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Philadelphia College of Osteopathic Medicine
School of Professional and Applied Psychology
Department of Clinical Psychology

PEDIATRIC HEALTH CARE PROVIDERS' PERCEPTIONS AND KNOWLEDGE OF
CAREGIVING YOUTH

By Brianna Bliss

Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Psychology

December 2021

DISSERTATION APPROVAL

This is to certify that the thesis presented to us by Brianna Bliss

on the 30th day of September, 2021, in partial fulfillment of the requirements for the

degree of Doctor of Psychology, has been examined and is

acceptable in both scholarship and literary quality.

COMMITTEE MEMBERS' SIGNATURES

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ABSTRACT

Many young people younger than the age of 18 years are involved in providing care to family members who are unable to manage their own medical, physical, or mental illnesses. Youth caregivers are an understudied population in the United States. The small yet growing research base has illustrated the relationship between the caregiving role, academic performance, and an individual's social and psychological well-being. Medical settings are uniquely positioned to identify caregiving youth and provide supportive resources. A survey was created and administered to pediatric health care providers who offered medical and psychosocial support to children and adolescents. Providers were recruited via email to participate in a survey examining their knowledge and perceptions of youth caregivers. The data were combined with archival data from another study. The results of this survey indicated that the majority of respondents were not aware of caregiving youth within their practices and that there are significant barriers to identifying caregiving youth within health care settings, such as provider attitudes, lack of a validated screening tool, and lack of supportive resources. The results of this study highlight the importance of increasing provider awareness as a means of increasing identification and support for caregiving youth in the United States.

CHAPTER 1: INTRODUCTION

Statement of the Problem

Families are the largest providers of informal care, with an estimated 53 million caregivers in the United States (National Alliance for Caregiving [NAC]/AARP, 2020). This number reflects an increase of 9.5 million caregivers since the last *Caregiving in the U.S. 2015* research report. To date, much of the research on family caregiving has focused on adult and spousal caregiving, as well as on parents caring for ill children (Kavanaugh et al., 2016). Many studies have documented the social, emotional, financial, and physical effects of caregiving that may contribute to caregiver burden (Adelman et al., 2014). Caregiver burden occurs when caregiving negatively affects an individual's life and is associated with depression, anxiety, loneliness, and social isolation (Adelman et al., 2014; Denno et al., 2013). The robust body of research on caregivers has laid the foundation for caregiver programs and policies that aim to improve lives of adult family caregivers (Kavanaugh et al., 2016).

In many families, adolescents are involved in providing care, typically on a long-term basis, to parents or other family members who have physical and mental health conditions. Yet, much less is known about their experiences, as they have been largely absent from the caregiving research and continue to remain an understudied population. Youth younger than the age of 18 years who care for an ill parent or relative are referred to as “young carers” (Aldridge & Becker, 1993) in international literature and as “caregiving youth” in U.S. studies. According to Becker (2007), caregivers can be conceptualized on a continuum ranging from “caring about” the person to “caring for”

the person. In families in which a parent or relative has a disability or illness, the young person may transition from a caring about status, which reflects typical activities conducted by most young people (e.g., cleaning and chores) to a caring for status characterized by increased time spent engaging in domestic chores, as well as personal, emotional, and physical care (Becker, 2007; Joseph et al., 2020).

The most recent national prevalence study of caregiving youth was conducted in 2005. It is estimated that there are between 1.3 and 1.4 million child caregivers between the ages of 8 and 18 years in the United States (Hunt et al., 2005). This study also found that caregiving youth were more likely to experience depression and school problems compared to noncaregiving youth (Hunt et al., 2005). Despite these findings, research on this population has been limited during the last decade. However, the research available has shown that long-term illnesses that necessitate extensive caregiving can have negative impacts on youth caregivers, including poor academic performance; difficulty with social interactions; and poor psychological well-being, including depression, anxiety, and low self-esteem (Aldridge, 2006; Cohen et al., 2012; Early et al., 2006; Howatson-Jones & Coren, 2013; Warren, 2007).

Moreover, the most up-to-date survey of caregivers by the NAC did not include individuals younger than the age of 18 years (2020). As a whole, youth caregivers are largely unacknowledged in the United States. Conversely, in such countries as the United Kingdom and Australia, policies and resources are in place that have increased support for youth and have led to the establishment of legal rights (Leu & Becker, 2017). In the United Kingdom, young carers have legal rights to an assessment of their personal needs

and their ability to provide care, with the option of receiving payment for their care services (Leu & Becker, 2017).

Evidently, youth play a critical role in family-based care in the United States, yet the limited research base continues to perpetuate the invisible nature of this group, thus limiting identification of caregiving youth. In a scoping review of research on caregiving youth in the United States, Kavanaugh et al. (2016) identified 22 published peer-reviewed empirical papers, compared to more than 2,000 adult caregiving papers. Accordingly, many gaps in the research need to be addressed in order to better support caregiving youth. One such path to provide support that remains unaddressed in the literature is the medical setting. Health care professionals, specifically pediatricians and other pediatric health care providers, can play a critical role in identifying and supporting this population. At present, not much is known about pediatric health care providers' knowledge and perceptions regarding caregiving youth.

Purpose of the Study

Despite their prevalence in the United States, not much is known about caregiving youth. The purpose of the study was to better understand pediatric health care providers' knowledge and perceptions regarding caregiving youth. The study aimed to explore pediatric health care providers' understanding of the prevalence of caregiving youth within their practice, of the services health care providers offer, of the delivery of these services, and of any barriers to identifying caregiving youth in medical settings. As such, the overall goal of this study was to clarify current practices in order to increase support for caregiving youth.

Research Question

What are pediatric health care providers' perceptions and knowledge of caregiving youth, and how do they perceive their role in identifying and supporting this population?

CHAPTER 2: REVIEW OF THE LITERATURE

Family members often play an important role in caring for ill and/or disabled members of their families. Family caregivers, also called informal caregivers, are relatives, spouses, friends, or neighbors who have a personal relationship with an individual with a chronic or disabling condition and who provide a range of assistance (Family Caregiver Alliance [FCA], 2014). An informal caregiver may live with or separately from the care recipient and may be in the role of primary or secondary caregiver (FAC, 2014). The health care system in the United States is structured in a way that encourages family caregiving and has been significantly influential in contributing to family members being the largest providers of informal care (National Alliance for Caregiving [NAC]/AARP, 2020). According to the latest *Caregiving in the U.S. 2020* research report conducted by the NAC and the AARP Public Policy Institute, an estimated 53 million people aged 18 years or older had provided unpaid care to an adult or child within the previous 12 months (NAC/AARP, 2020). In fact, the value of services provided by informal caregivers was an estimated economic value of \$470 billion in 2013, reflecting an increase from \$450 billion in 2009 and \$375 billion in 2007 (Reinhard et al., 2015). This statistic combined with the high prevalence of chronic diseases in America makes it likely that family caregivers will continue to fulfill this role for years to come. Chronic diseases, such as diabetes, heart disease, cancer, stroke, and Alzheimer's disease, have been found to be the leading causes of death and disability, affecting six in 10 Americans (Buttorff et al., 2017). The complex nature of chronic illnesses, coupled with increased health care costs influencing earlier transitions to home, leads to a reliance

on family caregivers (Reinhard et al., 2015). Owing to the social, health, and economic climates of the United States, family caregiving is more costly, stressful, and demanding now than at any other time in the nation's history (Reinhard et al., 2015).

Family caregiving is an important public-health concern in the United States, and studies have provided an extensive research base for examining the family caregiver experience. The negative impact of caregiving on adults has been well documented, with studies indicating that caregivers are at an increased risk for poor physical health (Darragh et al., 2015; Pinquart & Sörensen, 2007); engagement in poor health-related behaviors, such as smoking, sedentary behavior and regular fast-food consumption (Hoffman et al., 2012); sleep problems (Byun et al., 2016); caregiver burden and compassion fatigue (Adelman et al., 2014; Lynch et al., 2018), and development of psychological disorders, especially depression and anxiety (Caputo et al., 2016; Joling et al., 2015). The literature also describes positive outcomes of caregiving, including experiencing satisfaction from caregiving duties (Lynch et al., 2018).

Data from the *Caregiving in the U.S. 2020* research report indicate that the majority of caregivers in the United States provides care for a relative (89%), and of those individuals, 50% care for a parent or parent-in-law (NAC/AARP, 2020). Women provide 61% of caregiving support in the United States (NAC/AARP, 2020). On average, caregivers reported spending 24 hours a week providing care. When asked if they had a choice in taking on caregiving responsibilities, more than half (53%) of caregivers reported they had no choice (NAC/AARP, 2020). In regard to the intensity of the caregiving situation, 40% of caregivers reported high-intensity situations, 16% reported

medium intensity, and 43% reported low -intensity (NAC/AARP, 2020). Furthermore, this survey assessed caregivers' perceptions of their need for caregiving information and support. Fewer than one third of caregivers (29%) reported that a health care provider had asked what was needed to care for their recipients, and only 13% reported that a health care provider had inquired about what they may need to care for themselves (NAC/AARP, 2020). Of note, caregivers who are involved in more complex care situations, such as those who dedicate more hours than average, who are caregivers for persons with Alzheimer's disease, and who perform medical/nursing tasks, are most likely to report having conversations with health care providers about their needs, as well as the needs of their care recipients (NAC/AARP, 2020). Nevertheless, caregivers are largely left out of conversations with health care providers.

Individuals may take on the caregiving role at any time during the lifespan. Given the aging population in the United States, a significant amount of research focuses on family caregivers who provide care to older adults, as well as older adults who provide care to their spouses. However, more recently, research exploring the experiences of young-adult caregivers has increased. Data from the *Caregiving in the U.S. 2015* research report found that one in four family caregivers is part of the millennial generation (Flinn, 2018). Of millennial family caregivers, 35% are younger millennials (aged 18-24 years), 31% are aged 25-29 years, and 34% are aged 30-34 years (Flinn, 2018). Thus, emerging adults (aged 18-25 years; Arnett, 2000) and young adults make up a significant proportion of caregivers nationally. Although the *Caregiving in the U.S. 2020* research report did not survey caregivers younger than the age of 18 years, the report highlights a

rising trend of child caregivers and estimates that at least 5.4 million children younger than the age of 18 years are caregivers for a family member (NAC/AARP, 2020). Among the adult caregivers surveyed, 7% reported a child helps provide care to the care recipient (NAC/AARP, 2020).

Caregiving Youth

Caregivers younger than the age of 18 years are an understudied population. As such, their identity as a group continues to remain unclear for various reasons. First, the definition of caregiving youth lacks consistency across studies (Kavanaugh et al., 2016; Shifren & Chong, 2012;). This is mainly because the young caregiver status is broadly influenced by an individual's experiences in this role; their level of care responsibility; their relationships with care recipients; their age, gender, and ethnicity; and their cultural practices (Kavanaugh et al., 2016). Because the operationalization of caregiving youth has not been clearly outlined, studies have focused on a variety of aspects of caregiving and have used diverse samples varying in age ranges. For example, some studies have focused on experiences of youth caring for family members with specific medical conditions, such as frontotemporal dementia (FTD; Nichols et al., 2013) and Huntington's disease (HD; Kavanaugh, 2014; Kavanaugh et al., 2015; Williams et al., 2009), while others have focused on the amount of time spent caregiving and the nature of the caregiving tasks (Assaf et al., 2016 Nickels et al., 2018).

The only national survey on caregiving youth in the United States was conducted in 2005 with the purpose of determining the prevalence of child caregiving (Hunt et al., 2005). Surveys were randomly sent to 2,000 households, and respondents were asked if

there were children aged 8 to 18 years old in the household providing unpaid care or help to any person (Hunt et al., 2005). Specifically, the survey stated, “the care recipient need not live with you, and the care may include help with personal needs, meals, household chores, shopping, paperwork, medication, getting around, or visiting regularly to see how they are doing” (Hunt et al., 2005, p. 3). Findings from this survey estimated a prevalence of 1.3 to 1.4 million caregiving youth in the United States.

More recently, the American Association of Caregiving Youth (AACY), the only organization in the United States dedicated to addressing issues faced by caregiving youth, offered an updated definition. Caregiving youth are defined as individuals younger than 18 years of age who provide “significant assistance to relatives or household members who suffer from physical or mental illness, disability, frailties of aging, or substance misuse” (AACY, 2015). This definition considers individuals’ ages, the levels of care they are responsible for, and the care recipients’ experiences.

Variations in nomenclature used to describe caregiving youth are also apparent across countries, further perpetuating the lack of consistency in defining this group (Kavanaugh et al., 2016). Youth who care for an ill parent or relative are referred to as “young carers” in such countries as the United Kingdom., Canada, and Australia (Aldridge & Becker, 1993; McDougall et al., 2018; Nichols et al., 2013) and as “caregiving youth” in the United States (Assaf et al., 2016; Cohen et al., 2012; Kavanaugh et al., 2016; Nickels et al., 2018). Furthermore, this population is predominantly characterized by their young age status, yet countries vary on their interpretations of “young.” In Australia, young carers are classified as individuals

younger than the age of 25 years, while the United Kingdom, Canada, and the United States consider this population to be within the ages of 8 to 18 years. Despite the various definitions in use, a common thread is that young people are providing significant support and care that typically are performed by an adult.

Because no single definition captures the experiences of youth caregivers across the world, estimating the prevalence of this population is challenging (Joseph et al., 2020). At first glance, a standardized definition of youth caregivers seems to be greatly needed in order to facilitate identification of this population. However, Joseph et al. (2020) made the point that a universal definition would not allow for meaningful comparisons across cultures, as caring is a social construction that varies by country. Thus, research must be conducted from within each culture's frame of reference and then analyzed comparatively across countries (Joseph et al., 2020).

Furthermore, caregiving is a subjective experience that impacts each individual differently. Not all youth caregivers are adversely affected by their experiences. And, those who do have unfavorable experiences, vary in those experiences. Moreover, caring is a difficult construct to define, as it is not a dichotomous experience in which a young person either is a caregiver or is not a caregiver (Joseph et al., 2020). According to Becker (2007), caregiving can be conceptualized on a continuum ranging from caring about the person to caring for the person. In families in which a parent or relative has a disability or illness, the young person may transition from a caring about status, which reflects typical activities conducted by most young people (e.g., cleaning and chores), to a caring for status characterized by increased time spent engaging in domestic chores, as

well as personal, emotional, and physical care (Becker, 2007; Joseph et al., 2020). A young person's status on the continuum is influenced by the type of care provided and the amount of time spent caring (Joseph et al., 2020).

A uniform definition of young caregivers would be advantageous for research purposes, as it would allow researchers to estimate the prevalence and the extent of the problem, resulting in the data needed to fuel policy change (Joseph et al., 2020). Yet, this population is not homogenous, and considering all young caregivers to be within a single group facing the same challenges would be disadvantageous. Thus, the current state of the literature reflects a need to promote locally based research and international comparisons (Joseph et al., 2020).

Theoretical Frameworks for Understanding Youth Caregivers

Developmental Frameworks

Much of the research on youth caregivers is descriptive and guided by several general theories. According to lifespan development theory, development is a life-long process influenced by biological, cognitive, and psychosocial changes and depends on history and context (Baltes, 1987). When conceptualizing youth caregivers in the context of current U.S. society, many factors have led to an increased reliance on youth caring for family members. Some factors include developments in medicine allowing people to live longer, the increasing cost of care, changes in family structure with more single-parent households and intergenerational households, and multiple adults in the household being employed (Kavanaugh et al., 2020; Siskowski, 2009). Therefore, adolescents are faced

with taking on roles within the family that are beyond those typically expected for their age and often receive little or no training for this role (Siskowski, 2009).

At the individual level, Erikson's (1950) theory of psychosocial development affords a framework for understanding the impact of caregiving on child development. His theory proposes that individuals proceed through subsequent stages of development throughout the lifespan and experience a crisis during each stage that leads to either a sense of mastery or a sense of inadequacy (Erikson, 1950). Erikson (1950) believed that individuals are influenced by their social experiences and develop a healthy personality through resolution of these crises. From the perspective of Erikson's theory, youth caregivers likely in the fourth (Industry vs. Inferiority) or fifth (Identity vs. Confusion) psychosocial stage may have more difficulty resolving crises than their same age peers who are not assuming caregiving responsibilities. For example, a youth caregiver who spends a significant amount of time caring for an ill parent may have trouble navigating the Identity versus Confusion stage. This stage occurs during adolescence and is a time of self-exploration. It can be accompanied by feelings of independence and control (Erikson, 1950). Adolescents who do not receive encouragement and reinforcement through self-exploration, perhaps because of their caring role, may feel insecure about themselves and their futures.

Coping Frameworks

Another relevant theory is the stress and coping theory (Lazarus & Folkman, 1984). In addition to understanding the impact of caregiving from developmental theories, research has also focused on adjustment outcomes and coping styles of

caregivers. Lazarus and Folkman's (1984) transactional theory of stress and coping is a foundational theory that has been used across many fields of research and has guided research in youth caregiving (Boumans & Dorant, 2018). According to Lazarus and Folkman (1984, p. 141), coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person." In the youth caregiving context, responsibilities that exceed a youth's maturity level may produce stress. The stress and coping theory (Lazarus & Folkman, 1984) postulates that as a result of stress, individuals engage in problem-focused coping (i.e., active coping), whereby one may seek information or support, or emotion-focused coping (i.e., passive coping), whereby one may adapt to the stressor by way of avoidance or denial. The literature demonstrates mixed findings regarding which coping style is more prominent among youth caregivers, with one study indicating that youth caregivers more frequently engage in problem-focused and emotion-focused coping styles as compared to noncaregivers (Cohen et al., 2012). Yet, another study found that young caregivers relied less on problem-solving coping compared to noncaregivers (Pakenham et al., 2006). Additionally, Lazarus and Folkman's (1984) model provides a framework for understanding the positive experiences reported by youth caregivers, such that if individuals perceive their experiences in a favorable way (i.e., building a close relationship with the care recipient) rather than as a threat, stress can be offset (Rose & Cohen, 2010). Thus, the stress and coping theory appears to be helpful in gaining an understanding of youth caregivers'

perceptions of the demands of their environments and, consequently, of the ways they cope with the caregiving role.

The family ecology framework draws on the stress and coping theory, human ecology, and systems theory, with the aim of illuminating the relationships between parental illness characteristics, family functioning, and adolescent well-being (Pedersen & Revenson, 2005). The model hypothesizes that the type and severity of parental illness influence individual and family level mediators and produce distal effects (i.e., shapes family and adolescent well-being; Pedersen & Revenson, 2005). Individual and family level mediators include appraisals of stigma and threat, stress responses, the distribution of roles and responsibilities among family members, and daily hassles (Pedersen & Revenson, 2005). Moreover, the individual and family level mediators impact each other. For example, Pedersen and Revenson (2005) noted that a parent's illness may influence certain perceptions of stigma, possibly producing increased physiological stress responses for adolescents and ultimately influencing overall well-being. An Australian study by Pakenham and Cox (2015) used the family ecology framework to explore how the family level mediator of role redistribution impacts youth caregivers. This study expanded upon the family ecology framework to include nonparent family members (i.e., grandparents and siblings) and specifically focused on the psychological impact of role redistribution, which involves caregiving tasks and responsibilities (Pakenham & Cox, 2015). Findings from this study indicate that the presence of any family member with a serious illness is linked to more intense youth caregiving experiences as compared to those of same aged

peers with healthy family members, therefore supporting the family ecology model as a framework for understanding caregiving youth experiences (Pakenham & Cox, 2015).

International Young Carer Research

Interestingly, international studies have indicated that youth caregivers exhibit similar characteristics and experiences across countries (Evans & Becker, 2009; Leu & Becker, 2017). Youth caregivers are believed to be more similar in terms of their experiences and needs regardless of geographic location and each country's unique social policies (Evans & Becker, 2009; Leu & Becker, 2017). Although research on youth caregivers is sparse globally, the majority of the research thus far has been conducted in other countries, with the United States demonstrating a small research base.

Adolescents and teens take on the role of family caregiver worldwide. In order to understand the state of caregiving youth affairs in the United States, one must understand young caregiver awareness and policy response in other countries (Kavanaugh et al., 2016). Some countries have well-developed services and acknowledge caregiving youth in public policy, while others are just beginning to recognize this population (Joseph et al., 2020). Since the early 1990s, the United Kingdom has led the charge in creating awareness of and conducting research on caregiving youth. Since then, young carers have been identified and studied in Australia, Africa, Canada, the United States, and several European countries.

The United Kingdom remains the most advanced society in regard to its acknowledgement of young carers (Joseph et al., 2020). Becker (2007) was the first to establish a framework for conceptualizing young carer awareness and policy response

globally. Becker (2007) created a country-specific classification system to address the variations in the recognition of young carers in law, policy change, and supportive services (Joseph et al., 2020). The United Kingdom, Australia, the United States, and Sub-Saharan Africa were among the countries included in this classification system. Becker (2007) analyzed the extent to which a country was aware of this population and any policies that existed in support of this group. Countries were originally classified as “advanced,” “intermediate,” “preliminary,” or “emerging,” with the United Kingdom meeting criteria for the intermediate level (Becker, 2007). This classification system was refreshed by Leu and Becker (2017) and includes a model with seven levels of response. Response levels are characterized by the number of legal rights, entitlements, or other benefits available for young carers (Leu & Becker, 2017). Various factors are considered when determining a country’s appropriate level of awareness and policy response. One consideration includes whether children have rights to an assessment of needs as young carers, whether these rights are legal, and, if not, whether they are enforceable (Leu & Becker, 2017; Joseph et al., 2020). Other aspects considered include whether countries have social policies that incorporate young carers, if they have codes of practice for health and social service professions that are specific to young carers, and if they are recognized as a distinct group by professionals (Joseph et al., 2020; Leu & Becker, 2017). Furthermore, this analysis also takes into account whether young carers are recognized by the general population, whether supportive projects or interventions are aimed at helping this group, and whether specific therapeutic interventions are identified (Joseph et al., 2020; Leu & Becker, 2017).

Given these considerations, Leu and Becker (2017) classified countries from the highest level (Level 1), entitled “Incorporated/Sustainable,” to the lowest level (Level 7) entitled “No Response.” A country is considered to be “Incorporated/Sustainable” when it has exhibited extensive awareness of young carers in all levels of government and society, has sustainable policies and interventions aimed at promoting young carers’ well-being, and enforces policies grounded in valid research evidence (Leu & Becker, 2017). According to their classification system, currently no countries meet criteria for a Level 1 status. Thus, Leu and Becker (2017) argued that this is essentially the standard that countries should aim to attain.

At present, the United Kingdom is the only country in the “Advanced” (Level 2) category. The United Kingdom’s placement in this level reflects a significant awareness of young carers in research and policy leading to certain legal rights (Joseph et al., 2020; Leu & Becker, 2017). For example, such policy changes as the Children and Families Act 2014 and the Care Act 2014 came about as a result of advocacy efforts that cited the published research, depicting the local issues in detail (Joseph et al., 2020; Leu & Becker, 2017). Leu and Becker (2017) classified Australia, Norway, and Sweden in the “Intermediate” (Level 3) category, as these countries demonstrate some awareness and recognition of young carers among the public, policy makers, and professionals. The “Intermediate” level is also characterized by a medium-sized research base, partial rights for young carers in some regions, a small but developing body of professional guidance, and some supportive services and interventions (Leu & Becker, 2017). Austria, Germany, and New Zealand are classified in the “Preliminary” (Level 4) category, as there is

currently little public awareness and recognition of young carers in these countries (Leu & Becker, 2017). The “Preliminary” level is characterized by a growing but limited research base, possible relevant laws, no specific legal rights for young carers, and few, if any, supportive services or interventions (Leu & Becker, 2017). Belgium, Ireland, Italy, Sub-Saharan Africa, Switzerland, The Netherlands, and the United States are classed in the “Emerging” (Level 5) category. These countries demonstrate growing public awareness and recognition of young carers, a small but growing research base, possible relevant laws, no specific legal rights, and no specific services or interventions for young carers, but other general services may be applicable (Leu & Becker, 2017). Greece, Finland, United Arab Emirates, and France are classed in the “Awakening” (Level 6) category, as they are considered to have some limited awareness of young carers as a distinct group (Leu & Becker, 2017). All other countries are classed in the “No Response” (Level 7) category, as they are considered to have no awareness or policy response to young carers (Leu & Becker, 2017).

Thus, Leu and Becker's (2017) country-specific classification and analysis are helpful in understanding the key characteristics that influence a country's awareness and responses to young carers. Moreover, their analysis illuminates the fact that some countries acknowledge the well-being of young carers as a priority for social policy, while most others do not (Leu & Becker, 2017). In regard to the reasons for the range of different responses regarding young carers across countries, Leu and Becker (2017)'s analysis indicated that countries with strong nongovernmental organizations (NGOs) were more advanced in the classification. For example, the Children's Society and Carers

Trust are two NGOs in the United Kingdom that have been critical in raising awareness and advocating for policy change (Leu & Becker, 2017). Because of these NGOs, young carers in the United Kingdom have legal rights to assessments and have access to a variety of supportive services. In the United States, such NGOs as the National Alliance for Caregiving, the National MS Society, and Cancer Care provide supportive resources for young carers (Leu & Becker, 2017). However, in comparison to the United Kingdom and Australia, NGOs in the United States have made much less of an impact, as they lack the power to influence policy change and service development (Leu & Becker, 2017).

Global Prevalence

Approximately between 2% and 8% of children in industrialized capitalist societies are carers (Becker, 2007; Joseph et al., 2020). This imprecise range in estimates of prevalence reflects a variety of methodology and sampling methods, studies with small samples, and an inconsistent definition of young carers (Joseph et al., 2020). The most up-to-date survey data on the prevalence of young carers in England were from the Multidimensional Assessment of Caring Activities Checklist for Young Carers (MACA-YC18; Joseph et al., 2019). The study recruited a sample of 925 young people from 21 schools and surveyed two age groups: 11- and 12-year-old children in their 7th year of education and 14- and 15-year-old children in their 10th year of education. Of the 925 young people, 200 (22%) responded that they cared for someone in their home who suffers from an illness or disability (Joseph et al., 2019). In regard to whom they helped, 46% identified providing care for their mothers, 40% for their siblings, 23% for their fathers, 23% for their grandparents, and 16% indicated other. The study found that 7% of

young people were engaging in a “high amount” of caring, and 3% were engaging in a “very high amount,” according to their scores on the MACA-YC18; Joseph et al., 2019). Second to the United Kingdom, Australia has conducted a significant amount of research on young carers. According to Australia’s 2016 Census of Population and Housing, one in 20 individuals aged 15 to 24 years (5.6%) were young carers (Australian Bureau of Statistics, 2016). However, unlike in the United Kingdom, Australia’s young carer population is representative of youth in their teen and young-adult years. Switzerland, another country classified at the Intermediate level, estimates the prevalence of young carers at 7.9% of the population (Leu et al., 2019). The population estimate of prevalence was derived by conducting an online survey of children in Grades 4 through 9, ranging in age from 10 to 15 years old. The study collected data from 3,991 respondents, of which 307 (7.7%) were identified as young carers (Leu et al., 2019). Findings from this survey suggest approximately 38,400 young carers in Grades 4 through 9 in Switzerland, and when generalizing these findings to youth aged 9 to 16 years old, the prevalence is estimated to be 51,500 (Leu et al., 2019). Taken altogether, countries that have conducted significant research, including prevalence studies on youth carers, reported prevalence estimates upwards of 5% of the population.

Extent and Nature of Caring Activities

Studies in Europe and Australia show that young carers spent more time on a variety of caring activities as compared to noncaregiving youth (Ireland & Pakenhan, 2010; Kallander et al., 2018 Nagl-Cupal et al., 2014; Pakenham & Cox, 2012). Simply living in a household with an ill family member is linked to higher levels of caregiving

for youth compared to same-aged peers living with healthy family members (Pakenham & Cox, 2015). Moreover, Pakenham and Cox (2015) found that the youth caregiving experience was intensified if the ill family member was a parent and if more than one illness was present.

The international literature on the effects of caring for young carers is wide ranging and highlights many important considerations. Studies indicate that the experience of caring is uniquely subjective and personalized. At the same time, research has demonstrated that young carers may experience a variety of difficulties with their health and well-being, as well as educational and social disadvantages (Joseph et al., 2020). Encouragingly, studies have also indicated that caring can be associated with positive changes, including increased resiliency and maturity and the ability to foster compassion and empathy (Fives et al., 2013; Stamatopoulos, 2018; Svanberg et al., 2010).

Studies point out that many young carers are untrained and may be engaging in various caregiving tasks with little formal guidance (Kavanaugh et al., 2019). In comparison to adult caregivers, young caregivers are more likely to lack knowledge and understanding about the care recipient's medical or physical needs. A study conducted in Northern Ireland examined factors that challenged resilience of young carers and explored their perceptions of care recipients' illnesses or disabilities within the family (McGibbon, et al., 2019). Findings indicated that a young carer's knowledge of and response to the trajectory of and type of illness or disability contributed to their capacities for resilience (McGibbon et al., 2019).

Caring responsibilities have been found to be impactful on a young carer's educational training. A qualitative study conducted with 16 young carers (aged 10-17 years) and 14 young-adult carers (aged 18-25 years) in Switzerland found that carers reported trouble concentrating and difficulties focusing on their social lives as a result of worrying about their family members (Leu et al., 2018). A qualitative study of Canadian young carers found that young carers reported having difficulty with finding time to complete homework and were often late to school or absent (Stamatopoulos, 2018). An Australian study explored differences in school engagement of noncarers, young carers of a family member with a disability, those caring for a family member with mental illness, and those caring for a family member with a drug/alcohol problem (Hamilton & Redmond, 2020). This study used results from a national school-based survey of 5,220 children aged 8-14 years, of whom 465 identified as carers. The survey asked students if anyone in their families was seriously affected by a disability or long-term illness, depression or mental illness, or using alcohol or drugs. If a student answered yes, a young-carer status was then determined by asking students if they did extra work around the house because a family member could not complete certain tasks. Results from this study indicated that school engagement among young carers of family members with a disability was similar to that of noncarers (Hamilton & Redmond, 2020). However, school engagement among young carers of a family member with a mental illness or using drugs/alcohol was significantly lower (Hamilton & Redmond, 2020). Additionally, studies have shown that young carers are less likely than noncarers to seek higher education upon completion of high school (Redmond et al., 2016; Robinson et al., 2017).

Social disadvantages and difficulties as a result of caregiving have also been noted in the literature. Studies show that young carers report strained family relationships, exhaustion from communication with extended family members, and feelings of isolation from and not being understood by their peers (Leu et al., 2018; Stamatopoulos, 2018). One such social difficulty experienced by young carers is the stigma associated with this role, possibly leading to secrecy, social withdrawal and/or social exclusion, and feelings of invisibility or lack of acknowledgement (Smyth et al., 2011). An Australian research study explored the issue of self-identification among young carers. Qualitative data were gathered through focus groups and interviews with 68 young carers (aged 11-25 years) and 16 service providers and policy makers. Results suggested that overall self-identifying as a young carer was empowering for those who participated in this research, especially when learning that others their age experienced similar circumstances (Smyth et al., 2011). Accordingly, young carers who participated in a Swiss qualitative study by Leu et al. (2018) were divided in that some openly communicated with peers about an ill or disabled family member, while others tried to hide this aspect of their family life completely. Furthermore, even when choosing to talk openly about their experiences to peers, many felt that peers did not understand; the young carers described feeling understood only when talking with other carers (Leu et al., 2018).

Thus, international research has been crucial in creating awareness of this population and demonstrating the diverse impacts of caregiving on young people. As previously stated, not all research has demonstrated adverse effects for young carers, with

several studies indicating posttraumatic growth or finding benefits resulting from caregiving responsibilities, resiliency, maturity, an ability to foster compassion and empathy, and establishing close relationships with care recipients (Doutre et al., 2013; Fives et al., 2013; Pakenham & Cox, 2018; Svanberg et al., 2010; Stamatopoulos, 2018). Moreover, the international literature paints a picture of the experiences of young carers across countries and continues to serve as a valuable template for researchers in the United States.

Youth Caregivers in the United States

A small, yet growing research base has begun to tap into the experiences of caregiving youth in the United States. According to a scoping review of research on caregiving youth by Kavanaugh et al. (2016), the current state of the research offers a descriptive picture of who caregiving youth are, their experiences, and certain measures used to assess well-being and relational factors associated with the care recipient. Additionally, the majority of the studies conducted include samples of fewer than 40 youth caregivers (Kavanaugh et al., 2016). Qualitative methods, including semistructured interviews and focus groups, have been the predominant form of data collection (Kavanaugh et al., 2016).

Knowing the exact prevalence of this population is difficult, as the only national survey on caregiving youth was conducted more than a decade ago and estimated a prevalence of 1.3 million caregivers, whereas newer data collected from adult caregivers estimate that 5.4 million children are providing care for family members (Hunt et al., 2005). Findings from the 2005 National Survey on Caregiving Youth indicated that 31%

of child caregivers are aged 8 to 11 years, 38% are aged 12 to 15 years, and 31% are aged 16 to 18 years. Both male (49%) and female (51%) child caregivers provided care equally. Furthermore, youth predominantly cared for a parent or grandparent (72%), followed by a sibling (11%). Youth caregivers from minority families are more likely to care for their mother (42%) as compared to youth in nonminority families (Hunt et al., 2005). Additionally, youth caregivers in minority households indicated that they took on more caregiving responsibilities without the help of other family members (e.g., chores, meal preparation, dressing, giving medications) compared to their nonminority counterparts (Hunt et al., 2005). In August 2020, researchers conducted a study to explore youth experiences and perspectives on caregiving using MyVoice, a national text message poll of youth aged 14 to 24 years (Raj et al., 2021). Data were collected from 1,076 participants, and more than one third (35%) reported previously or currently engaging in caregiving tasks either independently or by helping another family member (Raj et al., 2021). Youth in this survey reported providing care to adults with chronic conditions (e.g., dementia, cancer) and acute illnesses (e.g., COVID-19, postoperative care; Raj et al., 2021). Additionally, participants reported a desire for specific training and indicated that caregiving has already impacted or would likely impact their educational or career goals (Raj et al., 2021).

Since its establishment in 1998, the AACY continues to be the only organization in the United States exclusively dedicated to supporting caregiving youth. In 2006, the AACY partnered with The School District of Palm Beach County, a large school district in Florida, to create the Caregiving Youth Project (CYP). This project offers needs-based

services, including skills-building classes and lunch-and-learn sessions at school, home visits by a social worker, resources for families, respite, tutoring, and fun activities for students in 6th through 12th grade (AACY, 2020). The AACY reported that as of June 2018 more than 1,500 youth caregivers and their families had participated in the CYP (AACY, 2020). Furthermore, youth who chose to continue with the CYP in high school completed the program with a 97.7% graduation rate, and more than 90% attended postsecondary education (AACY, 2020).

A recently published *Social Policy Report* provides a thorough description of the sociological factors that have led to the rise of caregiving youth within the United States during the last few decades (Armstrong-Carter et al., 2021). In addition to those factors already mentioned (i.e., high prevalence of chronic disease, increased life expectancy, the increasing cost of health care, and changes in family structure with more single-parent households and intergenerational households), Armstrong-Carter et al. discussed some other critical factors that have led to an increase in youth caregiving. One such factor is the current opioid crisis. Children whose parents become dependent on opioids may be more likely to live with their grandparents and, ultimately, be well positioned to take on a caregiving role should grandparents need assistance (Armstrong-Carter et al., 2021). Additionally, adolescent pregnancy and increases in incarceration rates are both factors that may prompt youth to live with aging relatives (Armstrong-Carter et al., 2021). Finally, the COVID-19 pandemic has likely increased caregiving responsibilities for youth. Some youth may be becoming caregivers for the first time, while others may find

that the pandemic has exacerbated caregiving responsibilities, leaving them with little time away from caregiving tasks (Armstrong-Carter et al., 2021).

Caregiving Youth Experiences

Care Recipient Illness

Both international and U.S. studies indicate that the caregiving experience is moderated by the care recipient's illness. Therefore, youth caregivers vary greatly in the variety of tasks performed, length of time in the caregiving role, and level of support received (Kavanaugh et al., 2016). Studies have documented the experiences of youth caregivers who care for family members with a variety of chronic illnesses, including cancer, dementia, diabetes, HIV/AIDS, HD, and ALS (Bauman et al., 2006; Gates & Lackey, 1998; Jacobson & Wood, 2004; Kavanaugh, 2014; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Kavanaugh et al., 2020 Nichols et al., 2013; Williams et al., 2009). Additionally, studies have explored experiences of youth caring for family members who are in need of care because of advanced aging and physical disabilities (Assaf et al., 2016; Cohen et al., 2012).

Caregiving Tasks

Youth may engage in a variety of caregiving tasks, depending on the care recipient's illness. Studies indicate that youth assist with activities of daily living (ADLs), such as eating, bathing, dressing, toileting, and mobility, as well as instrumental activities of daily living (IADLs), such as grocery shopping, cooking, managing medications, transportation, and housework (Kavanaugh et al., 2016). A recent study by Kavanaugh et al. (2020) explored the experiences of 38 youth caregivers (aged 8-18 years) who

provided care to a family member with ALS. Parent/family data were collected through online surveys, and follow-up interviews were conducted with youth caregivers.

Caregiving tasks were assessed by asking the person with ALS about the tasks the child engaged in and by asking caregiving youth to complete the MACA, a measure developed for and tested on youth caregivers across different disorders (Kavanaugh et al., 2020).

Results indicated that youth participated in an average of 12 tasks and spent an average of 5 hours a day providing care. Some of the caregiving tasks included household upkeep, assistance with ADLs, transferring (i.e., helping the family member get in and out of a bed or chair and helping with walking or getting around), assisting with communication, keeping the family member company, and taking care of siblings (Kavanaugh et al., 2020).

Similarly, other studies have explored the caregiving experiences and tasks provided by youth who care for a family member with HD (Kavanaugh, 2014; Kavanaugh et al., 2019; Williams et al., 2009). Findings from these studies indicated that youth caregivers engaged in extensive caregiving tasks (e.g., bathing, toileting, assisting with medication, providing company, helping the family member walk). One such study explored the experiences of caregiving youth providing care to a parent with HD and found that frequency of caregiving was correlated with higher conflict with the parent and more problems with school (Kavanaugh, 2014). In another study, Kavanaugh et al. (2019) sought to understand how young caregivers in families living with a person with rare neurological disorders (i.e., ALS and HD) receive training in care tasks. This study drew on data from three studies involving 96 youth aged 8 to 20 years old. Findings

indicated that the majority of youth (61%) received no training or guidance. The participants who shared they had no training were asked how they knew what to do, and six themes emerged: (a) patient tells me what to do, (b) watching and observing, (c) common sense, (d) treating patient like child or self, (e) process of figuring it out, and (f) I don't know (Kavanaugh et al., 2019). Thus, this study underscores the need for health care providers to identify youth who are providing care in families with persons with neurological disorders and to develop education and training programs that foster skill building and offer support (Kavanaugh et al., 2019).

In addition to studies that explored the experiences of youth caregivers providing care for a family member with a certain illness, such as ALS, other studies included samples of youth caregivers who provided care across disorders (Assaf et al., 2016; Hunt et al., 2005). One study explored the participation rates, demographics, and caregiving tasks among sixth graders participating in the CYP of the American Association of Caregiving Youth (Assaf et al., 2016). Data were analyzed based on a retrospective review of participant information and included 396 sixth graders from eight middle schools between 2007 and 2013. Among the caregiving youth studied, 62% identified as girls, and the median age was 11 years old. Thirty-one percent identified as Hispanic, 21% as Haitian, 17% as Caucasian, and 21% as more than one ethnic/racial group, unidentified, or other (Assaf et al., 2016). This study showed that caregiving youth cared mostly for a grandparent (40.6%) or parent (30.5%), and care recipients most commonly had diagnoses of diabetes, arthritis/bone or joint problems, or stroke/paralysis or other neurologic problem (Assaf et al., 2016). In regard to caregiving activities, caregiving

youth reported they kept the care recipient company (85.6%), provided emotional support (74.5%), and provided assistance with mobility (46.7%), among other tasks. One should also note that 36% of youth indicated that they provided assistance with medication, and 25% reported that they were responsible for translating at medical visits. Youth who assist in medication management may lack the training and knowledge to administer or organize medications, potentially causing harm to the care recipient (Assaf et al., 2016; Nickels et al., 2018). Additionally, youth may be faced with the task of translating medical visits for a parent or grandparent, as language brokering is common in certain cultures and is often a result of generational differences in language acquisition (Rainey et al., 2014). One study concluded that children who were language brokers were more likely to experience depression, and young adults who assumed the language broker role during their preadolescent years reported higher levels of anxiety than their bilingual nonbrokering equals (Rainey et al., 2014). Conversely, another study found that Mexican American emerging adults who did not experience language brokering as a burden demonstrated high self-esteem and self-efficacy (Weisskirch, 2013). Thus, caregiving tasks can be positively and negatively impactful on the young caregiver's mental health and self-esteem (Assaf et al., 2016; Rainey et al., 2014; Weisskirch, 2013). Overall, sixth graders who participated in the CYP reported improvements in school (85.5%), caregiving knowledge (88.5%), and self-esteem (89.5%; Assaf et al., 2016).

As previously mentioned, several studies have found that caregiving youth reported involvement in medication administration and organization. Only one study thus far has explored the circumstances in which youth are involved in medication

administration and management (Nickels et al., 2018). Focus groups were conducted using semistructured interviews with 28 caregiving youth aged 12-19 years old who were recruited from the CYP. Caregivers provided care for family members with neurologically related disease, diabetes, functional decline, asthma, and vision loss. Several informative themes emerged, including tasks involve organizational and administrative responsibilities, youth vary in their knowledge about medications, most share this responsibility with other family members, youth lack formal education about how to provide assistance in this area, many challenges exist regarding this task, managing medications is associated with emotional responses, and safety issues are of concern (Nickels et al., 2018). Caregiving youth expressed worry about several aspects of their medication responsibilities. Moreover, youth in this study indicated that they have substantial interaction with medical professionals, yet lack training and knowledge about medication administration (Nickels et al., 2018). Therefore, recognition of youth caregivers by health care providers would benefit the well-being of the care recipient and caregiver, and would allow for youth to be referred for supportive services and training.

Caregiving Role

The youth caregiving experience is influenced by the presence of other family members providing care, as well as by the length of time spent in this role (Kavanaugh et al., 2016). A national prevalence study indicated that 75% of youth were not caring for their family members alone (Hunt et al., 2005). This study also found that youth caregivers were more often providing care in single-parent, low socioeconomic status (SES) households (Hunt et al., 2005). Although some articles broadly discuss family and

social support as a protective factor to the caregiving experience, no U.S. studies to date have explicitly explored the influence of family composition and family caregiving roles on the way youth provide care (Kavanaugh et al., 2016). Thus, more research on family demographics is needed to understand the nature of the caregiving role for youth and to determine whether they are considered primary or secondary caregivers for family members.

The length of time spent in the caregiving role varies depending on a variety of factors, including but not limited to care recipient illness, family structure, SES, health insurance, and available resources and support. Youth caring for a parent with HD reported providing care for as many as 10 years (Kavanaugh, 2014). Shifren's (2008) study of youth caring for family members with a variety of conditions indicated that youth provided care for an average of 6 years. The average age that youth began caregiving was 13.53 years, and youth provided care for family members with physical and mental health problems, as well as with drug/alcohol problems (Shifren, 2008).

Interestingly, Greene et al. (2017) examined the experiences of emerging young adult caregivers (i.e., between ages 18-24 years) and found that caregivers provided care for many years, with half of caregivers in the study taking on responsibilities between the ages of 16 and 20 years and one third assuming responsibilities between the ages of 11 and 15 years. A study exploring early caregiving experiences of former young caregivers and emerging adult caregivers found that the mean age former young caregivers began to care for a family member was 13.70 years (Shifren et al., 2014). In this study, 28 individuals met criteria as "former young caregivers," as they provided assistance with

ADLs and/or IADLs for a parent or relative before they were 18 years of age (Shifren et al., 2014). Of these individuals, one person reported being 3 years old when beginning caregiving experiences, four individuals were between 7 to 10 years of age, and 22 individuals were between 11 to 17 years of age (Shifren et al., 2014).

School Outcomes

Consistent with international studies, researchers in the United States have found that youth caregiving impacts school performance and attendance (Hunt et al., 2005; Kavanaugh, 2014; Siskowski, 2006). Siskowski (2006) explored the effects of a young person's caregiving role on school performance by using data from the 2002 *What Works Survey*, which consisted of 12,681 public-school students in Palm Beach County, Florida. This study found that 6,210 students reported providing "hands on" care for a family member, and only 32.9% reported their engagement in caregiving activities had no effect on school performance (Siskowski, 2006).

Additionally, schools are an important setting for identifying caregiving youth. More recently, a question about caregiving was included in the Youth Risk Behavior Survey, a national school-based survey conducted by the Centers for Disease Control (Armstrong-Carter et al., 2021). The survey was completed by 11,000 students, and results indicated that 24% of middle-school students and 16% of highschool students provided some type of care once a week for a family member who was elderly, was disabled, or had a chronic illness (Armstrong-Carter et al., 2021).

Psychological Impact

A small research base has explored how caregiving responsibilities impact the psychological well-being of young caregivers in the United States. Similar to the adult-caregiving literature, studies reflect both positive and negative effects on mental health (Cohen et al., 2012; East, 2010; Hunt et al., 2005; Shifren & Kachorek, 2003). Although the 2005 National Survey on Caregiving Youth was conducted more than a decade ago, findings from this survey were fundamental in bringing awareness to the effects of caregiving on children's behaviors and emotional well-being. For example, according to parents' reports, youth caregivers were more likely to show anxious and depressed behavior as compared to noncaregivers (Hunt et al., 2005). Caregivers in the 12- to 18-year age range were more likely to exhibit antisocial behavior, including trouble getting along with teachers, bullying, being disobedient at school, and associating with children who get in trouble, as compared to noncaregivers the same age (Hunt et al., 2005). Additionally, findings indicated that 56% of 8- to 11-year olds who provided care to a family member in the household were likely to be depressed compared with 19% not living with the care recipient (Hunt et al., 2005). In a more recent study, Cohen et al. (2012) reported similar findings: Youth caregivers, especially those living with the care recipient, were at a significantly higher risk for depression and anxiety as compared to noncaregivers. This study used a survey dataset of 1,281 middle-school students aged 10 to 14 years from two schools in Florida that participated in the CYP. In addition to exploring whether youth caregivers were at an increased risk for depression and anxiety, the study examined how youth coped with their caregiving responsibilities. The study

included three groups of youth: caregivers living with the care recipient, caregivers not living with the care recipient, and noncaregivers. In comparison to the noncaregiving student group, youth caregiver groups showed greater use of both disengagement coping (i.e., wishing to be smarter, wishing the problem would go away) and engagement coping (i.e., trying to think of other ways to solve a problem, asking other people for help) strategies (Cohen et al., 2012). Both groups of youth caregivers, those who lived with the care recipient and those who did not, used more disengagement coping strategies compared to noncaregivers (Cohen et al., 2012). Thus, the findings from this study indicated that caregiving youth used more strategies in both coping-style categories, which may be related to their perception of heightened family stress or their process of trying out different ways to cope because of the limited guidance they received regarding their caregiving responsibilities (Cohen et al., 2012).

Qualitative studies have provided insight into the emotional impact on young caregivers. One such study examined the experiences of youth between the ages of 11 to 18 years who cared for a family member with frontotemporal dementia (FTD; Nichols et al., 2013). Two focus groups were conducted with a total of 14 young caregivers from the United States and Canada. Overall, youth reported that their experiences of caring for a parent with early-onset dementia were positive; however, many also discussed experiencing anger, embarrassment, guilt, fear, confusion, and frustration (Nichols et al., 2013). Additionally, youth shared that they experienced social difficulties when interacting with outsiders who had little knowledge of FTD, as many assumed the care recipient was acting belligerent (Nichols et al., 2013). They also noted issues at school,

including gossip and rumors among peers. Youth varied in their coping styles when approached with these situations; some reported ignoring judgmental remarks, while others chose to educate individuals about FTD (Nichols et al., 2013). Furthermore, this study highlights youth caregivers' desire for more support, as many expressed wanting health care professionals to assist them in overcoming stigma and the challenges of caregiving during adolescent years (Nichols et al., 2013).

Social Support

Consistent with the international literature, youth caregivers in the United States experience psychological, social, health, and educational problems as a result of their caregiving responsibilities (Kavanaugh et al., 2016). Research demonstrates a need for increased social support in the form of systemic support at school and medical levels. According to the most up-to-date review of research on caregiving youth in the United States, only two studies (i.e., Kavanaugh et al., 2015; Shifren, 2008) examined social support needs (Kavanaugh et al., 2016). This gap in the research is critical given that many caregiving youth report feeling isolated (Kavanaugh et al., 2016). Given that the AACY's CYP is a school-based caregiver intervention program and the only comprehensive program offering support to youth in the United States, studies, although limited, have focused on the school system as a supportive intervention setting. Moreover, data from the CYP indicate that schools are critical systems to provide support, and school-based interventions have been successful in improving school performance and in increasing caregiving knowledge and self-esteem (AACY, 2020; Assaf et al., 2016).

Health care settings are another critical avenue of intervention, as medical professionals, such as physicians, nurses, social workers, and psychologists, are uniquely positioned to identify caregiving youth and connect them to resources. To date, no U.S. studies have focused on pediatric health care providers' knowledge and perceptions regarding caregiving youth. However, primary-care providers' experiences with adult family caregivers have been explored in the literature, with studies indicating several barriers to supporting caregivers, including insufficient education about caregivers, lack of time and reimbursement, and caregiver characteristics (Parmar et al., 2019). With regard to caregiver characteristics, studies have documented caregivers' preference to not self-identify or ask for help, thus limiting health care providers' awareness of an individual's caregiving role (Burrige et al., 2017; Carduff et al., 2014; Parmar et al., 2019; Skufca, 2019). As an example, a study of 241 American physicians found that 54% rated patients as having multiple caregivers and 44% reported not being aware of who the caregivers were as the top barrier to supporting caregivers (Skufca, 2019).

Comparably, qualitative studies conducted globally with young caregivers indicate their reluctance to call attention to themselves and their caring responsibilities (Bjorgvinsdottir & Halldorsdottir, 2014; Leu et al., 2018; Smyth et al., 2011). Yet, these studies also reflect that youth desire more support from professionals, including training, guidance, advice, and opportunities to engage with "like" peers who are in similar situations (Kavanaugh et al., 2017; Kavanaugh et al., 2019; Leu et al., 2018). Furthermore, a Swiss study exploring the experiences of young carers found that caregivers described situations of being overlooked by health care providers, even when

they tried to inform providers of their caregiving role (Leu et al., 2018). Young carers shared that communication with health care professionals was often challenging, possibly because of lack of awareness on the part of the health care providers about provider's roles and responsibilities (Leu et al., 2018). Interviewees in this study consisted of 16 young carers (aged 10-17 years) and 14 young-adult carers (aged 18-25 years). Young-adult carers reported finding their own ways of gathering information and resources, while younger carers reported more challenges (Leu et al., 2018). Thus, qualitative studies with young caregivers provide valuable information regarding their perceptions of seeking support from health care providers.

In other countries (e.g., the United Kingdom, Australia), policies regarding caregiving youth have been put into place and serve to inform practices of health care providers. For example, in the United Kingdom, the 2014 Children and Families Act and the Care Act are legislation created for young caregivers to ensure individuals are identified, offered an assessment, and provided with resources to support their mental health (Leu & Becker, 2017). The Young Carers Bursary Program in Australia is another example and offers financial support. Thus, countries with an extensive research base have used their research to increase awareness and recognition of young carers among policy makers and health care professionals (Leu & Becker, 2017). Currently, policies are nonexistent in the United States, and the medical setting is a supportive avenue that remains unaddressed in the literature. Therefore, future research regarding health care providers' knowledge and perceptions of caregiving youth in the United States is needed. Such research is critical in arming health care professionals with the tools and

mechanisms to identify caregiving youth so that providers are in a position to provide support and resources.

CHAPTER 3: METHOD

The purpose of this study is to examine pediatric health care providers' knowledge and perceptions regarding caregiving youth. This study surveyed pediatric health care providers and allied professionals who provide services to caregiving youth in a medical setting. A mixed methods survey was used to collect quantitative (i.e., years practicing, barriers to identifying caregiving youth) and qualitative (i.e., subjective experiences, opinions, beliefs) data from health care providers. The aim of the survey was to determine health care providers' awareness of the prevalence of caregiving youth within their practice, services health care providers offer to caregiving youth, the delivery of these services, and any barriers to identifying caregiving youth in medical settings. Overall, the goal of this study was to determine current practices in order to increase support for caregiving youth.

Participants

Data were collected from 85 participants, with 55 participants completing the survey in its entirety. Among the survey participants, 82 pediatric health care providers and allied professionals specified their occupational title. As shown in Table 1, the majority of participants identified their job title as "general pediatrician" (26.8%), followed by "pediatric medical or surgical sub-specialist" (17.1%), and "Advanced Registered Nurse Practitioner (ARNP)/ Advanced Practice Registered Nurse (APRN)" (15.9%). Of note, six participants chose "other" to describe their occupations, including Pediatric Registered Nurse (2), Registered Nurse (1), Physician Assistant (2), and School Nurse (1). Additionally, the majority of the participants were from the mid-Atlantic

(56%) and northeast (30%) regions. The remainder of the participants were from the west (9%), midwest (3%), and southwest (1%) regions. Data regarding the participants' primary employment settings were also collected. The majority of the participants indicated that they worked in a medical school/academic setting (28.4%), in a city/county/state government clinic (23.5%), and in pediatric group practices (13.6%). Years practicing since completing residency/training spanned a wide range, with 30.9% reporting practicing for 5 years or fewer, 22.2% practicing for 6-10 years, 17.3% practicing for 11-20 years, and 29.6% practicing for 20 years or more.

Table 1*Summary of Occupational Titles*

Occupation	Response percent	Response count
Pediatric Resident or Fellow	12.2	10
General Pediatrician	26.8	22
Hospitalist	2.4	2
Pediatric Medical or Surgical Subspecialist	17.1	14
Family Physician	1.2	1
ARNP/APRN ^a	15.9	13
Practice Manager	1.2	1
Allied Health Professional	11	9
Nonclinical	3.7	3
Not working	1.2	1
Other	7.3	6

^a ARNP/APRN (Advanced Registered Nurse Practitioner/Advanced Practicing Registered Nurse)

Inclusion Criteria

Participants were pediatric health care providers or allied professionals with access to a computer.

Exclusion Criteria

There were no exclusion criteria if inclusion criteria are met.

Screening and Recruitment

The screening process relied on self-report of being a pediatric health care provider or allied professional. Participants were recruited from physician organizations, academic medical centers, and personal contacts. A short summary of the study, encouraging pediatric health care provider and allied professional participation, was posted either on an online forum or an email and sent out to health care providers. The study also used archival data that had already been screened to include pediatric health care providers and allied professionals.

Measures

The goal of this study was to clarify current practices of pediatric health care providers and allied professionals in order to increase support for caregiving youth in medical settings. In order to obtain these data, a survey format was selected. Two versions of the survey were created at the University of Miami by Julie Belkowitz, MD, and Toni Chanroo, MD candidate. The original survey was an expanded version, including perceptions of implications of caregiving youth. However, a more simplified version with targeted objectives was created after taking into account feedback received from survey participants that the survey could be more concise. Both versions of the survey included a few demographic questions, such as participant's occupation, employment setting, zip code of primary employment setting, and years practicing in health care since completing residency/training. Additionally, both surveys asked participants to watch a brief video that narrated the challenges faced by one caregiving youth in providing care for his mother. The remaining survey questions varied depending

on the participants' answers to a question about their awareness of this population within their work settings. If participants indicated that they were aware of patients in their practices caring for an ill or disabled relative or household member, survey questions were aimed at assessing awareness. If participants indicated that they were not aware, or that the question was not applicable, the remainder of the survey questions was intended to create awareness. Other survey questions were aimed at understanding the methods that pediatric health care providers use to identify caregiving youth and the resources they might offer caregiving youth. A ranking question was used to gather information about pediatric health care providers' perceptions of barriers to identifying caregiving youth. The ranking question offered seven choices, asking respondents to rank the choices in order, with 1 being most likely to be a barrier and 7 being least likely to be a barrier. The survey also collected qualitative responses from the participants, including questions that prompted respondents for more information if they were willing to provide such information.

Procedures

This study included both an archival data set and newly collected data. New data were collected by disseminating the simplified version of the survey to pediatric health care professionals who were recruited from physician organizations, from academic medical centers, and through personal contacts. The survey link was sent to personal contacts and posted in online forums of which pediatric health care providers were members (e.g., Pennsylvania Chapter of the American Academy of Pediatrics, Belmont University alumni forum). Survey participants solicited through personal contact were

provided with a brief description of the purpose of the study via email. Those participants who were reached via an online forum had the opportunity to read an introductory paragraph posted with the survey link. After reading about the study and determining their interest in taking the survey, pediatric health care providers and allied professionals consented to participate in the online survey by voluntarily selecting the link. The survey was distributed through REDCap, and participants had the option of clicking on the REDCap link giving them the choice to participate in the survey. In order to verify that participants identified as pediatric health care providers or allied professionals, they were asked to disclose their occupation.

Statistical Package for the Social Sciences (SPSS) was the statistical software used to analyze the quantitative data collected. Data from REDCap were transferred to an SPSS file to be combined with the existing data set. All collected data were password protected, and information remained confidential. As this is a mixed methods survey design, grounded theory was used to analyze the qualitative data collected (Glaser & Strauss, 1967). Grounded theory is a form of qualitative research that aims to construct theory based on data (Glaser & Strauss, 1967).

CHAPTER 4: RESULTS

Data Analyses

The survey was created to examine the perceptions and involvement of pediatric health care providers in supporting caregiving youth. Descriptive statistics were used to characterize the study sample, including means, standard deviations, percentages, and frequencies. Characteristics collected included occupation, employment setting, years practicing, and geographic location. Descriptive statistics were used to better understand health care providers' perceptions, such as when they might assess for youth caregivers, what they perceived as barriers to asking about youth caregiving in their practice, and resources they offered youth.

Additionally, qualitative data were collected from participants if they chose to provide more information in response to open-ended questions. Grounded theory was used to look at emerging patterns in participants' answers (Glaser & Strauss, 1967). Applying grounded theory helped to characterize participants' statements into themes. These themes were analyzed and used to predict theories and inform interventions.

Results

Survey Questions

The survey questions and their descriptive statistics are included in this section. Descriptive statistics were used to simplify the data in order to create an organized understanding of health care providers' perceptions regarding caregiving youth. Additionally, qualitative data were collected to obtain subjective perceptions from the participants.

Prior to taking this survey, had you ever heard the term caregiving youth, youth caregivers or young carers?

Of the 78 participants who answered this question, 30.8% indicated that they had heard the terms caregiving youth, youth caregivers, or young carers, while 57.7% had not heard any of these terms, and 11.5% were unsure. As shown in Table 2, a chi-square test of independence was conducted to explore whether the number of years practicing since completing training had a significant impact on health care provider's awareness of young caregivers. The relation between these variables was not significant, $X^2(6, N = 78) = 9.1, p = .16$.

If yes, please explain what "caregiving youth," "youth caregivers," or "young carers" means to you.

Eighteen participants shared their opinions. Responses were diverse and varied regarding age of caregiver, who they care for, the role they take on, the challenges they face, and circumstances around caregiving. Regarding age, many participants indicated that youth caregivers are under the age of 18 years; however, one respondent reported "people under age 20," and another respondent stated, "informal caregivers between the age of 8-18 years old." Additionally, participants reported their opinions regarding care recipients. Interestingly, some participants were of the opinion that being a youth caregiver means providing care to adults. For example, participants stated, "a person under the age of 18 who is the primary caregiver for an ill parent," "children who care for adult relatives," and "young people who care for parents." Other participants specified a variety of care recipients, including "a grandparent, parent or sibling," and "younger

family members, including siblings or extended relatives.” Some participants provided opinions on caregiving tasks, such as assisting with activities of daily living (ADLs) and providing “direct care (medical and non-medical activities).” Regarding challenges youth face, one participant commented, “it impacts them emotionally, academically, and socially,” and two participants shared their opinions that support is limited for this population. Of note, one participant stated that a younger person may be in a caregiving role “due to a lack of other adult presence in the family structure.”

Table 2*Impact of Years Practicing on Awareness of Caregiving Youth*

Years practicing		0-5 years		6-10 years		11-20 years		>20 years	
Whether participant has heard of caregiving youth		<i>N</i>	% of total	<i>N</i>	% of total	<i>N</i>	% of total	<i>N</i>	% of total
	Yes	4	5.1	3	3.8	8	10.3	9	11.5
	No	16	20.5	12	15.4	5	6.4	12	15.4
	Not sure	2	2.6	3	3.8	1	1.3	3	3.8

Note: The relationship between these variables was not significant. $\chi^2 (6, N = 78) = 9.1, p = .16$.

Video on caregiving youth

A brief video depicting the responsibilities of one young caregiver was included within the survey. After viewing this video, participants were asked to choose the response that best described their reactions to the content. Of the participants, 11.8% responded that they were already familiar with all the information presented in the video; 48.5% said they knew some of the information but learned more from the video; and 39.7% reported that they learned about a new topic by watching this video.

Do you know of any patients in your practice caring for an ill or disabled relative or household member?

As previously noted, a participant's response to this survey question determined which questions would follow (i.e., questions aimed at assessing awareness or questions aimed at creating awareness). Of the 71 participants who responded to this question, 35.2% indicated they were aware of patients in their practice caring for an ill or disabled relative, 57.7% answered that they were not aware of any patients in their practice caring for an ill or disabled relative, and 7% indicated not applicable.

Please rate from most likely (1) to least likely (7), how often you encounter each of these possible barriers to identifying caregiving youth in your practice.

A rating question was used to gather information regarding health care providers' perceptions of barriers to identifying caregiving youth. Participants were asked to identify the frequency in which they encountered the following seven barriers: unsure how to ask, I do not think this is an important issue to ask about, lack of resources to support caregiving youth, patient fear of repercussions if they disclose being a caregiver, lack of a

validated tool, insufficient appointment time, and I am not currently practicing. Data provided by participants who indicated they were not currently practicing were removed from the dataset in order to better understand providers' perceptions of barriers to identifying caregiving youth. Four participants provided responses, as this question was asked only of participants who reported an awareness of caregiving youth in the most recent version of this survey. Among the participants, two of four felt that lack of resources to support caregiving youth and lack of a validated screening tool were often barriers.

This rating question was also asked of respondents who answered not applicable (e.g., they were in a nonclinical role or not working) or that they were not aware of any patients in their practice caring for an ill or disabled relative (Group 2). Nineteen participants answered this question. Table 3 shows the participants' ratings of items that are most likely to be barriers. Participants indicated that the top two barriers (e.g., ratings of 1 and 2) were insufficient appointment time (6) and thinking that this is not an important issue to ask about (6). Overall, participants' rankings of their top two barriers were evenly distributed across barriers, with participants ranking lack of a validated tool (5), lack of resources to support caregiving youth (5), patient fear of repercussions if they disclose being a caregiver (3), and unsure how to ask (3) as significant barriers. Therefore, participants who are in nonclinical roles or not aware of caregiving youth within their practices may perceive a variety of different barriers to identifying youth.

Table 3

Perceived Barriers to Identifying Caregiving Youth Reported by Health Care Providers in Group 2 (Create Awareness)

Barriers:	Unsure how to ask	I do not think this is an important issue to ask about	Lack of resources to support caregiving youth	Patient fear of repercussions if they disclose being a caregiver	Lack of a validated tool	Insufficient appointment time
<i>N</i>	19	19	19	19	18	17
Frequency	3	6	5	3	5	6
Cumulative Percentage	15.8	31.6	26.3	15.8	27.8	35.3

Data regarding barriers to identifying caregiving youth were also collected from previous versions of this survey. Participants were asked to rank some barriers to asking about youth caregiving in their practices in likeliness of importance (1= most important and 7= least important). Only the participants in Group 2 (Create Awareness) were asked this question in the first version of the survey. Among the 11 participants who responded, six of 11 felt that lack of resources to support caregiving youth was the most important barrier (e.g., ratings of 1 and 2) to asking about caregiving youth. Additionally, five of 10 participants endorsed patient fear of repercussions if they disclosed being a caregiver and lack of a validated tool as the most important barriers to asking about youth caregiving.

Participants who completed the simplified version of the original survey were also asked this ranking question. Of the nine participants who responded to this question, six

reported an awareness of caregiving youth within their practice (Group 1), and three reported no awareness of youth within their practices or not applicable (Group 2). Among the health care providers who were aware of caregiving youth within their practices, four of six felt that lack of resources to support caregiving youth and insufficient appointment time were the most important barriers to asking about caregiving youth. Two of the three participants who responded to this question from Group 2 indicated that the most important barrier was that this was not an important issue to ask about.

About how many children are caregivers in your practice?

Of the 24 health care providers who reported being aware of caregiving youth within their practices, 45.8% indicated that they had fewer than five patients who were caregivers in their practices, and 37.5% indicated that they had between 5 and 10 patients. Moreover, 8.3% had between 11 and 20 patients, and 8.3% reported being aware of more than 21 patients in their practices.

Which best describes how you identify caregiving youth within your practice?

Among the respondents, 43.5% of health care providers indicated that they discussed this matter only when it was brought up by patients, family, or staff, and 26.1% reported that they asked only under certain circumstances.

Would you use a validated screening tool in your practice to identify caregiving youth if available?

Only nine participants answered this question. Four participants indicated that they would use a validated screening tool, while two would not, and three were unsure.

What resources do you offer caregiving youth in your practice?

Participants were provided with a list of resources and asked to choose which resources they offered within their practices. Of note, a limited number of participants selected resources, indicating that most participants are not offering resources. Five participants reported that they offered guidance during the appointment, four participants offered therapy or support groups, four involved child protective services, and three indicated communication with school contact. Additionally, this question was asked in a different format when the first version of this survey was disseminated. Participants were asked to choose always, often, sometimes, rarely, or never. Among the 12 participants who responded, offering guidance during the appointment was the highest rated (e.g., five people picked “always” or “often”), followed by mentoring programs (three people chose “often”).

What resources would you find helpful that you do not have available in supporting caregiving youth?

Participants indicated that a targeted caregiving youth program (22.4%) would be the most helpful resource, followed by educational material (17.6%) and therapy/support groups (16.5%). Of note, this question was also asked on an earlier version of this survey; however, participants were asked to consider responses that were not asked on later versions of the survey (e.g., validated tool and communicating with school contact). Additionally, more recent versions of the survey asked about other resources, including school-based services specifically for caregiving youth and disease-specific organizations.

This survey makes me more likely to routinely screen and offer support to caregiving youth within my practice.

Overall, 75% of participants agreed or strongly agreed that this survey made them more likely to routinely screen and offer support to caregiving youth. Of participants who reported an awareness of this population prior to taking the survey, 81% indicated that they agreed or strongly agreed that this survey made them more likely to routinely screen and offer support to caregiving youth. Of those who indicated no awareness or not applicable, 71% said they agreed or strongly agreed that this survey made them more likely to screen and offer support to caregiving youth.

What is the best way you could integrate questions about youth caregiving into your practice?

Many of the participants (45.7%) reported that asking questions on standardized patient intake forms is the best way to integrate questions about youth caregiving into their practices. Moreover, 14.3% of participants reported they could verbally ask every patient during an appointment. Of note, participants who completed a former version of the survey were given the option of selecting, "Simply asking about a child's responsibilities at home" as a way to integrate questions about youth caregiving into their practice. Five participants selected this answer, and these responses were added to the "Verbally ask every patient during an appointment" category. Taken altogether, 28.6% of participants reported verbally asking every patient during an appointment or asking about their responsibilities at home.

What resources could you potentially offer caregiving youth in your practice?

Respondents who indicated not applicable or that they are not aware of any patients in their practice caring for an ill or disabled relative were asked about potential resources to offer youth. Among respondents, 52% indicated that they would offer guidance during appointments, 33% would offer educational material, 30% would offer therapy or support groups, and 24% would offer child protective services.

Please describe the certain circumstances where you ask about caregiving youth within your practice.

Six participants provided qualitative responses to this question, and a common theme emerged among responses. Health care providers indicated that they would ask about caregiving youth if they suspected family issues or had knowledge of a family member with a significant illness. One pediatric resident stated, "If the patient or family member says that there is an ill family member, or if this has been elicited in the past and was documented by another provider." This qualitative response is interesting and supports the notion that pediatric health care providers are more likely to ask about this matter if they are made aware of social and family circumstances.

CHAPTER 5: DISCUSSION

Interpretation and Implications

This study was conducted to better understand pediatric health care providers' knowledge and perceptions regarding caregiving youth. The study explored pediatric health care providers' understanding of the prevalence of caregiving youth within their practices, the services health care providers offer, the delivery of these services, and any barriers to identifying caregiving youth in medical settings. Thus, the overall goal of this study was to assess provider attitudes, knowledge, and perceptions of caregiving youth in order to clarify current practices and increase support for youth.

Overall, the results indicated that the majority of pediatric health care providers reported limited knowledge about this population and their caregiving responsibilities. As such, many are not aware of youth caregivers within their practices. Most of the survey participants indicated that they had not heard of the terms "caregiving youth," "youth caregivers," or "young carers." Qualitative information collected by those who reported an awareness of this population further supports the findings in the literature regarding a lack of consistency in defining caregiving youth. Participants varied in their descriptions of what constitutes a young caregiver, likely because this role is broadly influenced by individuals' experiences; their level of care responsibility; their relationships with care recipients; their age, gender, and ethnicity; and their cultural practices (Kavanaugh et al., 2016). Furthermore, youth caregivers are an underexposed population, as individuals younger than the age of 18 years have historically been left out of national surveys. This

is likely because people in the United States commonly assume that adults provide care to children, and children do not provide care for family members.

Additionally, the data further suggest that the barriers to identifying caregiving youth are significant. The majority of pediatric health care providers in this study reported they would ask about this matter if it was brought up by patients, family, or staff, or if they had a relevant reason to ask. Identification of this population may be limited by a child's willingness to self-identify as a caregiver or ask for help. As indicated in the literature, many young caregivers are reluctant to call attention to themselves and their caring responsibilities, further warranting consideration of more effective methods of identification, such as questions on standardized patient intake forms and verbal screening of patients.

Providers who indicated an awareness of caregiving youth within their practices reported lack of supportive resources, lack of a validated screening tool, and insufficient appointment time as the most significant barriers to identifying youth. Creating validated screening tools and resources, such as disease-specific support groups, youth caregiver camps, and academic support programs, can assist providers in supporting these children. Regarding current practices and resources offered to caregiving youth, responses of health care providers indicated that they most commonly offer guidance during the appointment and referrals to therapy. Researchers in the United States can look to the United Kingdom for a model that has had success in identifying, assessing, and providing resources to youth caregivers.

Those who indicated that they were in a nonclinical role, not working, or did not have awareness of youth caregivers within their practices reported this issue is not important enough to ask about, insufficient appointment time, and lack of resources to support caregiving youth as the most significant barriers to identifying youth. The opinion that caregiving is not an important issue to ask about could stem from little knowledge about this population, provider assumptions that young people cannot or should not be caregivers because of their age, or perhaps beliefs that caregiving responsibilities are normative or not impactful. Results from this survey indicate a need to educate pediatric health care providers in order to increase awareness and a need to shift attitudes so that more young people may be identified and supported. Additionally, participants in both groups indicated insufficient appointment time as a significant barrier, further warranting the need to develop a quick and easy screening tool to assist providers in identifying youth.

Lastly, in addition to learning about pediatric health care providers' perceptions about caregiving youth, this survey was intended to educate providers and increase awareness. As a result, the majority of respondents indicated that they agreed or strongly agreed that this survey made them more likely to screen and offer support to caregiving youth. Therefore, providers are likely open to understanding more about this population and may be more willing to assess for caregiving responsibilities if equipped with adequate screening tools and supportive referral resources.

Health professionals are likely the first people to whom a family comes for help with an illness or disability. As such, pediatric health care providers are in a unique

position to ask the right questions in order to identify children and adolescents with caregiving responsibilities. Timely interventions in health settings can increase identification of this population and may lead to more positive psychosocial outcomes.

Strengths and Limitations

A major strength of this study is its mixed methods survey design, which allows for collection of quantitative and qualitative data. As such, it captures the health care providers' voices and allows for in-depth information regarding their unique perceptions and how and why they practice.

One of the biggest limitations of this study is that the survey was adapted from previous survey versions and was not created specifically for this study. Therefore, some questions were not asked that could have been helpful in better understanding the population. For example, this survey did not collect data on the health care provider's race/ethnicity, gender, or age. As cited in the literature, family reliance on youth caregivers is influenced by cultural norms and expectations (Kavanaugh et al., 2016). Collecting data on a health care provider's race/ethnicity would have been informative, as culture may influence a provider's perceptions and identification of caregiving youth. Additionally, other more specific demographic information would have been useful. For example, the survey asks health care providers for their occupations, with one of the options being "Allied health professionals"; however, this category is broad and does not clearly define their occupations. Moreover, the initial survey created and disseminated was a longer version of the survey used later in the study. Feedback from early participants indicated that the survey was too long, and therefore, the authors of the

survey edited it into a shorter version. Participants completed different versions of the survey, with the extended version of the survey asking more detailed questions.

Another limitation of this study relates to external validity. External validity refers to how well the findings of the study can be generalized to other settings. The inclusion criteria for the sample in this study was broad and included a wide-ranging group of pediatric health care providers (e.g., pediatricians, nurses, psychologists), a limitation given occupational roles vary greatly. A more specific population sample would have allowed for greater external validity. Therefore, these findings may not capture the experiences of all pediatric health care providers and may not generalize to pediatric health care providers who vary in occupation and training.

An additional limitation of this study is the reliability of the survey. Because this survey had not been previously tested, no evidence is available to support the survey's reliability. Construct validity may also be a limitation, as this survey was created separately from the literature review. Ranking questions were selected as a way to answer some of the survey questions and may be considered a limitation, as this format may not have accurately captured the content of the question and required individuals to rank items that may not have been relevant to them. Providing forced choice may limit the richness of the data collection; however, the use of open-ended questions as well alleviated some of this concern. Additionally, a common problem with asking for self-reported information is that participants may not accurately report their true behaviors but rather their perceptions of the way they think about caregiving youth (Kazdin, 2003).

Future Directions

No known studies explore health care providers' perceptions regarding caregiving youth in the United States. Future research is needed to increase awareness of this population among health care professionals and to explore how youth can be better identified and supported in medical settings. An important first step in increasing awareness of this population is to conduct another national prevalence study to collect up-to-date demographic information on youth caregivers in the United States. This is greatly needed given the last prevalence study that continues to be used to drive research was conducted in 2005. Also beneficial would be an examination by future researchers of demographic variables not mentioned in this survey (e.g., race/ethnicity, gender, age, occupation) that influence health care providers' perceptions of caregiving youth. Additionally, not much is known about youth's perceptions of seeking support from health care providers in the United States. International studies have described the challenges reported by young carers in seeking support (Bjorgvinsdottir & Halldorsdottir, 2014; Leu et al., 2018; Smyth et al., 2011). An understanding of youth's perceptions of self-identifying as a caregiver in the context of the American health care system would be informative.

Furthermore, the current state of the research highlights a need for a shift toward family-centered care and programs to assist young caregivers and their families. Many studies looked at qualitative experiences of youth caregivers and excluded the parent or ill family member from the research. Youth caregiving experiences are best understood with consideration to social context and family environment. A gap in the research

continues about family demographic information (i.e., socioeconomic status (SES), number of caregivers in the household, support received from family members, if any). Kavanaugh's (2020) recent study exploring the experiences of youth caregivers who provided care to a family member with amyotrophic lateral sclerosis (ALS) is a first to collect parent/family data. This study allowed for a greater understanding of family demographic information (i.e., family members reported primary reason for relying on youth was cost of healthcare), as well as of care recipient experiences regarding being cared for by a younger person. Continuing to take a family-centered approach to studying the role of youth caregivers would be beneficial.. Moreover, researchers have explored the benefits of family-centered care within health care settings for the purposes of identifying and providing support to adult family caregivers. Future research is needed to explore how pediatric health care providers can implement a family-centered approach to increase identification of caregiving youth and be in a position to offer supportive resources.

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