with the caregivee’s decline in health. Similar findings were noted by Svanberg, Stott, and Spector’s (2010) mixed method study ‘Just Helping’: children living with a parent with young onset dementia, in which their participants (age 11-18), detached themselves emotionally from their family in order to cope or to hide their feelings. Their participants also used distancing to become more self-sufficient. Likewise, Earley, Cushway, and Cassidy (2007), found that distancing was used as a coping mechanism by their caregiving participants (age 10-16) for family with mental
illness, disability, learning disability, or chronic illness. Some participants did not have to use distancing to cope as they felt caregiving was instinctual.

Caregiving appears to be instinctive and to come more naturally to some young caregivers compared to others. One sibling may withdraw from caregiving if another sibling steps forward and is more at ease with the caregiving role. James reported his brother withdrew from the caregiving role despite being close in age. Rachel stated her brother was out of the house during the time their mother needed caregiving help. Emily, Adam, and Sara found caregiving to be instinctive. Adam reported he was naturally able to step outside the boundary that normally should not be crossed. Participant Eric had no choice in caregiving, as he was the only child and started caregiving at the age of five.

In summary, caregiving for a family member with MS, is less distressing to some adolescents, and indeed they may feel caregiving is natural role for them and that they enjoy helping. Those adolescents that have a closer bond with the caregivee tend to step into the caregiving role more readily than those who do not have this bond. If a sibling is uncomfortable with caregiving and another sibling steps forward in this role, they may use it as an opportunity for distancing. When the caregivee’s health declines or the caregiving tasks are difficult, adolescents use both emotional and physical distancing as a coping method.
Invisible in My Role

When society thinks of caregivers, they typically think of adults who fill this role. Research, media, and services has focused on adult caregivers. Little to no attention is being placed on the ‘behind the scenes’ caregivers who take on a primary or secondary caregiver role. With the lack of attention from society, adolescent caregivers do not recognize themselves as caregivers. They frequently reported they didn’t know what caregiving was. The participants saw themselves as just being ‘part of the family’ and doing what they needed to do to help. According to Adam, there was no recognition for what he and his sister did, it was just part of their lifestyle. Eric also found that caregiving was a part of life and he was just trying to be a good child. The participants believed their caregiving was typical of other families, and it was something that everyone did. These findings are consistent with previous studies conducted by Moore & McArthur (2007) and Nagl-Cupal, Metzing, & Mayer (2015) in which young caregivers had a hard time self-identifying as a caregiver and thus their role was invisible to them, and to those they knew. Sometimes, caregiving becomes essential to one’s identity when started at a young age, as they don’t know any different (Nagl-Cupal, Metzing, & Mayer, 2015).

The caregivee often did recognize the caregiver role in the adolescents. Tammy stated she didn’t know she was a caregiver until her mother told her she was. Adam, Sara, and James reported that the caregiving tasks were harder on the caregivee than on them. James recalled his father’s frequent apologies for his caregiving needs. Adam reported his grandmother saw him and his sister as her caregivers, “nobody ever recognized us as
caregivers other than potentially, my grandmother.” Similarly, Sara also reported her grandmother acknowledged her caregiving, “I mean, my grandmother never—she was always so appreciative and she always, always felt like, ‘Oh, I wish you didn’t have to do this, these things.’” When Rachel’s mother asked for help, it meant she really needed it. Rachel gave an example of a quote her mother used to say, “I do what I can when I can so when I ask for help you know I really need it.” From what participants shared in their responses, it appeared the caregivee was cognizant of the adolescent caregiving role, and disliked having to cross a boundary and ask for help. The question then arose, does the caregivee contribute to adolescent caregiver invisibility because of their guilt? In past research, a reason given for young caregiver invisibility was guilt on behalf of the caregiving recipient. In their study on fifty young carers and their families in Australia, Moore & McArthur (2007) found that often times the family felt guilty because they placed their needs on their children.

Invisible in Healthcare: The Uninformed

When the parents/caregiving recipients became aware of their adolescent’s caregiving, it became important to acknowledge the caregiving role despite their desire to protect the adolescent and relieve their burden. Acknowledgement involves discussing MS, keeping them informed of disease progression, and including them in MS health care.

Most of the participants reported they were uninformed about MS. Multiple Sclerosis was not explained to them and they had to learn about MS on their own through
online sources, teachers, and other adults whom they trusted. With limited knowledge about the disease, and what to expect, they were anxious about what would come next, and ill prepared to manage changes in their family member’s deteriorating health. Rachel and James felt resentment and anger when the caregiving recipient tried to keep their disease progression a secret from them. James felt his family was non-communicative and didn’t like to talk about what was happening despite his strong desire to know more. Sara and Adam felt their lack of information was due to the lack of knowledge about MS at that time. The participants reported they desired knowledge and an open and honest dialog with the caregiving recipient. Emily took the desire for knowledge a step further than the other participants, as her experience led her to an interest in medicine. Tammy and Beth felt their mother kept them well informed, and they adjusted to the caregiving role better because of it. Beth reported she desired education from physical therapists on how to help her mother exercise. The lack of being informed about the caregivingee’s illness was also noted by Aldridge and Becker (1993). In their phenomenological study on *Punishing children for caring: The hidden cost of young carers*, Aldridge and Becker (1993) found their participants lacked knowledge, “depressingly unaware about the nature of the condition of their parent/care receiver” (p.385) and expressed a need for more information.

Most of the participants felt they were not recognized by healthcare personnel. They were unacknowledged caregivers, left out of the treatment rooms and discussions about the caregivingee. Eric reported an instance where he was told to ‘scram’ by medical
staff because of his age. His role was limited to driving his mother to medical appointments, urgent cares, and the emergency rooms, but not included in health care decisions which could affect him. Adam described being involved with getting his grandmother ready for her appointments while Sara recalled bringing her grandmother to her appointments with her mother but being asked to stay out of the treatment room. Emily went with her mother to her neurologist and was not recognized as a caregiver. It wasn’t until Emily showed an interest in medicine as a career that her mother’s neurologist began to acknowledge her. The exclusion from the health care of their family member with MS, caused the adolescents to feel ignored, confused, and worried.

This theme of overlooking or ignoring the adolescent caregiver is not new. Findings from three prior studies with young caregivers, were that professionals unconsciously ignore young caregivers, and instead exclusively focus on the needs of adult caregivers and the afflicted family member (see Thomas, et al., 2003; Keigher, Zabler, Robinson, Fernandez, & Stevens, 2005; Aldridge, 2006). Gray, Robinson, and Seddon (2008) reported that this was partially due to provider fears of having to get involved with mandated reporting and child protective services. Health care providers have a responsibility to protect children and adolescents, ensure they are safe, and their needs are being met. Therefore, young caregivers must be recognized in their role and their needs evaluated.
Invisible in the Community

Although the majority of young caregivers wanted to be acknowledged by members of the healthcare system and the community around them, two participants mentioned the desire to stay hidden from others in the community. James talked about an experience when his father accompanied him and his friends to a movie. James relayed mixed feelings about this. He was excited that his father wanted to do something with him, but he was also embarrassed that he had to caregive in front of his friends. Eric was the most vocal about staying hidden. He talked about his concerns of unwanted pity, fear of burdening others, desire for privacy, fear of ridicule or bullying by peers, and a disdain for the typical response of outsiders when they found out about his mother’s MS.

In addition to not identifying as a caregiver, a second common reason for invisibility found through research was fear. Fear of embarrassment was noted by Aldridge and Becker (1993) and Moore & McArthur (2007). In these studies, fear of embarrassment, or guilt on behalf of the young caregiver and the caregiving recipient were related to the desire to remain hidden. Multiple other studies also found that caregiving should be a private family matter (see Keigher, et al., 2005; Bolas, Wersch, & Flynn, 2007; Moore & McArthur, 2007). The fear of bullying and ridicule by peers was discussed by Banks et al., (2002), Butler & Astbury (2005), and Keigher, Zabler, Robinson, Fernandez, & Stevens (2005). The dislike for negative reactions of strangers upon learning of the family member’s illness was not discussed by past research. However, six studies (see Table 2) noted a stigma associated with caring. In their
interpretive, phenomenological analysis of young caregivers for a dependent relative, Bolas, Wersch, and Flynn (2007) found their participants (age 14-18) disliked the negative reactions when outsiders found out about their caregiving activities. Unwanted reactions, whether they be about the caregiver illness or about the caregiving itself, can negatively affect adolescent caregivers as they are establishing their identity and outside opinions tend to be important.

Support

The overarching theme of support was noted early in the data collection phase. Interview after interview, the participants touched upon support in different ways. Early in the pre-caregiving years, they described having no needs and no use for support. As their new role as caregiver progressed, they went through a role change and maturation phase. With their new-found caregiver role, they became the support for their family member with MS. Participants discussed their needs and desires as adolescent caregivers and gave recommendations to improve future support for adolescent caregivers in MS.

All the Support I Need

This was the first study of its kind to have the participants recall what life was like prior to caregiving along with their experience’s caregiving. Participants frequently mentioned their pre-caregiving life was fun, they had less worries and a more carefree outlook. They tended to look back on these years fondly with a positive attitude. They described the caregivee as more active, fit and strong, frequently exercising and eating
right, described activities and bonding time with the caregivinge, and emphasized a great relationship. Emily described it as a time of ‘less worry.’ James reflected on this time as father and son bonding time. He described frequent activities they would work on together which included gardening and recycling and just staying active. Rachel recalled her mother as an athlete who enjoyed running marathons, a hard worker, being social with friends, and being an active member of their church. Tammy recalled her mother being active, going for frequent family walks with their dog. Adam and Sara recalled when their grandmother lived in her own home and they would visit. They reported they had a wonderful grandparent-grandchild relationship where their grandmother spoiled them and had sleepovers.

Despite the passage of time, participants were able to express the pre-caregiving years as memorable and carefree. There were able to be a child and enjoy the freedom of childhood without concerns or worry for the health of their family members. The family member was seen as healthy, strong, and active, and the participants relationships with family member was that of a child to a caring adult.

I Am Your Support; I Am Your Rock

This section describes the experiences of the adolescent as they transitioned into the role as caregiver for their family with MS and interprets those shared experiences. The participants caregiving experiences helped transform them into who they are today: A stronger, more self-sufficient adult who is more in tune with the needs of others, and willing to step forward and lend a hand.
Participants described their role change as a confusing time where they didn’t understand what was happening. Role changed was discussed in the previous studies on young caregivers (see Table 2). The participants felt lost, unsure, and yet, felt they had matured quickly. With the decline of the family members health, they felt as though their roles reversed; they viewed themselves as the adult taking care of their family member with MS. Adam described his role reversal and compared it to the circle of life, “…when you were a baby I changed your diapers, and then when you are older I’m going to change your diapers.” The participants’ worries and concerns were put on hold as the needs of the family member with MS was more important. Rachel, Sara, and Eric described situations where their ‘typical’ adolescent desires were found as meaningless compared to the welfare of the caregivee. Adam described role change as a decision-making time where he could either be selfish and focus on his own needs and desires or put his feelings aside and do what was “right”. Adam describe it as stepping over a threshold or boundary. In the past research, this role reversal was described as ‘parentification’ (Earley, Cushway, & Cassidy (2007). Some participants described a shift of parental focus from the child to the ill family member. The participants in this study reported needs of the family member with MS were more important than their own and their needs were ‘trivial’ in comparison. During a crisis or stressor such as a diagnosis of MS or seeing MS progression, adolescent caregivers are able to think abstractly; comprehend the severity of the caregivee’s illness and compare and contrast
James’s role change led him to feel more comfortable with adults than with peers. He felt that with the caregiver role, he was more mature than others his age and felt he had more in common with his friend’s parents than his own friends. James described hanging out with friend’s parents while his friends would play video games. He acknowledged this was because he did not have a father-son relationship at home anymore. Only one previous study described the loss of key family relationships. The study by Svanberg, Stott, & Spector (2010) looked at children who had parents with early-onset dementia and found that children described a loss of the parent-child relationship.

James also reported his role change and lack of parental guidance led him to seek out drugs and alcohol for a brief time, “Decision-making and making wise choices, I think, suffered because of not having that parental guidance.” This was also seen in a study by Cree (2003) which exposed the misuse of substances by young caregivers. James continued to describe a resentment for his father in that he was not able to be a typical father figure because of the MS. He conveyed jealousy of his friend’s father-son relationship and described it as the “ultimate relationship.” The loss of a parental figure was also recognized in a previous study by Kavanaugh (2014) which looked at the caregiving of children and adolescents for a parent with Huntington’s disease.
It became evident that despite MS and the cargivee’s progression, adolescent caregivers still desire normalcy when it comes to relationships with the caregivee. Even though the caregivee may not be able to do the things they once did, keeping the bond/relationship with the adolescent caregiver should be top priority for the caregivee in order to keep a sense of normalcy. This may involve adjusting the bonding activities to suit both adolescent and caregivee.

Like James, Rachel reported the role change to caregiver put a strain on her relationship with her mother. Except in this case, Rachel stopped communicating with her mother about her life because she perceived this would put undue stress on her mother. She believed her problems were trivial compared to her mother’s illness. As a result of not sharing her life problems with her mother, Rachel became emotionally distant from her mother, saying that “she wasn’t the same mom anymore because she wasn’t able to help me the way she used to.” Rachel shared feelings of resentment as she did not have the relationship she desired with her mother. Adolescent caregivers may feel a lack of parental support due to concerns about burdening the caregivee, and the lack of a continuing parent-child relationship. Aldridge & Becker’s (1993) study on the hidden cost of young carers, revealed that young caregivers had strong desire that the caregivee (parent) maintain their adult role.

Young caregivers also described a loss of social support. During the time of role change, Emily reported being torn between her desires as an adolescent and the needs of her mother with MS. Similarly, Sara described her role struggle of not being able to fully
enjoy activities outside the home because of the constant worry about her grandmother’s needs at home. Worrying in caregiving is not a new finding as it was mentioned by nine young caregiver studies (see Table 2). Adam discussed his desire to make new friends but explained his caregiving activities kept him from developing long-lasting relationships. Eight previous studies touched upon young caregiver difficulty in forming friendships (see Table 2). Eric found that his stressors were greater than that of his peers and became agitated when they would complain about ‘typical’ adolescent stressors. Seven previous studies have discussed the increased stressors on young caregivers (see Table 2).

Socially, adolescents are looking to establish relationships with those around them. Caregiving may interfere with establishing friendships because of rapid maturity, worry, caregiving availability and tasks, and guilt on behalf of the adolescent.

**Daily Routine and Tasks**

Adolescent caregivers gave detailed descriptions of their caregiving activities as adolescent caregivers. They described their typical routines, responsibilities, and talked about the hours they spent caregiving daily. The participants frequently described themselves as the caregee’s body part that was affected by MS: His hands and feet, her eyes, her ears. For example, James stated, “My dad jokes that I was always his hands and feet.” Sometimes, participants described themselves as an assistive device. For example, Eric recalled helping support his mother when her balance was affected by MS, “she calls me her stick…I’d have to walk her. She’d basically just grab my arm and kind of lean on me and stuff and start walking.” Emily recalled “I was kind of like her ears.”
The tasks ranged from household chores, fetching items for the caregivee to more physical activities such as lifting, moving, and transferring. Sometimes more personal tasks of bathing, hygiene, and helping with toileting were performed. In a few cases, administering oral and injectable medications and medical tasks such as caring for a catheter were reported (see Figure 2).

Tasks and daily routines for the participants increased as the family members MS progressed, or when relapses occurred. Common caregivee MS symptoms reported by the participants included: difficulty ambulating, moving, transferring, foot drop; spasticity; numbness; problems with fine motor skills such as cutting food, preparing food; fatigue; vision problems; and depression. Much of the caregiving occurred because of events that occurred from the MS symptoms. For example, Eric reported many times he had to bring his mother to the hospital emergency department due to her accidently cutting herself while cooking or falling due to troubles with ambulation. As a result of the fall, Eric had to lift his mother off the ground, put her in the car, and drive her to the emergency room. He also had to call out of school that day to take care of her.

All participants reported they helped with chore-like tasks such as taking out the trash, doing laundry, cleaning around the house, shoveling, cooking and cleaning. All the participants reported fetching things or putting things away for the caregivee. This was due to difficulty with ambulation and increased fatigue. Participants reported comfort support ‘setting them up’ with water, remotes, food, and pillows within reach.
When ambulation difficulty and fatigue set in, adolescent caregivers reported they would assist with support, standing/sitting, pivoting, transporting, transferring, getting in and out of cars, up and down stairs, in and out of bed, lifting, repositioning, and transferring using hoyer lift (see Figure 2). More personal tasks include helping use the bathroom, incontinence care, care of Foley catheters, hygiene related tasks, and dressing and undressing. Less frequently mentioned tasks included paying bills, contributing to household finances, reading, messages, and coordinating care.

Caregiving tasks were similar to past studies (see Table 1) with a strong emphasis on mobility and activities of daily living. Caregiving tasks involved support for the ailments of the caregivee with MS. For example, if the caregivee had vision problems, the adolescent caregiver would drive, read for them, or count steps; if they had foot drop, the adolescent would help lift each foot going up stairs and support their weight. As the caregivee’s MS progressed, so did the intensity of caregiving tasks to include personal care. As the caregivee MS progressed, so did the intensity of caregiving tasks to include personal care. The correlation between task load with disease progression was reflected in Metzing-Blau & Schnepp (2008) young caregiver study with multiple caregiving recipient ailments: MS, stroke, Parkinson’s disease, asthma, cardiac insufficiency, cancer, depression, psychosis, post-traumatic disease, or a mixture of both somatic and mental illness.
Figure 2: Physical Support

Besides caregiving physically, emotional support was also provided (see Figure 3). Emily reported she was her mother’s primary emotional support especially with her bouts of depression. Emily would frequently ‘check in’ on her mother after school and would spend time with her and just listen. Many participants such as Adam, Sara, James,
Rachel, Emily, and Beth described their emotional support as spending time with the caregivee/keeping them company, listening, accompanying them to appointments or out in the community. Beth reported she frequently reassured her mother when her mother was depressed and down on herself. Adam provided emotional support to his grandmother by hanging out with her, watching her favorite shows, cooking her favorite donuts and playing music for her. Emotional support was discussed in six studies (see Table 1). For the participants in this study, emotional support involves spending time with the caregivee, comforting, reassuring, and listening to them. In Warren’s quantitative (2007) study comparing young caregivers to their non-caregiving peers, young caregivers are more likely to provide emotional support (>3->26 hrs/week) to a caregivee/family than non-caregiving peers (<2 hrs/week).

Figure 3: Emotional Support

Hours in a day involved in caregiving ranged from one to ten hours/day. With the majority being less than six hours per day. Four of the participants reported they were on
call in their caregiving. Adam and Sara reported their grandmother would call out to them all hours of the day and night for assistance. Eric and Beth reported they had a cell phone at school and would call the caregivee during the day to check in on them.

Caregiving’s Effect on Future

The participants clearly described how they believed caregiving has affected them today. All the participants reported an increased awareness of others in need and reported to have increased sensitivity to those needs. Not only are they aware, they also feel more comfortable to step forward and help. In the study *Influence of social environment on young carers, assistance and consequences of caregiving*, Sahoo & Suar (2010), found that young carers are more nurturing, sympathetic, and enduring as compared to non-caregivers. Similarly, in *Experiences of being a former young carer: effects in the transition into adulthood and in the present life situation*, Nagl-Cupal Metzing, and Mayer (2015) noted their participants felt enhanced coping mechanisms which allowed them to better handle difficult situations as an adult. These attributes were similar to the participants in this study. Sara gave many examples of how her caregiving experience helped her see the bigger picture and to put the needs of others before herself. Sara gave examples of helping her extended family and strangers. She reported that service for others became rewarding. Caregiving also gives inner strength as was described in Sara’s examples of helping strangers, helping clean up vomit/stool, and just dealing with everyday stressors. Sara described that caregiving has help her appreciate the small things in life, enjoy her family, and not stress over the small stuff. She compared herself to other
moms who have a hard time doing everyday life, get stressed about minor things, and turn to alcohol, or time away from their families to cope.

Rachel reported her experience helped her appreciate what she has and what she is able to do. It also has helped her be more aware of others in need. Similarly, Beth reported she is able to recognize those that may need care and offer support. She believes she has more patience and kindness due to her caregiving experience, and that this has helped her at her workplace. Eric described how he is more likely to help someone when they are struggling, and senses when someone is not being truthful about how they are feeling.

James’s experience has given him a greater appreciation for caregiving. He is thankful for handicap entrances and accommodations and is more understanding of the caregiver situation. James reported that if he didn’t come to an understanding of it, it could have ruined him. Emily is more sensitive to her patients because she has experienced caregiving firsthand and therefore has a greater understanding of what her patients are experiencing. The positive effects of adolescent caregiving reported by the participants are similar to Lackey and Gates (2001) findings, in which young carers become more caring and nurturing adults.

Four out of the eight participants in this study chose careers in service (military, teacher, medical field, cleaning industry). Two of the younger participants were still undecided about their careers. The remaining two participants chose careers which interested them in information technology and automotive technology. Every participant
in this study reported caregiving positively affected their future by making them sensitive to the needs of others and willing to help when able to do so. Similarly, Lackey and Gates (2001) found several of their young caregiver participants entered career fields which focus on helping others.

**Caregiving’s Effect on Development**

Much of the past research on young caregivers has focused on the negative effects of caregiving with limited positive effects. This is because focus has been on young caregivers who were actively caregiving. Young caregivers are immersed in caregiving and may feel overwhelmed with their dual roles as caregiver and adolescent. Feelings of stress and uncertainty ensue, and they have difficulty seeing the bigger picture which develops over time. Despite their feelings of egocentrism during this time of development, they are asked to step outside their comfort zone and consider others needs before their own. Caregiving requires them to change roles, mature faster, put their own feelings and desires aside, and increase their daily workload. These secondary stressors may impede upon the natural primary stressors of adolescent development such as identity formation, moral development, establishing friendships and relationships, and developing independence. The secondary stressors are what place adolescent caregivers in the “at risk” category.

In continuity with the past research on young carers, the participants of this study described many negative feelings as an adolescent caregiver: loss of parent/caregiver relationship; loss of “carefree” life; increased feelings of confusion, stress, worry, anger,
helplessness; less time for community activities; less time for friends and developing friendships; and increased fear of the unknown. James described the loss of a father figure and guidance when it came to decision making, leading him to try drugs and alcohol. The participants reflected on their adolescent caregiving years and described themselves as “young and dumb” lacking the ability to understand at that time, the greater picture. They frequently described wishing to go back in time to change their attitude towards the caregivee and the situation. When reflecting on the typical selfishness of adolescents, Adam stated, “Wake up. Stop thinking about yourself. There’s other people out here that need your care, your love, and your support.”

Caregiving had a significant positive impact on the development of identity and morality which participants were unable to recognize as an adolescent. Caregiving taught them to be altruistic and sensitive to the needs of others. Sara, Adam, Rachel, and James described the feelings of the caregivee became more important than their own. This positive impact was also noted in identity formation as the career many participants chose was one of service: healthcare, cleaning, teaching, and military. It was also seen in their eagerness to offer recommendations on adolescent caregiver needs. Adolescent caregiving improved their coping skills to daily stressors; helped them focus on the important things in life; and to not stress over small things they faced.

Despite all the positive effects of caregiving found in this study, it is important to recognize the difficulties adolescent caregivers face and to find ways to alleviate the burden secondary stressors may place on their development. It appears time and
knowledge can help adolescents gain a positive viewpoint on caregiving. Participant James said it best, “I’m only a better person because I’ve come to an understanding of it. I think; however, that was, whether it was the grace of God or whatever, I think if I wouldn’t have come to an understanding it would have ruined me.” In the meantime, adolescent caregivers require guidance and knowledge from family and healthcare professionals to help promote a positive outlook on caregiving.

Support for My Needs

The participants were able to recall their needs as adolescent caregivers and gave clear description of their desires at that time and things that would have benefited them. Knowledge, good communication, and support were important to all the participants. Participants described confusion because they lacked information on what was happening to their ill family member. They didn’t clearly understand what MS was or anything about the stages or progression. They desired to know more and felt they were not able to ask questions due to increased stress at home or the parents desire to keep them ‘protected.’ In order to educate themselves they sought out information from ‘google’ and trusted adults outside their family: e.g. teacher, parent of a friend. The need for knowledge was recognized in past research by Aldridge and Becker (1993) and Gates and Lackey (1998).

The second most frequently mentioned need was open communication between the caregivee and the adolescent caregiver. Many of the participants reported feeling they could not communicate openly with the caregivee. They became resentful that they were
left out of updates and communication on the health of the caregivee. Participant’s experiences seeking information and communication led this researcher to believe adolescent caregivers strongly desire information from their parental figure or caregivee. They want to hear it directly from the source who is experiencing the symptoms. This would also improve the relationship between adolescent caregiver and caregivee by starting open and honest dialog between them, where they feel they can approach the caregivee with questions when they arise. The difficult communication between the caregivee and the caregiver was noted by Ali, et al. (2012) in their study: *Daily life for young adults who care for a person with mental illness: A qualitative study*. In their study, Ali et al., interviewed 12 young adult caregivers aged 16-25 and discovered their participants had a difficult time communicating with the caregivee; instead, participants would confide in others.

The participants also reported the desire for support: being kept abreast of the MS advancements and caregivee progression. They reported in the past, the medical community has not acknowledged them as the caregivers for the family member with MS. It is important that healthcare workers be aware of these adolescents as they report being more mature than the typical adolescent. Adolescents can think abstractly, they are acutely aware of their family member’s MS symptoms, and are extensively involved in their care. They should be given the chance to ask questions and be given age-specific information on MS as well as updated information on research and advancements in this area. Aldridge and Becker (1993) recognized this need in their statement, “Children are
obliquely accredited competence to deal with adult responsibility but are denied the fundamental right of being listened to and of being involved in decisions which affect their lives.”

Participants described ways to support adolescent caregivers. Rachel suggested an online MS news feed for adolescents via Facebook or Instagram. Sara suggested a 24-hour hotline where they could get immediate support at all hours of the day. Emily suggested having age-specific pamphlets about MS in the waiting rooms of MS centers and MS community. She also suggested having a social worker who is educated on recognizing young caregivers work at the MS centers.

Support groups were also discussed by a few participants: Adam, Rachel, James, and Emily. They recommended having fun youth caregiver outings to draw the young caregivers in. Also, allowing them to bring a friend to decrease their anxiety of going to support group event. James recommended a support group being run by somebody who has been a caregiver in their youth…like a ‘big brother.’ The adolescent caregivers may feel more willing to talk to someone who can relate to them.

When reviewing the past research on young caregivers, there are a variety of needs described in the studies ranging from personal needs to needs for the family. Six studies reported the needs of information/knowledge/education and nine studies reported the need for support (see Table 4). Moore and McArthur (2007) emphasized the importance of recognizing the needs the entire family as well as the young caregiver.
CHAPTER 7

IMPLICATIONS

Introduction

The participants’ experiences were vivid and for the most part, hidden from public eye. Despite some concerns for revealing their caregiving activities, the majority of participants believed it was important for nurses, other healthcare professionals, and the MS community to recognize their role in caregiving and offer their support. In short, they sought to make the invisible visible.

Adolescents taking on caregiving responsibilities report an increased maturity compared to their non-caregiving peers. They face challenging and often difficult tasks in their role as caregiver which requires them to put their own needs aside for the needs of the caregivee. This selflessness hastens their maturity and often leads the adolescent caregiver to feel the child-parent role is reversed. With their increased responsibilities and maturity, adolescent caregivers’ thoughts, opinions, questions, and needs must be acknowledged by family, community, healthcare professionals, and society.

In this chapter the implications of the study findings as they pertain to nursing and other health professional care and the MS community are discussed. Insights for family and caregivee are also offered to support the needs of adolescent caregivers. Finally, recommendations are made for future inquiry in young caregiving research.
Implications for Nursing Practice

Nurses are optimally suited to recognize adolescent caregivers. Nurses have multifaceted roles such as case managers, visiting nurses, bedside nurses, healthcare management, supervisors, educators, researchers, and more. Nurses also work in various health care environments including: home health care, school nursing, camp nursing, rehab nursing, primary care and ambulatory health care specialties, urgent care nursing, emergency nursing, medical surgical nursing, telemetry nursing, etc. Compared to other healthcare professions, nurses spend more time at the bedside helping ill family members. This gives nurses the ideal opportunity to assess patient’s family dynamics and identify previously hidden adolescent caregivers.

Adolescent caregivers and their families may be more willing to confide in nurses, as compared to other professionals, because of trust. According to the Gallup poll of 2018, nurses are considered the most honest and ethical professionals for the 17th year in a row (Gallup Organization, 2018). Being the highest trusted professional gives nurses the unique advantage in establishing rapport and talking with families and young caregivers. Nurses can also relate to the adolescent caregivers, in that they have chosen caregiving as their career and have extensive knowledge on caregiving tasks, procedures, role strain, caregiving needs, disease, disability, and treatments. Nurses are well educated to engage, teach, and encourage patients, and patient families, in the management of chronic disease, they are ideally suited to provide this needed service to adolescent caregivers.
It is also important for other healthcare professionals: physicians, physical therapists, occupational therapists, counsellors, etc. to be able to recognize adolescent caregivers as this is vital to the assessment and ongoing health of the patient with MS. For example, in awareness of the caregiver’s needs, the provider might request the caregiver accompany the patient to the appointments, provide appropriate education to the caregiver, discuss the MS patients needs with the caregiver, and offer services and support to assist as needed with caregiving. Participant Emily suggested immediate family accompany the patient upon first meeting the provider. This research study provides support for this practice along with periodic family visits in order to keep the family updated and have their needs and concerns addressed.

Educational material on MS should be available in neurology offices and MS centers written for all ages. Resources for additional age-related information should be referenced. According to the participants, more support services for caregivers are needed, these include: 24-hour hotlines; peer support groups, online age appropriate MS news feeds; and anonymous, moderated discussion groups for adolescent caregivers.

Implications for Caregiving Recipients

Participants were clear of their concern for the family member with MS and their health condition and progression. They desired to be informed of their health and updated with any changes to the family members health. In some instances, the caregivers acknowledged this withholding of information may have been an attempt by family members to protect them; however, they preferred to be informed. Left uninformed, they
felt resentment, confusion, anger, worry, and jealousy. These negative feelings led to the negative consequences of fractured bonds and relationships with the caregivee, feelings of loss, and jealousy of peers’ family bonds. The participants also described a sense of not wanting to burden the caregivee with their own issues, therefore they kept their feelings, emotions, and events of their own life away from the caregivee.

It is important for the caregivee to understand that hiding information is often bidirectional. If they keep information from the adolescent caregivers, the caregivers will start to hide their own lives from the family members out of a sense of mistrust or fear of overburdening the caregivee. In order to avoid this, it is important to first stress that despite the illness, it doesn’t change your role as mother, father, grandmother, or grandfather. Second, keep communication with the adolescent caregivee open by frequently engaging them in dialog, such as inquiring about their day, discussing interests, and being present emotionally and physically. Third, spend quality time with the adolescent caregiver. Time spent together should not always be about your caregiving needs. Spend time together doing things the adolescent caregiver enjoys. This may be difficulty due to your symptoms; however, activities can be tailored to suit your needs. The adolescent caregivers will appreciate the effort you make in support of them.

Lastly, the caregivee should stay open and honest about their present condition to establish trust. Keep the adolescent caregiver abreast of any new developments in the caregivee’s health and bring them to appointments periodically to allow them to ask questions and obtain information from medical professionals firsthand. This will show
the adolescent caregiver that they are valued for the care they provide and respected for their need for information and communication.

Implications for Future Research

The majority of research has been conducted by the disciplines of psychology and social science, in the countries of Australia and Europe. Only nine studies were conducted by nurses and very little research has been conducted in the United States. Therefore, more research spearheaded by the discipline of nursing in the United States is warranted.

The previous research on young caregivers has allowed for a wide age range of participants from children to young adults. This study was the first to delineate young caregivers in their sample by focusing on adolescent caregiving years of age 13-17. More focus needs to be made in defining the age groups of young caregivers, as their development may affect their needs in the role of caregiver. In past research, many studies did not indicate the caregiving recipient illness (see Appendix A). The majority simply reported the caregiving recipient had a chronic illness, mental illness, or disability. It is important to specify the disease being studied in order to improve the generalizability of the findings. If multiple caregiving recipient illness are used in a study with young caregivers, the reasoning as to why they grouped them together needs to be explained.
Because of the lack of programs, policies, and services for young caregivers in the United States, this population continues to go unnoticed and remains in need. It is with great hope that this study will help promote awareness for this understudied population by acknowledging their caregiving, making them visible. By making them visible, nurses can address their needs and concerns and offer them support. Nurses should be educated to include of the entire family in management of MS, especially young caregivers in the family. Age-appropriate literature such as MS pamphlets and online news feeds need to be developed and piloted based on understanding and usefulness for this age group. Lastly, the development of fun, activity centered, support groups are needed, based on the knowledge gained from the participants. Future evaluation of the efficacy of the support groups will be needed.

**Strengths and Limitations of the Study**

Since only one previous young caregiver study focused on the caregiving recipient ailment of multiple sclerosis, this phenomenological study broadened the knowledge base for this population and contributes to nursing research by expanding our understanding of adolescent caregiver experiences. This study provided significant data for analysis and interpretation considering sixteen interviews were conducted. Despite the in-depth interviews about young caregivers’ experiences, the number of participants is limited, which decreases the generalizability of the findings. Generally, qualitative research is limited by the number of people who were not interviewed and therefore, not able to share their experiences. Additionally, all the participants were reflecting on
previous experiences, a few to many years past. Therefore, recollection of events may have been inaccurate, and some details may have been forgotten. Concerning data collection methods, the use of both in-person and online interviews may have influenced participant comfort levels and candidness.

**Closing Remarks**

Access to the hidden group of young caregivers can be challenging for researchers because these caregivers continue to go unnoticed by the healthcare system, the greater society, and do not recognize themselves as caregivers, thus limiting research with this population. Past studies have found that young caregivers are an ‘at risk’ population due to their precarious developmental stage of transition in which secondary stressors and the parentified role can threaten their successful development. In an effort to understand their experiences, this study provided a retrospective look and in-depth examination of eight adults who cared for a family member with MS while they were adolescents (13-17).

The theme of “Invisibility” in their caregiving role was recognized from the beginning, challenging the recruitment process. The participants reported they did not recognize themselves as caregivers during adolescence and described being uninformed about the MS symptoms and progress; which contributed to their invisibility. While a few participants described reasons they wanted to stay invisible, the majority reported the desire to become visible to both family, the community, and healthcare professionals.

Support was described by the participants in a few ways. Their pre-caregiving years was generally described as carefree, with needed family and social support, and no
need for additional support. Participants experienced a role change, in which they described rapid maturation and reversal of roles as they became a caregiver. The adolescent caregivers described becoming the support for their family member with MS, and shared detailed caregiver tasks, both physical and emotional.

Participants described their overall experience as difficult but recognized that their experience was crucial to their development, and who they had become today. Generally, a positive outlook was described despite the negative outcome of their family members MS progression, and in some cases ending in death. The participants spoke of the caregiving recipient fondly and with love and reported they were now more sensitive to the needs of others because of their caregiving experience. The participants were excited about the study and wanted to support other adolescent caregivers who may be going through the same situation. Multiple recommendations were given on how to identify adolescent caregivers and improve their experience caring for a family with Multiple Sclerosis.
### APPENDIX A

#### CHARACTERISTICS OF THE RESEARCH

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<tr>
<th>Year</th>
<th>Author</th>
<th>Discipline</th>
<th>Country</th>
<th>Design</th>
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<td>1993</td>
<td>Aldridge, &amp; Becker</td>
<td>Social Science</td>
<td>UK</td>
<td>Qualitative: Phenomenology (not explicitly stated), convenience sample</td>
<td>N=15 caregivers; n=11 age 3-18; n=4 adults who had been caregiving since early childhood. Recipient condition not mentioned.</td>
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<td></td>
<td></td>
<td></td>
<td>[2 separate interviews in the home, verbal questionnaire.]</td>
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<td>Beach</td>
<td>Public Health</td>
<td>USA</td>
<td>Qualitative: Grounded Theory [semi-structured interviews, open-ended questions]</td>
<td>N=20 adolescent caregivers mean age of 18, mostly secondary caregivers. Recipient: Alzheimer’s Type dementia.</td>
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<td>Gates &amp; Lackey</td>
<td>Nursing</td>
<td>USA</td>
<td>Qualitative: Phenomenology [interviews, selected participant observation, &amp; unstructured needs survey]</td>
<td>N=11 caregivers age 10-19, Recipient: cancer</td>
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<td>Smith-Battle</td>
<td>Nursing</td>
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<td>Looks at teenage mothers caregiving and how they extend family caregiving traditions (part of a larger longitudinal study)</td>
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<td>2003</td>
<td>Cree</td>
<td>UK</td>
<td>Social Science</td>
<td>Qualitative: Grounded Theory [questionnaire, follow-up interview]</td>
<td>61</td>
</tr>
<tr>
<td>2003</td>
<td>Shifren &amp; Kachorek</td>
<td>USA</td>
<td>Psych</td>
<td>Qualitative: appears to use a retrospective descriptive method, [brief semi-structured phone interviews, 3 instruments.]</td>
<td>24</td>
</tr>
<tr>
<td>2003</td>
<td>Thomas, et al.</td>
<td>UK</td>
<td>Social Science</td>
<td>Qualitative: Phenomenology [informal focus groups, loosely structured interviews]</td>
<td>21</td>
</tr>
<tr>
<td>2004</td>
<td>Eley</td>
<td>UK</td>
<td>Social Science</td>
<td>Qualitative: Phenomenology [unstructured interview]</td>
<td>11</td>
</tr>
<tr>
<td>2005</td>
<td>Keigher, et al.</td>
<td>USA</td>
<td>Social Science</td>
<td>Qualitative: Longitudinal [interview narratives; interviewer field notes]</td>
<td>7</td>
</tr>
<tr>
<td>2005</td>
<td>Butler &amp; Astbury</td>
<td>UK</td>
<td>Social Science</td>
<td>Qualitative: Case study [comparative national statistics local pilot study, monthly and quarterly data capturing instrument, and service user focus group]</td>
<td>7</td>
</tr>
<tr>
<td>2006</td>
<td>Aldridge</td>
<td>UK</td>
<td>Social Science</td>
<td>Qualitative: Phenomenology, [interview with parents, interview with child carer, interview with key workers]</td>
<td>140</td>
</tr>
<tr>
<td>2006</td>
<td>Early, Cushway, &amp; Cassidy</td>
<td>UK</td>
<td>Psych</td>
<td>Quantitative: Quasi-experimental [focus groups to administer questionnaire] YCPSS (young Carers Perceived Stress Scale) tested</td>
<td>108</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Discipline</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample Size</td>
</tr>
<tr>
<td>------</td>
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<td>-------------</td>
</tr>
<tr>
<td>2006</td>
<td>Smith-Battle</td>
<td>Nursing</td>
<td>USA</td>
<td>Qualitative: Hermeneutic [interview, field notes]</td>
<td>N=253 interviews and field notes, longitudinal data set looked at n=16 teenage mothers, n=18 grandparents, n=3 teens’ male partners. Recipient: not defined.</td>
</tr>
<tr>
<td>2007</td>
<td>Bolas, Wersch, &amp; Flynn</td>
<td>Social Science/Psychology</td>
<td>UK</td>
<td>Qualitative: Phenomenology [semi-structured interviews]</td>
<td>N =5 young carers age 14-18. Recipients: parents, siblings with multiple illnesses (ADHD, stroke, lymphedema, alcoholism with nerve damage)</td>
</tr>
<tr>
<td>2007</td>
<td>Early, Cushway, &amp; Cassidy</td>
<td>Psych</td>
<td>UK</td>
<td>Qualitative/descriptive [focus groups, interviews, and survey for support group workers]</td>
<td>Caregiver N=17 ages 10-16. Recipients were brothers, sisters, mothers, a grandparent, and multiple family members. With a physical, mental, or learning disability or chronic illness</td>
</tr>
<tr>
<td>2007</td>
<td>Packenham Chiu, Burnsnall, &amp; Cannon</td>
<td>Psych</td>
<td>Australia</td>
<td>Quantitative: [Questionnaires]</td>
<td>N=100 young carers age 10-25. Recipient: mother, father, or both parents with</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Discipline</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample</td>
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</tr>
<tr>
<td>2007</td>
<td>Siskowski, Diaz, Connors, &amp; Mize</td>
<td>Nursing</td>
<td>USA</td>
<td>Mixed Method: Retrospective chart review, retrospective interview.</td>
<td>N=1 interview, &amp; Retrospective chart reviews young carers no age defined. Recipient: hospice/home health patients.</td>
</tr>
<tr>
<td>2008</td>
<td>Gray, Robinson, &amp; Seddon</td>
<td>Psych</td>
<td>UK</td>
<td>Qualitative: Interviews (not specific)</td>
<td>65 professionals interviewed.</td>
</tr>
<tr>
<td>2008</td>
<td>Metzing-Blau &amp; Schnepp</td>
<td>Nursing</td>
<td>Germany</td>
<td>Qualitative grounded theory study [semi-structured interviews] Framework: systemic, family-oriented approach which places child as center and an expert in their own life.</td>
<td>N=82 semi-structured interviews, n=41 with children ages 4-19; n=41 parents Caregiving recipient: chronically ill parent, father, grandmother, sibling, parent and grandparent with Multiple Sclerosis, Stroke, Parkinson’s Disease, Asthma, Cardiac insufficiency, cancer, depression, psychosis, posttraumatic disease, or a mixture of both somatic and mental illness.</td>
</tr>
<tr>
<td>2009</td>
<td>Fraser &amp; Pakenham</td>
<td>Psych</td>
<td>Australia</td>
<td>Quantitative: Questionnaires</td>
<td>Young carers: N=44 Age 12-18 Care Recipients: Parent with Mental Illness.</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Field</td>
<td>Location</td>
<td>Methodology</td>
<td>Sample Details</td>
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<td>------</td>
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</tr>
<tr>
<td>2009</td>
<td>Joseph, Becker, S., Becker, F., &amp; Regel</td>
<td>Social Science</td>
<td>UK</td>
<td>Quantitative test 2 instruments (MACA-YC18 &amp; PANOC-YC20)</td>
<td>Study 1: N=410 young carers ages 6.5 to 22 were recruited from Princess Royal Trust for Carers database. Send 2 questionnaires, 75 questions about their caring outcomes and 42 regarding caregiving activities. Recipient data unavailable. <strong>Study 2</strong>: validation of instruments N=124 young people ages 8-21. Caregiving recipient data unavailable. Sampled from 10 young carer projects not involved in Study 1.</td>
</tr>
<tr>
<td>2009</td>
<td>Moore, McArthur, &amp; Morrow</td>
<td>Social Science / Education</td>
<td>Australia</td>
<td>Qualitative: method not defined. [structured phone interviews and focus groups]</td>
<td>N=51 young carers age 12-21. n=44 (phone interviews) n=7 focus group young Recipient: physical, intellectual &amp; sensory disabilities, neurological conditions, mental illness, alcohol/drug dependence.</td>
</tr>
<tr>
<td>2009</td>
<td>Skovdal, Ogutu, Aoro, &amp; Campbell</td>
<td>Social Science</td>
<td>Africa: Kenya</td>
<td>Qualitative: Phenomenology 48 interviews; 2 focus groups; 10 interviews with local adults. [photovoice utilized]</td>
<td>Caregivers N=48 age 11-17. 20 boys, 28 girls. Caregiving recipient: illness not identified</td>
</tr>
<tr>
<td>2009</td>
<td>Unknown</td>
<td>Social Science</td>
<td>UK</td>
<td>Mixed Methods: Literature review; secondary analysis of census data from 2001; surveys of young carer projects and adult carer services; focus groups with young carers age 16 &amp; 17; discussions</td>
<td>Young carers: N=29 Young adult carers: N=25 Caregiving Recipients: not described.</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Caregiving Details</td>
</tr>
<tr>
<td>------</td>
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<tr>
<td>2010</td>
<td>Ireland &amp; Pakenham</td>
<td>Australia</td>
<td>Quantitative: Questionnaire (YACS)</td>
<td>Young carers N=135 age 10-24</td>
<td>Caregiver recipient: ill/disabled family member</td>
</tr>
<tr>
<td>2010</td>
<td>O'Dell, Crafter, De Abreu, &amp; Cline</td>
<td>UK</td>
<td>Mixed Method -Part of larger study: Survey on working activities of 1002 young people In-depth interviews</td>
<td>Participants N=46 young carers, language brokers, or young people who have a job.</td>
<td>Caregiving Recipient: family member with a disability.</td>
</tr>
<tr>
<td>2010</td>
<td>Sahoo &amp; Suar</td>
<td>India</td>
<td>Mixed Method: Thematic Apperception Test using 5 black and white picture cards; 2 open ended questions (for carers only).</td>
<td>Caregivers N=100; 50 carers, 50 non-carers/ 25 girls and 25 boys in each group.</td>
<td>Caregiving recipient: mental illness (40%), chronic illness (30%) and substance abuse (30%).</td>
</tr>
<tr>
<td>2010</td>
<td>Svanberg, Stott, &amp; Spector</td>
<td>UK</td>
<td>Qualitative study using constructivist grounded theory methods [in-depth interview]</td>
<td>Caregivers age 11-18, N=12</td>
<td>Recipients: parent with young set dementia</td>
</tr>
<tr>
<td>2011</td>
<td>Barry</td>
<td>UK</td>
<td>Qualitative: semi-structured interviews</td>
<td>N=20; 10 males 10 females</td>
<td>Caregiver age 12-23, Recipient: parents or siblings with mental or physical disabilities, alcoholism, physical illness, mental health problems or ADHD.</td>
</tr>
<tr>
<td>2011</td>
<td>Elf, Skarsater, &amp; Krevers</td>
<td>Sweden</td>
<td>Qualitative/descriptive design. [focus group and interview (4 telephone and 4 face-to-face)]</td>
<td>Caregiver N=12 ages 16-25</td>
<td>Recipient: close friend, family, or partner with mental illness.</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Journal</td>
<td>Country</td>
<td>Methodology</td>
<td>Sample Details</td>
</tr>
<tr>
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</tr>
<tr>
<td>2011</td>
<td>Moore, McArthur, &amp; Noble-Carr</td>
<td>Social Science</td>
<td>Australia</td>
<td>Qualitative Participatory research [In-depth interviews using open ended questions and focus group] Member checking with 5 young people to discuss interpretations and conclusions.</td>
<td>Caregivers N=15 age 11-17 Caregiver recipient: alcohol or another drug</td>
</tr>
<tr>
<td>2012</td>
<td>Ali, et al.</td>
<td>Nursing</td>
<td>Sweden</td>
<td>Qualitative, descriptive design using semi-structured interview and focus group.</td>
<td>Caregivers age 16-25 Recipient = family and friends with mental illness N=12</td>
</tr>
<tr>
<td>2012</td>
<td>Cluver, Operario, Lane, &amp; Kganakga</td>
<td>Social Services/ Psyc</td>
<td>Africa</td>
<td>Mixed-methods. Qualitative and Quantitative.</td>
<td>Caregivers N=659 age 10-20 Recipient: parents or primary caregiver with AIDS or other illnesses (not specified).</td>
</tr>
<tr>
<td>2013</td>
<td>Hamilton &amp; Adamson</td>
<td>Social Science</td>
<td>Australia</td>
<td>Qualitative findings from a larger mixed method study. Interviews (semi-structured) and online questionnaire</td>
<td>Examined 2 cohorts: YC aged 7-17 (n=23) and YC 18-25 (n=13). Total N=36 Caregiving recipient: Physical, mental health, intellectual, long-term illness, sensory, alcohol/drug, limited mobility and other.</td>
</tr>
<tr>
<td>2013</td>
<td>Nichols, et al.</td>
<td>Unknown</td>
<td>Canada &amp; USA</td>
<td>Qualitative: 2 focus groups (telephone or via Skype) Thematic analysis</td>
<td>14 young caregivers age 11-18 Caregiving recipient: parent with frontotemporal dementia.</td>
</tr>
<tr>
<td>2014</td>
<td>Cox &amp; Pakenham</td>
<td>Psyc</td>
<td>Australia</td>
<td>Quantitative: confirmatory factor analysis. Testing YCOPI-A and YCOPI-B</td>
<td>N=2,429: n=1760 healthy families, n=446 parental illness, n=130 youth with parent with MS.</td>
</tr>
<tr>
<td>2014</td>
<td>Kavanaugh</td>
<td>Social Science</td>
<td>USA</td>
<td>Quantitative: cross-sectional study using</td>
<td>N=40 children and adolescents age 12-20.</td>
</tr>
</tbody>
</table>
Parental illness: Huntington’s Disease.

| 2015 | Nagl-Cupal, Metzing & Mayer | Nursing | Austria Germany | Qualitative Retrospective Explanatory study using semi-structured interviews. | N=16 former Young carers age 32-60. Family member illness’ include MS, diabetes, mental illness, stroke, cancer, heart disease, and epilepsy. | semi-structured interviews. Descriptive and correlational statistics. |
APPENDIX B

ADOLESCENT CAREGIVER FLYER

Adolescent Caregiver Study
Were you an adolescent caregiver for a family member with Multiple Sclerosis?
A retrospective study is being conducted to learn about past experiences of adolescent caregiving for family with Multiple Sclerosis (MS).

Eligibility Criteria:
1. Must have been a primary or secondary caregiver between the ages of 13-17.
2. Must now be an adult between the ages of 18-50.
3. Must have been caregiving for at least 6 months.
4. Must have been caregiving for a family member with MS in the same residence.
5. Must be English speaking.

What’s Involved:
2 face-to-face or Skype interviews with researcher lasting approximately 60 minutes.
Face-to-face interviews will be conducted in a place of the participants choosing.
Second interview will take place 1-2 weeks after first interview.

Compensation:
$20 Amazon gift card will be provided at the end of each interview (2 interviews per participant).

Please help: promote visibility of this currently ‘invisible’ population of caregivers; give the Multiple Sclerosis community and medical community insight into the experience and needs of adolescent caregivers. If you are interested in participating in this study please contact researcher below.

Principal Investigator
Renee Oteri PhD(c), RN, BSN
University of Massachusetts, Amherst

Phone: 978-835-9202
reneeoteri@nursing.umass.edu

UMASS

*Numbers and titles are for contact purposes only.*
APPENDIX C

POSTCARD FRONT & BACK

MAKE YOUR VOICE HEARD!

WERE YOU AN ADOLESCENT CAREGIVER FOR A FAMILY MEMBER WITH MULTIPLE SCLEROSIS?

WE WANT TO HEAR FROM YOU!

EVERYONE HAS A STORY AND YOUR STORY CAN HELP!
Adolescent Caregiver Study
Were you an adolescent caregiver for a family member with Multiple Sclerosis?

A retrospective study is being conducted to learn about past experience of adolescent caregiving for family with Multiple Sclerosis (MS).

Eligibility Criteria:
1) Must have been a primary or secondary caregiver between the ages of 13-17.
2) Must now be an adult between the ages of 18-50.
3) Must have been caregiving for at least 6 months.
4) Must have been caregiving for a family member with MS in the same residence.
5) Must be English speaking.

What's Involved:
2 face-to-face or Skype interviews with researcher lasting approximately 60 minutes. Face to Face interviews will be conducted in a place of the participants choosing. Second interview will take place 1-2 weeks after first interview.

Compensation:
$20 Amazon gift card will be provided at the end of each interview (2 interviews per participant).

Please help promote visibility of this currently ‘invisible’ population of caregivers: give the Multiple Sclerosis community and medical community insight into the experience and needs of adolescent caregivers. If you are interested in participating in this study please contact researcher below.

Principal Investigator
Renee Crizer RN, BSN, PhD (c)
University of Massachusetts, Amherst

978-855-3602
rcrizer@nursing.umass.edu
APPENDIX D

INITIAL PHONE INTERVIEW AND INTERVIEW QUESTIONS

Interview Questions

Initial Phone Screening Interview

An initial semi-structured phone interview will be conducted to screen the participants based on inclusion/exclusion criteria. During this phone interview, the researcher will determine eligibility and assess their availability for participating. A general description of the study, its methods (2 face-to-face interviews lasting approximately 60 minutes each within a 1-2 week timeframe) and need for consent will be provided. If appropriate, an interview time will be scheduled with the participants during the phone conversation. It is desirable to hold the interviews in a setting that is familiar and comfortable for the participant. Interviews will be conducted at a place of the participants choosing.

“Hello, my name is Renee Crizer and I am a PhD candidate in the Department of Nursing at the University of Massachusetts, Amherst. I am conducting a study which looks back at the adolescent caregiving experience for an adult family member with Multiple Sclerosis. To be included in the study participants must: be English-speaking; been a caregiver (primary or secondary) during adolescence (aged 13-17) for a family member with MS; provided care for at least six months; and not have any mental or physical illness during the time of caregiving. In order to participate, I will need your consent prior to starting the first interview. At the time of the first interview, I will bring the written consent for you to look over and sign. If you have any further questions at that time, I would be happy to clarify further.”

Face-to-face Interview 1 (Approximately 60 minutes)

The first interview will begin with an inquiry about demographics, family dynamics, type of MS the adult family member had, what they knew about the chronic disease, their involvement as primary or secondary caregiving, months or years involved in caregiving, and time (daily) involved in caregiving:

“I’d like to start off by asking you some questions about yourself and your family”

1. How old are you?
2. How old were you when you started caregiving?
3. How many years did you care for your family member with MS?
4. Specifically, what ages during adolescence were you involved in caregiving?
5. What is your ethnicity/race?
6. How many immediate family members did you have in your household as an adolescent?
7. Tell me more about your family. For example: What were their roles and relationships with each other? Out of these family members, how many siblings do you have? What was their age difference from you? Were they involved in caregiving?
8. Was anyone in your home working full time or part time?
“Next, I’d like to understand what you knew about Multiple Sclerosis (MS) as an adolescent.”

1. Do you recall what type of MS your family member had (at that time)? How long have they had it?
2. Had anyone ever talked with you about MS?
3. Did the medical community involve you in the discussions/updates/care plan during that time?

“Caregiving is helping another person in need. Caregiving can include emotional support, helping your family member out in the community, physical support such as fetching items, cooking, chores, etc., or more personal tasks such as helping with walking/transport, feeding, dressing, etc.”

1. Were you the only caregiver or did you help another family member provide care?
2. How long have you been caregiving?
3. How much time (in hours/day) do you recall providing care?

These introductory questions will be followed by two broad questions based on Seidman’s interview technique (2013):

1. What was life like prior to caregiving?
2. What was life like as a caregiver?

The researcher will allow adequate time for each response, and if necessary, prompts and follow up questions will be used.

Face-to-face Interview 2 (Approximately 60 minutes)

A second in-depth interview will be conducted at a time convenient to the participant, ideally between 1-2 weeks after the first interview. To understand the meaning of the experience, this researcher will ask the third question following Seidman’s interview technique (2013):

3. What does caregiving mean to you and how has it influenced who you are today?
   - Looking back, is there anything you needed or would have changed in your caregiving role?
   - How can the MS community and the medical community identify and support young caregivers?

Follow-up questions and prompts [tell me more, what do you mean by that?, go on...], will be used, as in the first interview, to fully explore the meaning of their experience.
APPENDIX E

CONSENT FORM

Consent Form for Participation in a Research Study
University of Massachusetts Amherst

<table>
<thead>
<tr>
<th>Researcher(s):</th>
<th>Renee Crizer RN, PhD (c)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Title:</td>
<td>Adolescent Caregiver Study</td>
</tr>
</tbody>
</table>

1. WHAT IS THIS FORM?
This form is called a Consent Form. It will give you information about the study so you can make an informed decision about your participation in this research.

This consent form will give you the information you will need to understand why this study is being done and why you’re being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. I encourage you to take some time to think this over and ask questions now and at any other time. If you decide to participate, you will be asked to sign this form and you will be given a copy for your records.

2. WHO IS ELIGIBLE TO PARTICIPATE?
English speaking adults between the ages of 18 and 50 who were adolescent (age 13-17) caregivers for a family member with multiple sclerosis in the past. Must have been caregiving for six months or more for the family member within the same residence. May have been the primary caregiver or secondary caregiver (helping another parent or older family member).

3. WHAT IS THE PURPOSE OF THIS STUDY?
_The purpose_ of this retrospective study is to explore adolescent caregiving for a family member with Multiple Sclerosis from the viewpoint of an adult who experienced it.

4. WHERE WILL THE STUDY TAKE PLACE AND HOW LONG WILL IT LAST?
The study will involve 2 in-person or Skype interviews. Each interview will last approximately 60 minutes. The interviews will take place within a 1-2 week time period. Interviews will be audio recorded and notes will be taken.
5. WHAT WILL I BE ASKED TO DO?
Initially, a telephone interview will be conducted to determine eligibility followed by two interviews.

If you agree to take part in this study, you will sign this consent form.

Topics included in the interview will include: daily routines/caregiving activities; knowledge base on multiple sclerosis; life experience prior to caregiving; experience as a caregiver; meaning of caregiving; how caregiving has affected who you are today; your opinion on adolescent caregiver needs.

You may skip any question that makes you feel uncomfortable answering.

6. WHAT ARE THE BENEFITS OF BEING IN THIS STUDY?
There is no direct benefit to being in the study. You will be compensated with a $20 amazon gift card after each interview (total of 2 interviews per participant). Your participation in the study will help professionals, family members, and the MS community to gain a greater understanding of young caregivers and promote visibility of this currently invisible population. This, in turn, will advance research for their population and address their specific needs. Some future outcomes could include nursing guidelines for adolescent caregiver assessment and needs, conditions for outside discipline referral, establishment of online support sites and community support groups, and establishment of adolescent caregiver respite camps.

7. WHAT ARE THE RISKS OF BEING IN THIS STUDY?
There is minimal risk to the participant in this study.

The interview process may bring up mixed emotions. Participants are allowed to skip questions or stop the interview altogether if they choose. Participants may be referred to a local psychologist if desired.

8. HOW WILL MY PERSONAL INFORMATION BE PROTECTED?
The following procedures will be used to protect the confidentiality of your study records.

- Anonymity is protected by removing most identifiers from the data and providing the participants with a pseudo name upon publication.

- The information obtained by the researcher is confidential and the findings will not be distributed until publication.
• All data (including researcher notes, audio tapes, and computer) are kept in a secure location: a locked desk with a security system when not in use by researcher.

• Research records will be labeled with a code (a pseudo name). A master key that links names and codes will be maintained in a separate and secure location.

• The master key and audiotapes will be destroyed after the completion of the study. All electronic files (*including researcher notes and spreadsheets*) containing identifiable information will be password protected.

• The computer hosting such files will have password protection to prevent access by unauthorized users. Only the researcher will have access to the password.

• At the conclusion of this study, the researcher will publish the findings. Information will be presented in summary format and the participants *will not* be identified in any publications or presentations.

• Privacy will be protected by letting the participant choose a private setting that is most comfortable to them.

9. WHAT IF I HAVE QUESTIONS?

I will be happy to answer any question you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the researcher, Renee Crizer 978-855-3802. If you have any questions concerning your rights as a research subject, you may contact the University of Massachusetts Amherst Human Research Protection Office (HRPO) at (413) 545-3428 or humansubjects@ora.umass.edu.

10. CAN I STOP BEING IN THE STUDY?

You do not have to be in this study if you do not want to. If you agree to be in the study, but later change your mind, you may drop out at any time. There are no penalties or consequences of any kind if you decide that you do not want to participate.

11. SUBJECT STATEMENT OF VOLUNTARY CONSENT

By signing this form I agree to participate in this study and I understand that it is voluntary. I have had a chance to read this consent form, and it was explained to me in a language which I use and understand. I have had the opportunity to ask questions and have received satisfactory answers. I understand that I may withdraw at any time. A copy of this signed Informed Consent Form has been given to me.
By signing below I indicate that the participant has read and, to the best of my knowledge, understands the details contained in this document and has been given a copy.

Signature of Person Obtaining Consent

Participant Signature: ________________________ Print Name: ________________________ Date: ________________________

Signature of Person Obtaining Consent

Signature of Person Obtaining Consent

Participant Signature: ________________________ Print Name: ________________________ Date: ________________________

Participant Signature: ________________________ Print Name: ________________________ Date: ________________________

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Participant Signature: ________________________ Print Name: ________________________ Date: ________________________

Participant Signature: ________________________ Print Name: ________________________ Date: ________________________
APPENDIX F
SUPPORT CONTACT INFORMATION

Contact List
If you would like to speak with someone further about your experience, thoughts, or emotions you can contact a local councillor in the list provided.

Counselors and Psychologists
Below is a small list of local counselors and psychologists in your area. You can find more detail about them and others online at https://therapists.psychologytoday.com
This easy to use website directs you to certified professionals in your area. Just insert your town or zip code and your age range and it will show a long list of counselors and psychologist in your area.

Northern MA

Deborah A Kelly
Clinical Social Work/Therapist, Med, LICSW
Leominster, Ma
(978) 598-3256 x23
“I am a seasoned therapist with over 25 years assisting individuals and families. Presently I see individuals from age 12 to 90. My specialties include treatment of current and past traumas, complicated grief, anxiety, depression and adjustment to chronic illness. Self care is an important element that I bring to work with all individuals. To that end I often recommend adjunctive exercise, yoga, martial arts and meditation. Psychopharmacological consultation can be arranged with area psychiatrists as needed. I am a certified EMDR therapist as well as having training in EFT, Cognitive Behavioral, Family and Psychodynamic Schools of treatment.”

Elizabeth M Henrickson
Counselor, LMHC
(978) 743-9976
Near Leominster, Ma
“Are you overwhelmed with life? Frustrated dealing with the day to day? There is hope and rest here as I offer compassionate person centered counseling. With all of the demands of today’s world, it is difficult to be the perfect spouse, parent, employee, or child. My goal is to provide you with tools and insight so that you may live a more fulfilling, balanced and healthy life. Child, adolescent, adult, family, and Christian counseling Treatment modalities: person centered, CBT, REBT, play therapy, mindfulness training, and sandtray.”

Central Ma

Donna Hamil Talman
Clinical Social Work/Therapist, MA, LCSW
(508) 556-6260
Worcester, Ma
“I have 30 years of clinical training and experience counseling adults dealing with stress, anxiety, depression, and grief/loss, abuse, spiritual issues, other life concerns. I work with couples experiencing intimacy, sexual, anger management or other relationship difficulties, and divorce, family reactions to it, stepfamily issues. With a psychiatrist I co-lead therapy groups for women and highly recommend this approach. Having received many varieties of training over the years, I integrate therapies depending on the client and the issues and offer compassion and humor when appropriate. In addition to talk therapy, I teach relaxation, meditation, and guided imagery techniques.”

Anne Kulakowski
Counselor, LMHC, OTRL
(617) 505-1108
Worcester, Ma

“A safe and supportive environment is one of the most important factors in therapy being successful. I work with young children, adolescents, and adults to help them move through stuck, challenging, and confusing phases of life. I offer a grounded and professional approach and weave curiosity and creativity into my work. I believe that the professional relationship is a huge factor in therapy and prioritize helping children and adults feel comfortable and inspired in therapy.”

Annemarie Sampson
Counselor, MA, LMHC
(508) 731-8290
Worcester, Ma

“Whether you are struggling with depression, anxiety, parenting concerns, the effects of trauma, or are feeling overwhelmed by life stress, I believe you are doing the best you can with the resources you have available to you. My goal is to help you build on those resources, as well as discover within yourself the solutions that will enable you to take the steps toward improving your life.”

Frances Aschheim
Counselor, MEd, LMHC
Northborough, Massachusetts
(508) 213-4954

I am experienced in the treatment of depression, anxiety, Post-traumatic stress disorder, body-image issues, and relationship difficulties.
I draw from a varied background, including training in expressive therapy, family systems and couple therapy. I have experience addressing trauma, eating problems, chronic illness, stress management, and coping with loss.
I use a mind/body approach to address body image issues. When appropriate, I may incorporate EMDR to neutralize traumatic memories.

Sara E Hart
Counselor, MA, LMHC
(413) 650-5571
Framingham, Ma

“I believe that one of the key components to successful therapy is fostering a strong therapeutic alliance through having compassion, empathy and respect for my clients. I use a non-judgmental, strengths-based and client-centered approach. I believe that seeking therapy is an important decision that shows personal courage and vulnerability. My approach to therapy is integrative, collaborative, and tailored to meet the unique needs of each individual. I work with adolescents and adults living with anxiety, depression, low self-esteem, sleep disorders, communication difficulties, or who are going through a life transition.

When indicated, I incorporate the five modules of DBT into my work (mindfulness, distress tolerance, emotion regulation, interpersonal effectiveness and walking the middle path) and CBT techniques. I also have my Master's Degree in Art Therapy and integrate forms of creativity when the client prefers this type of expression in addition to talk therapy.”

Western, Ma

Jon Holcombe
Clinical Social Work/Therapist, LICSW, MSW
(413) 337-3005

Amherst, Ma

“The biggest factor in successful therapy is the client-therapist relationship itself. With this in mind, I adopt a warm and collaborative approach with each client. I enjoy working with a wide variety of issues, including treating mood disorders such as depression and anxiety; addressing relationship challenges and life transitions; enhancing skills for management of trauma history; supporting recovery from alcoholism or other addictions (either in oneself or in a loved one); and exploring issues of racial and cultural identity.

I often use Cognitive Behavioral Therapy (CBT), which proposes that if you change what you think and do, then you can improve how you feel. In some cases I incorporate Family Systems theory, which deepens understanding of the family you grew up in, in order to help you make positive changes in your present life.

Finally, as part of supporting a diverse community of clients, I draw upon my significant range of experiences among people of different racial, cultural and class backgrounds, and I welcome clients of all sexual orientations and gender identities.”

Southern, Ma

Becky Howard
Counselor, MA, CAGS, LMHC
(508) 815-4137

Oxford, Ma

“Whether you’re feeling depressed, anxious, hopeless, or irritable, making that first call for help can be hard. You desperately want to feel better, but you’re afraid of what it will be like to share your thoughts with a therapist. I understand. My guiding principles are respect, appreciation of differences, and a balance between acceptance and change. I listen carefully and center the therapy around your needs.

Through a truly mutual collaboration, we can find ways to solve problems and create healing. I love seeing clients with a broad range of concerns, and I tailor my approach to your specific needs and goals.

My office is located across from Park n Shop in Auburn, near mass pike entrance, 290 and rt 20.”
Support Groups

Worcester Ma Self Help Group: Recurring Event
2nd Wednesday of each month from 12:00-1:30pm
In Person
First Presbyterian Church
125 Holden St
Worcester, MA 01606

A National MS Society affiliated support group for people living with MS, their families, friends and caregivers. Besides sharing the realities of living with MS, we share good times, laughter and information in a positive, upbeat environment. Everyone comes full of ideas to take home and perhaps try out. Join a monthly meeting for education, information and good company!

Contact information
Wayne
(508) 835-3993

But You Look So Well Group: Recurring Event
4th Tuesday of each month from 6:00-7:30pm
In Person
YWCA of Central Mass
One Salem Square
Worcester, MA 01608

A National MS Society affiliated support group for people living with MS, their families, friends and caregivers. Besides sharing the realities of living with MS, we share good times, laughter and information in a positive, upbeat environment. Everyone comes full of ideas to take home and perhaps try out. Join a monthly meeting for education, information and good company!

Contact information
Joan
774-261-3136

Facilitated Support Group: UMASS MS Center
3rd Wednesday of the month (Sept – June) 5:45pm - 6:45pm
UMass MS Center, University Campus
55 Lake Ave North Worcester, Ma
MS Center’s waiting room
Parking: $2 handicap access or garage rates.

For those diagnosed with MS, their friends and families. Led by MS Certified Nurse
Contact: Carolyn Griffin RN 508-856-5006

Caregiver Chat Room
MS Connection Newsletter refers a Caregiver chat room Wednesday nights at 8pm. This moderated chat room is weekly, and allows you to chat with others who have similar experiences and questions. To access log onto MSworld.org and sign up for a username. Go to General Chat Room and click on the Caregivers chat.

Hot Line
MSFriends®
MSFriends volunteers complete a rigorous screening and training program and are focused on the needs of those who call for support.

MSFriends:
know first-hand what it is like to live with MS.
are there to help you deal with the changes brought about by MS.
are a sounding board for good decision-making and problem solving.
Family members of people living with MS may leave a message with the volunteer who answers, and a trained volunteer who also has a family member with MS will call you back to provide support.
Call 1-866-673-7436

Volunteers with MS are available 9 a.m. to midnight ET, 7 days a week. All of your conversations are confidential.
APPENDIX G

BRACKETING

Interest in the population of adolescent caregivers’ stems from my own experience as an adolescent caregiving for a father with brain cancer. Diagnosed when I was eleven, I quickly became his secondary caregiver, my mother was his primary caregiver. With the additional role of caregiver, the time of fun and play was over, I seemed to mature overnight. My adolescent years flew by and I missed out on many teenage experiences. I remember being constantly worried, sad, and anxious about his status and I especially disliked not being included in the updates on his condition.

My daily tasks included: assisting my father with ambulation, transferring with a Hoyer lift, adjusting position in bed, assist with grooming and feeding, fetching items, cooking, cleaning, monitoring, checking glucose levels, giving daily injections, and passing oral medications. At times my concentration in school was affected and teachers did not seem to show any concern or inquire about my situation at home. I enjoyed helping my mother care for him, felt excited to learn from visiting nurses, and in a sense grew from the whole experience. Six years after he was diagnosed, when I was at the age of seventeen, my father passed away. I have always questioned if my experience is common to other adolescent caregivers and what may have helped to improve the normalcy of those adolescent years.
I chose the chronic illness of Multiple Sclerosis because I have a close family member affected by the disease and I am intimately familiar with the disease etiology, epidemiology, progression, side effects, and potential need for care by young caregivers.

I assume female adolescents tend to fill the caregiving role more often than male adolescents and that some cultures expect their children to take on this caregiving role more than others. Socioeconomic status may play a part in the need for adolescents to become caregivers, particularly low and middle income families. I assume that higher income families tend to utilize outside help with caregiving.

I presuppose most parents instinctively protect their children from suffering and tend to limit adolescent involvement in their caregiving when possible. Family members tend to do whatever they can for those in their family that need assistance. This may be from a sense of obligation and/or close relationships. Children and adolescents have a tendency to want to lend a helping hand, possibly resulting from the desire to please, be rewarded, or to gain more responsibility.

I presuppose adolescents usually want to know the condition of the care recipient and be included in on decision making. Being kept in the dark about the health condition of the adult may cause the adolescent to feel they are being lied to, may breed distrust and fear, as well as potentiate the feeling of isolation.
Caregiving changes the traditional role of an adolescent and leads to premature maturation. The obligations/responsibilities, pressures, fears, and sacrificing of one’s own desires for that of another appears to cause one to mature quickly.

Caregiving impacts the adolescent both positively and negatively. Adolescents may gain a sense of personal satisfaction in caregiving as well as emotional strength. Emotional strength is gained by continuously dealing with difficult situations. Adolescents tend to lose some aspect of their social lives due to their increased responsibilities as a caregiver. Conversely, the adolescent may seek out social activities to get away from their role at home. An adolescent might seek out a parental figure if the recipient cannot provide it as before.

Adolescents may be inclined to hold all their feelings, emotions, fears, and needs within themselves and not express them to others potentiating the risk for an emotional and physical breakdown. Caregiving may negatively affect the adolescents’ grades in school because of less time to study and/or lack of concentration due to the situation at home. Adolescent caregivers participate in less extracurricular activities than their peers because of their increased responsibilities or inability of primary caregiver to transport. Adolescents tend to do less intimate care (e.g. perineal care, bathing) because of the preference of both the adolescent caregiver and caregivee.
### APPENDIX H

#### PARTICIPANT DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Ethnicity</th>
<th>Current Age Range</th>
<th>Age Started Caring</th>
<th>Age During Adolescents Caring</th>
<th>Caregiving Recipient</th>
<th>Type of Caregiving</th>
<th>Hours per Day Caring</th>
<th>Family Working</th>
<th>Future</th>
<th>Interview Method</th>
<th>Location</th>
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<tbody>
<tr>
<td>Adam</td>
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<td>40-49</td>
<td>12</td>
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<td>Primary</td>
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<td>13-17</td>
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<td>Undecided</td>
<td>Skype</td>
<td>New York</td>
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