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An Exploration Of The Manifestation Of Parentification Among Young Carers Of Persons With Huntington’S Disease

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AN EXPLORATION OF THE MANIFESTATION OF PARENTIFICATION AMONG YOUNG CARERS OF PERSONS WITH HUNTINGTON'S DISEASE

by

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A DISSERTATION

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AN EXPLORATION OF THE MANIFESTATION OF PARENTIFICATION AMONG YOUNG CARERS OF PERSONS WITH HUNTINGTON'S DISEASE

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NURSING

ABSTRACT

Due to the progressive deterioration of motor, cognitive, and psychological function experienced by individuals diagnosed with Huntington's disease, there is the potential for children in the home to adopt a caregiving role. These young carers typically serve as informal, secondary caregivers, providing multifaceted, extended care without any lessening of typical family, home, or school/work-related responsibilities. In time, this role may result in parentification, a type of role reversal with both positive and negative outcomes for the child. A secondary analysis of qualitative data of the experiences of children who have a parent with Huntington's disease from a parent study was conducted. Transcripts of qualitative interviews were explored for the manifestation of parentification among young carers in the context of Huntington's disease. A directed content analysis of interview data was conducted and guided by a literature derived framework of parentification among young carers. The sample consisted of 28 individuals with a mean age of 16.6 who all self- identified as engaging in activities to help their parent with Huntington's disease. Most of these children had been providing care for 1-3 years (53.6%) with an average of 25.4 hours of care provided per week. Data analysis resulted in three main themes: 1) being a young carer, 2) dealing with it, and 3) facing the uniqueness of being a Huntington's disease caregiver. Subthemes related to the topics of caregiver burden, feelings regarding the young carer role, coping, personal growth, school/peer relationships, feeling unheard and alone, acknowledging end of life, genetic risk, and stigma and isolation surrounding the illness. Being a young carer of a person with Huntington’s disease presents unique challenges. Elements of parentification were evident in some, but not all carers. Exploring how parentification may manifest in the context of a genetic disease that can be transmitted to the young carer is important for guiding future policy, research, and support services.

Keywords: young carers, Huntington’s disease, parentification, caregiving, role reversal

DEDICATION

I would like to dedicate this work to all the children and families impacted by Huntington's disease.

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CHAPTER 1

INTRODUCTION

Due to the type and severity of symptoms associated with Huntington's disease, children of persons with Huntington's disease often need to adopt a caregiving role (Kavanaugh, Noh, & Studer, 2015). It is estimated that there are approximately 1.4 million young carers (aged 8-18) in the United States (National Alliance for Caregiving, 2005). However, this number is believed to be a vast underestimation because often neither these children, nor the individuals they are helping care for, a) know they are acting as a caregiver or b) want to acknowledge that they are (National Alliance for Caregiving, 2005). As caregivers, children often provide multifaceted, extended care without any lessening of family, home, or school/work-related responsibilities (McGuire, Grant, & Park, 2012). In time, caregiving can become a role that requires more than a child can provide, both emotionally and physically, due to their age and/or developmental level (Hooper & Doehler, 2012). This can result in parentification, a type of role reversal where the child takes on the roles and responsibilities of the adult (Hooper & Doehler, 2012). Parentification can result in numerous consequences for the child, both positive and negative (Earley & Cushway, 2002). Despite this, little is known about parentification among young carers, especially in the context of Huntington's disease.

This chapter will provide justification for the current study which aims to explore the manifestation of parentification in young carers of persons with Huntington's disease.

The purpose of this chapter is a) to provide background and significance for the problem, b) to provide an explanation of the purpose, specific aims, and research questions of the study, and c) to provide definitions of the terms presented in the following chapters.

Problem Statement

Despite the potential for children to assume a caregiving role for persons with Huntington's disease due to the prolonged disease trajectory and stigmatizing symptoms, there is a paucity of research related to children in these situations (Kavanaugh et al., 2015). Similarly, very little is known about parentification among young carers who have had to adopt a caregiving role because of Huntington's disease affecting their family member, despite the risk for a variety of both positive and negative consequences (Earley & Cushway, 2002). Research is needed to understand how parentification manifests in young carers of persons with Huntington's disease in order to help mitigate the potential consequences.

Background and Significance

The Caregiving Role

In the United States, caregivers provide 70-80% of care at all points along the treatment continuum (Given, Given, & Sherwood, 2012). Caregivers are those who provide personal care or emotional support to a dependent individual, especially outside of a healthcare setting (Barbosa, Figueiredo, Sousa, & Demain, 2011). According to the 2020 Report of Caregiving in the United States, approximately 21% of Americans, or 53 million people, act as a caregiver for a person with a sickness or disability (AARP & National Alliance for Caregiving, 2020). This is an increase from 43.5 million people in 2015 (AARP & National Alliance for Caregiving, 2020). These caregivers provide an estimated 24 hours of care each week, with 99% assisting with Instrumental Activities of Daily Living (IADLs) and 60% assisting with Activities of Daily Living (ADLs) (AARP & National Alliance for Caregiving, 2020). Caregiving is typically a shared experience between primary and secondary caregivers (Barbosa et al., 2011). The primary caregiver is the individual who provides most of the assistance to the dependent individual, while secondary caregivers are many times other family members or friends (Barbosa et al., 2011). Young carers typically act as secondary, informal caregivers because they are family members providing care without compensation (Blum & Sherman, 2010; McNamara & Rosenwax, 2010). Young carers most commonly are providing care to a parent or grandparent, but the caregiving role can also extend to siblings and other relatives (National Alliance for Caregiving, 2005). They also provide care for a myriad of illnesses and conditions, such as Huntington's disease (National Alliance for Caregiving, 2005).

Caregiving Associated with Huntington's Disease

Huntington's disease is a genetic disorder resulting in progressive deterioration of the brain's nerve cells (Huntington's Disease Society of America, 2011). While Huntington's disease affects the whole brain, the basal ganglia is especially vulnerable (National Institute of Neurological Disorders and Stroke, 2019). This group of nerves is vital for movement and behavior control (National Institute of Neurological Disorders and Stroke, 2019). As the nerve cells deteriorate, an individual's physical and mental capabilities also diminish (National Institute of Neurological Disorders and Stroke, 2019). There is currently no treatment and no cure (Huntington's Disease Society of America, 2011; National Institute of Neurological Disorders and Stroke, 2019). The children of individuals with Huntington’s disease have a 50% chance of inheriting the illness themselves (Dondanville, Hanson-Kahn, Kavanaugh, Siskind, & Fanos, 2019). In the United States, there are approximately 41,000 people exhibiting the symptoms of Huntington’s disease and more than 200,000 who are at risk of inheriting the condition (Huntington's Disease Society of America, 2011; National Institute of Neurological Disorders and Stroke, 2019; Rawlins et al., 2016).

The symptoms of Huntington’s disease can appear as early as age two and as late as age 80, but for the majority, symptoms become evident between age 30 and 50 (Huntington's Disease Society of America, 2011). These symptoms progress and worsen following clinical diagnosis, until the death of the individual, typically 10-25 years later (Huntington's Disease Society of America, 2011). In the early stage, individuals remain functional and can continue living independently, performing both ADLs and IADLs (Huntington's Disease Society of America, 2011; Mumal, 2013). The symptoms are often minor and include minor involuntary movements, subtle loss of coordination, and difficulties with complex thought (Mumal, 2013). In the intermediate stages, individuals with Huntington’s disease are able to continue carrying out ADLs with minimal assistance, but they often require assistance with IADLs due to worsening symptoms (Huntington's Disease Society of America, 2011). At this stage, problem solving becomes more difficult and there are often problems with balance, coordination, and voluntary motor movements (Huntington's Disease Society of America, 2011; Mumal, 2013). In the late stage of Huntington's disease, individuals need assistance with ADLs and IADLs (Mumal, 2013). Symptoms progress to the point that individuals in this stage are often nonverbal and bedridden (Mumal, 2013). As symptoms progress, care needs also increase.

Individuals diagnosed with Huntington's disease experience a long disease trajectory and require care for a variety of symptoms (Huntington's Disease Society of America, 2011). Huntington's disease manifests as a "triad of motor, cognitive, and psychiatric symptoms" (Huntington's Disease Society of America, 2011). Motor symptoms include dance-like, involuntary, and uncontrollable movements, referred to as chorea (Family Caregiver Alliance, 2004; National Institute of Neurological Disorders and Stroke, 2019). There may also be "grossly exaggerated movements," which are small movements that become large and dramatic unintentionally (Family Caregiver Alliance, 2004). They may also develop muscle rigidity, affecting the individual's ability to walk, as well as difficulty swallowing (dysphasia) (Family Caregiver Alliance, 2004). Cognitive symptoms slow processing of information and organizational ability (Family Caregiver Alliance, 2004; National Institute of Neurological Disorders and Stroke, 2019). This can manifest as a difficulty remembering words and speaking (aphasia) (Family Caregiver Alliance, 2004; National Institute of Neurological Disorders and Stroke, 2019). They can also exhibit poor judgement and have short term memory problems (National Institute of Neurological Disorders and Stroke, 2019). Psychological symptoms include poor impulse control and difficulty in controlling one's emotions (Family Caregiver Alliance, 2004; Huntington's Disease Society of America, 2011). This manifests in outbursts, yelling, and/or aggression. These individuals can also exhibit depression, irritability and anxiety (Family Caregiver Alliance, 2004; National Institute of Neurological Disorders and Stroke, 2019).

Huntington’s is a disease that affects not just the diagnosed individuals, but it also has a devastating effect for the family, who often provide extensive care (Family Caregiver Alliance, 2004). The long-term nature of Huntington’s disease, where symptoms progressively worsen for years following diagnosis, means that the necessity for caregiving often lasts the entirety of a child’s time living at home (Kavanaugh, Noh, & Zhang, 2016). The symptoms of Huntington’s disease are also stigmatizing, which can “drive families into the closet where they suffer as a marginalized part of society” (Goodman, 2012, p. 1). This can lead to feelings of isolation and secrecy for families dealing with Huntington’s disease (Dondanville et al., 2019; Kavanaugh, 2014). The combination of prolonged disease trajectory, complicated symptomology affecting a variety of functions, and the stigma surrounding Huntington’s disease, all contribute to difficulties in proving care, especially for young carers.

Young Carers in the United States

Despite the number of young carers in the United States, the current state of the science regarding the population of young carers is limited due to a lack of research, services, and policies. It is suggested that this paucity is because child caregiving “transgresses societal expectations” of children (Smyth, Blaxland, & Cass, 2011, p. 153). Simply put, society views children as receivers of care and consequentially has a difficult time accepting children in a caregiving role. It is believed that because of this viewpoint, the awareness of the population of young carers is low, as is the awareness of the unique consequences young carers face, such as parentification (McMahon & Luthar, 2007).

In 2017, a global review of the awareness and support for young carers was conducted (Leu & Becker, 2017). The researchers determined the level of awareness and response to young carers for each country: either 1) incorporated/sustained, 2) advanced, 3) intermediate, 4) preliminary, 5) emerging, 6) awakening, or 7) no response (Leu & Becker, 2017). Nineteen countries were ranked from 1-6 and all other countries at the time of the review were given a rank of 7 (no response) (Leu & Becker, 2017). No country achieved the status of incorporated/sustained, and only the United Kingdom received an advanced ranking (Leu & Becker, 2017). The United States was ranked as emerging along with Belgium, Ireland, Italy, Switzerland, The Netherlands, and Sub-Saharan Africa. Countries with an emerging status are characterized as having a growing public awareness about young carers, a small research base, no specific legal rights for this population, and no dedicated services or interventions (Leu & Becker, 2017). To that point, there has only been one national survey and subsequent large-scale study on the population of young carers in the United States, conducted in 2005 by the National Alliance for Caregiving. Up until 2005, all the major surveys of caregivers in the United States included only individuals aged 18 years and older (National Alliance for Caregiving, 2005). This lack of research is further highlighted in a systematic review that was conducted in 2015 related to young carers in the United States (Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016). The authors determined that while there were over 2000 articles related to adult caregiving, there were only 22 articles related to child caregiving (Kavanaugh, Stamatopoulos, et al., 2016).

The health of the U.S. is projected to decline in the coming years. With each passing decade, there appears to be a 15-20% increase in the prevalence of Huntington's disease (Rawlins et al., 2016). In addition, the caregiver support ratio, which determines the number of potential family caregivers for every person most likely needing care, is declining (Reinhard, Feinberg, Choula, & Houser, 2015). In 2010, the ratio was approximately seven potential family caregivers for each person at risk of needing long term care. By 2030, it is estimated to decline to 4:1, and then to less than 3:1 in 2050 (Reinhard et al., 2015). This means that in the future, the availability of family caregivers in the primary caregiving years (those aged 45-64) will be severely limited (Reinhard et al., 2015). This declining caregiver support ratio, coupled with the rising rates of Huntington's disease, suggest that there could be an increased need in the future for children to act as caregivers. This potential increase in the number of young carers means that more children may also experience consequences of the caregiver role, such as parentification.

Parentification Among Young Carers

Being a young carer can become traumatic and harmful when it is long-term and excessive, with responsibilities that "transcend a child's age and maturity level" (Boumans & Dorant, 2018, p. 2). This can result in parentification, the alteration or removal of boundaries within family structures that occurs when children take on the role and responsibilities of the adult (Hooper & Doehler, 2012). These boundaries represent the implied and obvious rules and expectations that exist within familial relationships (Earley & Cushway, 2002). Parentification most commonly occurs in households where there is a disorganized family system due to parent dependency as the result of an illness, disorder, psychopathology, and/or substance abuse problems (Earley & Cushway, 2002). Two types of parentification, instrumental or emotional, may occur separately or simultaneously (Boumans & Dorant, 2018). Instrumental parentification refers to instrumental tasks that the child may complete, such as carrying out household chores and responsibilities for the well-being on the family that are typically done by an adult. (Boumans & Dorant, 2018; Khafi, Yates, & Luthar, 2014). Emotional parentification refers to the emotional tasks a child may complete, such as supporting the emotional needs of the parent through support and/or companionship (Boumans & Dorant, 2018; Khafi et al., 2014). Compared to instrumental parentification, emotional parentification can be much more damaging for young carers, because these children are often required to suppress their own emotional needs for their parent's (Boumans & Dorant, 2018; Hooper & Doehler, 2012).

Parentification has both positive and negative consequences (Earley & Cushway, 2002). The positive consequences can include an increase in the young carer's responsibility, maturity, coping skills, empathy, life skills, and autonomy. (Boumans & Dorant, 2018; Dearden & Becker, 2000; Khafi, Yates, & Luthar, 2014; McMahon & Luthar, 2007; Petrowski & Stein, 2016; Thomas et al., 2003; Williams & Francis, 2010). The negative consequences of parentification can include an increase in the young carer's stress, compulsive caretaking, and risk for internalizing problems (Dearden & Becker, 2000; Hooper & Doehler, 2012; Hooper, Doehler, Jankowski, & Tomek, 2012; Jones & Wells, 1996; Khafi et al., 2014; McMahon & Luthar, 2007; Nuttall, Coberly, & Diesel, 2018; Van Loon, Van de Ven, Van Doesum, Hosman, & Witteman, 2017; Williams &

Francis, 2010). The negative consequences also include a decrease in the young carer's school performance/attendance, involvement in age appropriate activities, peer relationships, and self-concept (Dearden & Becker, 2000; Gelman & Rhames, 2018; Hooper & Doehler, 2012; Kelley et al., 2007; Thomas et al., 2003; Van Loon et al., 2017; Williams & Francis, 2010).

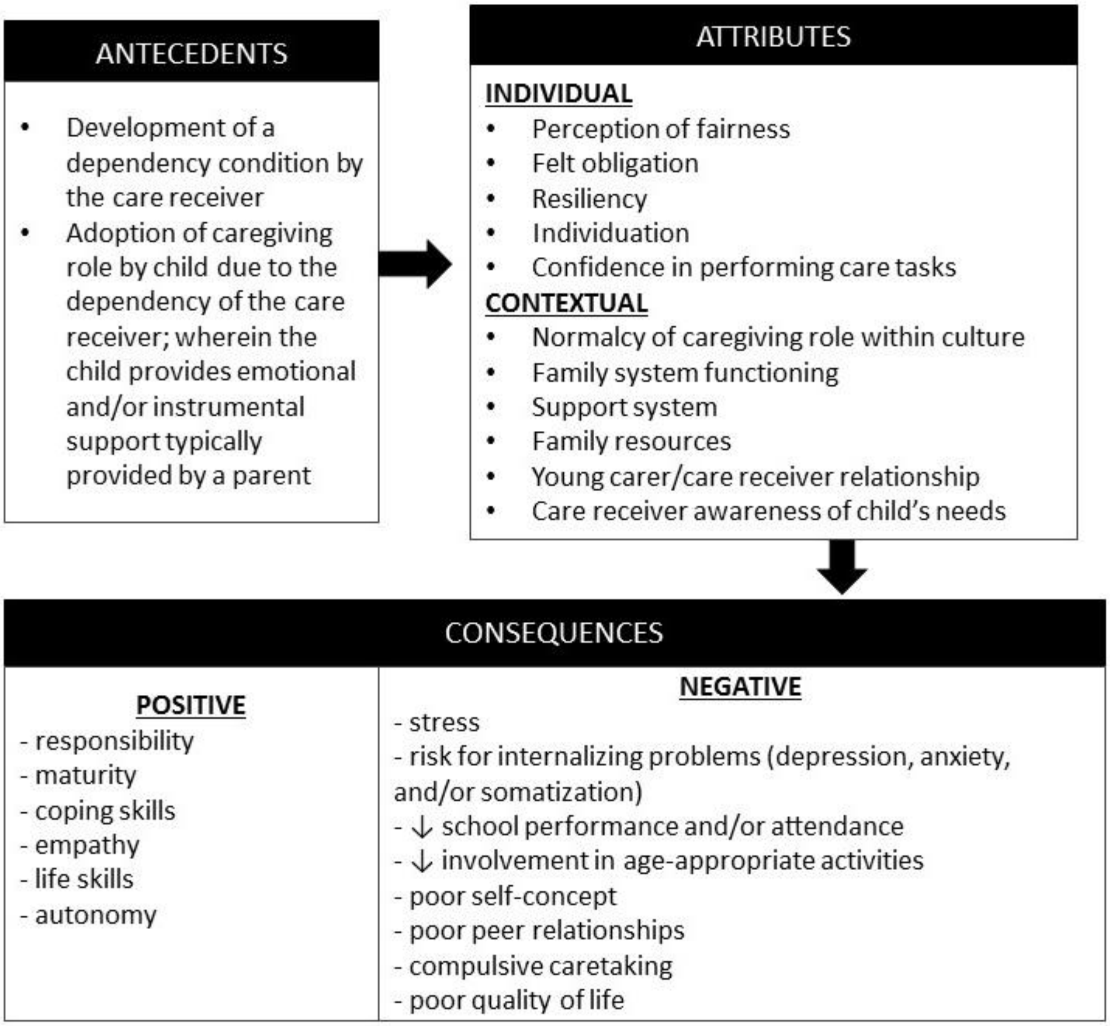
Conceptual Framework

The framework guiding this study is a conceptual framework of parentification among young carers (Hendricks et al., 2020a). This framework provides an overview of the concept including the antecedents, attributes, and consequences. In developing this framework, an induction was made regarding the components of the concept of parentification in young carers through thorough review and analysis of the literature, using the steps of the Rodgers' method (Hendricks et al., 2020a). These steps include 1) identifying the concept and its associated terms, 2) determining the setting and sample for data collection, 3) collecting relevant data, 4) analyzing the collected data to identify the attributes and the contextual basis (antecedents and consequences) of the concept, 5) identifying an exemplar, and 6) defining implications and hypotheses for future research and development (McEwen & Wills, 2014, p. 60). A search of the literature was conducted using the databases PsycINFO, CINAHL, Scopus, and PubMed (Hendricks et al., 2020a). The search terms were *(("parentification" OR "role reversal") AND ("caregiv*" OR illness OR cancer OR disease))* and were based on the interchangeability of the terms parentification and role reversal in the literature (Hendricks et al., 2020a). In addition, the term caregiving/caregiver is not always used, so the terms illness, cancer, and disease were added to account for this variability. The literature search resulted in 26 studies (19 quantitative, six qualitative, one mixed method) which were reviewed to identify the antecedents, attributes, and consequences of the concept of parentification in young carers (**Figure 1**) (Hendricks, 2020a).

Study Purpose and Aims

Not only is there a dearth of knowledge related to parentification in the population of young carers caring for persons with Huntington's disease, but there is also limited knowledge related to young carers as a whole, regardless of the projected increase in the need for children to act as caregivers and the United States' negligible focus on helping this vulnerable population (Becker, 2007; Kavanaugh, Stamatopoulos, et al., 2016; Rawlins et al., 2016; Reinhard, Feinberg, Choula, & Houser, 2015). Therefore, the purpose of this study is to contribute to the knowledge of the population of young carers by conducting research within this understudied population, but to also explore the manifestation of parentification in young carers of persons with Huntington's disease through a secondary qualitative analysis. The specific aims of this study are 1) to explore whether attributes of parentification are present in young carers of persons with Huntington's disease, 2) to explore the consequences of parentification (both positive and negative) of these children, and 3) to describe the context of parentification for young carers of persons with Huntington's disease.

Figure 1. Conceptual Framework for Parentification Among Young Carers



Note. From "Parentification among young carers: A concept analysis, by B.A. Hendricks, J.B. Vo, J.N. Dionne-Odom, & M.A. Bakitas, 2020, [Unpublished Manuscript], School of Nursing, University of Alabama at Birmingham.

Definition of Terms

For the purposes of this study, the key terms are defined as follows:

Activities of Daily Living (ADLs)

Activities of daily living refer to activities that comprise personal care such as bathing, grooming, eating, dressing, toileting, ambulation, and transferring (Berman & Kozier, 2008).

Caregiver

Caregivers are those who provide personal care or emotional support to a dependent individual, often due to illness or incapacitation, especially outside of a healthcare setting (Barbosa, Figueiredo, Sousa, & Demain, 2011).

Emotional Parentification

Emotional parentification refers to the situation where the child is responsible for the emotional and psychological needs of the adult. This can result in the child acting as a confidant and/or counselor to their parent (Boumans & Dorant, 2018).

Formal Caregiver

Formal caregivers are typically associated with a professional or formal service system. These individuals are typically paid workers (Family Caregiver Alliance, 2014).

Huntington’s Disease

Huntington’s disease is an incurable, hereditary, genetic disorder resulting in the progressive deterioration of the brain’s nerve cells causing motor, cognitive, and psychological symptoms (National Institute of Neurological Disorders and Stroke, 2019).

Informal (Family) Caregiver

Informal (family) caregivers are family members or friends who have a relationship with the dependent individual in need of care. These individuals are unpaid and often live with the individual they are providing care for (Family Caregiver Alliance, 2014).

Instrumental Activities of Daily Living (IADLs)

Instrumental Activities of Daily Living refer to activities that comprise independent living such as shopping, cooking, cleaning, using the telephone, managing finances, using transportation, and managing medications (Berman & Kozier, 2008).

Instrumental Parentification

Instrumental parentification refers to physical and practical tasks that a child may complete in carrying out household duties and responsibilities. These include, but are not limited to, cleaning, cooking, grocery shopping, taking care of younger siblings, and paying bills (Boumans & Dorant, 2018).

Parentification

Parentification is a type of role reversal or boundary distortion that occurs when a child takes on the developmentally inappropriate roles and responsibilities of the adult, often in instances of parental substance abuse, neglect, or illness/incapacitation. Consequences of parentification are varied and can be either positive or negative (pathological) (Earley & Cushway, 2002; Hooper & Doehler, 2012).

Primary vs Secondary Caregiver

A primary caregiver is the individual who provides the majority of the assistance to the dependent individual and is the person primarily responsible for their health and well-being, while a secondary caregiver is many times another friend or other family member who assists in the caregiving process (Barbosa et al., 2011) .

Young Carers

Young carers are typically defined as individuals 18 years old and younger (but can sometimes include young adult individuals up to age 25) who act as an informal caregiver, whether primary or secondary, for a dependent individual (Kavanaugh, Stamatopoulos, et al., 2016).

Summary

As the illness progresses, individuals with Huntington’s disease begin to experience greater motor, cognitive, and psychological symptoms. Because of the deleterious effect of their symptoms and the long-term trajectory of the illness, patients with Huntington’s disease require the assistance of a family caregiver (Huntington's Disease Society of America, 2011). Furthermore, persons with Huntington’s disease are often at an age where they may have children in the house (Kavanaugh, 2014). These children tend to adopt a caregiving role, providing both instrumental and emotional care tasks. The projected increase in the number of person’s with Huntington’s disease, coupled with the declining caregiving support ratio, means that there will likely be more children helping care for persons with Huntington’s disease in the future (Rawlins et al., 2016; Reinhard et al., 2015). Similar to all young carers, these children are at risk for parentification due to the role reversal that often occurs with the adoption of the caregiver role (Hooper & Doehler, 2012). Consequently, these children are also at risk for the consequences of parentification, both positive and negative (Earley & Cushway, 2002). However, little is known about parentification in young carers of persons with Huntington’s disease. Research is needed to not only address this gap in the knowledge, but to contribute to the body of research that can support interventions and supportive programs to help mitigate the consequences of caregiving faced by this vulnerable, understudied population.

This chapter provides the background and significance, the research problem, the study purpose, the specific aims, and the definition of terms. The next chapters will provide a review of the literature related to the concepts of interest (Chapter 2), a further explanation of the guiding conceptual framework (Chapter 2), a detailed description of the study design and methods (Chapter 3), and a discussion of findings from the analysis (Chapter 4).

CHAPTER 2

REVIEW OF LITERATURE

In the United States, it is estimated that there are approximately 1.4 million young carers (aged 8-18) (National Alliance for Caregiving, 2005). However, this number is believed to be a vast underestimation because often neither these children nor the individuals they are helping care for a) know they are acting as a caregiver or b) want to acknowledge that they are (National Alliance for Caregiving, 2005). This can be due to several reasons including stigma, fear, and lack of awareness/education surrounding the role. Due to the prolonged disease trajectory and both the type and severity of symptoms associated with Huntington's disease, children of these individuals often need to adopt a caregiving role (Kavanaugh et al., 2015). As caregivers, children provide multifaceted, extended care without any lessening of family, home, or school/work-related responsibilities (McGuire et al., 2012). In time, caregiving can become a role that requires more than a child can provide, both emotionally and physically, due to their age and/or developmental level (Hooper & Doehler, 2012). This can result in parentification, a type of role reversal where the child takes on the roles and responsibilities of the adult (Hooper & Doehler, 2012). Parentification can result in numerous consequences for the child, both positive and negative (Earley & Cushway, 2002). Despite this, little is known about parentification among young carers, especially in the context of Huntington's disease.

This chapter will provide a comprehensive and integrative review of literature for the current study which aims to explore the manifestation of parentification in young carers of persons with Huntington’s disease. The purpose of this chapter is a) to illustrate the search strategy and synthesize the relevant literature and b) to describe the conceptual framework guiding the study. The first literature review, pertaining to young carers in the U.S. and transnationally, and the section outlining the conceptual framework, will serve as individual manuscripts.

HOW FAR HAVE WE COME? AN UPDATED SCOPING REVIEW OF YOUNG CARERS IN THE U.S.

BAILEY A. HENDRICKS, MELINDA KAVANAUGH, MARIE A. BAKITAS

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Format adapted for dissertation.

Abstract

Approximately 1.4 million young carers (aged 8-18) in the United States are providing multifaceted, extended care to adults with serious illness, in addition to their family, home, and/or school responsibilities. In 2015 an initial review of U.S. research on young carers highlighted the need for longitudinal research, interventions, and national policy. The aim of this review is to identify young carer research since the original review to assess progress in better serving young carers' needs and to identify persistent gaps for future research. Using Arksey & O'Malley's Scoping Review Framework to answer our research question of how many studies have been conducted since the initial review, we 1) identified relevant studies, 2) performed study selection, 3) charted the data, and 4) summarized and reported results. We also reviewed young carer research outside of the U.S. to compare transnational progress. The search yielded only four U.S. studies representing 507 CC; age range 8-25 years. Most often the young carers reported more responsibilities than the adult care recipient and a variety of factors contributing to their experience. A separate review yielded eight non-U.S. studies and similar findings. Mirroring the 2015 review, results detail a lack of consistency regarding the terminology and age range for young carers. Despite a previous call to action, there exists both a continued need for tailored interventions to prevent or mitigate potential negative outcomes related to the caregiving role, and a need for further research and global policy development.

Keywords: caregiving, children, young carers, vulnerable population, scoping review

Introduction

Approximately 53 million, or more than 1 in 5 family members in the U.S. provide some measure of care to a dependent individual (AARP & National Alliance for Caregiving, 2020). These family caregivers serve as the largest providers of informal care in the country (Kavanaugh et al., 2015). Family caregiving is typically a shared experience between primary and secondary caregivers, with the primary caregiver providing most of the care to the dependent individual (Barbosa et al., 2011). However, an important component of this family caregiving system is overlooked in both research and policy: the population of young carers. Typically serving an secondary caregivers, an estimated 1.4 million children in the U.S. (aged 8-18), provide care to an adult a) in addition to their other school, home, and/or work related responsibilities , b) with unique age and developmental related challenges, and c) without the awareness, support, and education their older (aged >18) caregiver counterparts receive (National Alliance for Caregiving, 2005).

Young carers most commonly provide care to a parent or grandparent, but the caregiving role can also extend to siblings and other relatives across illnesses and conditions (National Alliance for Caregiving, 2005). Their involvement in providing care goes beyond simply helping with household chores; instead, extending to the completion of instrumental and emotional care tasks that are usually performed by adults (Kavanaugh et al. 2015). In 2015, the first scoping review of caregiving youth in the United States assessed what is known about this population and drew conclusions regarding the overall state of the science in this area (Kavanaugh et al., 2016). That review was comprised of 22 studies published from 1995-2015, reflecting the recognition of the role of young carers that began in the United Kingdom during the 1990s (Kavanaugh et al., 2016; Nagl-Cupal & Prajo, 2019). Compared to the 22 studies published related to young carers, more than 2000 studies have been published pertaining to adult caregivers over the age of 18 (Kavanaugh et al., 2015). This scoping review builds upon and updates the previous review by examining subsequent (2015-present) young carer research in the U.S., and by offering a comparison with non-U.S. studies, to assess progress and continued gaps in our understanding, awareness, and support for this population.

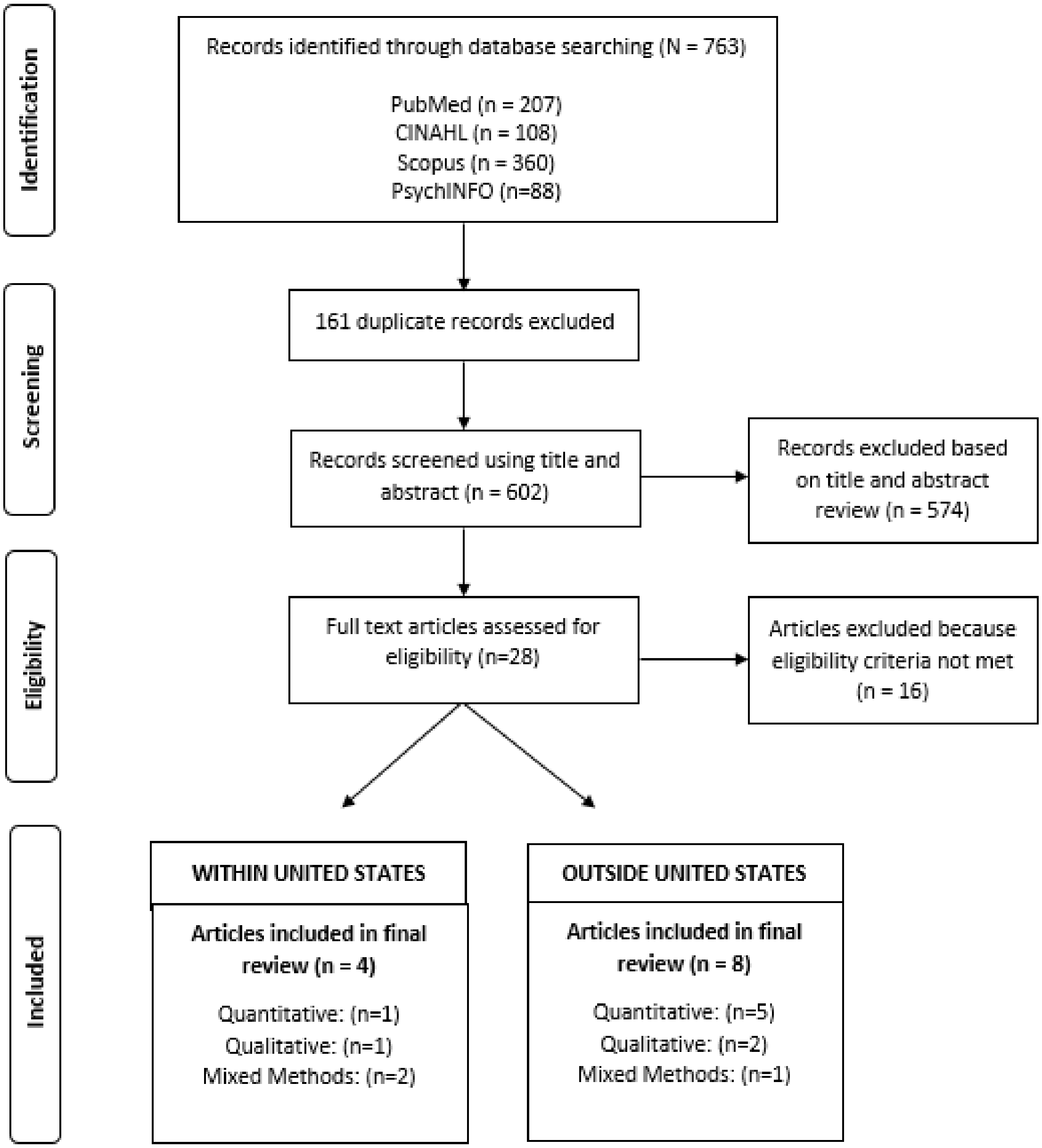
Methods

Similar to the methods of the initial 2015 review, the Arksey and O'Malley framework was used to summarize available peer reviewed, primary research related to young carers in order to summarize the current state of the science related to this population and to identify gaps in the literature without a quality assessment of studies included or a detailed review of findings. These steps included 1) identifying relevant studies, 2) performing study selection, 3) charted the data, 4) summarizing and reporting results, and 5) consulting with a known young carer expert to validate the overall review (Arksey & O'Malley, 2005; Oliver, 2001). A search of the literature was conducted of the databases, PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Scopus, and PsycINFO, using the search terms, *("young carer" OR "young caregivers" OR "childcarers" OR "children caregivers" OR "youth caregivers" OR "adolescent caregivers").* The search terms were chosen based on a lack of universality for a term encompassing the population of young carers, meetings with a reference librarian, and the search terms of the initial review. Article inclusion criteria included:

being written in English, having full text availability, and being published after May 2015 to coincide with the initial 2015 scoping review end date.

The initial search yielded 763 articles (PubMed=207, CINAHL=108, Scopus=360, PscyhINFO=88). After 161 duplicates were removed, 602 articles remained to undergo title and abstract review. Study inclusion criteria: 1) primary research on caregivers 18 and under in both the U.S and international, and 2) the role they pay as caregiver to any family member. Exclusion criteria included those articles that addressed the parent providing care, or those that used the term “young” to mean a young adult over 18. Articles were excluded for pertaining to caregiving in the sense of a parent taking care of their child or for using the term young caregiver in the sense of the caregiver being younger than the average caregiver age, but not less than 18 years old. Non-primary studies including reviews, instrument development papers, and dissertations were also not included. The resulting 12 studies were then divided into those studies conducted in the United States (n=4) and outside of the United States (n=8). A PRIMSA diagram detailing this search process is include included as Figure 1.

Figure 1. PRISMA Diagram of Literature Search-Young Carers 2015-2020



Results

From May 2015- July 2020 twelve studies were published pertaining to young carers. Four were conducted in the United States and eight were conducted in other countries including Austria, the U.K., Australia, Pakistan, and Norway. Methodology varied, including six quantitative studies, three qualitative studies, and three mixed methods studies.

Terminology describing young carers

As found in the initial scoping review (Kavanaugh et al., 2016), a variation in terminology persists. Studies from the U.S. primarily used the terms “caregiving youth” and “young caregivers” (Assaf et al., 2016; Dondanville et al., 2019; Kavanaugh et al., 2019; Kavanaugh et al., 2020), as noted in the initial 2015 scoping review (Kavanaugh et al., 2016). In contrast, the term “young carers” was used to define these children in all eight transnational studies (Gough & Gulliford, 2020; Kallander et al., 2017; Kallander et al., 2018; Kallander et al., 2020; Majeed et al., 2018; McDougall et al., 2018; Metzing et al., 2020; Nagl-Cupal & Prajo, 2019). The only variation was in the study by Majeed and colleagues, who did not provide a single term for young carers, but instead interchangeably use the terms “young caregivers,” “pediatric caregivers,” and “caregiving children” (Majeed et al., 2018).

Variation in age range of young carers

As with the terminology discussion above, there exists no consistent age range for child and youth caregivers. In the only U.S. national prevalence study, young caregivers were defined as aged 8-18 years (National Alliance for Caregiving, 2005), an age range used in two of the four studies taking place in the United States (Kavanaugh et al., 2019; Kavanaugh et al., 2020). Two studies stated that young carers were those individuals younger than 18 (Assaf et al., 2016; Dondanville et al., 2019), while two other studies (Kavanaugh et al, 2016; Dondaville, 2019) stated ages 8 to 18, yet included youth up to age 20 and 25, respectively. In the research outside of the United States, none of the studies defined a minimum age for "young carers," instead providing a definition stating that "young carers" were individuals under the age of 18. Similar to the studies in the United States, three of these studies included children older than the age of 18 including Majeed (2018), who included up to age 21, McDougall (2018) who included up to age 25, and Metzing (2020) who included up to age 22.

Diversity

With regards to race/ethnicity, the 2015 scoping review found that White participants were most prevalent in the included studies (Kavanaugh et al., 2016). This predominance of White participants is also evident in the current review from 2015 to the present. The exception is a study based in Florida describing participation rates and perceptions of caregiving youth in the Caregiving Youth Project which assessed caregiving youth across a variety of illnesses (Assaf et al., 2016). In this study, participants were more diverse: Hispanic (31%), more than one/unidentified (21%), Haitian (17%), White (17%) and African American (10%). In contrast, the other three studies either addressed a disorder found primarily in White populations (ALS and Huntington's disease), or did not specific ethnicity (Dondanville et al., 2019; Kavanaugh et al., 2019). In the 2015 scoping review, Kavanaugh and colleagues stated a need for more diverse samples, requiring research across a wide variety of diseases and illnesses, so that the variation in caregiving experiences across race and ethnicity could be explored. This issue is particularly critical in the U.S. where health and social disparities abound by race/ethnicity, often dictating access to care and treatment, which is disproportionately provided in populations of color. Thus, it continues to be vital to understand how these factors relate to young carers (Kavanaugh et al., 2016). Studies outside of the United States also paid little attention to race/ethnicity. The articles by Kallander (2017, 2018, 2020) and Metzing (2020) did mention ethnicity, but the samples were not diverse. The study by Majeed in 2018 was one that focused on research in low- and middle-income countries, making a step towards health and social disparities research, but even with that sample there was minimal ethnic diversity. The lack of diversity in samples may be understood by the context in which these studies took place – in countries with less diversity than others. For example, multiple studies were conducted in Scandinavian countries with a predominantly White, non-Hispanic population.

Impact of caregiving on young carers

Many of the findings suggested that caregiving is not only time-consuming, but requires some level of knowledge and training, much of which is not provided, (Assaf et al., 2016; Kavanaugh et al., 2019), and support from family and friends. Findings suggest perceived social support connectedness, self-efficacy, social skills, physical health, quality-of-life, emotional care, and external locus of control are all critical to young caregiver well-being, yet are often not assessed (Dondanville et al., 2019; Gough & Gulliford, 2020; Kallander et al., 2017; Kallander et al., 2018). Indeed, many participants stated that they felt “lost in the system” (Kavanaugh et al., 2020; McDougall et al., 2018; Nagl-Cupal & Prajo, 2019), while making sacrifices to their daily lives in order to take on the caregiving role, often having some sense of responsibility and/or obligation (Assaf et al., 2016; Kallander et al., 2020; McDougall et al., 2018; Metzing et al., 2020). Furthermore, the amount of time spent caregiving that is reported by children is typically higher than what is reported by their families (Assaf et al., 2016), potentially leading to negative outcomes such as stress and anxiety (Kallander et al., 2018; Kallander et al., 2020; Majeed et al., 2018). While the negative outcomes are often the primary aim, many of the studies discussed the potential benefits or positive outcomes of caregiving (Gough & Gulliford, 2020; Kallander et al., 2018; Kallander et al., 2020; McDougall et al., 2018). Indeed, Assaf (2016) found that the caregiving experience is complex and its impact on development is an individualized process.

Interventions

The above findings suggest a need for targeted interventions for this vulnerable and isolated population. McDougall (2018) argued a need for distance or virtual interventions because of their youth friendly format and capability of fitting into the time constraints experienced young carers. Majeed (2018) suggested screening for symptoms and culturally sensitive interventions that could help children cope. Kallander (2017) suggested a need for flexible home-based services that could be adapted based on the type of illness being cared for. Multiple researchers advocated for providers to take a step towards helping acknowledge this population by assessing children and providing assistance in the absence of interventions (Dondanville et al., 2019; Kallander et al., 2018; Majeed et al., 2018).

Discussion

Findings in this review highlight that research on young carers continues to be limited, descriptive, and exploratory in nature. It is still not clear why so many young carers are needing to take on this role, but as stated in the initial review, limited attention to diversity and little information pertaining to family level data abides. Without more research into this population, particularly with diverse samples and family level data, the question of why so many young carers are needed will continue to go unanswered. Until then, we do not have a full understanding of why children are in these positions, especially in the U.S., and the impact it has on our health resources and policy.

The only four U.S. studies published from 2015 to the present, used two datasets, while the articles outside of the United States used five data sets for the eight studies. These findings not only speak to the lack of overall data, but the need to develop new studies to broaden the science of caregiving in children and youth. Regardless of geographic location, there exists a clear gap in young carer research. Authors in all included studies discussed the need for more research in this population, including the need for prospective research (Assaf, 2016) and longitudinal designs (Gough and Gulliford, 2020). Additionally, all of the authors discussed the need for intervention research (Assaf et al., 2016; Dondanville et al., 2019a; Gough & Gulliford, 2020; Kallander et al., 2017; Kallander et al., 2018; Kallander et al., 2020; Kavanaugh et al., 2019; Kavanaugh et al., 2020; Majeed et al., 2018; McDougall et al., 2018; Metzing et al., 2020; Nagl-Cupal & Prajo, 2019). In addition, Metzing (2020) mentioned the lack of an internationally accepted theory for young caregivers, which could aid in distinguishing between those who simply help out in the home and those who are taking on a caregiver role. This need for more research was also highlighted in the 2015 review where Kavanaugh and colleagues specifically alluded to the need for more large-scale studies and longitudinal research.

Within the United States there has only been one large scale study, conducted in 2005, that provided initial, albeit limited, prevalence data (National Alliance for Caregiving, 2005). In addition to the lack of research data, general numbers of caregivers are unclear given the United States has no census questions targeting young carers, or even caregiving adults (Kavanaugh et al., 2016), as compared to countries like the United Kingdom, Canada, and Australia, which all include questions about caregiving in their census. While large scale data exists for the adult caregiver population, informing the development and implementation of programs and support for adults (Kavanaugh et al., 2016), young carers are overlooked and underrepresented. Thus, it is difficult to develop and implement large or national targeted interventions, leaving these vulnerable youth with few tailored programs and support, outside local or school-based programming. In addition, with cross-sectional data, it is unknown how caregiving affects the individual and the family over time. Longitudinal data on adult caregivers details clear changes over time, both positive and negative, suggesting the need for flexible interventions. While it may be assumed the changes are similar in the young carer population, without the longitudinal data, it is unclear.

The health of the U.S. is projected to decline in the coming years. Yet the caregiver support ratio, which determines the number of potential family caregivers for every person most likely needing care, is declining (Reinhard et al., 2015). In 2010, the ratio was approximately seven potential family caregivers for each person at risk of needing long term care. By 2030, it is estimated to decline to 4:1, and then to less than 3:1 in 2050 (Reinhard et al., 2015). Therefore, the availability of family caregivers in the primary caregiving years (those aged 45-64) will be severely limited (Reinhard et al., 2015) as time moves on. The declining caregiver support ratio, coupled with the declining health of the nation, suggests an increasing need for all family members, including children and youth, to act as caregivers. Yet, despite this projected future need, the current state of the science regarding the population of young carers in the U.S. limits how we can support and develop programming for this potentially large future caregiving group.

The paucity of research also extends to policy and programs. In 2017, a global review of the awareness and support for young carers was conducted (Leu & Becker, 2017). The researchers determined the level of awareness and response to young carers for each country: either 1) incorporated/sustained, 2) advanced, 3) intermediate, 4) preliminary, 5) emerging, 6) awakening, or 7) no response (Leu & Becker, 2017). Nineteen countries were ranked from 1-6 and all other countries at the time of the review were given a rank of 7 (no response) (Leu & Becker, 2017). No country achieved the status of incorporated/sustained, and only the United Kingdom received an advanced ranking (Leu & Becker, 2017). The United States was ranked as emerging along with Belgium, Ireland, Italy, Switzerland, The Netherlands, and Sub-Saharan Africa. Countries with an emerging status are characterized as having a growing public awareness about young carers, a small research base, no specific legal rights for this population, and no dedicated services or interventions (Leu & Becker, 2017).

In addition to calling for more research in young carers, authors included in this review also stress the need for programs and policies specific to young carers. Assaf (2016) specifically says that programs need to be integrated into the school system similar to the Caregiving Youth Project, throughout the whole United States. Kavanaugh (2019) states the need for caregiver education that allows for engagement with “like peers” in similar situations, which informed the development of the YCare, young caregivers training and education program for young caregivers in neurological disorders (Kavanaugh et al, 2018; Kavanaugh et al, 2020). Moreover, there exists a need for a whole family approach to developing and implementing interventions, therefore acknowledging care does not exist within the operon, rather within the family unit as a whole (Kavanaugh et al., 2020). These suggestions are reflected outside the U.S. as well. Nagl-Cupal (2019) states that political awareness is low for this population and there is a need to raise that awareness. Kallander (2017, 2018, 2020) stated similarly that there is little recognition of young carers and little research and policy for the population in Norway. While, McDougall (2018) calls for more policy and a more sensitive and accurate portrayal of young carers in the medial, potentially reducing stigma surrounding the caregiver role (McDougall et al., 2018). As acknowledged in the 2015 scoping review, the United Kingdom and Australia have county and state-based rights and targeted programs for young carers, however, the United States still does not have such programs (Kavanaugh et al., 2016). As suggested in the initial review, the opportunity exists to expand existing national and state programs to those under the age of 18. As of 2020, the same programs that existed in 2015, including primarily school-based services such as the caregiving youth project based in Florida, and disease-based education and training programs (Kavanaugh et al, 2020), remain the only known programs. Until there is more awareness in this population and an increase in research and policy, the population of young carers will remain unrecognized and underserved, and we will continue to have limited understanding as to why so many are taking on this role.

Conclusion

Like the scoping review conducted in 2015, this review illustrates a lack of consistency regarding the terminology for young carers as well as the age range. More diverse research is still needed in this population to understand and combat potential health disparities. In addition, more research, specifically with family level data, is still needed to understand the reason so many children find themselves in the young carer role. Findings from this review suggests a need for future interventions that target young carers in order to prevent or mitigate the outcomes related to the caregiving role. Despite variations in their discipline and background, all researchers across the twelve studies agreed on the need for more research and awareness for the young carer population, as well as an increase in programs and policy pertaining to caregivers younger than 18, both within and outside of the United States.

There are steps that can be made to reach this goal. For clinicians who are treating an adult with a chronic illness it is important to consider whether or not they have a child, as that child may be contributing to the caregiving going on at home and consequently, may benefit from support and education related to that role. As educators, it is important to acknowledge that if a parent of a student has a chronic illness, the child may be taking on roles and responsibilities outside of the norm for a child and that it may have an impact on the child’s ability to participate in school related activities and their peer relationships. As a society, it is important acknowledge that children of ill parents may be taking on a caregiving role and to help eliminate the stigma and isolation they may feel, but also to allow the child to feel that they can reach out for assistance if they find that they need it. Finally, going forward, researchers should include children under the age of 18 in their caregiving studies, especially investigating the support and resources that may benefit young carers.

Table 1. Research in Population of Young Carers: 2015-Present

References	Study Population	Study Aim (s)	Definition of young carers	Methods	Main Findings	Strengths/Limitations Gaps/Future Research
Within the United States						
Assaf et al. 2016 U.S.A. Medicine *Participation Rates and Perceptions of Caregiving Youth Providing Home Health Care*	N=396; sixth graders participating in CYP; mean age= 11 Male 38% Female 62% Hispanic 31% Haitian 17% Caucasian 17% Black 10% More than one, other or unidentified 21%	**1)** To describe the participation, demographic and caregiving tasks among sixth grader who were part of the Caregiving Youth Project (CYP). **2)** To evaluate the perceived benefit of the CYP program.	*Caregiving youth:* individuals younger than 18 providing assistance to relatives or household members suffering from psychical or mental illness, disability or substance abuse.	Quantitative Study; Retrospective observational	a) Time spent caregiving is higher than what is reported by the families b) Caregiving youth make personal and academic sacrifices to act as caregivers c) interaction between development and caregiving is a complex, individualized process d) students felt the CYP improved school performance, knowledge of caregiving skills, stress management, and self-esteem.	Strengths: first U.S. study describing population of caregiving youth who received supportive services Limitations: generalizability limited due to limited sample. Inconsistency in data collection tools. Gaps/Future Research: prospective research should be conducted to learn the true size and circumstances of the population of young carers. Integrated system, similar to CYP, should be established for whole U.S. to support this population

Dondanville et al. 2019 U.S.A. Medicine *“This could be me”: exploring the impact of genetic risk for Huntington’s disease young caregivers*	N=15; aged 15-25 who self-identified as caregivers Demographics not reported	**1)** To explore the interaction between genetic risk, plans for future testing, and the caregiving experience	*Young caregivers:* children and young persons under age 18 who provide care or support to a family member with a level of responsibility usually associated with an adult	Qualitative study; inductive data driven analysis approach	a) Built on past research looking at caregiver burden b) genetic risk is a factor that compounds the emotional distress felt by young caregivers. c) Impact of caregiving experience on plans for future predictive testing.	Strengths: contributes to limited research about youth who care for parent with HD Limitations: Small self-selected sample. Findings may not be representative. Retrospective experiences were described thus there is potential for recall bias. Gaps/Future Research: Findings can be used to help genetic counselors support and counsel needs of this population. Future research should establish if/when providers acknowledge or ask about work of young caregivers in the home so that support can be provided.
Kavanaugh et al. 2019 U.S.A. Social Work *“I Just Learned by Observation*	N=96; aged 8-20; cared for a parent with HD or ALS Male 33% Female 62%	**1)** To provide initial understanding as to how caregiving youth gain skills and training **2)** inform the development of skill and training interventions	*Young caregivers:* children and youth between age 8-18 providing care to ill family member	Mixed methods study; combining results from three previous studies. Quantitative: demographics, caregiving	a) the care being provided is not only time consuming, but requires knowledge of what to do next b) many youth do not receive any specific training and instead relied on care recipient for guidance, “watching and observing”, “common	Strengths: first study in the U.S. to explore young caregiving knowledge and training Limitations: questions about training were only a small number of questions. Different methods of data collection. Sample was

and Trial and Error”: Exploration of Young Caregiver Training and Knowledge In Families Living with Rare Neurological Disorders				skills, and training Qualitative: thematic analysis approach	sense”, or “trial and error”	recruited from disease-based organizations only. <u>Gaps/Future Research:</u> research needed to assess how teaching and learning occur in the home of young caregivers. Need for interventions to provide caregiver education to young caregivers. Need for caregiver to engage with “like” peers in similar situations.
Kavanaugh et al. 2020 U.S.A. Social Work *US data on children and youth caregivers in amyotrophic lateral sclerosis*	N=38; aged 8-18; identified by family member with ALS as proving care Male 55% Female 45 % Caucasian 76% Black 5.2% Hispanic 16% Native American 3.3%	1) to identify and describe characteristic and perceptions of care from family and youth caregivers	*Young caregivers:* children and youth between age 8-18 providing care to ill family member	Mixed methods study; Quantitative: cross sectional, observational Qualitative: conventional content analysis approach	a) young caregivers more engaged in basic care skills than complex devices b) congruence in care tasks from adults and children c) lack of support and need for more information d) young caregivers showed the ability to engage in personal coping to manage their role	<u>Strengths:</u> reverses assumptions that adults alone provide care. Results can be used to inform future research and programs. <u>Limitations:</u> purposeful, limited sample. Sample is primarily white. Unclear whether parent was in the room during telephone interview. <u>Gaps/Future Research:</u> future research and caregiver programs need to be adapted to target caregivers less than 18

						years old. Interventions for care that target a whole-family approach.
Outside the United States						
Cupal & Prajo 2019 Austria Nursing *It is something special: How children and their parents experience a camp for young people who care for a parent with a severe physical illness*	N=19; aged 10-14; caring responsibility for a parent with severe physical illness Demographics not reported	1) to describe the experience of a young-carer summer camp in Austria	*Young carers:* children and adolescents involved in care of an ill family member	Qualitative study; content analysis approach	a) child’s participation in support programs is influenced by parents b) children felt responsible for parent and felt conflict regarding attendance c) sense of belong in community and engagement with “like” peers was important	<u>Strengths:</u> shows that camps can make a significant contribution to giving young caregivers a feeling of normality and a break from their roles. <u>Limitations:</u> lack of clear theoretical foundation. Small sample size. Presence of parents during interviews could have affected openness of children. Preventing the negative effects of the caregiving role for children supporting ill family members should be on the high priority list of every government. <u>Gaps/Future Research:</u> Political awareness is low for this population. There is a strong need of raising awareness. Future research

						and practice should focus on relieving and supporting young carers.
Gough & Gulliford 2020 U.K. Psychology *Resilience amongst young carers: investigating protective factors and benefit-finding as perceived by young carers*	N=46; aged 12-17; recruited from two Young Carer Projects Male =17 Female=29	1) identify factors related to adjustment of young carers 2) investigate benefit finding associated with caregiving as a child	*Young carers:* children and young people under age 18 who provide care or emotional support to a family member who is physically or mentally ill, disabled, or misuses substances.	Mixed methods study-2 phase sequential design Phase 1: Qualitative: thematic analysis approach Phase 2: Quantitative: exploratory, cross sectional correlational analysis	a) perceived self-efficacy, social support satisfaction, and school connectedness were correlated with adjustment b) perceived self-efficacy and school connectedness were correlated with benefit finding c) self-efficacy had the strongest relationship with adjustment outcomes	Strengths: provides a foundation and began to map out factors that promote adjustment for young carers. Limitations: unable to determine causal relationships. Small sample size. Directionality of relationships needs more investigation. Gaps/Future Research: need to gain a more "holistic understanding" of caregiving for children as most research to date focuses on the negative outcomes. Need for longitudinal designs.
Kallander et al. 2018 Norway Medicine	N=236; aged 8-18; recruited along with parents from 5 hospitals	1) to determine whether children have different outcomes whether their parent has physical illness,	*Young carers:* children and young people under age 18 who provide care or emotional	Quantitative study; cross sectional, explorative	a)10% of children reported negative outcomes at clinical level of concern b) half the children reported stress	Strengths: linked data between parent and child, data comparing three parent groups. Use of well-established questionnaires.

Outcomes for children who care for a parent with a severe illness or substance abuse	Male 43 % Female 57%	mental illness, or substance abuse 2) to explore whether any factors are associated with the positive and negative outcomes	support to a family member who is physically or mentally ill, disabled, or misuses substances.		c) outcomes were not different across three groups of parents d) positive and negative outcomes were associated with caring activities, social skills and external locus of control	<u>Limitations:</u> Unknown inclusion rate. Many eligible people were excluded due to issues with provider reluctance to inform patient. Difficulties with participation due to illness. <u>Gaps/Future Research:</u> need to explore how different types of caring activities impact outcomes. Providers must provide a better assessment of needs of young carers.
Kallander et al. 2017 Norway Medicine *Children with ill parents: extent and nature of caring activities*	N=246; aged 8-17; recruited along with parents from 5 hospitals Male 43 % Female 57%	1) to examine the extent and nature of caregiving activities done by children 2) to explore differences in caring activities between different types of illness 3) to explore factors associated with caring activities	*Young carers:* children younger than 18 who provide care and/or support to a family member providing regular and substantial caring tasks.	Quantitative study; cross sectional, explorative	a) children with ill parents reported more sibling care and household tasks than the general population b) significant differences in caring between illness groups, but not between SES. c) being older and female was significantly associated with caring activites d)social skills and external locus of control significantly impacted caring activities	<u>Strengths:</u> linked data between parent and child, data comparing three parent groups. Use of well-established questionnaires. <u>Limitations:</u> Unknown inclusion rate. Many eligible people were excluded due to issues with provider reluctance to inform patient. Difficulties with participation due to illness. <u>Gaps/Future Research:</u> Need for flexible home-based services that can be

						adapted to type of illness to promote coping and prevent children from taking on caregiving role.
Kallander et al. 2020 Norway Medicine *Factors associated with quality of life for children affected by parental illness or substance abuse*	N=246; aged 8-18 recruited via ill parents receiving treatment Male 43 % Female 57%	1) to explore factors associated with quality of life in children affected by parental illness	*Young carers:* persons under 18 who provide care for someone physically or mentally ill, disabled, or abusing drugs or alcohol	Quantitative study; cross sectional, explorative	a) Quality of life was positively associated with the ill parent's self-reported physical health status, child being a boy, the children's self-reported social skills, that other adults take over the responsibilities for the ill parents, provision of health care for the ill parent, and positive outcome of the caregiving. b) Quality of life was negatively associated with children's higher age, self-reported increased responsibilities due to parental illness, provision of emotional care, negative outcome of caregiving and external locus of control.	<u>Strengths: </u>large sample size, linked data between parent and child, broad recruitment, use of well-established questionnaires, few missing data points. <u>Limitations: </u>Skewed representability, No testing for co-morbidities in parents. No causal determinations can be made due to design. <u>Gaps/Future Research:</u> Little recognition of young carers and little research and policy for this population. Interventions that support families unmet needs to reduce negative outcomes in children.

Majeed et al. 2018 Pakistan Medicine *Frequency and correlates of symptoms of anxiety and depression among young caregivers of cancer patients: a pilot study*	N=90; aged 11-21 recruited via ill parents receiving treatment Male 42% Female 58%	1) to determine frequency of anxiety and depression symptoms among young caregivers of family members with cancer 2) to determine the correlation with role of gender, age and socio-economic status.	*Young caregivers*, *pediatric caregivers*, and *caregiving children* were used interchangeably.	Quantitative study; cross sectional, explorative	a) High percentage of adolescents reported anxiety and depression symptoms b) females reported more symptoms than males c) More anxiety symptoms in younger children d) lower frequency of symptoms among children with higher SES and families with multiple care providers.	<u>Strengths:</u> adds to gap in research in low and middle income countries. <u>Limitations:</u> Small sample size, minimal ethnic diversity. Convenience sampling, limited generalizability. Inability to show causation. <u>Gaps/Future Research:</u> High risk groups should be screened for symptoms. Culturally sensitive interventions should be developed. Providers can assist in helping children cope in the absence of interventions.
McDougall, O'Connor & Howell 2018 Australia Psychology *"Something that happens at home and stays at home": An*	N=13; aged 14-25; recruited from online platforms Male =6 Female =7	1) to explore the lived experiences of young carers.	*Young carers:* persons who provide ongoing support and care to family member with disability, mental illness, chronic condition, terminal illness, alcohol or other drug issue, or frail age	Qualitative study: phenomenological approach; thematic analysis approach.	a) young caregiving is something done for the family (family obligation and reciprocity) b) carers experience some positives from their role c) tensions and a need to navigate different roles d) conflict between young person and obligation to care e) carers managed their role with solitude.	<u>Strengths</u>: Focuses on the perspectives of young carers instead of just service provisions and policy. <u>Limitations:</u> limited diversity of sample. Challenges in recruiting participants. Not a longitudinal study. <u>Gaps/Future Research:</u> Resources in a youth

exploration of the lived experience of young carers in Western Australia					f) challenges with feeling lost in the system and problems accessing support services.	friendly format. Distance or virtual interventions. A more sensitive and accurate portray of young carers in media to reduce stigma surrounding the role. Interventions and policy to assist this population.
Metzing et al. 2020 Germany Nursing *The prevalence of young carers: A standardized survey amongst school students*	N=6313 students; aged 10-22; recruited from 44 secondary schools. 383 identified themselves as a young carer. Male 43% Female 57%	1) to provide prevalence data of young carers in Germany 2) to describe and quantify the nature and extent of the care they provide	*Young carers:* children who provide care, assistance or support for a chronically ill family member.	Quantitative study; cross sectional, explorative	a) Higher proportion of girls in the caregiving role b) young cares estimated a lower level of finances than non-carers c) parents are most often the care recipients with mothers receiving care more than fathers d) motivation to help at home was high regardless of illness type	Strengths: results are based on student's own responses not proxy responses. Limitations: Many schools did not agree to participate. Some young carers did not receive permission from parent to participate. Therefore, true prevalence rate may be higher. Gaps/Future Research: no internationally accepted theory about young carers; difficult to make a distinction between a helping/assisting and a caring child.

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LITERATURE REVIEW 2

Young Carers and Huntington's Disease

Search Strategy

A search of the literature was conducted using the databases, PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Scopus, and PsycINFO to examine the state of the science pertaining to young carers and Huntington's Disease. The search terms were as follows: *(("Huntington's Disease" OR "Huntington Disease")) AND (("young carer" OR "young caregivers" OR "childcarers" OR "children caregivers" OR "youth caregivers" OR "adolescent caregivers" OR "early carer" OR "early caregiving" OR "early caregiver"))*. The search terms were based on lack of universality for a term encompassing the population of young carers and meetings with a reference librarian. Articles searched for were English and full text.

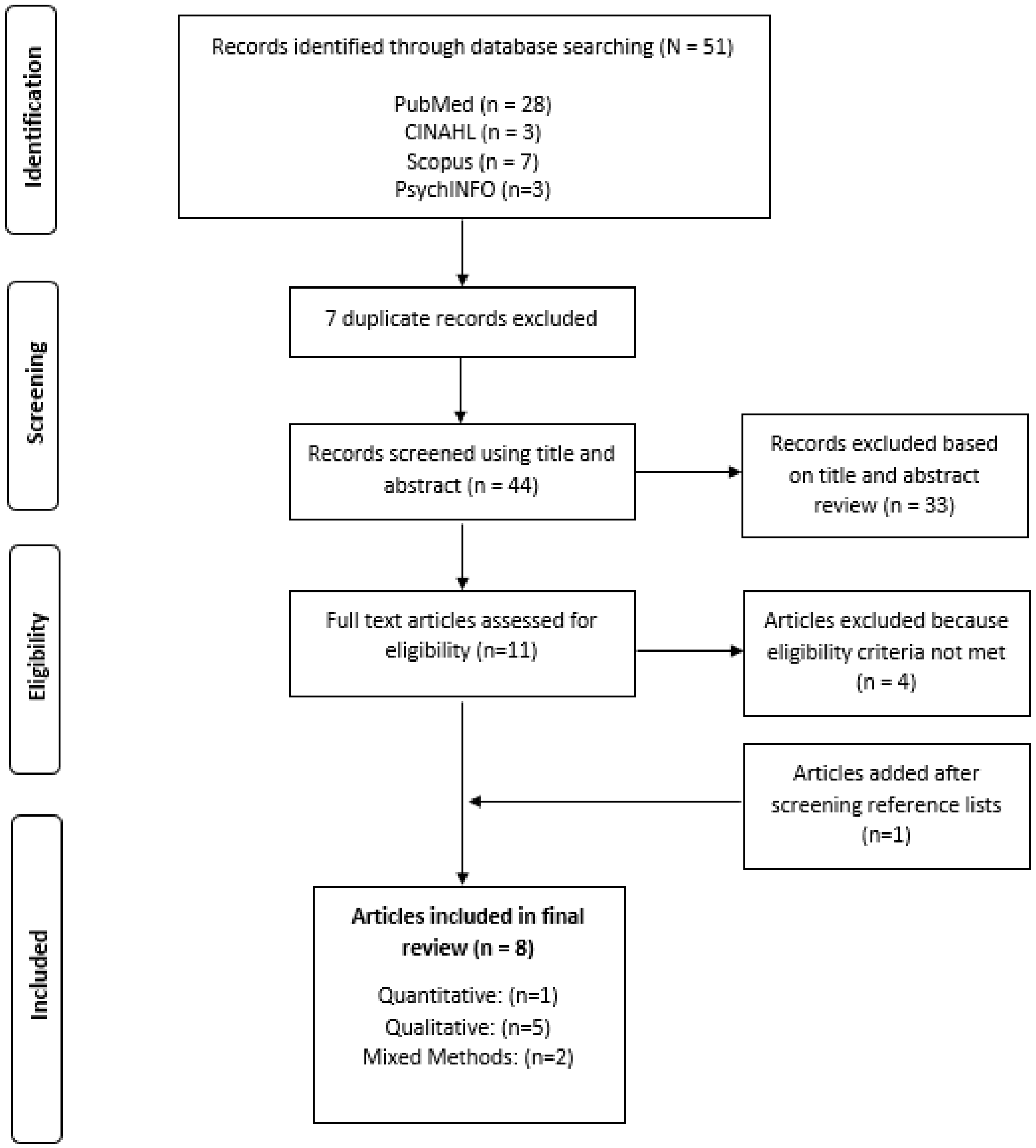
The initial search yielded 51 articles (PubMed=38, CINAHL=3, Scopus=7, PscyhINFO=3). After seven duplicates were removed, 44 articles remained to undergo title and abstract review. Included studies had to: 1) pertain to the population of caregiving under the age of 18, 2) relate to the adoption of a caregiving role by the child, and 3) describe a context for caregiving involving Huntington's Disease. Articles were excluded for pertaining to caregiving in the sense of a parent taking care of their child or for using the term young caregiver in the sense of the caregiver being younger than the average caregiver age, but not being less than 18 years old. Non-primary studies including reviews, instrument development papers, and dissertations were also not included. This resulted in the removal of 33 articles. Eleven articles then underwent full text review. An additional four articles were excluded for not meeting eligibility criteria. One article was then added after screening reference lists of the remaining studies. This resulted in a total of eight articles being included in the review. A PRIMSA diagram detailing this search process is include included as **Figure 2**.

Analysis of Literature

Origins of Research

The same variability in the definition and age range of young carers was evident in this review as it was in the previous review. The terminology included "caregiving children", "young carers", and "caregiving youth." In this search, four studies took place in the United States, one in the United Kingdom, one in Norway, and one based in both Canada and the United States (Dondanville et al., 2019; Keenan et al., 2007; Kavanaugh, 2014; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Røthing et al., 2014; Williams et al., 2009). The disciplines of the researchers also varied and included medicine, social work, public health, and nursing. This variation in setting and discipline illustrates that, despite difficulty in reaching consensus regarding a universal definition for the population, steps are being taken to contribute research to these understudied and underserved children, regardless of where the research originates. This highlights acceptance of the need for research in this area as was discussed in the prior review.

Figure 2. PRISMA Diagram of Literature Search-Young Carers and Huntington's Disease



The Caregiving Role

The caregiving role is unique for children, especially those caring for a person with Huntington's disease. The descriptions of the caregiving role, including the caregiving tasks and duration spent caregiving, varied by study. The majority of the participants in the studies were providing care for a period of one to three years, but across studies this proportion was around 50% indicating that a similar number of participants spent more than three years caring for an individual with Huntington's Disease (Kavanaugh, 2014; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019). In addition, most of the participants reported that they were not the only caregivers in the family and received assistance from parents, siblings, grandparents, or professional caretakers (Dondanville et al., 2019; Kavanaugh, 2014; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019). The time spent caregiving each week was similar across studies as well, with approximately 50% providing more than 10 hours of care per week (Kavanaugh et al., 2016; Kavanaugh et al., 2019). Participants in one study specifically reported that they did not have time to fill all the roles that needed to be filled (Kavanaugh et al., 2015). Furthermore, young carers in these roles provided care for numerous types of symptoms. The study by Kavanaugh and colleagues in 2015 reported that the average number of care tasks that young carers were involved in was 11, while another study reported an average of 12 (Kavanaugh et al., 2015; Kavanaugh et al., 2019). To this point, participants in one study reported that they felt they "had a lot of responsibility" (Kavanaugh et al., 2016).

The types of care tasks being provided were similar to those provided by an adult caregiver, including tasks both instrumental and emotional and nature (Keenan et al., 2007; Røthing et al., 2014; Williams et al., 2009). Specifically, participants reported that "having to behave like an adult" was part of their caregiving experience (Williams et al., 2009). Some of the care tasks required, specifically those dealing with personal care, such as bathing and toileting, may feel "developmentally out of synch" for children (Kavanaugh, 2014). Consistently, young carers reported that they had little training or education related to their caregiving role (Keenan et al., 2007; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Williams et al., 2009). Instead, children had to rely on other means to educate themselves including "watching and observing", "common sense", or "trial and error" (Kavanaugh et al., 2019). To further complicate this issue, the age of the young carer could affect their ability to comprehend care tasks (Kavanaugh et al., 2019).

Unique Aspects of Huntington's Disease for Caregiving

Huntington's disease makes the caregiving experience unique for various reasons. First, genetic risk is a factor that may compound the emotional distress felt by young caregivers and this risk and worry about the risk was discussed in many of the studies (Dondanville et al., 2019; Keenan et al., 2007; Kavanaugh, 2014; Kavanaugh et al., 2016; Røthing et al., 2014; Williams et al., 2009). In addition, this fear contributed to plans for predictive testing and distress related to witnessing effects of the disease progression that they these children were potentially at risk for inheriting (Dondanville et al., 2019; Keenan et al., 2007). Because of the triad of motor, cognitive, and psychiatric symptoms, Huntington's disease is an illness that is difficult to care for. This difficulty is especially evident with regards to the psychiatric symptoms (Kavanaugh, 2014; Kavanaugh et al., 2015). In fact, even adult nursing home staff report difficulty in dealing with these types of symptoms (Kavanaugh, 2014). Young carers reported that these symptoms were frustrating and complicated and because of that, the parent was sometimes “hard to get along with” (Kavanaugh, 2014).

To combat the issues faced by caregiving for Huntington’s disease, children reported various needs. First, they reported a need for more information and education pertaining to Huntington’s disease including end-of-life decision making, caregiving skills, genetic risk, and understanding of symptomology (Keenan et al., 2007; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Williams et al., 2009). Young carers also discussed the fact that they had the responsibility of being a caregiver, but not the power or authority to make decisions and changes (Kavanaugh et al., 2016; Kavanaugh et al., 2015; Williams et al., 2009). They felt that they were being left out of important conversations, even though as caregivers, they would see the effects of those decisions (Kavanaugh et al., 2016; Williams et al., 2009). Lastly, young carers for persons with Huntington’s disease discussed a need for normalcy. They wanted more understanding from their peers about their caregiving role and for their family to be treated as normal, despite Huntington’s Disease (Keenan et al., 2007; Kavanaugh et al., 2015). They also expressed a desire to have more interaction with people going through the same situation (Kavanaugh et al., 2016; Kavanaugh et al., 2019).

Gaps

Similar to the gaps in the research for young carers as a whole, young carers caring for persons with Huntington’s disease need more information and education related to their caregiving role, specifically training on how to deal with the care tasks unique to Huntington’s disease (Keenan et al., 2007; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Williams et al., 2009). Researchers from all studies called for future research addressing the need to understand the unique situation young carers of persons with Huntington’s disease face (Dondanville et al., 2019; Keenan et al., 2007; Kavanaugh, 2014; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Røthing et al., 2014; Williams et al., 2009). This includes not only research in young carers, but also dyadic research looking at the experiences of both parents and children (Kavanaugh et al., 2016). Researchers across studies also called for research in outcomes related to the caregiving experience in Huntington’s disease and the potential mitigating factors to prevent these consequences (Dondanville et al., 2019; Keenan et al., 2007; Kavanaugh, 2014; Kavanaugh et al., 2016; Kavanaugh et al., 2015; Kavanaugh et al., 2019; Røthing et al., 2014; Williams et al., 2009).

Summary

Research pertaining to Huntington’s Disease and young carers originates from a variety of settings and disciplines. The caregiving role in this population is characterized as having a long duration and requiring a variety of care tasks. These tasks can be difficult, not only due to age and development level, but also because children are performing them without any education or training. In addition, the symptoms of Huntington’s disease, and the specific care required for them, can be complex and time consuming. Caregiving in the context of Huntington’s disease is also unique due to the implications of the genetic risk faced by the child. Children providing care in this context discussed frustration and difficulty related to the caregiving experience, as well as to their limited involvement and authority in decision making. Both researchers and children expressed a need for more education, research, and tailored interventions to better assist and understand children in this role.

Table 2. Huntington’s Disease and Young Carers

References	Study Population	Study Aim(s)	Design	Caregiving Role	Unique Aspects of Huntington’s	Strengths/Limitations Gaps/Future Research
Dondanville et al. 2019 U.S.A. Medicine *“This could be me”: exploring the impact of genetic risk for Huntington’s disease young caregivers*	N=15; 15-25 years old; who self-identified as caregivers Demographics not reported	**1)** To explore the interaction between genetic risk, plans for future testing, and the caregiving experience	Qualitative study; inductive data driven analysis approach	-All were actively providing care or had been caregiving in the last 18 months -Many indicated caregiving assistance from parents, siblings, grandparents or professionals	a) genetic risk is a factor that compounds the emotional distress felt by young caregivers. b) Impact of caregiving experience on plans for future predictive testing. c) they witnessed the effects of disease progression that they may be at risk for	Strengths: contributes to limited research about youth who care for parent with HD Limitations: Small self-selected sample. Findings may not be representative. Retrospective experiences were described thus there is potential for recall bias. Gaps/Future Research: Findings can be used to help genetic counselors support and counsel needs of this population. Future research should establish if/when providers acknowledge or ask about work of young caregivers in the home so that support can be provided.

Kavanaugh 2014 U.S.A. Social Work *Children and Adolescents Providing Care to a Parent with Huntington's Disease: Disease Symptoms, Caregiving Tasks and Young Carer Well-Being*	N=40; 12-20 years old; had parent with HD and engaged in caregiving activities Male 23% Female 77% All but one participant identified as Caucasian.	**1)** To describe children and adolescents who care for parent with Huntington's and their caregiving experience	Quantitative study; cross sectional, explorative	-Majority provided care for a period of 1-3 years (54%) -Most frequent caregiving task was providing company to parent (85%) -Frequency of caregiving was correlated with parental conflict and school problems	a) conflict resulting not only from time spent caregiving, but also in combination with knowledge that they may get HD as well b) relationship between symptom "parent being hard to get along with" and parental conflict, school problems, and depression. c)Especial difficulty dealing with psychological symptoms d)complicated and frustrating symptoms e) some tasks feel "developmentally out of synch"	Strengths: Highlights the need for social workers, nurses, counselors, and providers to acknowledge caregiving children. Results can assist in lobbying for changes. Limitations: Purposeful sample limited to Huntington's' Disease Society of America. Not a diverse sample. Gaps/Future Research: Need future research on how these children prepare for the caregiving role. Explore the role of schools in supporting young carers. Exploration as to what supports are needed and how that impacts psychological well-being.

Kavanaugh et al. 2019 U.S.A. Social Work *“I Just Learned by Observation and Trial and Error”: Exploration of Young Caregiver Training and Knowledge In Families Living with Rare Neurological Disorders*	N=96; aged 8-20; cared for a parent with HD or ALS Male 33% Female 62%	**1)** To provide initial understanding as to how caregiving youth gain skills and training **2)** inform the development of skill and training interventions	Mixed methods study; combining results from three previous studies. Quantitative: demographics, caregiving skills, and training Qualitative: thematic analysis approach	-61% received no guidance or training for the caregiver role -assisted with walking (76%), toileting (32%) and medication administration (37%) -Participants involved in an average of 12 tasks -49% provided care 1-3 years -46% provided more than 10 hours of care per week -82% said they were not the only caregiver	a) HD requires assistive devices, detailed medications, and heavy lifting and transferring b) Care tasks are complicated and require skills and knowledge c) age can affect their ability to comprehend care tasks d) many youth do not receive any specific training and instead relied on care recipient for guidance, “watching and observing”, “common sense”, or “trial and error”	Strengths: first study in the U.S. to explore young caregiving knowledge and training Limitations: questions about training were only a small number of questions. Different methods of data collection. Sample was recruited from disease-based organizations only. Gaps/Future Research: research needed to assess how teaching and learning occur in the home of young caregivers. Need for interventions to provide caregiver education to young caregivers. Need for caregiver to engage with “like” peers in similar situations.
Kavanaugh, Noh & Studer 2015 U.S.A. Social Work	N=40; aged 12-20; provide care to parent with symptomatic HD	**1)** To explore the support needs of children and adolescents providing care to a parent	Qualitative study; conventional content analysis approach	-involved in an average of 11 care tasks -46% providing care for 1-3 years	a) need for others to spend time with parent, to reduce need for child to always be with the parent b) need for information and advice about HD	Strengths: Findings can be used to bring awareness to caregiving children of HD. May be used to develop and inform services or programs in the U.S.

It'd be nice if someone asked me how I was doing. Like, 'cause I will have an answer": Exploring support needs of young careers of a parent with Huntington's disease	Male 23% Female 77% Majority were reported as non-Hispanic white.	with Huntington's Disease		-77% reported not being the only caregiver -parents had an average of 11 symptoms including involuntary movements (95%), depression (68%), and trouble talking (70%).	c) need for friends who understand their caregiving situation and interaction with other HD caregiving children d) need for others to treat their family as normal e) need to be asked about how they are, not just their parent f) expressed they did not have enough time for all the roles needed to be filled	<u>Limitations:</u> Purposeful sample limited to Huntington's' Disease Society of America. Not longitudinal. Lack of diverse sample. <u>Gaps/Future Research:</u> Future research is needed to address racial and cultural differences among carers for HD. Need for future research and programs to meet needs discussed in findings.
Kavanaugh, Noh & Zhang 2016 U.S.A. Social Work *Caregiving Youth Knowledge and Perceptions of Parental End-of-Life Wishes in*	N=40; aged 12-20; have a parent with symptomatic HD Male 23% Female 77% Majority were reported as non-Hispanic white.	**1)** To explore caregiving youth's knowledge regarding end of life (EOL) wishes and their willingness to discuss these wishes	Mixed methods study; combining results from three previous studies. Quantitative: demographics, caregivers' knowledge of parents LW and DPAHC. Qualitative: conventional content	-54% providing care for 1-3 years -51% provided more than 10 hours of care per week -77% reported not being the only caregiver -36% reported having "a lot" of responsibility	a) less than 50% knew about living will or health proxy b) Their opinion not valued in EOL discussions c) more focused on parents need and emotion well being d) need support from professions who understand HD to help them process e) lack of knowledge surrounding EOL can increase stress and	<u>Strengths:</u> provides new understanding about caregiving children and EOL experiences in HD <u>Limitations:</u> Purposeful sample limited to Huntington's' Disease Society of America. Did not capture parents' feelings surrounding EOL. <u>Gaps/Future Research:</u> providers need to support families in EOL discussions. Education is

Huntington's Disease			analysis approach		anxiety in emergency situations f) isolating for children to be treated as caregiver but not participate in important discussions	needed for providers to increase their capability of having these conversations. Dyadic research needed in this area.
Keenan et al. 2007 U.K. Public Health *Young people's experiences of growing up in a family affected by Huntington's disease*	N=33; aged 9-28 Male (n=12) Female (n=21) All participants described themselves as Caucasian.	**1)** To explore young people's experiences finding out about HD in their family, perceptions of their risk, caregiving activities and the impact of HD on their relationships	Qualitative study; thematic analysis approach	-engaged in household tasks as well as personal care of the parent -some participants were young carers (n=12), while others were young adults over age 18	a) despite receiving external support, they all reported difficulty getting needs met b) caregivers anxious about their risk for HD c)needed support and information d) good social support systems and strong relationships were protective factors e) professionals may have difficulty reaching this population due to parents protecting or neglecting their children	<u>Strengths: </u>Provides information about the varied experiences of growing up in a family with HD. Findings suggest protective and risk factors for coping. <u>Limitations: </u>young cares were contacted through their parents. Small sample size. Snowball sampling method. <u>Gaps/Future Research:</u> future research needed to understand the frequency and predictors of coping. Additional research to determine best ways to identify, access, and provide interventions to this vulnerable population

Rothing, Malterud & Frich 2014 Norway Public Health *Caregiver roles in families affected by Huntington's disease: a qualitative interview study*	N=15; aged 20-67; had experience caring for person with HD across all five stages Male (n=3) Female (n=12) Race and Ethnicity Not Reported	**1)** To explore caregivers' experiences and the impact of Huntington's disease (HD) on the family structure	Qualitative study; systematic text condensation (STC) thematic analysis approach	-average years of caregiving experience =11.6 -12 of the 15 participants had children -many reported being a caregiver while they were a child/teenager	a) HD impacted the family system; children could compensate by taking on adult responsibilities b) Increasing need for care causes conflict between roles of family member and caregiver c) family difficulties when HD disease coincides with parental obligations for children d) children felt their own needs put aside to care for parent e) relationship conflicts later in life f) less openness about emotional responsibilities compared to practical tasks	Strengths: Provides novel insights about the significance of context in the caregiving role. Limitations: Small sample size and purposeful sampling method. Gaps/Future Research: Children and teenagers in families with HD deserve more attention. More knowledge about appropriate interventions is needed.
Williams et al. 2009 U.S.A. & Canada Nursing *Caregiving by Teens for*	N=32; aged 14-18; have a family member with HD Female to male ratio = 3:1	**1)To describe caregiving by teens for family members with HD**	Qualitative study; content analysis approach	-provided caregiving activities similar to those provided by adults -"having to behave like an adult" was a component of their experience	a) provided direct care, especially when other parent was at work b) had to structure their behavior in a way to minimize outbursts or undesired behavior c) caregiving caused a burden in the form of emotional distress, social	Strengths: Findings can be helpful for other teens who adopt the caregiving role. Adds knowledge needed for intervention development Limitations: exploratory study with results gained from focus groups.

Family Members With Huntington Disease	Race and Ethnicity Not Reported				restrictions, and financial concerns d) worries regarding getting HD e) decisional responsibility but little authority to make decisions or changes	Limited generalizability of sample. <u>Gaps/Future Research:</u> Information sources that are designed for adults need to be adapted for children/teens.

LITERATURE REVIEW 3

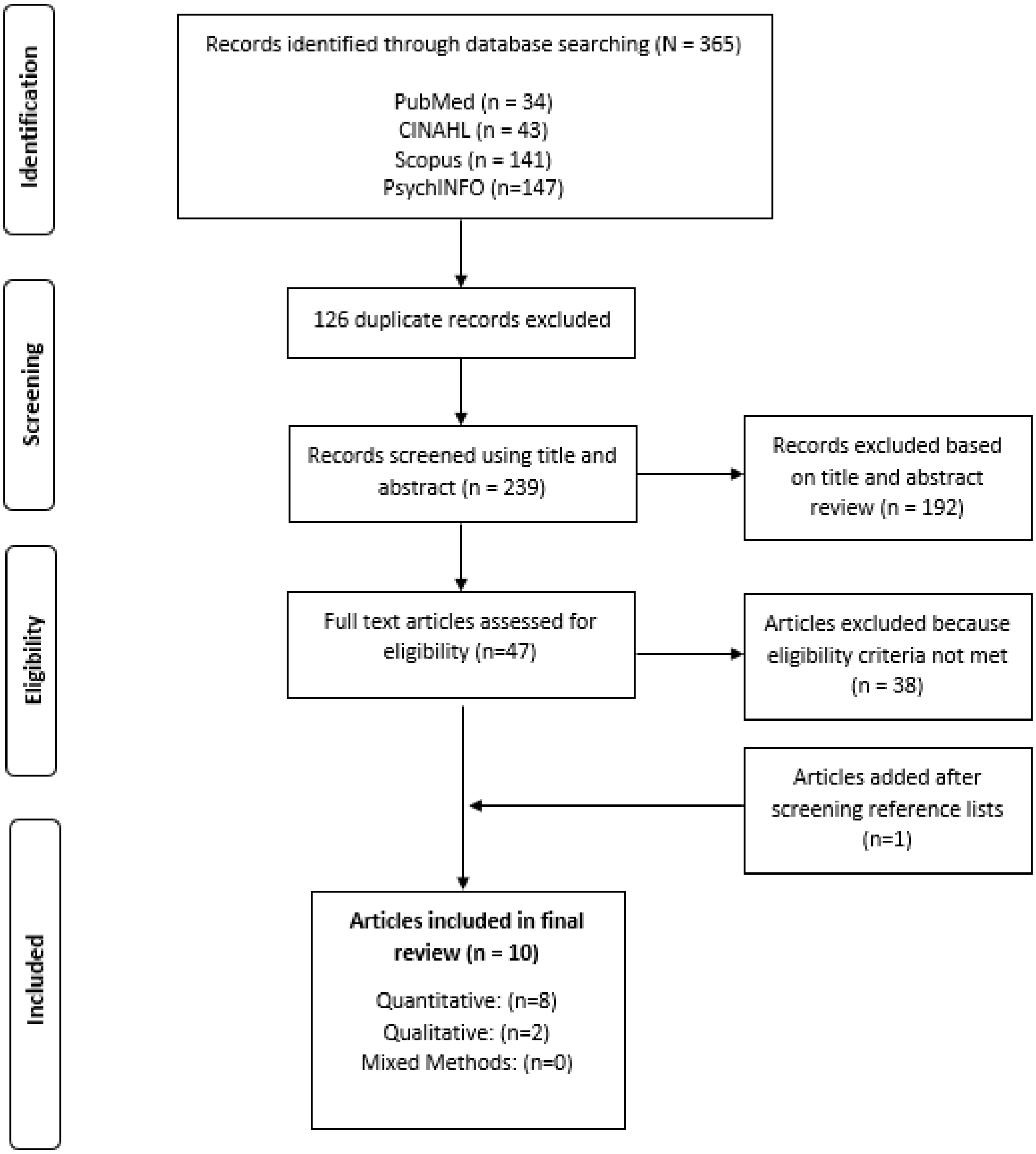
Young Carers and Parentification

Search Strategy

A search of the literature was conducted using the databases, PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Scopus, and PsycINFO to examine the state of the science pertaining to young carers and parentification. The search terms were as follows: *(("parentification" OR "role reversal") AND ("caregiv*" OR illness OR cancer OR disease)).* The search terms were based on terminology found in the literature and meetings with a reference librarian. Role reversal was included as a term due to the interchangeability of parentification and role reversal in the literature. A date range of 1995-2020 was searched. This date range reflects the emergence of the topic of "young carers" during the 1990s (Nagl-Cupal & Prajo, 2019). Articles searched for were English and full text.

The initial search yielded 365 articles (PubMed=34, CINAHL=43, Scopus=141, PscyhINFO=147). After 126 duplicates were removed, 239 articles remained to undergo title and abstract review. Included studies must: 1) pertain to the population of young carers under the age of 18, 2) relate to the experience of parentification or role reversal due to parental illness or incapacitation and 3) describe a context where children are in some way taking on caregiving responsibilities for a parent. Articles were excluded for pertaining to caregiving in the sense of a parent taking care of their child or for using the term young caregiver in the sense of the caregiver being younger than the average caregiver age, but not being less than 18 years old. Non-primary studies including reviews, instrument development papers, and dissertations were also not included. This resulted in the removal of 192 articles. Forty-seven articles then underwent full text review. An additional 38 articles were excluded for not meeting eligibility criteria. One article was then added after screening reference lists of the remaining studies. This resulted in a total of 11 articles being included in the review. A PRIMSA diagram detailing this search process is include included as **Figure 3**.

Figure 3. PRISMA Diagram of Literature Search-Young Carers and Parentification



Analysis of Literature

Population and Design

In contrast to the studies presented in the previous two reviews, the studies in this review included diverse samples. Many of the studies had predominantly African-American participants including the studies by Bauman (61%), Kelley (34%), Khafi (58%), and McMahon (52%) (Bauman et al., 2006; Kelley et al., 2007; Khafi, Yates, & Luthar, 2014; McMahon & Luthar, 2007). Furthermore, many studies also included a large percentage of Hispanic participants including the studies by Bauman (33%), Hooper (19%), and Kelley (20%). Participants across studies were primarily female. Settings for the studies varied with six from the United States, one from Belgium, one from Canada, and one from both the United States and Zimbabwe (Bauman et al., 2006; Hooper et al., 2008; Keigher et al., 2005; Kelley et al., 2007; Khafi et al., 2014; McMahon & Luthar, 2007; Tompkins, 2007; Van Loon et al., 2017; Van Parys et al., 2014; Williams & Francis, 2010). The disciplines of the researchers for the studies also varied and included medicine, psychology, social work, behavioral science, and family therapy. While the majority of the studies dealt with cross-sectional research in children less than the age of 18, three of the studies were retrospective, using college students as their sample (Hooper et al., 2008; Kelley et al., 2007; Williams & Francis, 2010) Many of the studies used data from both parents and children, but only one study collected data from the parent and thus information pertaining to the child was parent reported (Keigher et al., 2005). Studies in this review primarily used a quantitative design and of note, two studies in this review employed a longitudinal design looking at the effects of parentification from childhood into adolescence or adulthood (Khafi et al., 2014; Van Loon et al., 2017).

Parentification

Definitions of parentification varied across studies. Some referred to this phenomenon as a role reversal, others as a family process change or a distortion of boundaries, but all definitions expressed in some way that the child was assuming roles and responsibilities that are typically undertaken by an adult (Hooper et al., 2008; Khafi et al., 2014; McMahon & Luthar, 2007; Tompkins, 2007; Van Loon et al., 2017). The only exception was Keigher (2005) who instead offered the definition of a parentified child as, "a child who acts as a caretaking parent to his or her own parent." In addition to variations in definitions for parentification, the measures also varied. The majority of the studies utilized *The Parentification Questionnaire*, whether in its original format or its later modifications for specifically adult-reported or child-reported items (Hooper et al., 2008; Kelley et al., 2007; Van Loon et al., 2017; Williams & Francis, 2010). In addition, two studies utilized *The Child Caretaking Scale* which, while not solely looking at parentification, includes items that are used to measure this phenomenon (Khafi et al., 2014; McMahon & Luthar, 2007). The context in which the child was parentified in these studies were primarily parental HIV/AIDS, parental mental illness, parental substance abuse, or some combination thereof. Only two studies did not specify the context of the parentification (Hooper et al., 2008; K. Williams & Francis, 2010).

Findings

The findings for these studies in some way all reported parentification as a component of the caregiving experience for children. Numerous studies found that the child's report of caregiving activities was higher than that of the parents (Bauman et al., 2006; McMahon & Luthar, 2007; Tompkins, 2007; Van Parys et al., 2014). This finding was also evident in the previous review of young carers in Huntington's disease. Also, similar to the previous review, female participants and those who were the oldest child, reported the highest levels of caregiving (Bauman et al., 2006; McMahon & Luthar, 2007) Studies in this review found that emotional parentification was more associated with pathological consequences than instrumental parentification (Bauman et al., 2006; Hooper et al., 2008; McMahon & Luthar, 2007). Oftentimes, these consequences refer to internalizing pathology, such as depression and anxiety, as well as psychological well-being (Bauman et al., 2006; Hooper et al., 2008; McMahon & Luthar, 2007; Van Loon et al., 2017). Across studies in this review, the consensus was that parentification exists on a continuum and is multidimensional (Khafi et al., 2014; McMahon & Luthar, 2007; Williams & Francis, 2010).

Multiple studies also looked at moderating factors for parentification. Williams and Francis (2010) found that internal locus of control acted as a moderator in the relationship between parentification and pathological outcomes. Hooper (2008) stated that resiliency might explain why some outcomes of parentification are positive. Researchers across multiple studies reported that parentification is not always a pathological process. Khafi and colleagues (2014) referred to this in idea in their study stating that parentification is not a "uniformly detrimental process that requires intervention". This idea was represented in findings as well, as multiple studies noted the positive consequences of parentification. One study stated that there is a potential for post traumatic growth (Hooper) while another stated that parentification facilitates a sense of self (Kelley) (Hooper et al., 2008; Kelley et al., 2007). Van Parys and colleagues (2014) stated that the caregiving role is positive in the sense that it may function as a way for children to manage the situation they are in and feel like they are helping their family.

Gaps

In addition to similarities in findings across studies, researchers similarly agreed that more information was needed regarding the phenomenon of parentification. Specifically, more research is needed to understand the normalcy of caregiving in numerous cultures and across races. Few studies in this review looked specifically at differences in culture, as Bauman (2006) did, or looked at differences between racial groups, as Khafi (2014) did. In the study taking place in both the United States and Zimbabwe, Bauman and colleagues (2006) found the children in Zimbabwe were more likely to perform care tasks and to experience a higher burden of caregiving than their United States counterparts. In the study conducted by Khafi and colleagues (2014), African Americans were found to experience more parentification, but fewer negative outcomes than their Caucasian counterparts. In addition to more diverse research, there was a call for more longitudinal research to explore parentification across points in time, but to also see if protective factors moderate that relationship over time (Hooper et al., 2008; Khafi et al., 2014; Van Loon et al., 2017). Lastly, numerous researchers stated a need for research to focus on the family as a whole, looking at how family influences the children, reciprocity between parents, and recognition for their child's caregiving role in family structure (Bauman et al., 2006; Kelley et al., 2007; Khafi et al., 2014; Van Parys et al., 2014).

Summary

In summary, while this review of parentification in young carers had more diverse samples than studies in the previous two reviews, there is still a need for more research examining the differences across race and culture. Despite variations in definitions and measures of parentification, researchers found that parentification was a phenomenon experienced by young carers, often with more consequences arising from emotional parentification. In addition, researchers acknowledged a potential for positive consequences of parentification, not just those that are pathological, and identified factors that may moderate the relationship between parentification and its outcomes. Researchers across all studies, as in the previous two reviews, cited a need for more research in the population of young carers, as well as a need for more research to examine the multidimensional nature of parentification and its potential moderators, mediators, and outcomes. Lastly, research is needed for parentification in contexts outside of HIV/AIDS, mental illness, and substance abuse. Of note was the fact that none of the studies of parentification looked at it in the context of Huntington’s disease.

Table 3. Parentification in Young Carers

References	Study Population	Study Aim (s)	Definition of P. & Context	Design & P. Measure	Main Findings	Strengths/Limitations Gaps/Future Research
Bauman et al. 2006 U.S.A. & Zimbabwe Medicine *Children caring for their ill parents with HIV/AIDS*	N=50; aged 8-16; one or both parents had to have HIV/AIDS that caused illness or disability U.S.: Black 61% Hispanic 33% Female Children 64% Zimbabwe: Zimbabwean 96% Mozambican 4% Female Children 58%	**1)** To document the degree to which children of parents with HIV/AIDS take on adult responsibilities **2)** To document the kinds of responsibilities they have **3)** To document their psychological status	*Parentification:* "children assume responsibilities performed more appropriately by an adult" Context: HIV/AIDS	Quantitative study; cross sectional, explorative *Parentification Scale* (Mika et al., 1987) *Emotional Parentification Questionnaire* (Martin, 1996)	-In the context of HIV/AIDS, children provide substantial amounts of care -children reported more care tasks than their mothers in the U.S. - Children in Zimbabwe were more likely to perform care -higher burden of emotional parentification in Zimbabwe than U.S. -child depression and caregiving were not related -older children and girls not more likely to take on caregiving role - most important predictor of child mental health was a strong parent–child relationship	Strengths: diverse sample based in two countries. Contributes knowledge to understudied area of research. Limitations: sample size is too small to trust significance tests, not able to determine causation Gaps/Future Research: more research is needed to better understand the norms of caregiving and how they vary by family and culturally.

Hooper, Marotta & Lanthier 2008 U.S.A. Psychology *Predictors of Growth and Distress Following Childhood Parentification: A Retrospective Exploratory Study*	N=156; Mean age=22: retrospective; recruited from community college Male 30% Female 70% White 36% Black 22% Hispanic 19%	1) To examine how bimodal growth and distress consequences might be predicted by childhood parentification	*Parentification:* "role reversal wherein a child becomes responsible for a parent's and/or other family members' emotional or behavioral needs" Context: Unspecified	Quantitative study; cross sectional, retrospective, explorative *Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	-parentification predicts a mild level of post traumatic growth -emotional parentification is a predictor of distress -parentification should not always be assumed to be pathological -resiliency might explain positive psychological outcomes of childhood parentification	Strengths: examines the potential positive consequences of parentification. Limitations: retrospective which may had recall bias. Self-report data. Some instrument reliability was low. Gaps/Future Research: examine how and when parentification leads to positive outcomes. Longitudinal research. Exploration of resiliency factors.
Keigher et al. 2005 U.S.A. Social Work *Young caregivers of mothers with HIV: Need for supports*	N=7; single mothers providing descriptions of their 26 children aged 18 and younger. Female 100% Black (n=4)	**1)** To examine issues facing young caregivers by analyzing narratives of the everyday lived reality of their mothers who have HIV	*Parentified child:* "child acts as a caretaking parent to his/her own parent" Context: HIV/AIDS	Qualitative study; close narrative analysis	-most prominent type of care provided was emotional care, specifically motivating their mother to continue living -also provided instrumental care, like medication administration and housekeeping as well as sibling care - negotiating on behalf of their family in their	Strengths: Contributes knowledge to understudied area. Acknowledges potential positives of parentification. Limitations: small sample size; purposive sampling. Not from the child's point of view

	Caucasian (n=3)				neighborhood and community -parentification is not always pathological	Gaps/Future Research: need for support for children in this role. Social policy needs to acknowledge, legitimize and support these children
Kelley et al. 2007 U.S.A. Psychology *Parentification and family responsibility in the family of origin of adult children of alcoholics*	N= 368; Mean age=21; recruited from university Female 100% 34% White 34% Black 20% Hispanic 3% Multicultural 3% Asian 1% Pacific Islander 3% Other	**1)** To examine parentification and family responsibility between families with alcoholism and those without	*Parentification:* “children or adolescents assume adult roles before they are emotionally or developmentally ready” Context: alcoholism	Quantitative study; cross sectional, retrospective, explorative *Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	-women in family with alcoholism more likely to report parentification -reported greater responsibility for practical and emotional problems in families -parents with alcoholism are more likely to give their children adult responsibilities, creating environment that encourages role reversal - role reversal often facilitates a sense of self that is based on the ability to care for others -daughter assumes more responsibility	Strengths: use of sound measures. Extend understanding of alcoholism in families. Large sample. Limitations: Did not collect data from parent as well. Generalizability limited. Causality cannot be established. Gaps/Future Research: how family influences later behavior in children. Research focusing on reciprocity

Khafi, Yates & Luthar 2014 U.S.A. Psychology *Ethnic Differences in the Developmental Significance of Parentification*	N=143; T1 Mean age = 10 years, T2 Mean age = 15 Male 48% Female 52% Black 58% Caucasian 42%	**1)** To describe patterns of emotional and instrumental parentification from early to late adolescence **2)** to assess the impact of parentification on youth's adjustment **3)** to assess the moderating role of ethnicity on relations between parentification and adjustment	*Parentification:* "an outgrowth of a family process wherein children provide emotional and/or instrumental care for their parents" Context: anxiety, affective, and/or substance use disorders	Quantitative study; longitudinal, explorative *Child Caretaking Scale* (Baker & Tebes, 1994)	-parentification is a process that varies based on the interaction of characteristics of the individual, environment and time -AAs are more likely to have parentification and potentially benefit from it due to cultural values -parentification was moderately stable from childhood to adolescence -rates of parentification were similar across groups -parentification was more likely to be associated with negative outcomes in Caucasians - not a "uniformly detrimental process that requires intervention"	Strengths: first study to examine long term effect of parentification. Assesses parentification specifically in AA families Limitations: only two time points were collected. Some data regarding the family was not collected. Convenience sample. Gaps/Future Research: research needed to determine the mechanisms by which parentification operates. Research to help inform practice to help children.
Van Loon et al. 2017 The Netherlands Behavioral Science	N=118; aged 11-16; parents had mental health problems (i.e., anxiety, depression, or alcohol-related problems)	**1)** To examine the effect of parentification on both internalizing and externalizing problems	*Parentification:* "a type of role reversal, boundary distortion, and inverted hierarchy between parents and children in which they	Quantitative study; longitudinal, explorative *Parentification Questionnaire-Youth* (Godsall and Jurkovic, 1995)	- More parentification was significantly associated with more internalizing problems -Parentification predicted an increase in internalizing problems after 1 year -important not to burden children with too many caregiving tasks	Strengths: only study examining parentification and internalizing problems in adolescents when their parent has mental health problems. Longitudinal design. Limitations:

Parentification, Stress, and Problem Behavior of Adolescents who have a Parent with Mental Health Problems	Male 49% Female 51% Race/Ethnicity not reported.		assume developmentally inappropriate levels of responsibility in the family” Context: Mental Illness		- adolescent parentification predicts internalizing, but not externalizing problems - perceived stress explained the relationship of parentification with internalizing and externalizing problems in the cross-sectional data, but not the longitudinal data	does not show causation due to study design, generalizability is limited due to sampling method, self-report measures Gaps/Future Research:, make parents aware of potential negative consequences if their child is a caregiver
McMahon & Luthar 2007 U.S.A. Psychiatry *Defining Characteristics and Potential Consequences of Caretaking Burden Among Children Living in*	N=361; Mean age=12; mothers with psychiatric or substance related problems Male 46% Female 54% Black 52% Caucasian 42% Hispanic 6%	**1)** To examine the psychosocial correlates of caretaking burden within a sample of children living in high-risk family systems characterized by maternal psychopathology	*Parentification:* “a family process involving developmentally inappropriate expectations that children function in a parental role within stressed, disorganized family systems” Context: Mental Illness	Quantitative study; cross sectional, explorative *Child Caretaking Scale* (Baker & Tebes, 1994)	-Child caretaking burden is positively correlated with psychological distress -Moderate level of caretaking associated with less internalizing pathology, compared with high or low levels -parentification and caretaking burden are multidimensional -girls and oldest children reported more involvement in caretaking -children reported higher levels of care involvement than the parents -emotional caretaking was more associated with	Strengths: results consistent with parentification conceptual model (Jurkovic), filled a research gap Limitations: generalizability is limited due to convenience sampling method, low reliability of 2 out of 3 *Child Caretaking Scale* subscales, use of self-report measures Gaps/Future Research: parentification should be viewed as a multi-

Urban Poverty					psychosocial adjustment problems.	dimensional phenomenon; clinicians should be sensitive to circumstances where children are expected to provide emotional care
Van Parys & Rober 2013 Belgium Family Therapy *Trying To Comfort The Parent: A Qualitative Study Of Children Dealing With Parental Depression*	N=14; aged 7-14; one of the parents is hospitalized for depression Male (n=5) Female (n=9) All families were Flemish.	**1)** To determine how children, experience parental depression **2)** To explore their caregiving experience in the family	*Parentification:* "children feel the vulnerabilities in their parent and try to act in ways that cause the least trouble or try to actively contribute to the family's well-being" <u>Context:</u> Depression	Qualitative study; thematic analysis approach	-some children felt that their parent prevents them from adopting a caregiving role -children may "hang on" to their caregiver role as a way of managing -children long for recognition and permission regarding their role - parent's feelings of vulnerability and guilt related to their child's role	<u>Strengths:</u> microanalysis techniques allowed more in depth understanding of data. Results have implications for family therapy <u>Limitations:</u> generalizability is limited. Parents were present for interview <u>Gaps/Future Research:</u> research is needed to address reciprocity and recognition in caregiving children.
Tompkins 2007 U.S.A. Psychology	N= 43; aged 9-16; mothers diagnosed with HIV	**1)** To examine the relationship between parentification, parenting, and child adjustment	*Parentification:* "role reversal in which the child assumes some or all of the	Quantitative study; cross sectional, explorative	- No significant relationships were evident between the parentification variables and child depression with the exception of [mother's	<u>Strengths:</u> few studies address parentification especially in HIV-affected family, inclusion of a control

Parentification and Maternal HIV Infection: Beneficial Role or Pathological Burden?	Gender Not Reported Black 44% Hispanic 44% Caucasian 14%	among a) children whose mother was HIV infected and b) same age peers whose mothers were not infected.	instrumental and expressive caretaking functions for the parent” Context: HIV/AIDS	*Parentification Scale* (Mika, Bergner, & Baum, 1987)	reports of child adopting parenting role] were associated with lower rates of depression - child reports of more “parental role” behaviors were associated with mother reports of more involvement and positive parenting. -the type of parentification, rather than the care tasks, fostered an association between positive parenting and child adjustment	Limitations: does not show causation due to study design, generalizability is limited, authors did not provide thorough description of methods for sampling and data collection, small sample size, self-report measures Gaps/Future Research: Future research is needed to determine which variables mediate or moderate the relationship between parentification and child outcomes
Williams & Francis 2010 Canada Psychology *Parentification and Psychological*	N=99; Mean age =24; retrospective; recruited from undergraduate university students Male 17% Female 83%	**1)** To examine the role of the internal locus of control as a moderating variable between childhood parentification and adult psychological adjustment	*Parentification:* “functional and/or emotional role reversal in which a child forfeits his or her own needs to become responsible for the emotional and/or	Quantitative study; cross sectional, explorative *The Parentification Questionnaire* (Sessions and Jurkovic, 1986)	- childhood parentification scores were positively correlated with adult depression - internal locus of control was found to moderate the relationship between parentification and psychological outcomes -parentification exists on a continuum	Strengths: few studies have identified variables that may impact the association between parentification and adjustment later in life Limitations: does not show causation due to study design, generalizability is

Adjustment: Locus of Control as a Moderating Variable	Race/Ethnicity Not Reported		behavioral needs of a parent” Context: Not specified			limited due to sampling method, use of self-reports Gaps/Future Research: clinicians working with clients who experience childhood parentification they should examine the individual’s locus of control

PARENTIFICATION AMONG YOUNG CARERS: A CONCEPT ANALYSIS

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Abstract

There are approximately 1.4 million young carers in the United States alone. Being a young carer can result in parentification, a type of role reversal that occurs when children take on the role and responsibilities of the adult. The purpose of this concept analysis is to provide a better understanding of the phenomenon of parentification among young carers through a description of its antecedents, attributes, and consequences using the steps of Rodgers' evolutionary method. The databases CINAHL, PubMed, PsychINFO, and Scopus were searched to identify 25 articles. The antecedents of the concept include the dependency of the care receiver and the child's adoption of a caregiving role. The attributes include fairness, obligation, resiliency, individuation, confidence in performing care tasks, cultural normalcy, family system functioning, support system, family resources, caregiver-care receiver relationship, and awareness of child's needs. Parentification has both positive and negative consequences that impact the young carer. The antecedents, consequences, and identifiable attributes of the concept are presented through this work to provide a comprehensive picture of parentification among young carers. These findings showcase the multidimensional nature of parentification and the broad impact that it can have on young carers. While these findings do provide greater insight into young carers, the fact remains that little is known about this underserved and underacknowledged population. This concept analysis provides a foundation of understanding that specifies potential targets for intervention development, as well as modifiable outcomes, that can be explored through future research and intervention work.

Keywords: young carers, caregiving children, parentification, concept analysis

Introduction

In the United States alone, approximately 53 million individuals (aged 18 and older) act as a caregiver (AARP & National Alliance for Caregiving, 2020). Caregiving is typically shared among primary and secondary caregivers, where the primary caregiver is the person providing most of the assistance (Barbosa et al., 2011). However, important contributors to this caregiving system, children aged younger than 18, are often overlooked. It is estimated that in the United States there are approximately 1.4 million young carers (aged 8-18) (National Alliance for Caregiving, 2005, March). This number is based on the only national survey conducted in this population in 2005 and is understood to be a vast underestimation because often neither these children nor the individuals they are helping care for a) know they are acting as a caregiver or b) want to acknowledge that they are (National Alliance for Caregiving, 2005). As caregivers, children often provide multifaceted, extended care as a secondary caregiver without any lessening of family, home, or school/work-related responsibilities (McGuire, Grant, & Park, 2012). In time, caregiving can become a role that requires more than a child can provide, both emotionally and physically (Hooper & Doehler, 2012).

Being a young carer can become traumatic and harmful when it is long-term and excessive, with responsibilities that exceed the capabilities of a child’s age or maturity level. (Boumans & Dorant, 2018, p. 2). This can result in parentification, the alteration or removal of boundaries within family structures that occurs when children take on the role and responsibilities of the adult (Hooper & Doehler, 2012). These boundaries represent the implied and obvious rules and expectations that exist within familial relationships (Earley & Cushway, 2002).

While there is an acknowledgement within the literature of the consequences of caregiving among children, the literature rarely addresses a) how these consequences may be related to parentification and b) what the resulting consequences of parentification can be for these children. The term parentification has its origins in sociology/psychology and over the years its usage has expanded to include children taking on adult roles and responsibilities in instances of not just parental neglect, but also in instances of parental illness or incapacitation (Earley & Cushway, 2002; Khafi et al., 2014). It has also been determined that parentification is a multidimensional concept unique to the individual experiencing the phenomenon, as well as to the context they find themselves in, resulting in both positive and negative outcomes (Khafi et al., 2014; McMahon & Luthar, 2007; Williams & Francis, 2010). Research pertaining to parentification among young carers is limited as this is a relatively new area of research and because the population of young carers is difficult to reach (Keenan et al., 2007). The aim of this concept analysis is to use Rodgers evolutionary concept analysis method to describe the antecedents, attributes, and consequences of parentification among young carers. The long-term intention is to use findings from this analysis to form a foundation for future research and intervention development and to allow future refinement of this concept as new research arises.

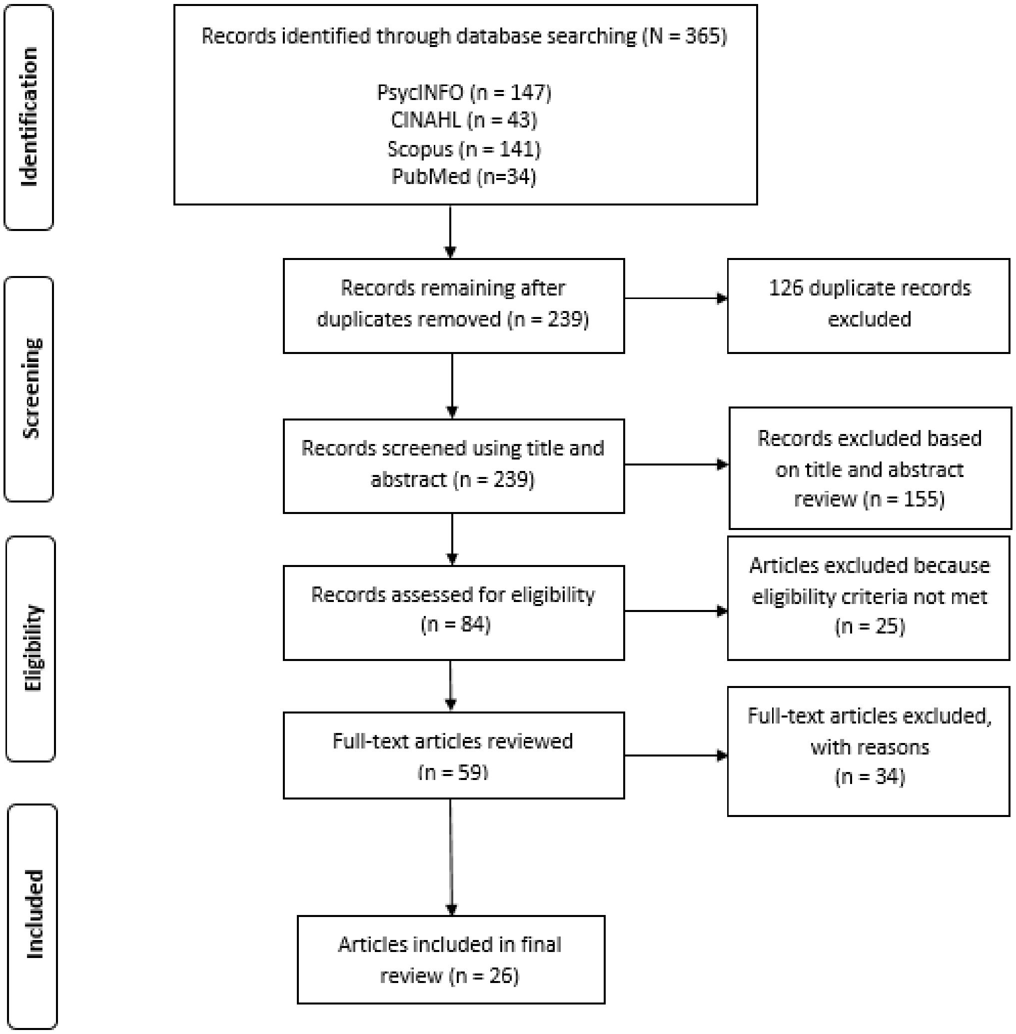
Methods

The Rodgers' method was selected to conduct this concept analysis because of a) its focus on "relevant purpose" b) its use of the inductive method, c) its goal in directing research, and d) its belief that concepts are influenced by context and are thus continually evolving over time (McEwen & Wills, 2014; Rodgers & Knafl, 1993, p. 81; Tofthagen &

Fagerstrom, 2010). An induction was made regarding the components of the concept of parentification among young carers through thorough review and analysis of the literature, using the steps of the Rodgers' method. These steps include 1) identifying the concept and its associated terms, 2) determining the setting and sample for data collection, 3) collecting relevant data via systematic review of the literature, 4) analyzing the collected data to identify the attributes and the contextual basis (antecedents and consequences) of the concept, 5) identifying an exemplar, if needed, and 6) defining implications and hypotheses for future research and development (McEwen & Wills, 2014, p. 60). Antecedents refer to the situations or events which must occur before the concept can occur, attributes are the characteristics of a concept that make its identification possible, and consequences occur after the concept occurs or as a result of the concept (Rodgers & Knafl, 2003; Tofthagen & Fagerstrom, 2010).

The literature search was conducted by the primary author using the databases PsycINFO, CINAHL, Scopus, and PubMed. The search terms were *(("parentification" OR "role reversal") AND ("caregiv*" OR illness OR cancer OR disease))* and were based on the interchangeability of the terms parentification and role reversal in the literature. In addition, the term caregiving/caregiver is not always used, so the terms illness, cancer, and disease were added to account for this variability. Article inclusion criteria included: being written in English, having full text availability, and being published in the last 25 years (1994-2019). The search yielded 365 articles. After 126 duplicates were removed, 239 articles remained. A review of titles and abstracts was then conducted. Study inclusion criteria: 1) primary research addressing parentification or role reversal in a child, and 2) related to caregiving due to familial illness, disease, or cancer. Exclusion criteria included studies that addressed parentification in settings not related to familial illness or in situations where the child was not the main subject of the discussion on parentification. Non-primary studies including reviews, instrument development papers, and dissertations were also not included. The search results were reviewed by one of the authors (M.A.B.) An illustration of this process is included in **Figure 4** as a PRISMA diagram.

Figure 4. PRISMA Diagram of Literature Search Method



Results

The search yielded twenty-five studies which varied by method (19 quantitative, five qualitative, one mixed method) and country of origin (U.S.A., Zimbabwe, The Netherlands, United Kingdom, Canada, South Africa, Belgium, and Italy) **(See Table 4).** These studies were reviewed to identify the antecedents, attributes, and consequences of the concept of parentification among young carers. The results of the analysis conducted using the steps of Rodgers method are organized as follows: antecedents, attributes, consequences (positive and negative).

Antecedents

The antecedent of parentification among young carers is the adoption of a caregiving role by a child due to the dependency of care receiver; wherein the child provides emotional and/or instrumental support that is typically provided by parent (Boumans & Dorant, 2018; Hooper & Doehler, 2012; Khafi, Yates, & Luthar, 2014; Van Loon, Van de Ven, Van Doesum, Hosman, & Witteman, 2017).

Attributes

The attributes of parentification among young carers include perception of fairness, felt obligation, resiliency, individuation, confidence in performing care tasks, cultural normalcy of caregiving role, family system functioning, familial support, family resources, caregiver-care receiver relationship, and care receiver awareness of child's needs **(See Figure 5)**. These are further divided into individual attributes, those related to the child themselves, and contextual attributes, those related to the context the child finds themselves in.

Individual Attributes

Perceived fairness is the extent to which caregiving tasks are acknowledged, supported, and reciprocated (Jurkovic, Thirkield, & Morrell, 2001). When their caregiving role is not acknowledged and supported, young carers are more likely to perceive the role as unfair (Tompkins, 2007). Young carers are often caring for a parent or family member, and because of this relationship, they may feel it is required that they adopt a caregiving role. This is referred to as '*felt obligation*.' Felt obligation encompasses the feelings of the child to provide obligatory assistance to the care receiver based on their relationship (Petrowski & Stein, 2016). Conversely, when a child does not feel that it is required that they adopt a caregiving role, and instead feels that they are voluntarily or willingly adopting the role, they may not experience felt obligation.

Resiliency is the ability of an individual to overcome challenges that may impact their development. In doing so, they are moving through the developmental stages towards adulthood (Hooper et al., 2008). For example, if children can negotiate the challenges resulting from caregiving, their development will not be impacted. When a child possesses resiliency, they are less likely to experience the negative outcomes that can result from parentification. *Individuation* occurs when an individual maintains their sense of self amid stressful environments and/or relationships (Hooper et al., 2008). One such stressful environment and/or relationship is that which is imposed upon young carers due to role reversal. If a child lacks individuation, they are more likely to be affected by the stressful experience of caregiving and therefore, more likely to experience negative outcomes.

Confidence in performing care tasks can relate to the developmental appropriateness of the care task, the education provided related to the care task, the child's age and/or maturity level, and their comfort related to performing their caregiving role (Fagan, 2003; Hooper & Doehler, 2012; Laghi et al., 2018). When a child lacks confidence in performing care tasks, they may be more likely to experience negative outcomes; whereas, a child who has confidence in performing care tasks, may be more likely to experience positive outcomes such as increased life skills, responsibility, and autonomy.

Contextual Attributes

Lack of normalcy of caregiving role within culture is an attribute of parentification among young carers that is more likely to result in negative consequences. Within certain cultures, including many in Latin American, Asia, and Africa, caregiving is often viewed differently from the typical western or U.S. perspective (Khafi et al., 2014). For example, compared to those of European American descent, who typically focus on autonomy and independence, native Latin American, Asian, and African individuals tend to have an increased focus on family, duty, and responsibility (Khafi et al., 2014). When caregiving is seen through this perspective, negative effects of the role diminish (Gelman & Rhames, 2018; Khafi et al., 2014).

Poor family system functioning and *lack of support* within a family are both attributes of parentification among young carers that can result in more negative outcomes. A well-functioning family system involves cohesion, a family's emotional bonding and flexibility, and the ability of the family to adapt to change (Laghi et al., 2018). When a family does not possess these characteristics, it is unable to provide support for its members, including young carers (Laghi et al., 2018). Another component related to lack of support within a family is its construction. In single parent households or households with multiple young children, there is an increase in the demands of the child as well as a lack of support (Boumans & Dorant, 2018; Hooper & Doehler, 2012; Khafi et al., 2014). *Limited family resources* stem from the socioeconomic status of the family. When a family has lower socioeconomic status, they are typically unable to hire additional caregivers and may require all members of the household to have a job out of necessity (Boumans & Dorant, 2018; Gelman & Rhames, 2018; Khafi et al., 2014). This lack of family resources can increase the burden of young carers and inhibit their ability to receive support. Therefore, limited family resources is also an attribute.

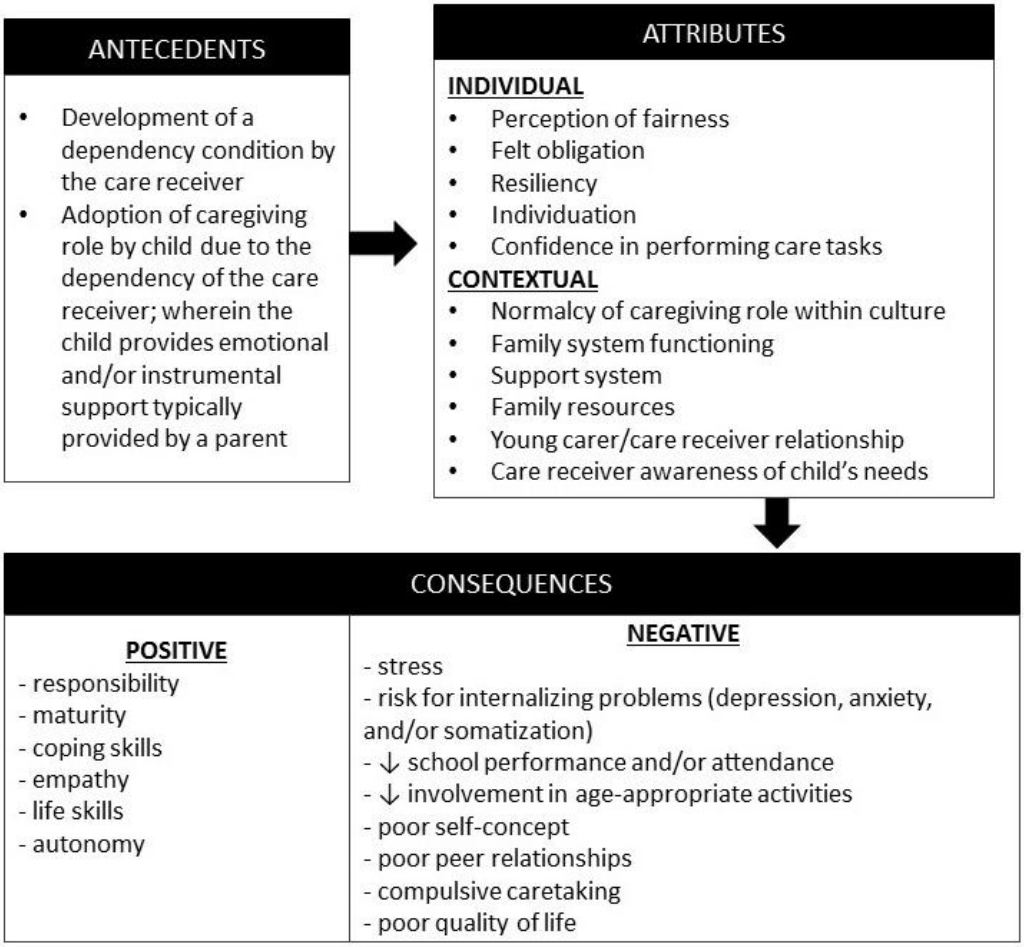
Awareness of child's needs occurs when the care receiver is able and willing to provide support to a young carer or when the care receiver prioritizes the needs of the child over their own (Hooper & Doehler, 2012; Kelley et al., 2007; Nuttall, Coberly, & Diesel, 2018; Thastum, Johansen, Gubba, Olesen, & Romer, 2008). When there is a lack of this awareness of the child's needs, negative outcomes are more likely to occur. Similarly, *a poor relationship between the young carer and the care receiver,* characterized by lack of communication and/or resentment, is also an attribute of parentification that may result in negative outcomes (Khafi et al., 2014; Nuttall et al., 2018; Petrowski & Stein, 2016). The relationship between the young carer and care receiver is also affected by the dependency of the care receiver on the young carer (Khafi et al., 2014; Stein, Riedel, & Rotheram-Borus, 1999). The dependency of the care receiver is contingent upon the type, severity, and onset of their illness. When their illness is more severe, more life-threatening, and/or more debilitating, there is an increase in their dependency on the young carer (Khafi et al., 2014; Stein et al., 1999). This dependency can negatively impact the relationship between the young carer and care receiver.

Consequences

The concept of parentification among young carers has both positive and negative consequences. The negative consequences include an increase in the young carer's stress, compulsive caretaking, and risk for internalizing problems. The negative consequences also include a decrease in the young carer's school performance/attendance, a decreased involvement in age appropriate activities, poor peer relationships, and poor self-concept (**See Figure 5**). Due to the demands of their caregiving role, young carers are prone to have higher stress levels than their non-caregiving peers (Hooper & Doehler, 2012; Van Loon et al., 2017). Additionally, due to the child's demanding role, they may be unable to develop lasting relationships with their peers. Consequentially, their involvement in age appropriate activities can become limited (Gelman & Rhames, 2018; Kelley et al., 2007; Thomas et al., 2003). Furthermore, young carers are likely to have problems with school performance and attendance due to the demands of their caregiving role (Dearden & Becker, 2000, March; McMahon & Luthar, 2007; Thomas et al., 2003; Williams & Francis, 2010). Parentification can place young carers at an increased risk for internalizing problems, including depression and anxiety (Dearden & Becker, 2000, March; Hooper et al., 2012; Khafi et al., 2014; Van Loon et al., 2017; Williams & Francis, 2010). As a result of parentification, young carers may also develop a lack of sense of self (poor self-concept) (Hooper & Doehler, 2012; McMahon & Luthar, 2007). Their sense of self can become tied to their caregiving role in such a way that they become compulsive caretakers. As compulsive caretakers they may seek a caregiving role in future relationships, even when unnecessary (Jones & Wells, 1996; McMahon & Luthar, 2007; Nuttall et al., 2018).

The positive consequences of the concept include an increase in the young carer’s responsibility, maturity, coping skills, empathy, life skills, and autonomy (**See Figure 5**). Due to the child’s involvement in care tasks, both instrumental and emotional, there is potential for the skills obtained to be used in the future (life skills) (McMahon & Luthar, 2007; Thomas et al., 2003). The young carers not only have ability to use these skills, but they also have the ability recognize when they need to be utilized (maturity and responsibility) (Dearden & Becker, 2000, March; Khafi et al., 2014). Because of parentification, a young carer can become more capable of making their own decisions (autonomy), and they can be better at dealing with difficult situations (coping skills) (Boumans & Dorant, 2018; Petrowski & Stein, 2016; Williams & Francis, 2010). Lastly, a young carer can have a greater ability of understanding the feelings and needs of others (empathy) (Petrowski & Stein, 2016).

Figure 5. Conceptual Framework for Parentification Among Young Carers



Discussion

The findings of this analysis provide a greater understanding of the concept of parentification among young carers. The antecedents, consequences and identifiable attributes of the concept are presented to provide a comprehensive picture of this concept. These findings showcase the multidimensional nature of parentification and the broad impact that it can have on the lives of young carers. While these findings do provide greater insight into the population of young carers, the fact remains that very little is known about this vulnerable, underserved, and underacknowledged population. Young carers continue to adopt the caregiving role without the awareness, education, support, and education their older (aged >18) caregiver counterparts receive. The current state of the science regarding the population of young carers is limited due to a lack of a) research, b) services, and c) policy. It is suggested that this paucity is due to the fact that child caregiving "transgresses societal expectations" of children (Smyth, Blaxland, & Cass, 2011, p. 153). Simply put, society views children as receivers of care and consequentially has a difficult time accepting children in a caregiving role. Because of this, the awareness of the population of young carers is low, as is the awareness of the unique consequences young carers face, such as parentification (Smyth et al., 2011).

To illustrate this lack of research and awareness of the population of young carers, a global review was conducted by Leu and Becker in 2017. This review determined the level of awareness and response to young carers for each country: either 1) incorporated/sustained, 2) advanced, 3) intermediate, 4) preliminary, 5) emerging, 6) awakening, or 7) no response (Leu & Becker, 2017). Eighteen countries were ranked from 1-6 and all other countries at the time of the review were given a rank of 7 (no response) (Leu & Becker, 2017). No country achieved the status of incorporated/sustained, and only the United Kingdom received an advanced ranking (Leu & Becker, 2017). Of the eighteen countries receiving a ranking, only seven received a rank higher than that of emerging status (The United Kingdom, Australia, Norway, Sweden, Austria, Germany and New Zealand). The remaining 11 countries (Belgium, Ireland, Italy, Sub-Saharan Africa, Switzerland, The Netherlands, United States, Greece, Finland, United Arab Emirates, and France) are therefore considered to have little public awareness about young carers, a limited research base, no specific legal rights for this population, and few, if any, dedicated services or interventions (Leu & Becker, 2017).

A strength of the framework of parentification among young carers resulting from this analysis is that it provides a foundation to be built upon through continued research. Studies focusing on parentification among young carers are severely limited, especially when reviewing existing literature pertaining to specific chronic illnesses or conditions. This framework, therefore, provides a foundation for the exploration of parentification in an area that is previously unstudied. Consequently, it has the potential to be expanded upon by researchers studying the phenomenon in illness specific contexts. Another strength of this framework is that it reflects research showing that parentification is not a purely pathological phenomenon. Much of the research related to parentification prior to the early 2000s examined only the negative consequences of parentification (Hooper et al. , 2008). As a result, researchers viewed parentification as a detrimental experience and sought to determine ways in which to prevent parentification from occurring. This changed with more recent research exploring parentification as a phenomenon with bimodal outcomes (Hooper et al., 2008). These studies showcase the fact that role reversals, such as parentification, may result in positive consequences along with the expected negative consequences (Hooper et al., 2008; Tompkins, 2007). This framework illustrates both the potential positive consequences and potential negative consequences of parentification among young carers, thus recent studies showing its potential benefits are incorporated. Therefore, by acknowledging the bimodal outcomes of parentification, it allows a more complete foundation for the continued exploration of the consequences experienced by young carers.

Implications and Conclusions

While research exists related to the antecedents and consequences of parentification, there is little research exploring how parentification can be prevented. Research needs to be conducted to determine how health care professionals and/or family members can identify children at risk of parentification and how they can help those at risk. Additionally, due to the differences in development stages within the population of young carers, further research needs to be conducted to determine if the consequences of parentification vary by developmental stage and if certain stages of development exhibit more parentification. Most of the research conducted in the population of young carers thus far is exploratory in nature. Future research should focus on the development of interventions aimed at mitigating the consequences of parentification and the subsequent efficacy of those interventions. In doing so, programs and services for young carers can be developed. Ultimately, the increase in research may lead to an increase in understanding and awareness of young carers and the unique challenges they face, such as parentification. This increase in awareness and understanding may lead to the development of programs and services for this population. In time, this combination of increased research and increased services may lead to the development of policy, which would result in even more research and services of the population of young carers. Therefore, future research exploring parentification among young carers will not only fill gaps related to parentification, but also gaps existing in the state of the science related to young carers.

The fact remains that little is known about young carers and the unique challenges they face. Parentification is a potential outcome they may experience due to their role as a caregiver. This concept analysis, conducted using the Rodgers' method to outline the antecedents, attributes, and consequences of parentification among young carers, is a first step towards increasing our understanding of these children and their caregiving experiences. By refining this concept, it can lead to future research in this population, which can in time, fill the gaps, justify program and/or policy creation, and consequentially increase awareness of this understudied and underserved population.

Table 4. Literature Search Results for Conceptual Analysis of Parentification Among Young Carers

	Sample	**Study Aim (s)**	**Design, Setting, Context**	**Definition of Parentification Given**	**Parentification Measure Utilized**	**Relationship to Framework**
(Abraham & Stein, 2013)	N=52 Mean age 19.8±2.3, Female: 81%	**1)** To examine whether emerging adults' affection, reciprocity, felt obligation and role reversal in their relationship with their mother mediate the association between their mother's mental illness and their own psychological symptoms	Design: Quantitative Setting: U.S.A. Context: Mental Illness	*Parentification:* "role reversal characterized by a one-sided nature of exchange where children or adolescents assume the role of parenting their parents"	*The Relationship with Parents Scale* (Alexander, 2003)	-
(Boumans & Dorant, 2018)	N=56 Mean age: 19.2±1.9 Female: 76.8%	**1)** To explore young adult carers' perceptions of parentification, resilience, and coping compared to young adult noncarers.	Design: Quantitative Setting: Netherlands Context: Chronic Medical Condition	*Parentification:* "a reversal of roles within the family system, whereby the child is acting as a parent or as a 'mate' to its parent"	*Maastricht Parentification Scale* (Dorant & Boumans, 2015)	Attributes: Support system, Family resources Consequences: Autonomy, Coping skills
(Bauman et al., 2007)	N=50 Aged 8-16 U.S.A.: Female: 64% Zimbabwe:	**1)** To document the degree to which children of parents with HIV/AIDS take on adult responsibilities and the kinds of responsibilities they have **2)** To document their psychological status	Design: Quantitative Setting: U.S.A. & Zimbabwe Context: HIV/AIDS	*Parentification:* "children assume responsibilities performed more appropriately by an adult"	*Parentification Scale* (Mika et al., 1987) *Emotional Parentification Questionnaire* (Martin, 1996)	-

	Female: 58%					
(Dearden & Becker, 2000)	N=60. Aged 16-25 Gender Not Reported	**1)** To investigate the extent to which caring influenced young people's decisions and activities in relation to education, training and employment, leaving home and becoming an adult.	Design: Qualitative Setting: United Kingdom Context: Long term illness or disability	*Parentification:* definition not provided	N/A	<u>Consequences:</u> School, Internalizing Problems, Maturity, Responsibility
(Fagan, 2003)	N=25; mothers with children aged 3-17 Child Gender Not Reported	**1)** To investigate the relationship between mothers' migraines and the roles and expectations of their children	Design: Quantitative Setting: Canada Context: Migraine	*Parentification:* "children assuming adult roles inappropriately or prematurely before they are emotionally or developmentally able to manage these roles successfully"	*Adult-Adolescent Parenting Inventory* (Bavolek, 1984)	<u>Attributes:</u> confidence in performing care tasks
(Hooper et al., 2012)	N=51 Mean age: 13.8±1.3 Female: 51%	**1)** To explore the link between family factors, parent health, and adolescent health.	Design: Quantitative Setting: U.S.A. Context: Not Specified	*Parentification:* "a process, whereby parental roles and responsibilities are abdicated by parents and carried out by children and adolescents."	*Parentification Questionnaire —Youth (PQ-Y)* (Godsall & Jurkovic, 1995)	<u>Consequences:</u> internalizing problems

(Hooper & Doehler, 2012)	N= 787 Mean age: 20.86±3.5 Female: 76%	**1)** To report on the relations between retrospective childhood parentification and adult functioning—both psychological health and physical health—which may engender confidence in their use among therapists in the clinical and practice community	Design: Quantitative Setting: U.S.A. Context: Not Specified	*Parentification:* ‘‘a disturbance in generational boundaries that can be evidenced by a reversal of roles within the family system”	*Parentification Questionnaire* (Jurkovic & Thirkield, 1998) *Parentification Scale* (Mika et al., 1987) *Parentification Inventory* (Hooper, 2009)	Attributes: confidence in performing care tasks, support system, awareness of child’s needs Consequences: Stress, self-concept
(Hooper, Marotta, & Lanthier, 2008)	N=156 Mean age=22 Female: 70%	1) To examine how bimodal growth and distress consequences might be predicted by childhood parentification	Design: Quantitative Setting: U.S.A. Context: Not Specified	*Parentification:* “role reversal wherein a child becomes responsible for a parent’s and/or other family members’ emotional or behavioral needs”	*Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	Attributes: resiliency, individuation
(Jones & Wells, 1996)	N=360 Mean age: 21 Female: 67%	**1)** To examine the relationship between parentification and predicted characterological adaptations	Design: Quantitative Setting: U.S.A. Context: Not Specified	*Parentification:* “the expectation that a child will assume a caretaking role for the parent(s)”	*Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	Consequences: compulsive caretaking

(Jurkovic et al., 2001)	N=382 (assigned to confirmatory (C) or exploratory (E) group) Mean age C: 23.1 Mean age E: 23.2	**1)** To compare the responses of late adolescent and young adult children on a new multidimensional measure of parentification assessing the extent and fairness of past and present caregiving.	Design: Quantitative Setting: U.S.A. Context: Not Specified	*Parentification:* definition not provided	*Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	Attributes: perception of fairness
(Keigher et al., 2005)	N=7 Female: 100%	**1)** To examine issues facing young caregivers by analyzing narratives of the everyday lived reality of their mothers who have HIV	Design: Qualitative Setting: U.S.A. Context: HIV/AIDS	*Parentified child:* "child acts as a caretaking parent to his/her own parent"	N/A	-
(Kelley et al., 2007)	N= 368 Mean age=21 Female: 100%	**1)** To examine parentification and family responsibility between families with alcoholism and those without	Design: Quantitative Setting: U.S.A. Context: Alcoholism	*Parentification:* "children or adolescents assume adult roles before they are emotionally or developmentally ready"	*Parentification Questionnaire-Adult* (Jurkovic and Thirkield, 1998)	Attributes: awareness of child's needs Consequences: poor peer relationships
(Khafi, Yates & Luthar, 2014)	N=143 T1 Mean age = 10 years, T2 Mean age = 15	**1)** To describe patterns of emotional and instrumental parentification from early to late adolescence	Design: Quantitative Setting: U.S.A. Context: anxiety, affective, and/or substance	*Parentification:* "an outgrowth of a family process wherein children provide emotional and/or instrumental care for their parents"	*Child Caretaking Scale* (Baker & Tebes, 1994)	Attributes: Relationship between young carer and care receiver, family resources

	Male 48% Female 52%	**2)** to assess the impact of parentification on youth's adjustment **3)** to assess the moderating role of ethnicity on relations between parentification and adjustment	use disorders			<u>Consequences:</u> Internalizing problems, maturity, responsibility
(Laghi et al., 2018)	N=86 Mean age: 16.74±3.8 Gender Not Reported	**1)** To investigate how family functioning, the degree to which family members feel happy and fulfilled with each other, and the demographical characteristics of siblings impacted on sibling relationships	Design: Quantitative Setting: Italy Context: Autism	*Parentification:* "a phenomenon in which tasks typically reserved for parents or adults are completed by daughters and sons"	N/A	<u>Attributes:</u> confidence in performing care tasks, family system functioning
(Lane et al., 2014)	N=349 Mean age: 13.4±2.3 Female: 60.7%	**1)** To explore the nature of responsibility among children affected by illness in deprived South African communities	Design: Mixed Methods Setting: South Africa Context: Not Specified	*Parentification:* definition not provided	N/A	-
(McMahon & Luthar, 2007)	N=361; Mean age=12 Male 46% Female 54%	**1)** To examine the psychosocial correlates of caretaking burden within a sample of children living in high-risk family	Design: Quantitative Setting: U.S.A. Context: Mental Illness	*Parentification:* "a family process involving developmentally	*Child Caretaking Scale* (Baker & Tebes, 1994)	<u>Consequences:</u> poor self-concept, school, compulsive caretaking, life skills

		systems characterized by maternal psychopathology		inappropriate expectations that children function in a parental role within stressed, disorganized family systems”		
(Murphy et al., 2008)	N=108 Aged 6-11 at time of recruitment	**1)** To investigate autonomy among early and middle adolescents affected by maternal HIV/AIDS.	Design: Quantitative; Longitudinal Setting: U.S.A. Context: HIV/AIDS	*Parentification:* “refers to children who assume parental responsibility in the home.”	*Early Responsibility-Taking Due to Maternal HIV* (Murphy, 2008)	-
(Nuttall et al., 2018)	N=108 Mean age: 20.37± 1.6 Female: 69.4%	**1)** To descriptively understand childhood experiences of parentification and future caregiving intentions **2)** to understand the processes through which childhood experiences of parentification impact future intentions to provide caregiving	Design: Quantitative Setting: U.S.A. Context: Autism	*Parentification:* “high levels of caregiving behaviors”	*Parentification Inventory* (Hooper, 2011)	Attributes: awareness of child’s needs, relationship between young carer and care receiver Consequences: compulsive caretaking
(Petrowski & Stein, 2016)	N=10 Aged 18-22 Female: 100%	**1)** To examine young adults’ accounts of ways that maternal mental illness has impacted their lives.	Design: Qualitative Setting: U.S.A. Context: Mental Illness	*Parentification:* “a one-sided exchange in family roles where children or adolescents assume a caregiver or parenting role for their parents and/or siblings”	N/A	Attributes: Relationship between young carer and care receiver, felt obligation

						<u>Consequences:</u> coping skills, life skills
(Stein et al., 1999)	N=183 Mean age: 14.8± 2.1 Female: 54%	**1)** to assess the predictors and outcomes of parentification among adolescent children of parents with AIDs using a two-phase longitudinal study. Phase 1 assessed adolescent demographics and parentification. Phase 2 assessed outcome variables.	Design: Quantitative; Longitudinal Setting: U.S.A. Context: HIV/AIDS	*Parentification:* "a situation in which children are prematurely forced into fulfilling parental roles and assuming adult responsibilities"	*Parentification Scale* (Mika, Bergner, & Baum, 1987)	<u>Attributes:</u> Relationship between young carer and care receiver <u>Consequences:</u> Coping skills, empathy
(Thomas et al., 2003)	N=21 Mean age: 14 Female: 61.9%	**1)** To learn about the characteristics of 'young carers', their experiences of life, their perspectives on their situation and role as 'young carers', and their hopes and expectations for the future.	Design: Qualitative Setting: United Kingdom Context: Not Specified	*Parentification:* "role reversal where children are seen as 'parenting their parent'"	N/A	<u>Attributes:</u> felt obligation
(Tompkins, 2007)	N= 43 Aged 9-16 Gender Not Reported	**1)** To examine the relationship between parentification, parenting, and child adjustment among a) children whose mother was HIV infected and b) same age peers	Design: Quantitative Setting: U.S.A. Context: HIV/AIDS	*Parentification:* "role reversal in which the child assumes some or all of the instrumental and expressive caretaking functions for the parent"	*Parentification Scale* (Mika, Bergner, & Baum, 1987)	<u>Consequences:</u> school, peer relationships, age appropriate activities, life skills

		whose mothers were not infected.				
(Van Loon et al., 2017)	N=118 Aged 11-16 Male 49% Female 51%	**1)** To examine the effect of parentification on both internalizing and externalizing problems	Design: Quantitative; Longitudinal Setting: Netherlands Context: Mental Illness	*Parentification:* "a type of role reversal, boundary distortion, and inverted hierarchy between parents and children in which they assume developmentally inappropriate levels of responsibility in the family"	*Parentification Questionnaire-Youth* (Godsall and Jurkovic, 1995)	<u>Consequences:</u> Stress, internalizing problems
(Van Parys & Rober, 2013)	N=14 Aged 7-14 Male (n=5) Female (n=9)	**1)** To determine how children, experience parental depression **2)** To explore their caregiving experience in the family	Design: Qualitative Setting: Belgium Context: Depression	*Parentification:* "children feel the vulnerabilities in their parent and try to act in ways that cause the least trouble or try to actively contribute to the family's well-being"	N/A	-
(Williams & Francis, 2010)	N=99 Mean age =24 Male 17% Female 83%	**1)** To examine the role of the internal locus of control as a moderating variable between childhood parentification and adult psychological adjustment	Design: Quantitative Setting: Canada Context: Not Specified	*Parentification:* "functional and/or emotional role reversal in which a child forfeits his or her own needs to become responsible for the emotional and/or behavioral needs of a parent"	*The Parentification Questionnaire* (Sessions and Jurkovic, 1986)	<u>Consequences:</u> school, internalizing problems, coping skills

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Chapter Summary

This chapter provided descriptions of the 1) search strategies, 2) analyses of literature, and 3) conceptual framework. Three literature reviews were presented exploring a) research in young carers in the United States and transnationally, b) young carers and Huntington's Disease, and c) young carers and parentification. All three literature reviews culminated with a discussion of gaps in the research, specifically the need for more research exploring the unique situation of young carers, this role in the context of Huntington's disease, and the concept of parentification. This dissertation study makes a step in filling these gaps by aiming to provide further understanding of the experiences of caregiving for these children and the potential outcome of parentification in the context of Huntington's disease. The next chapter will focus on the data, design, and analysis procedures for the study.

CHAPTER 3

METHODS

In the United States, it is estimated that there are approximately 1.4 million young carers (aged 8-18) (National Alliance for Caregiving, 2005). However, this number is believed to be a vast underestimation because often neither these children nor the individuals they are helping care for a) know they are acting as a caregiver or b) want to acknowledge that they are (National Alliance for Caregiving, 2005). This can be due to several reasons including stigma, fear, and lack of awareness/education surrounding the role. Due to the prolonged disease trajectory and both the type and severity of symptoms associated with Huntington's disease, children of these individuals often need to adopt a caregiving role (Kavanaugh et al., 2015). As caregivers, children provide multifaceted, extended care without any lessening of family, home, or school/work-related responsibilities (McGuire et al., 2012). In time, caregiving can become a role that requires more than a child can provide, both emotionally and physically, due to their age and/or developmental level (Hooper & Doehler, 2012). This can result in parentification, a type of role reversal where the child takes on the roles and responsibilities of the adult (Hooper & Doehler, 2012). Parentification can result in numerous consequences for the child, both positive and negative (Earley & Cushway, 2002). Despite this, little is known about parentification among young carers, especially in the context of Huntington's disease.

This chapter will provide an overview of the methods for this study which explored the manifestation of parentification in young carers of persons with Huntington's disease. The purpose of this chapter is to provide information regarding a) sampling, b) informed consent procedures, c) data collection, d) data analysis, and e) the rigor of the study.

Purpose

Despite the potential for children to assume a caregiving role for persons with Huntington's disease due to the prolonged disease trajectory and stigmatizing symptoms, there is a paucity of research related to children in these situations (Kavanaugh et al., 2015). Similarly, very little is known about parentification in young carers who have had to adopt a caregiving role because of Huntington's disease affecting their family member, despite the risk for a variety of both positive and negative consequences (Earley & Cushway, 2002). Research is needed to understand how parentification manifests in young carers of persons with Huntington's disease in order to help mitigate the potential consequences that can result from this phenomenon. Therefore, the purpose of this study was to explore the manifestation of parentification in young carers of persons with Huntington's disease through a secondary qualitative analysis.

Specific Aims

The specific aims of the study are 1) to explore whether attributes of parentification are present in young carers of persons with Huntington's disease, 2) to explore the consequences of parentification (both positive and negative) of these children, and 3) to describe the context of parentification for young carers of persons with Huntington's disease.

Design

A qualitative design was used for this study. Qualitative research is founded upon the idea that knowledge is constructed by people as they interact with and attribute meaning to an activity, experience, or phenomenon (Merriam & Tisdell, 2015). A qualitative design holds central the interpretive nature of qualitative research and the constructivist viewpoint while allowing researchers to ask questions regarding how people interpret their experiences and attribute meaning in their lives (Creswell & Poth, 2016). The goal of a qualitative researcher utilizing this approach is to understand how people "make sense of their lives and experiences" (Merriam & Tisdell, 2015, p. 24). The goal of this study is to understand the experience of parentification in young carers caring for a person with Huntington's disease and therefore, a qualitative design is appropriate.

Sampling

Recruitment

The parent study from which the data comes included a purposeful sample of 40 participants who were recruited from local chapters of the Huntington's Disease Society of America (HDSA) representing 18 states (Kavanaugh et al., 2015). The strategy for recruitment through the HDSA included contacting the HDSA boards in Missouri, Wisconsin, Iowa, Illinois, Minnesota, and Indiana for permission to advertise for the study (Kavanaugh et al., 2015). In addition, chapter social workers were contacted to send flyers and permission was obtained to advertise and conduct interviews at national HDSA conventions (Kavanaugh et al., 2015). After permission was obtained, a) flyers were mailed to families on the HDSA list, b) ads were placed in chapter newsletters and websites, c) the primary investigator for the study attended Huntington's disease conferences, support groups and state events, and d) information about the study was posted to state websites, Facebook, and the national HDSA website (Kavanaugh et al., 2015).

A call or email was then received from the parent or participant if over the age of 18. The parent study principal investigator met with the parents in the case of the children under 18 to obtain consent to interview (Kavanaugh et al., 2015). In order to participate in the study participants had to 1) be between the ages of 10 and 20, 2) have a parent who was experiencing Huntington's disease symptoms, and lastly 3) identify as engaging in an activity to help their parent with their illness (Kavanaugh et al., 2015). All the interviews were conducted with the child participants only and were completed in a single session at a location of the participant's choice (Kavanaugh et al., 2015). The interviews lasted between 30 and 55 minutes (Kavanaugh et al., 2015).

Consent/Assent Procedures

Because this study involved child participants, special considerations were made regarding the consent process. Since children had not yet reached the age where they could legally consent for themselves it was necessary to obtain consent from their parent or guardian, in addition to the child's assent (National Institutes of Health, 2016; University of Alabama at Birmingham, 2015). Assent is defined as the child's verbal agreement to participate in research (National Institutes of Health, 2016). For the child to give assent, they were first deemed capable of providing it through consideration of the child's age, development and cognitive capacity (National Institutes of Health, 2016). Parental consent occurred when parents were informed about the research and provide consent for the child (National Institutes of Health, 2016). As this is a secondary data analysis, consent and assent procedures have already taken place.

In the parent study, before the interviews, parental consent and child assent forms were obtained for children under the age of 18 (Kavanaugh et al., 2015). If the children were over the age of 18, they signed their own consent forms. The interviews were audio taped and transcribed verbatim by a professional transcriptionist (Kavanaugh et al., 2015). The parent study received approval from the Institutional Review Board of the University of Wisconsin Milwaukee (Kavanaugh et al., 2015). The current study received exemption through the University of Alabama at Birmingham Institutional Review Board as non-human subjects research.

Data Collection

Qualitative and quantitative data were collected during the interview utilizing the "Children caregivers of a parent with HD" questionnaire (Kavanaugh et al., 2015). The quantitative portion of the data contained demographic information including: the young carer's age, gender, race, education level, duration of caring, parent gender, where their parent lives, who else helps care for their parent, and their parent's symptoms (Kavanaugh et al., 2015). The remainder of the quantitative data is made up of responses to forced choice questions from eight sections focused on caregiving, interactions with parent, impact of caregiving, school, life satisfaction, physical health, depression, and social support (Kavanaugh et al., 2015). The sections include a combination of Likert scales, true/false, and open-ended questions (see **Table 1**). All responses were entered into an SPSS data file following data collection (Kavanaugh et al., 2015).

The qualitative data consists of transcripts from the interviews that lasted 30-55 minutes (Kavanaugh et al., 2015). During the forced choice portion of the interview, children had the opportunity to elaborate on their answers or to add additional information. For example, one question asks the child to rank the statement "I wish that I did not have to help my parent as much as I do" on a Likert scale from "0=strongly disagree" to "4=strongly agree." One of the children interviewed responded with "2=neither agree or disagree", but elaborated further, saying: *"I, I didn't wanna help her that much because I was a kid and I did wanna go have friends and play outside and stuff. I mean, I have friends, but like, I never got to hang out with them as much. But then again, like, I, I like taking care of my mom like I said before."* These responses were part of the transcripts in addition to the responses to three open ended questions: 1) What are things that people can do to help you care for your mom/dad?, 2) What things do you need to help you care for your mom/dad that you do not have?, and 3) Is there anything else you would like to tell me about your experiences helping your mom/dad? When responses to forced choice questions only included the forced choice response, for example, if the child simply said "2=neither agree or disagree" with no further elaboration, the responses were not transcribed and were simply recorded in the SPSS data file.

Table 1. Summary of Interview Questions

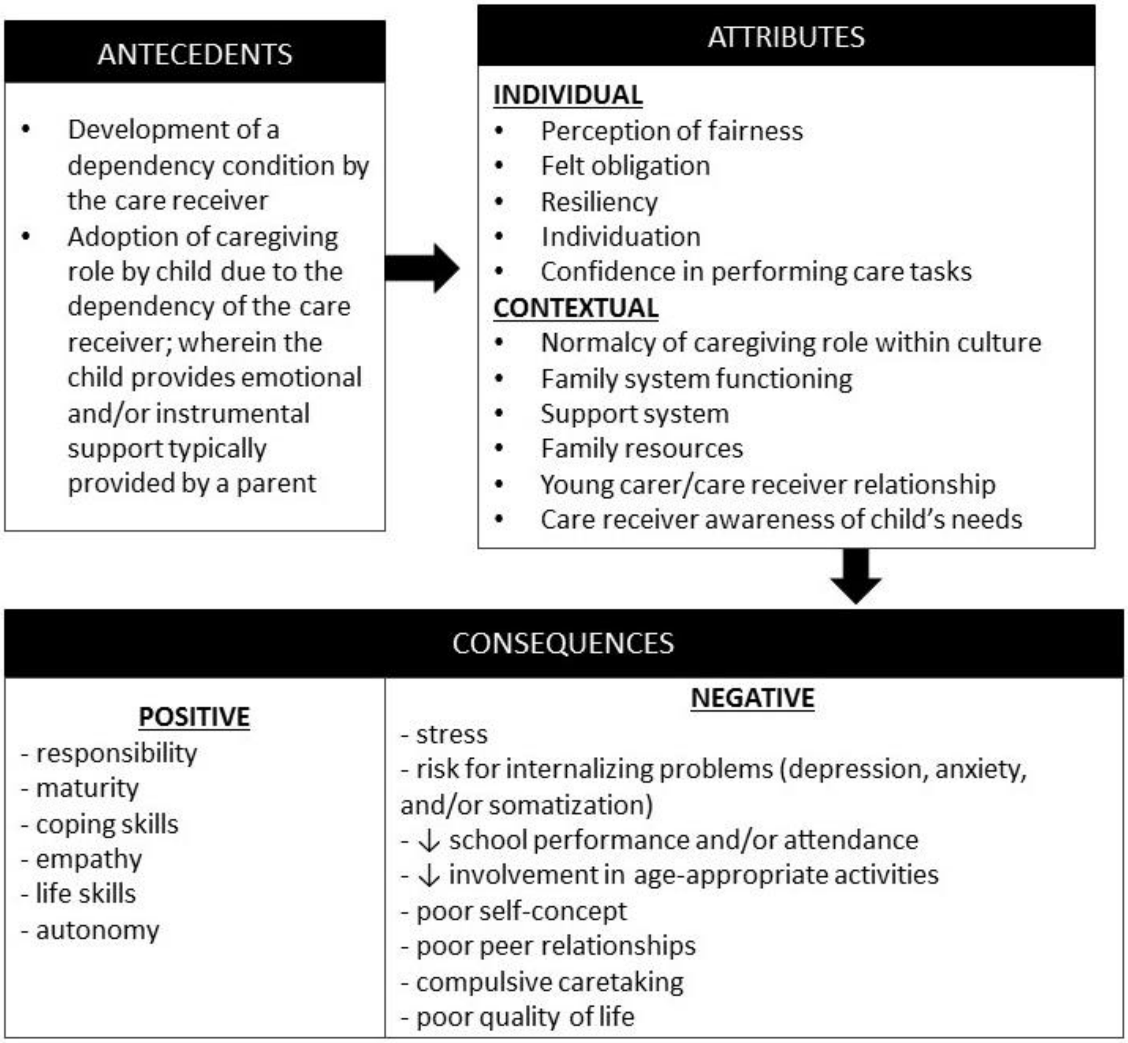
Section	Topic of Questions	Response Type
1.Caregiving	Frequency of care tasks, type of care tasks, education related to caregiving, total hours per week providing care, duration of caregiving, other persons who help with tasks	Open Ended, Likert Scale (0-2), Y/N
2. Interactions with Parent	How well they get along with their parent who has HD	True/False
3. Impact of Caregiving	How they feel about helping their parent, activities they did before caregiving that they no longer do	Likert Scale (0-4)
4.School	Experiences at school as a result of caregiving	Likert Scale (1-3)
5. Life Satisfaction	How they feel about life overall	Likert Scale (0-4)
6. Physical Health	How they feel physically	Likert Scale, Y/N
7. Depression	How they have been feeling the past two weeks, mood	CDI
8. Social Support	Family and friends, persons who provide support, frequency of support provided	Likert Scale (0-5), Open Ended, Y/N

Data Analysis

Analysis Approach

Data were analyzed using a directed content analysis approach. Directed content analysis is a deductive approach that uses an existing theory or framework as guidance for the initial coding structure to be expanded upon throughout the coding process (Hsieh & Shannon, 2005). The framework guiding this study is a conceptual framework of parentification in young carers (Hendricks et al., 2020a). This framework provides an overview of the phenomenon including the antecedents, attributes, and consequences (See **Figure 1**). In developing this framework, an induction was made regarding the components of the concept of parentification in young carers through thorough review and analysis of the literature, using the steps of Rodgers' method (Hendricks et al., 2020a). This conceptual framework for parentification in young carers, which outlines antecedents, attributes, and consequences for the phenomenon, guided the initial codes as parentification was explored in the context of Huntington's Disease (Hsieh & Shannon, 2005). The antecedents of parentification in young carers are the development of a dependency condition by the care receiver and the adoption of a caregiving role by a child due to care receiver dependency. Concept attributes included the perception of fairness, felt obligation, resiliency, individuation, confidence in performing care tasks, cultural normalcy of the caregiving role, family system functioning, support system, family resources, the caregiver-care receiver relationship, and awareness by the care receiver of the young carer's needs. Parentification can result in positive and/or negative consequences. The positive consequences of the concept include an increase in the young carer's responsibility, maturity, coping skills, empathy, life skills, and autonomy. The negative consequences include an increase in the young carer's stress, compulsive caretaking, and risk for internalizing problems. The components of this framework served as the initial coding structure during data analysis.

Figure 1. Conceptual Framework for Parentification Among Young Carers



Note. From "Parentification among young carers: A concept analysis, by B.A. Hendricks, J.B. Vo, J.N. Dionne-Odom, & M.A. Bakitas, 2020, [Unpublished Manuscript], School of Nursing, University of Alabama at Birmingham.

Analysis Procedures

Content analysis focuses on the development of understanding and knowledge surrounding phenomena (Assarroudi et al., 2018). There are three types of qualitative content analysis: conventional, directed, and summative (Hsieh & Shannon, 2005). The goal of conventional content analysis is to develop theories, models or conceptual frameworks (Assarroudi et al., 2018). The goal of directed content analysis is to then refine, test, or further develop these theories, models, and frameworks (Assarroudi et al., 2018; Hsieh & Shannon, 2005). A directed content analysis approach was used to analyze the data.

One of the challenges of content analysis is that it is not a standardized, linear process (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). The steps of analysis are, therefore, flexible depending on the specific research questions (Hsieh & Shannon, 2005). The analysis for this study was based on the method outlined by Assoroudi and colleagues (2018), which is comprised of three phases. The first phase is primarily focused on preparation. During this phase, a sampling strategy is chosen, an interview guide is created, and interviews are conducted and transcribed (Assarroudi et al., 2018). As this study is a secondary analysis, most of the preparation phase had been completed by the parent study principal investigator. Therefore, the analysis in this study began with the last step of this phase: data immersion. During data immersion, the researcher familiarizes themselves with the transcripts (Creswell & Poth, 2016). This is especially important in secondary data analysis since the researcher did not collect the data themselves. Throughout this process, memos were kept in the form of an audit trail while reading the transcripts. Memos are phrases, ideas, and/or key concepts that occur to the researcher while reading the transcripts (Creswell & Poth, 2016). These are useful for helping to identify initial codes, for summarizing codes into themes, and for comparisons between codes (Creswell & Poth, 2016). This initial immersion in the data allows the researcher to develop a more complete sense of the data, while not being encumbered with the details of the coding process.

Following immersion in the data, the organization phase began. The first step of this phase involved the development of a formative categorization matrix. In this matrix, main categories and related subcategories were created based on the underlying theory or framework (Assarroudi et al., 2018). In addition, it reflects the potential emergence of new categories through analysis of the transcripts (Hsieh & Shannon, 2005). The newly identified categories can either contradict the existing view of the phenomenon, or it can lead to further refinement or extension of the framework (Hsieh & Shannon, 2005). In the case of this study, an example of a potential categorization matrix is included as **Table 2**. The categories included in the matrix reflected the components of the parentification framework, including the attributes, consequences, and context (antecedents and demographics). Once the matrix was developed, a preliminary codebook was created with conceptual definitions and examples for each of the categories (Assarroudi et al., 2018; Bengtsson, 2016). The main analysis of the transcripts then began. During this step, the data was broken down into meaning units, which are words, phrases, or sentences that contain some insight the researcher may need for answering their research questions (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017). These meaning units were then labeled with codes. This list of codes evolved as analysis continued. After the initial coding of the transcripts, the data was re-read with the final list of codes to ensure that all aspects of the content related to the aims of the study were included (Bengtsson, 2016).

Table 2. Formative Categorization Matrix

	Attributes	**Negative Consequences**	**Positive Consequences**	**Context**
How does parentification manifest in young carers of persons with HD?	Support system Relationship with Parent Caregiving Confidence Feelings Regarding Role Other*	Internalizing Problems Quality of Life School Peer Relationships Other*	Coping Skills Responsibility Empathy Other*	Caregiving Requirements Severity of Parental Illness Family Structure Other*

*other inductively emerged categories

The codes were then grouped together based on their similarities and differences through a process called categorization. The result was a collection of "generic categories and subcategories" (Assarroudi et al., 2018). These generic categories were then compared to the main categories outlined in the categorization matrix and were either nested within a pre-existing main category or a new category was created (Assarroudi et al., 2018). The final phase of directed content analysis was the reporting phase, where a detailed description of the main categories and subcategories were presented with exemplars (See Chapter 4) (Assarouidi et al., 2018).

Limitations and Benefits of Secondary Data

This study uses data collected for a previous study, but new aims and questions were explored using data analysis strategies that were not part of the parent study. There are limitations that exist when using secondary data instead of prospective data. First, qualitative data is shaped by the context surrounding the participant at the time of data collection, including the social and cultural realities (Ruggiano & Perry, 2019). These things may change between the time of initial data collection and the secondary analysis. Because of this, the findings of the secondary study might not reflect of the context surrounding participants in the present day. In addition, with qualitative data, there is a risk of deductive disclosure when sharing transcripts (Kaiser, 2009). Deductive disclosure occurs when specific traits evident in the data make a person identifiable to others (Kaiser, 2009). This jeopardizes confidentiality and the anonymity of the participant (Kaiser, 2009; Ruggiano & Perry, 2019).

Perhaps the greatest limitation of secondary data analysis is that the existing data does not specifically address the aims of the secondary study. This can limit the analysis of the secondary researcher because they are unable to control what is contained in the data set (Polit & Beck, 2017; Ruggiano & Perry, 2019). Related to this study, a limitation of the existing data set is that it has a limited number of open-ended questions, which makes qualitative analysis more challenging. Furthermore, the open-ended questions asked of the participants are not ideal because they do not reflect the aims of this study. When conducting directed content analysis, the preferred organization of the interview guide is to ask broad questions pertaining to the categories outlined in the matrix followed by more direct, probing questions (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Since the data had already been collected, this method of interviewing is not possible and consequently, the data does not contain this information. Similarly, it would have been ideal for this study if the participants answered the questions included in *The*

Parentification Inventory (Hooper et al., 2011), a measure of parentification, during the forced choice portion of the interview. Lastly, secondary data analysis is disadvantageous because the secondary researcher is often unaware of exactly how the data collection process was completed (Ruggiano & Perry, 2019). As a result, they may have difficulty interpreting and understanding the existing data.

There are also benefits to conducting a secondary analysis. The first is that utilizing an existing data set is cost effective (Polit & Beck, 2017). The time and money needed to complete data collection is, therefore, not a hinderance to researchers. This is especially beneficial for persons experiencing time restrictions for their research or for those who find themselves in a situation where prospective data collection is not possible. Another benefit of using existing data is that is minimizes participant burden and makes research pertaining to hard to reach populations more feasible (Ruggiano & Perry, 2019). The population of young carers is difficult to reach due to lack of understanding, fear, and stigma (National Alliance for Caregiving, 2005). Because of this, it is difficult to not only identify this population, but also to recruit them for study participation. This issue is exacerbated because the population is comprised of children, therefore, the parent needs to also consent to study participation. Due to these issues, obtaining a sample is challenging and time consuming for researchers. Using secondary data eliminates this issue and makes research pertaining to hard to reach populations, such as young carers, more feasible.

Validity and Reliability

There is debate among researchers as to how reliability and validity should be determined in qualitative research because the processes and outcomes of qualitative research are very different from those of quantitative research (Merriam & Tisdell, 2015). In 1985, Lincoln and Gupta argued for the substitution of the terms credibility, dependability, and transferability for the terms internal validity, reliability, and external validity in qualitative research.

Credibility

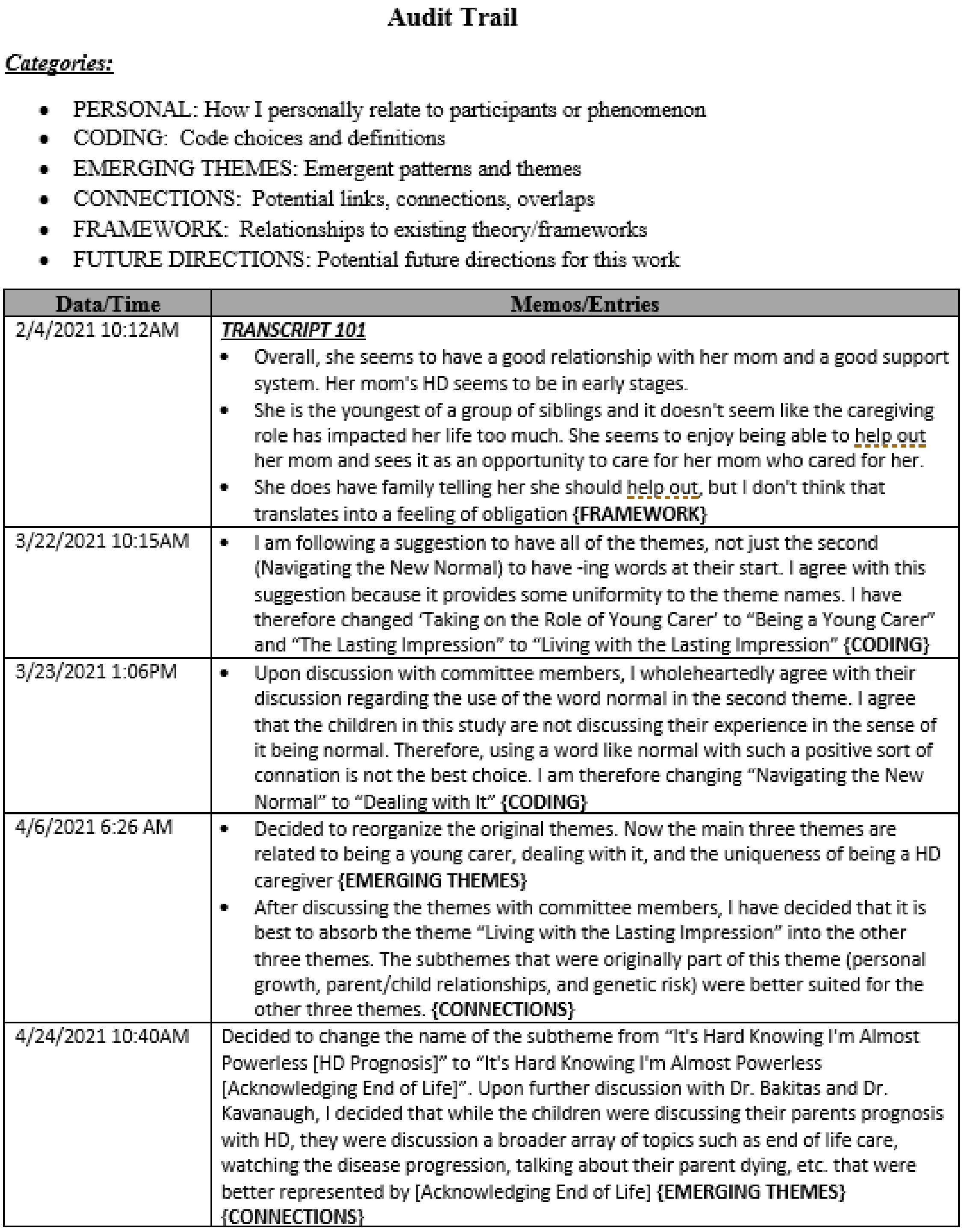
Credibility, or internal validity, refers to whether or not research findings are consistent with reality (Merriam & Tisdell, 2015). With regard to this study, strategies to increase the credibility of the findings included adequate engagement of the researcher, peer examination, and researcher reflexivity. *Adequate engagement of the researcher* refers to the necessity of the researcher to look at data that supports other explanations that are potentially negative or provide discrepancies in the analysis (Merriam & Tisdell, 2015). This allows the researcher to purposefully look for variation in their understanding of the phenomenon (Merriam & Tisdell, 2015). This was done in the present study by allowing for the potential emergence of new categories resulting from analysis of the data, even if the categories were not present in the guiding framework.

Reflexivity refers to the researcher's biases and assumptions that they are bringing to the data analysis process (Merriam & Tisdell, 2015). For the purposes of this study, the researcher's prior experience as a young carer could have led to potential biases and assumptions. For the present study, a reflexivity statement was included to address this. A reflexivity statement allows readers to understand how the researcher's "perceptual lens" may have influenced their interpretations (Merriam & Tisdell, 2015). Lastly, *peer examination* was used to increase credibility of the findings. For this study, the dissertation committee served as peer reviewers by providing feedback throughout the research process.

Dependability

Dependability in qualitative research, or reliability, is the extent to which the findings can be replicated (Merriam & Tisdell, 2015). Compared to quantitative research, it may be difficult to replicate findings; instead, the question is whether the results are consistent with the data collected (Merriam & Tisdell, 2015). Peer examination and reflexivity, as discussed in the previous section, were also employed to increase dependability of the findings. In addition, an *audit trail*, which describes how data was collected and how coding was completed in analysis, can be used (Merriam & Tisdell, 2015). An audit trail serves as a sort of research journal, which compiles memos throughout the analysis process and thus, provides a running record of the researcher's interaction with the data. These entries can include, but are not limited to, reflections on how one personally relates to the participants or the phenomenon, coding choices, potential connections, relationships to existing theories and frameworks, and future directions for the work (Saldana, 2009). In this study, an audit trail was kept which provided a detailed account of how the study was conducted (Merriam & Tisdell, 2015). A sample page of audit trail entries is included as **Figure 2**.

Figure 2. Sample Page of Audit Trail Entries



Audit Trail

Categories:

- PERSONAL: How I personally relate to participants or phenomenon
- CODING: Code choices and definitions
- EMERGING THEMES: Emergent patterns and themes
- CONNECTIONS: Potential links, connections, overlaps
- FRAMEWORK: Relationships to existing theory/frameworks
- FUTURE DIRECTIONS: Potential future directions for this work

Data/Time	Memos/Entries
2/4/2021 10:12AM	***TRANSCRIPT 101*** • Overall, she seems to have a good relationship with her mom and a good support system. Her mom's HD seems to be in early stages. • She is the youngest of a group of siblings and it doesn't seem like the caregiving role has impacted her life too much. She seems to enjoy being able to help out her mom and sees it as an opportunity to care for her mom who cared for her. • She does have family telling her she should help out, but I don't think that translates into a feeling of obligation **{FRAMEWORK}**
3/22/2021 10:15AM	• I am following a suggestion to have all of the themes, not just the second (Navigating the New Normal) to have -ing words at their start. I agree with this suggestion because it provides some uniformity to the theme names. I have therefore changed 'Taking on the Role of Young Carer' to "Being a Young Carer" and "The Lasting Impression" to "Living with the Lasting Impression" **{CODING}**
3/23/2021 1:06PM	• Upon discussion with committee members, I wholeheartedly agree with their discussion regarding the use of the word normal in the second theme. I agree that the children in this study are not discussing their experience in the sense of it being normal. Therefore, using a word like normal with such a positive sort of connation is not the best choice. I am therefore changing "Navigating the New Normal" to "Dealing with It" **{CODING}**
4/6/2021 6:26 AM	• Decided to reorganize the original themes. Now the main three themes are related to being a young carer, dealing with it, and the uniqueness of being a HD caregiver **{EMERGING THEMES}** • After discussing the themes with committee members, I have decided that it is best to absorb the theme "Living with the Lasting Impression" into the other three themes. The subthemes that were originally part of this theme (personal growth, parent/child relationships, and genetic risk) were better suited for the other three themes. **{CONNECTIONS}**
4/24/2021 10:40AM	Decided to change the name of the subtheme from "It's Hard Knowing I'm Almost Powerless [HD Prognosis]" to "It's Hard Knowing I'm Almost Powerless [Acknowledging End of Life]". Upon further discussion with Dr. Bakitas and Dr. Kavanaugh, I decided that while the children were discussing their parents prognosis with HD, they were discussion a broader array of topics such as end of life care, watching the disease progression, talking about their parent dying, etc. that were better represented by [Acknowledging End of Life] **{EMERGING THEMES}** **{CONNECTIONS}**

Transferability

Lastly, transferability, or external validity, deals with the extent to which findings can be applied to other situations (Merriam & Tisdell, 2015). In order to increase external validity, the researcher must provide *rich, thick descriptions* especially regarding the presentation of the setting and the findings of the study (Merriam & Tisdell, 2015). This includes the presentation of data in the forms of quotes from the transcripts. In doing so, the researcher provides a context that someone can compare themselves with to see if there are similarities between their own experiences and the findings of the study (Merriam & Tisdell, 2015).

Summary

This chapter provided descriptions of the a) sampling, b) informed consent procedures, c) data collection, d) data analysis, and e) the reliability and validity of this study. This study utilized data from 40 participants, who were recruited from the HDSA in a previous study (Kavanaugh et al., 2015). The data was collected in the form of interviews. Data analysis was conducted using a directed content analysis approach guided by a conceptual framework for parentification in young carers. Various strategies for improving the reliability and validity of the study were implemented, including, reflexivity, audit trails, and peer examination. The next chapter will focus on the major findings of this study.

CHAPTER 4

“MAN, THIS ISN’T EASY”: EXPLORING THE MANIFESTATION OF PARENTIFICATION AMONG YOUNG CARERS OF A PARENT WITH HUNTINGTON’S DISEASE

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In preparation for *Child and Youth Care Forum*

Format adapted for dissertation.

Abstract

Background: Due to the progressive deterioration of motor, cognitive, and psychological function experienced by individuals diagnosed with Huntington's disease, there is the potential for children in the home to adopt a caregiving role. These young carers typically serve as informal, secondary caregivers, providing multifaceted, extended care without any lessening of typical family, home, or school/work-related responsibilities. In time, this role may result in parentification, a type of role reversal with both positive and negative outcomes for the child.

Methods: A secondary analysis of qualitative data a parent study of the experience of children who had a parent with Huntington's disease was conducted. Transcripts of qualitative interviews were explored for the manifestation of parentification among young carers in the context of Huntington's disease. A directed content analysis of interview data guided by a literature derived framework of parentification among young carers was utilized.

Results: The sample consisted of 28 individuals with a mean age of 16.6 who all self-identified as engaging in activities to help their parent with Huntington's disease. Most of these children had been providing care for 1-3 years (53.6%) with a mean of 25.4 hours of care provided per week. Data analysis resulted in three main themes with subthemes: 1) being a young carer [feelings regarding the role, learning to be a caregiver, caregiver burden, coping], 2) dealing with it [school and friends, feeling unheard/alone, support system, personal growth], and 3) facing the uniqueness of being a Huntington's disease caregiver [stigma and isolation surrounding Huntington's disease, parent/child relationship changes, acknowledging end of life, genetic risk].

Conclusion: Being a young carer of a person with Huntington's disease presents unique challenges; elements of parentification were evident in some, but not all carers. Exploring how parentification may manifest in the context of a genetic disease that may be transmitted to the young carer is important for guiding future policy, research, and support services.

Reflexivity Statement: *As the oldest child in a family with a parent who had terminal, metastatic cancer, I somewhat understand and am aware of the roles, responsibilities, and difficulties faced by young carers. However, I lack understanding as to what this experience is like in other disease specific contexts, such as in Huntington's Disease. I wanted to understand what this experience is like for young carers especially given the unique symptomology of Huntington's, the prolonged and worsening trajectory, its terminal prognosis, and the potential for genetic transmission of the disease to the young carer.*

Introduction

Huntington’s disease is an uncurable, genetic illness that affects an individual’s motor, psychological, and cognitive function (Huntington's Disease Society of America, 2011). Due to Huntington’s disease debilitating effects, children living in the home may need to adopt a caregiving role. These young carers, while typically aged 8-18, can sometimes include young adults up to age 25. Young carers often take on the role of a secondary caregiver. The frequency, duration, and type of care tasks vary based on the individual’s family, circumstances, and the parents’ needs (Blum & Sherman, 2010; Kavanaugh, Noh, & Zhang, 2016; McNamara & Rosenwax, 2010). The role may also change as the disease progresses and symptoms worsen (Huntington's Disease Society of America, 2011).

In time, the role of young carer can result in parentification, a type of role reversal where the child takes on the roles and responsibilities typically held by an adult (Hooper & Doehler, 2012). The concept of parentification, while frequently associated with parental neglect, can also be seen in instances where the parent is unable to fulfill the typical adult roles and responsibilities due to illness or incapacitation (Earley & Cushway, 2002; Hooper & Doehler, 2012; Khafi et al., 2014). Little is known about the experience of young carers and the potential parentification that may occur, especially in the context of Huntington’s disease; therefore, the aim of this study is to explore the manifestation of parentification among young carers of person’s with Huntington’s disease.

Background and Significance

Huntington’s disease is an illness that results from the progressive deterioration of the brain’s nerve cells resulting in diminished motor, psychiatric, and cognitive function for diagnosed individuals (Huntington's Disease Society of America, 2011). These symptoms progress and worsen until the individual’s death and there is currently no cure for the condition (Huntington's Disease Society of America, 2011; National Institute of Neurological Disorders and Stroke, 2019). Furthermore, children of individuals diagnosed with Huntington’s disease have a 50% chance of inheriting the disease themselves (Walker, 2007). Currently in the United States there are approximately 41,000 people exhibiting the symptoms of Huntington’s disease and an additional 200,000 who are at risk of inheriting the disease (Huntington's Disease Society of America, 2011; National Institute of Neurological Disorders and Stroke, 2019; Rawlins et al., 2016).

Because Huntington’s disease is an illness with debilitating symptoms that affects the diagnosed individual for many years, it often falls on the family to provide care in the home (Huntington's Disease Society of America, 2011; Mumal, 2013). Diagnosis can occur anywhere from age two to 80, but most frequently occurs between the ages of 30 to 50 (Huntington's Disease Society of America, 2011). The diagnosis often manifests at a time when there are children living in the home (Kavanaugh et al., 2016). While a spouse or other adult is often the primary caregiver in these situations, families also rely on the help of secondary caregivers, such as the children in the home who act as young carers (Blum & Sherman, 2010; McNamara & Rosenwax, 2010). Ultimately, Huntington’s disease affects not just the individuals diagnosed, but it also impacts the family, who provide extensive care (Huntington's Disease Society of America, 2011; Kavanaugh et al., 2016).

Young carers are largely unacknowledged in the United States (Hendricks et al., 2020b; National Alliance for Caregiving, 2005). These individuals take on the caregiving role while simultaneously dealing with roles and responsibilities related to family, school, work, and home (McGuire et al., 2012). They do this without the education and resources or recognition provided to their adult (age >18) caregiving counterparts (Hendricks et al., 2020b). As young carers these children primarily complete instrumental care tasks, but their care can also extend to emotional care tasks (Boumans & Dorant, 2018; Khafi et al., 2014).

Because these young carers are taking on roles and responsibilities typical of an adult, there is also potential for parentification to occur (Hooper & Doehler, 2012). Parentification alters or removes boundaries representing the implied and obvious rules and expectations that exist within familial relationships, but should not be viewed as purely pathological (Earley & Cushway, 2002; Hooper & Doehler, 2012; Khafi et al., 2014) . While there are typically negative consequences such as stress, anxiety, poor school performance, and altered peer relationships, there are also positive consequences such as an increase in maturity, confidence, and responsibility (Hendricks et al., 2020a; Hooper et al., 2008; Kelley et al., 2007; Khafi et al., 2014). Because of the multidimensional nature of the concept of parentification and its bimodal outcomes, whether or not parentification occurs and how it presents itself varies based on the individual and their context (Hooper et al., 2008; Khafi et al., 2014; McMahon & Luthar, 2007; Williams & Francis, 2010). Because parentification is more frequently explored within the context of parental neglect, parental substance abuse, and parental mental illness, less is known about parentification among young carers with chronically ill parents (Earley & Cushway, 2002). In Huntington's disease, little is known about the experiences of young carers and how parentification manifests in this context, where a triad of degenerative, complicated symptoms occur over a long disease trajectory with a large genetic component.

Methods

A qualitative analysis of secondary data collected from individuals who were recruited from local chapters of the Huntington's Disease Society of America (HDSA) representing 18 states in 2013 (Kavanaugh et al., 2015). Recruitment was conducted by contacting the HDSA boards in Missouri, Wisconsin, Iowa, Illinois, Minnesota, and Indiana for permission to advertise for the and also by contacting chapter social workers to send flyers and obtain permission to advertise and conduct interviews at the national conventions (Kavanaugh et al., 2015). To participate in the study, individuals had to be between the ages of 10 and 20, have a parent with Huntington's disease, and self-identify as engaging in caregiving activities (Kavanaugh et al., 2015). The resulting sample of 40 individuals was interviewed utilizing the questionnaire "Children caregivers of a parent with HD" (Kavanaugh et al., 2015). The questions pertained to demographic data as well as questions from eight different sections including: caregiving, interactions with parent, impact of caregiving, school, life satisfaction, physical health, depression, and social support (Kavanaugh et al., 2015). The interviews were conducted after obtaining parental consent (with child assent for individuals aged <18) and lasted 30-55 minutes.

The interview transcriptions provided not only the responses to the three open ended questions, but also elaborated responses to the closed ended questions which utilized a combination of Likert scales and true/false questions. An example of this elaborated response is seen here when one of the children responded to a closed ended question with “2=neither agree or disagree”, but offered further elaboration saying *“I, I didn’t wanna help her that much because I was a kid and I did wanna go have friends and play outside and stuff.”* These elaborated responses, in addition to the responses to the open-ended questions, were analyzed using a qualitative directed content analysis approach.

Data Analysis

A directed concept analysis approach was used to perform a secondary qualitative analysis of the transcribed data. Directed content analysis is a deductive approach that uses an existing theory or framework as guidance for the initial coding structure to be expanded upon throughout the coding process (Hsieh & Shannon, 2005). This initial coding structure was outlined in a formative categorization matrix and was informed by the conceptual framework of parentification among young carers which describes its antecedents, attributes, and consequences (Hendricks et al., 2020a).

The analysis began with data immersion where transcripts were read and an audit trail was maintained to record phrases, ideas, and/or key concepts that occurred while reading the transcripts (Creswell & Poth, 2016). The data was then broken down into meaning units (words, phrases, or sentences that contain some insight) and labeled with codes (Bengtsson, 2016; Erlingsson & Brysiewicz, 2017). This list of initial codes evolved as analysis continued. These codes were then grouped together into themes and subthemes based on their similarities and differences through a process called categorization. The resulting themes and subthemes were compared to the categories outlined in the categorization matrix and were either nested within a pre-existing main category or a new category was created (Assarroudi et al., 2018). Lastly, the results were compared to the original framework to determine similarities and differences (Hsieh & Shannon, 2005). It is important to note that this analysis process allowed for the emergence of new categories during the coding process. Data was analyzed using the qualitative coding and analysis software, NVivo.

Results

Sample Characteristics

A subset of 28 was drawn from the sample used in the original study. This subset of 28 participants was chosen to include those individuals who consented to audio-recording and transcription of their interviews. The sample had a mean age of 16.6 and was primarily female (78.6%). Most children were caring for a mother with Huntington's disease (71.4%), as opposed to a father. They had been acting as a young carer for 1-3 years (53.6%) with an average of 25.4 hours of care provided per week. Of the participants, 67.9% reported that they were not the only caregiver providing care to their parent. The types of care tasks completed by the children can be seen in **Table 1**. Some of the most frequently reported care tasks were keeping the parent company (92.9%), helping parent walk/get around (82.2%), cooking (75%), and grocery shopping (71.5%).

More than half of the children (71.4%) reported that they received no education related to their caregiving role.

Table 1. Demographics and Care Tasks

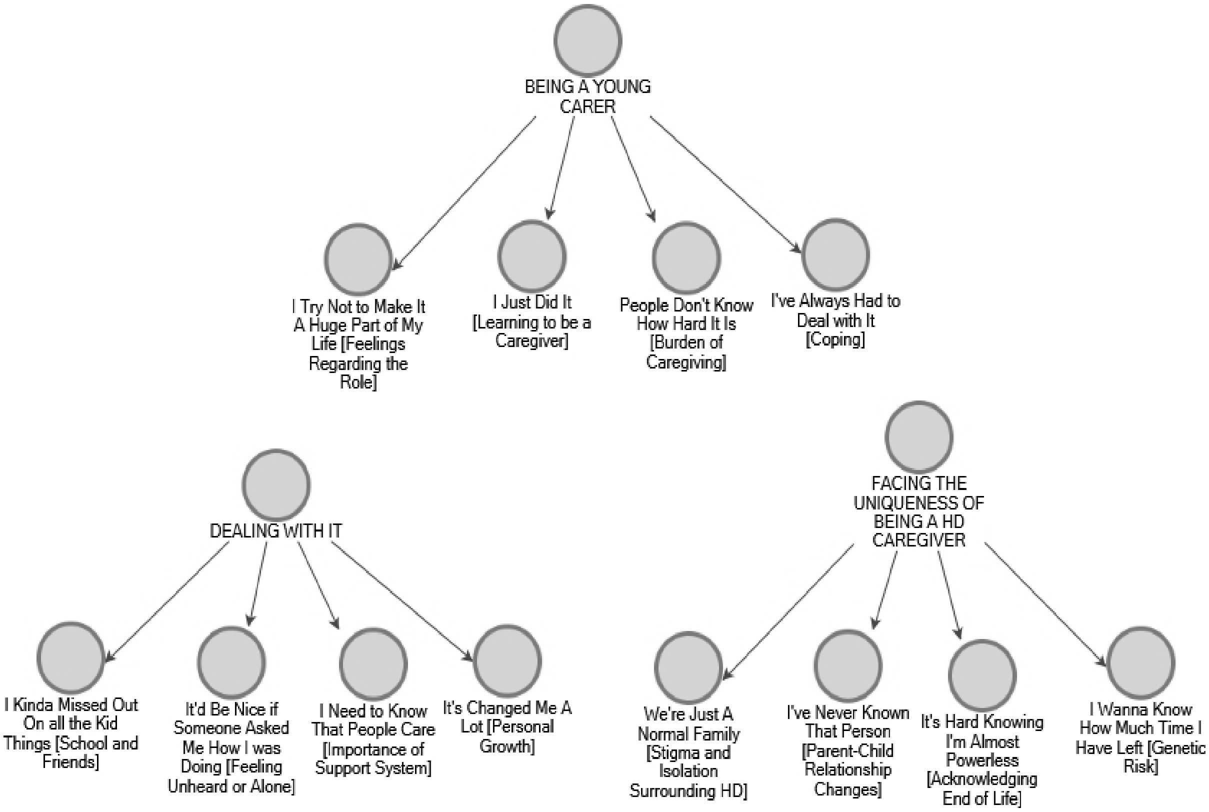
Sample Demographics (N=28)	*N (%)*
Caregiver Age (years)	
12-14	7 (24.9)
15-17	11 (39.3)
18-20	10 (35.7)
	M=16.6
Gender	
Female	22 (78.6)
Male	6 (21.4)
Parent with Huntington's	
Mother	20 (71.4)
Father	8 (28.6)
Duration of Caregiving	
1-3 years	15 (53.6)
4-6 years	8 (28.6)
7-10 years	5 (17.8)
Who Else Cares for Parent?	
No one	9 (32.1)
Other Parent	14 (50)
Sibling	4 (14.3)
Grandparent	1 (3.6)
Receive Care Education	
No	20 (71.4)
Yes	8 (28.6)
Hours per Week Caring	*M*= 25.43

Care Tasks Completed in Last Month	*N (%)*
Clean other rooms in house	26 (92.9)
Keep parent company	26 (92.9)
Do dishes	25 (89.2)
Help parent walk/get around	23 (82.2)
Cook meals	21 (75)
Laundry	21 (75)
Grocery shopping	20 (71.5)
Help parent write	16 (57.2)
Help parent with appearance	14 (50)
Help parent eat	13 (46.4)
Work part time	12 (42.9)
Drive parent places	12 (42.9)
Make phone calls for parent	12 (42.9)
Talk to Dr for parents/go to appointments	10 (35.7)
Help parent undress	10 (35.7)
Decorate rooms	9 (32.1)
Help parent with medication	7 (25)
Watching siblings with another adult around	5 (17.8)
Take siblings to school	4 (14.3)
Help parent toilet	4 (14.3)
Clean up accidents (incontinence)	4 (14.3)
Pay bills	3 (10.7)
Help parent bathe	3 (10.7)
Brush teeth	3 (10.7)

Thematic Results

The qualitative analysis of the data resulted in three main themes, each with four subthemes. The themes included 1) being a young carer, 2) dealing with it, and 3) facing the uniqueness of being a Huntington's Disease caregiver (See **Figure 1**). Pseudonyms are used for reporting of the data, but ages noted are accurate. **Table 2** includes exemplars from the data for each theme and subtheme.

Figure 1. Map of Qualitative Themes and Subthemes



Theme 1: Being A Young Carer

This theme deals with the feelings that a child has about taking on the role of young carer due to their parent's diagnosis with Huntington disease. There are four subthemes: a) feelings regarding the role, b) learning to be a caregiver, c) the burden of caregiving, and d) coping with the role.

Subtheme: I Try Not to Make It A Huge Part of My Life: Feelings Regarding the Role

All participants acknowledged that adopting the young carer role was a necessity due to their parents Huntington's disease diagnosis, but they differed in their feelings regarding taking on the role. Seventeen of the 28 children interviewed discussed their feelings at length. For many they saw the caregiving role as something that was just a part of their life, while others had overtly positive or negative feelings regarding the role. The majority of the children viewed the role of young carer as a normal part of their life, and for many it has been a part of their life for a number of years. Matthew (age 19) discussed the fact that he has been living with it since he was in elementary school and that now it "*seems a part of [his] natural life that [he's] just had to learn to deal with.*" When asked how he felt about taking care of his parent, he also said: *"the fact that my mom has Huntington's disease and that I'm a care-giver isn't a main part of my life. And so I just try not to make it a huge part of my life."* Matthew summarized his feeling regarding the role by saying:

> *"I feel like in every family there's always something, you know, that's not normal or, or just wrong. Or there's something bad, you know, that every family has to deal with and Huntington's disease is ours. Some*

> *people's moms have cancer. Some people's parents have a problem with alcohol or are separated or something like that, you know? Ours just happens to be Huntington's disease."*

Jane (age 20) discussed similar feelings regarding the role saying: "*I don't really think about it…I just, I do it."* Other children, like Samantha (age 20), viewed the taking on the caregiving role as something positive. She said that she started out doing things just to make things easier for her mom, but she does not think of it as a chore or a "*bad thing*". Instead she says, *"I'm not upset that I have to do it because I just feel like, you know, I was a baby, she took care of me. She did everything for me, so it's just like giving back what she did for me."* Sarah (age 13) similarly says that *"[she] is happy to do it*" because she feels that what she is going through *"seems kind of trivial compared to what [her mother] is going through."* Jennifer (age 16) simply says: "*I like taking care of my mom*", while Maria (age 16) says: "*it makes me feel good helping her*." Not all children viewed taking on the caregiving role this way. For some, taking on the role proved to be a difficult experience. Michael (age 17) discussed the fact that while he enjoyed helping his mom most of the time, he did not always feel that way. He said that sometimes when he helps his mom, he asks "*Why am I fueling what gave the disease to me?"*

Subtheme: I Just Did It: Learning to Be a Caregiver

Of the 28 children interviewed, 12 discussed the experience of learning to be a caregiver. Of these, most had little to no information regarding Huntington's disease or the caregiving role, but instead had to learn about it on their own. For most, their caregiving knowledge came from observation. Erin (age 12), when asked how she knew what to do, said: *"watching I guess."* Similarly, Katie said *"[she] just learned."* Some of the children, used their past experiences to guide them on what to do. Jane (age 20) said that she knew what to do from "*past experiences helping, just normal things around the house, and stuff like that.*" Susan (age 15) had experienced caring for someone with an illness in the past so she said: "*I had to do some of the things that I do with [her]. So it's kind of similar in that way."* For most of the children however, they learned to be a caregiver through common sense or intuition. Jennifer (age 16) drew parallels between caring for herself and caring for her mom saying:

> *"The things I did were kind of basic, so. Everyday, like, the cleaning obviously was easy and washing, helping my mom take showers every once in a while. It's just like bathing myself."*

Sarah (age 13) said that she doesn't know where she learned about what to do. She said: "*I just do. I don't know. Most of it seems like kind of common sense*" For some they were able to sense what needed to be done. Ellie (age 17) learned this way, saying, "*I guess just picking up on little things she needed help with. Noticing."* Jacob (age 15) also felt this way. He said: "*it just seemed like that's what you should do."* Some, like Madeline (age 20) felt that it "*just came naturally,"* while Hallie (age 17) said "*you just know. You know what's good for people."*

Subtheme: People Don't Know How Hard It Is: The Burden of Caregiving

Numerous children reported that the caregiving role placed a burden on them. This burden refers to the all-encompassing challenges felt by the children related to their new role of being a young carer. For some, simply being around their parent with

Huntington's disease was too much and they felt like they had to escape home in order to get away. For example, Abigail (age 20), said that *"the only time [she] could escape was when [she] had to go to school."* Isabelle (age 20) said similarly that she *"just didn't wanna go home, but there was like nowhere else [she] could go."* Mark (age 17) elaborated on this feeling of wanting to get away, saying that sometimes he just got "*fed up"* with his mom. Despite feeling this way, he also said that he *"really shouldn't feel that way because it's not her fault…it's just really hard sometimes. It's just a hard situation to deal with."* Summing up the conflict he feels about the role he simply states *"man, this isn't easy."* Susan (age 15) also expressed this difficulty saying that it "*definitely gets hard sometimes*." Pairing the negative with the positive, Maria (age 16) states that while it makes her feel good to help it also takes "*a big, big toll*." Ellie (age 17) also speaks to this idea saying that "*as much as [she] loves her mom and loves being able to help her, some days it's a little much."* The idea of unfairness regarding the role of young carer was also brought to light by Katie (age 14) who said "*it's almost unfair because, like, my friends don't have to help their parents…their parents help them instead*." Ellie (age 17) summarizes these feelings of difficulty and unfairness when she says "*it's a lot harder than what people see."*

Subtheme: I've Always Had to Deal with It: Coping with the Role

Coping with the role is also something that was discussed by 13 of the 28 children interviewed. While many simply said that they did or did not participate in some form of a coping activity, there were others who elaborated on what works best for them. For some, like Mark (age 17) who felt that they *"always had to deal with it*" he says, "*I don't* *really need ways to cope as much as other people do."* Regardless, he says that "*even just getting out sometimes helps a lot because you don't always have to be in the midst of Huntington's disease*." Maria (age 16) also mentioned that she likes to cope by "*going outside a lot*" just to be away from her mom with her friends. For Ellie (age 17) her main source of coping was singing or journaling in addition she said that she has "*people like [her] boyfriend that'll listen to [her] vent about anything and a couple really close friends that are the same way."* In contrast Michael (age 17) felt that he always "*dealt with it on his own*" and he just thought a lot about Huntington's disease. He said he thinks that the "*meditation such as that is what has given [him] the mindset that [he] has today,"* so he felt like he primarily "*coped with it through meditation.*"

Theme 2: Dealing with It

The second theme, dealing with it, relates to the situations that children have to face after taking on a caregiving role. This includes the four subthemes of a) school and peer relationships, b) feeling unheard and alone, c) the importance of a support system, and d) personal growth.

Sub-theme: I Kinda Missed Out on all the Kid Things: School and Peer Relationships

Sixteen of the children discussed how Huntington's disease and their caregiving role impacted their relationships with their friends and school. For many they had difficulties doing their homework at home because of their responsibilities or the behavior of their parents with Huntington's. Abigail (age 20) said "*I'd be trying to do my homework and I'd have to go in my room and shut the door or go in the basement.*"

Sometimes, she said she'd just "*stay at school in the library*" because she wouldn't be able to get her work done home. Isabelle (age 20) similarly said that she "*couldn't get any of [her] homework done*" because her father always wanted help with what he was doing. Allison (age 20) said that "*it seemed like every time I tried to study for a test [her mother] would be in her mood, so that it was kind of hard to study*." Aside from the difficulties related to completing schoolwork, many children also experienced difficulties related to making and maintaining friendships with their peers. Hannah (age 20) said that "*it was lonely and alienating in grade school and high school"* because she could "*never, ever go to anything*." As a result, she said *"I didn't have friends in grade school*." Katie (age 14) similarly said that it keeps her *"from doing other stuff and stuff that [she] wants to do."* Jennifer (age 16) explicitly states that she did not want to help her mom as much as she did because she was a kid and she just wanted *"to go have friends and play outside*." She elaborated on this feeling of missing out, saying:

> *"I kinda missed out on all the kid things that I, that you normally go through as you're growing up. I was more of, like, one of the adults at the age of what, like, thirteen?"*

For some, school was a place where they could go to escape the difficulty of their role. This idea was expressed by Isabelle (age 20) who said that at school, "*where there's just kids like you and its normal. You can be normal*." Wendy (age 15) had a unique viewpoint regarding how Huntington's disease impacted school. She said that "*it makes me want to do better in school because I can control that…I can't fix that my dad has Huntington's, but I can do all that I can in school so that I can do better and make a difference when I get out of school*."

Subtheme: It'd Be Nice if Someone Asked Me How I Was Doing: Feeling Unheard and Alone

A third of the children discussed the fact that they felt alone, unheard, and misunderstood by their peers, teachers, and family. For many, their friends were unable to relate to their situation of being a caregiver of a parent with Huntington's disease. Abigail (age 20) said that none of her friends had anything like that going on in their life so she "*felt like [she] was an outcast*." Jennifer (age 16) elaborates on this by discussing her belief that they "*can't really fully understand 'cause they've never really been through it."* She said that even when "*you're getting your feelings out to a friend,… deep down you know that they, they're really not gonna feel the way you feel and understand it 'cause they've never been through it."* Abigail (age 20) said similarly that she told her friends about it because "*it was nice to talk to someone*" but "*they didn't really do anything; And then they'd be like, 'That's too bad. Thanks*.' *They know, but they don't understand."* For Isabelle (age 20) she also felt that the teachers never understood what was going on. She said she was "*sleepy every day in class"* but the teachers never asked her why. Susan (age 15) also highlighted this issue saying "*teachers don't know about it and that's hard just like it is with friends. Because, like, sometimes we expect adults to know more than the kids do and they don't."*

In response to their feelings of being unheard, alone and misunderstood, many children discussed the desire to have a supportive friend who understood what they were going through. Susan (age 15) said "*I kind of need a friend who supports me more with it because a lot of my best friends just don't get it and that's hard*." Jane (age 20) said she just "*needs someone to talk to.*" More broadly speaking these children also discussed the fact that family and outsiders do not understand the impact that being a young carer has on them. Isabelle (age 20) elaborates by saying that her family asks about how her mom is doing, but no one asked how she is doing. She says:

> *"What about me?" Like, the whole time she's saying, like, "I feel so bad for your mom. She's under all this stuff." I'm like, "Um . . . like, I'm dealing with it too." She didn't say . . . she's just going on and on. I'm just like, "Hey, I'm just sitting right here."*

Many simply want recognition and awareness for their role. Carmen (age 17) says, "*just recognize that I do it… it's not easy,"* while Holly (age 17) simply says "*be there for me, that's about it."* Isabelle (age 20) gets to the root of the problem saying "*It's tough. That's honestly why I'm doing this study. 'Cause nobody kind of really ever acknowledges that teenagers are involved or kids."*

Sub-Theme: I Need to Know That People Care: Importance of Social Support

Besides finding awareness and understanding for their role, children also discussed the type of social support they had and/or the difficulties in getting social support. Sixteen of the children discussed social support during the interview. For Abigail (age 20), she said she asked people for advice but felt like "*they didn't really want to get involved*." She laments that people always say they want to help, but it's difficult to accept the help because *"[they] don't really know how they could help."* Mark (age 17) recalls that he had "*a pretty good support system,"* but luckily didn't have to use it all that often. Brenda (age 18) similarly felt that *"everyone is pretty supportive*." Michael (age 17) says that despite having friends that were pretty understanding they were "*kind* *of blankly supportive*" because "*they can't really understand*" and they *"don't completely comprehend everything that is involved*." For some, they had specific people that really helped them. Jennifer (age 16) recalls a friend who stayed with her frequently and would always help her. She said, "*she didn't really understand, but, like, she took the time to try to understand."* Wendy (age 15) discuss the fact that her mom "*makes as easy on [her] as she can"* and tries to make her life "*as normal as it can be*." Sadly, for some, they lacked a good support system or simply did not know how to ask for what they needed. This is expressed by David (age 13) who says, "*I could have asked [for help], but no one seemed to care."*

Sub-theme: It's Changed Me A Lot: Personal Growth

A third of the children reported experiencing some sort of personal growth as a result of their caregiving experience, whether through an increase in maturity, responsibility, self-confidence, or fortitude. Brenda (age 18) says it "*made [her] a lot more mature*" because she "*pretty much raised [herself]"* since the eighth grade. She says: *"I'm strong enough I guess to, like, take care of her and also, like, grow from it.*" Jennifer (age 16) feels like what happened to her "*made [her] stronger"* and that she can "*do more things*" and "*have more confidence."* Mark (age 17) believes he "*matured at a super early age because of Huntington's disease*" so he's already learned to "*cope and deal with this kind of stuff and other people haven't*" and Jennifer (age 16) said it "*made [her] more responsible*" because she "*became more of an adult at a younger age*" and "*had to be responsible and stuff*." She therefore said she has "*grown up faster than the normal person."* Others more broadly discuss their personal growth. Isabelle (age 20) said that her experience as a young carer "*molded [her] into the person [she] is today*" and Jane (age 20) said it "*inspired [her] to keep going no matter what life throws at you*." She says: "*you keep going, and you take it, and you use it, and you go on."* Halle (age 17) believes that there is always something to be positive about saying: *"it's hard, but there's always something to smile about."* Some of the children also discussed the experience in a reflective capacity, looking back on who they used to be. Michael (age 17) said that when he was a young child he "*always thought his life would be better off had [his] mom not had Huntington's disease, so [he] could have been a normal kid"* He elaborated saying:

> *"It forced a sense of maturity upon me, I would say, that most children don't have to acquire until, you know, life slaps them in the face when they get out on their own. And without that certain experience about my mom having Huntington's disease I definitely wouldn't be the person that I am today."*

Holly (age 16) offers a similar sentiment saying that "*it definitely makes you grow up"* and she wishes she could "*go back in time*" and tell herself "*how far [she's] come."*

Theme 3: Facing the Uniqueness of Being a Huntington's Caregiver

The third theme deals with the uniqueness of being a young carer to a person with Huntington's disease. The subthemes are: a) the stigma and isolation surrounding Huntington's, b) the difficulty in dealing with the prognosis and progression of the illness, and c) facing the risk of inheriting the disease.

Sub-theme: We're Just A Normal Family: Combatting Stigma and Isolation Surrounding HD

Eleven children in the study discussed embarrassing situations or feelings of awkwardness related to their parent having Huntington's disease. Isabelle (age 20) recalled the time that a neighbor saw her father "*get the mail in his underwear"* and that she was "*never allowed to play [with the neighbor's child] again*." Jennifer (age 16) recalls the time that they went out to eat and her mom "*choked on chips"* and everyone "*was laughing at [her mom] and it made [her] really mad."* For some, they learned to cope with the embarrassment and are less worried about it now. Mark (age 17) said that when he was really little "*it was kind of embarrassing*" but now most of his friends know about it and "*they're not judgmental or anything."* Many, like Sarah (age 13) stated the fact that they just wanted to be treated normally. She said that when it comes to her mom "*don't treat her like an alien, like, some total other being… just act like she's a normal person."* Jane (age 20) similarly said "*We're just a normal family. There's nothing different about us than the family next-door; we just have different issues to deal with*." Some of the children also expressed the desire for people to better understand what was going on for them. Abigail (age 20) said that "*no one knows exactly what to do with Huntington's disease 'cause it's so different for everybody*" and Wendy (age 15) simply requests that people "*just try to understand how it is with Huntington's…maybe study it enough so that they know what it is so they can understand what we're going through."*

Sub-theme: I've Never Known That Person: Parent Child Relationships

Eleven of the 28 interviewed children discussed their relationship with their parents. For some, they never got to have a relationship with their parents before they became symptomatic with Huntington's disease and for others the relationship changed dramatically after diagnosis. Many discussed the fact that they treat their parent more like a child than an adult. Isabelle (age 20) said that her family treated her father "*like a little brother"* because "*he's like a child."* She also discusses the fact that family members are always trying to compare her father to the way he used to be and that she gets frustrated because he is not that way anymore. She says: "*They all think he's the Dennis they knew. But it's like, I've never known that Dennis…they don't get it. Like, they're still stuck in the past of what he used to be like."* Maria (age 20) also says that talking to her mother is *"like talking to a seven-year-old sometimes*." Jane (age 20) offers a unique perspective saying that while she "*treats [her father] more like a child now*", their relationship has gotten closer since diagnosis because "*he has a lot more fun with them….he just kind of really just gets to be himself*."

For many they felt that they never got to have a relationship with their parent because of Huntington's disease and wish that they could have. Abigail (age 20) said that her and her dad never really talk and that "*he [isn't], like a father figure"* Mark (age 17) said: "*I can't remember my mom before Huntington's disease at all*," and Mathew (age 19) similarly said: "*I can only kind of remember her beforehand.*" Caitlin (age 18) discusses the difficulty with this lack of relationship when she says: "*It's just been hard for me because I never really had that emotional bond or connection towards her."* She says that *"if I would have had a relationship with her to bond it would be easier to take* *care of her. But I feel I just have more resentment than anything, so that's harder."* Wendy (age 16) similarly discusses difficulties with not having a relationship with her mom when she says that her mom "*doesn't understand [he*r*]*" likely because she never got to know her and her siblings before she became symptomatic.

Sub-Theme: It's Hard Knowing I'm Almost Powerless: Acknowledging End of Life

The fact that Huntington's disease is incurable and has a long prognosis with increasingly worsening symptoms is something that was discussed in different ways by 14 children in the study. For some, like Erin (age 12) they "*don't always like to talk about that 'cause sometimes [they] just don't like to think about it."* Samantha (age 20) tries not to "*picture [her mom] getting super sick and terrible*" because she *"[doesn't] like picturing it"* and she doesn't "*really like to think about it".* Jane (20) says that she just "*doesn't like focusing on [her dad's disease progression].*" For Michael (age 17), after he was told by his mother about her prognosis said: "*she didn't really talk about it much afterwards… it was part of her life and was evident and you didn't really have to speak of it because it was there and prominent*."

In addition to the progression of the illness, many also discussed the future death of their parent due to Huntington's disease. For some, like Jennifer (age 16), they expressed understanding the fact that their parent would die, even though they felt upset about the outcome. She reports that she knows everybody is going to die, but says: "*my mom is gonna die more than likely way before the average person. And, like, I don't know. Like, dealing every day, like, knowing that each day she's, like, getting worse and worse . . . it just . . . I don't know. It makes me . . . upset."* Susan (age 15) feels similarly and says: *"It's hard knowing that I'm almost powerless and that I can't do much to help her because there is no cure…she's still going to die. And that's, like, sad but you have to come to terms with it too. Otherwise you can't help her at all."* Other children discussed the situation in a way that frames their parent's death as something that just goes with dealing with Huntington's disease, even though they are sad about it. Mark (age 17) says "*[he's] pretty much come to accept it."* He recalls that *"it was emotional but not overwhelming*" and that it's just "*part of the whole thing of excepting Huntington's disease."* Matthew (age 19) similarly says that even though "*sometimes it can be depressing… you can't avoid it so it's not something to worry about."* He says: "*I realize my mom's probably going to die I don't know, within a couple years or a few years...but, you know I'm fine with that 'cause that's what Huntington's does."*

Sub-theme: I Wanna Know How Much Time I Have Left: Genetic Risk

While also struggling with the progression and prognosis of their parents' diagnoses, these children also must worry about their own genetic risk and whether they want to be tested. Many are always worrying about Huntington's disease like Abigail (age 20) who says: "*I worry about, like, you know, having kids and, like, my job – like, you know I wanna be a nurse. So I'm like, you know, how far can I get before something happens."* She discusses the fact that right now is "*a big time to think about [her future],"* but despite "*always worrying about having Huntington's*" she still feels apprehensive about being tested because "*it's too much to think about right now.*" For Isabelle (age 20) she wants to get tested "*so [she] can plan [her] life out,"* but shares that that was not always her feeling regarding testing. She says that thinking about it used to make her "really depressed," but now she says: *"I have a boyfriend now and I really, like, I wanna know how much time I have left to spend with him and everything. So I wanna know, like, where we're gonna live, how long I should stay in school for,… plan my college major and everything. And I gotta figure out how much time I have and, like, think of a career that didn't . . . like, I couldn't go to be a doctor – waste all my life in school."* Mark (age 17) said he planned to get tested after high school, but now he's "*not so sure*" after finding out his brother tested positive. He says: "*knowing that it's probably, the same things gonna happen to me. I still wanna know. Especially if I, like, when I start a family I wanna know."* Matthew (age 19) similarly says he wants to get tested because it would "*let [him] know how [he's] gonna plan [his] future*." He says that if he gets tested and has Huntington's it "*will just let [him] know that [he] has to live [his] life out to the fullest before then*." Jennifer (age 16) simply says: *"Sometimes I think about what it's gonna be like if I have it. And how my life is gonna change."*

Discussion

It was evident from the participants in the study that taking on the role of young carer presented many different challenges for themselves and their families. While some children discussed the fact that their feelings regarding the role were either overtly positive or negative, many felt that it was simply a part of their daily lives and something that they had to take on because their family dealt with Huntington's disease. They did not necessarily see it as something that they were obligated to do or that was unfair, it was just something they did.

McDougal, O’Connor and Howell (2018) found that young caring was something that was done for the family and reflected familial obligation. While there may have been underlying feelings of obligation or unfairness regarding taking on the role of young carer, for many, this issue did not specifically arise during the interview. Most of the children reported having little to no education regarding their caregiving role and the majority said that they learned from observation or simply intuition. Kavanaugh (2019) discussed similar findings in her study which showed that many young carers did not receive specific training, but instead relied on the care recipient for guidance and learned through watching and observing, common sense, or trial and error. The children in this study also reported a desire to better understand Huntington’s disease in order to help care for it. In 2015, Kavanaugh and colleagues similarly found that children wanted more information and advice about Huntington’s disease (Kavanaugh, Noh & Studer, 2015).

Caregiving burden was something with that was discussed frequently by the participants in terms of the role being too much or difficult for them to deal with. While caregiving burden was not something that was presented in the original framework for parentification among young carers, it is likely a component that should be considered in the future as it was very prevalent among the children interviewed. The idea of caregiving burden among young carers is also discussed by Van Loon and colleagues (2017) who found that it was important not to burden children with too many care tasks as it may be associated with higher levels of parentification, and by McMahon and Luther (2007) who found that child caretaking burden was positively correlated with psychological distress among young carers. Williams and colleagues (2009) found that caregiving caused a burden for young carers in the form of emotional distress, social restrictions, and financial concerns. In the present study the burden of caring was also discussed by participants related to emotional distress and social restrictions, but financial concerns were not reported.

With regards to coping, similar to the feelings related to taking on the caregiving role, many felt that it was just something they had to deal with and did not discuss specific coping mechanisms or difficulties with coping. While there were some who discussed specific coping methods, the majority felt that it was just something that they had to get through. McDougall, O'Connor and Howell (2018) discussed a similar report saying they found young carers managed the role primarily with solitude. Van Parys & Rober (2013) had an interesting idea with regards to young carers and coping when they posit that these children may hold onto their young caregiver role as a way of managing their situation.

The impact of the caregiver role was also something that was discussed at length by the participants. With regards to school and friends, many discussed the idea that they were unable to complete their schoolwork at home because of the behavior of their parent with Huntington's disease or their caregiving responsibilities. This finding was something discussed by Kavanaugh (2014) who found that there was a relationship between the parent with Huntington's being difficult to get along with and school problems. Assaf and colleagues (2016) also found that caregiving youth made personal and academic sacrifices to act as caregivers.

Participants in this study also discussed the impact of caregiving on their relationships with friends. They felt that they were unable to bring their friends to their home or were unable to go out with their friends due to their parent having Huntington's disease. They felt a disconnect among their friends as well, because they were unable to fully understand their situation. This same lack of understanding was discussed in terms of teachers and other adults as well. Most participants in the study did discuss a desire to have an individual who was going through the same situation in order to be able to talk with them. These feelings of loneliness and being unheard were also reported in other studies. McDougall, O'Connor, and Howell (2018) found that young carers felt lost in the system and Kavanaugh, Noh, and Studer (2015) reported that children said they needed friends who understood their caregiving situation. Children in this study also reported that they wished people would acknowledge them and their role. Kavanaugh and colleagues (2015) similarly found that children needed to be asked how they are doing, not just about how their parent is doing, while Rothing and colleagues (2014) found that children felt their own needs were put aside for their parent's. This idea is summed up by Van Parys and Rober (2013) who reported that the children in their study simply longed for recognition and permission regarding their role.

Participants in the present study discussed the support system that they had. For many, they felt they had a good support system even though the people in their support system did not know how to help or the family was unsure of asking for the help they needed. There were some participants, however, that felt that they did not have a good support system or that the support being provided to them was not effective. The importance of a good support system in young carers was discussed by Keenan (2007) who found that a good support system and strong relationships were protective against negative outcomes in young carers.

Participants in this study also discussed the positive side of taking on the role of young carer in their discussions of personal growth. For many, they felt that they had experienced increased maturity and self-confidence related to the caregiving role and that in their experience in that role did have a positive impact on their life in the end. This idea of personal growth and positive experiences is also reflected in the study by McDougall, O'Connor and Howell (2018) who found that some carers experienced positives from their role and by Hooper, Marotto and Lanthier (2008) and Keigher (2005) who both found that parentification among young carers is not always a purely negative experience.

With regards to the young carer experience as it relates specifically to Huntington's disease, some themes and subthemes arose from the data were not reflected in the original framework. The first pertains to the idea of stigma and isolation related to Huntington's disease. Multiple children discussed experiences of embarrassment when they were out in public with their parent that resulted in other people laughing or looking with disdain upon their parent. They discuss their desire to have people treat them as a normal family. Kavanaugh and colleagues (2015) also found this desire among young carers of persons with Huntington's disease.

Another unique component of being a caregiver of a person with Huntington's this is the fact that the parent and child relationship changes as a result of the illness or is in fact something that has never formed. For many children, they discuss the fact that they never really knew their parents before Huntington's disease and their parent likewise never got to know them before they were diagnosed. As a result, these children felt they did not have a strong relationship with their parents and many wished that they had the opportunity. The importance of the relationship these children are lacking was highlighted by Bauman (2006) who reported that an important predictor of child mental health was a strong parent-child relationship.

Discussions regarding disease progression and end of life were found to be especially pertinent to the experience of being a young care to a parent with Huntington’s disease. These children discussed the fact that it was hard to watch their parent deteriorate due to the illness, but many also expressed that despite their realization that their parent would die and that even though it’s hard, it was something that they understood and acknowledged. Kavanaugh, Noh, and Zhang (2016) discussed a lack of knowledge surrounding end of life in young carers of persons with Huntington’s disease, but participants in the current study did not report this lack of knowledge.

Lastly, a large component of caring for a person with Huntington disease that was discussed by participants is the potential genetic risk. The difficulty in caring for someone with the same illness that you are potentially at risk for and the need to plan for the future was reported frequently by the children. Many wanted to know whether or not they were positive for Huntington’s disease so that they could plan out their future with regards to loved ones, school, and careers. But many also discussed feeling apprehensive about being tested. Similar results were found by Williams (2009) and Keenan (2007) who reported that young carers were worried about getting Huntington’s disease. Dondanville (2019) also found the genetic risk compounded the emotional distress felt by young carers.

Overall, multiple components of the original model of parentification among young care were reflected in the findings of this study. In addition, emerging categories were found that relate specifically to the context of Huntington’s disease. This is to be expected as the original framework relates to parentification among young carers in a broad sense and is not disease specific. There is no doubt that the young carer role is something that is difficult for children who have a parent with Huntington’s disease to adapt to, but perhaps even more importantly the data shows that these children do it. Despite the impact it has on their lives, despite their feeling alone, unheard, and stigmatized, despite their parents’ terminal prognosis, despite the fact that they may have the same illness themselves, and despite the fact that they are just children, they still do it.

Implications

In the United States young carers remain an understudied and under resourced population, both in policy and research. Compared to the research being done in adult caregivers, there is very little being done for the population under age 18 (Kavanaugh et al., 2016). This is true not only for Huntington’s disease, but for all families who are dealing with serious illness and have a child who may potentially be taking on a caregiving role. In the future this may be even more important as the caregiver support ratio, which determines the number of potential family caregivers for every person most likely needing care, is declining (Reinhard et al., 2015). In 2010, the ratio was approximately seven potential family caregivers in the primary caregiving years (those aged 45-64) for each person at risk of needing long term care. By 2030, it is estimated to decline to 4:1, and then to less than 3:1 in 2050 (Reinhard et al., 2015). Therefore, there may be even more of a need for children to adopt the role of young carer in the future. Compared to other countries, the United States is behind in awareness and support for young carers as there is little public awareness about young carers, a limited research base, no specific legal rights for this population, and few dedicated services or interventions (Leu & Becker, 2017). It is important for healthcare providers, researchers, and educators to know young carers do exist and to include them in future research, policy, and support services.

Limitations

Limitations of the present study primarily deal with the fact that secondary data was utilized. Because the data was collected at an earlier timepoint, it is possible that the findings of the current study do not reflect of the context surrounding participants in the present day (Ruggiano & Perry, 2019). Perhaps the greatest limitation of secondary data analysis is that the contents of the data are not able to be altered by the researcher (Polit & Beck, 2017; Ruggiano & Perry, 2019). Therefore, the data may not be ideal for the aims of the study and may not be able to fully answer the questions posed by the researcher. Because the data was previously collected, questions pertained specifically to parentification in young carers were not asked of participants, so the exploration of this concept in the analysis is done through questions addressing similar topics.

Conclusion

A Huntington's disease diagnosis affects not only the individual diagnosed, but also the surrounding family. In families with children aged 8-18, these children may take on the role of young carer, providing secondary care for their ill parent. This role can conflict with other family, home, work and school related responsibilities and can result in potential consequences such as parentification. How parentification manifests in Huntington’s disease was explored in the current study. The analysis process was guided by a broad framework of parentification among young carers and many of these components were found to be reflected in the data. Huntington’s disease specific themes and subthemes did emerge from the data and presented new categories that were not reflected in this original model. Therefore, these components of the young carer experience should also be considered when addressing young carers of person with Huntington’s disease. The findings of this study also are supported by findings from studies conducted by other researchers exploring young carers. It is important to recognize that there are children providing care to a parent with Huntington’s disease and that they face numerous difficulties in taking on this role. By providing more information related to the experience of young carers and the manifestation of parentification in this context, the hope is that this study will inspire future studies that will increase research, policy, and support for these unacknowledged and underserved children.

Table 2. Example Quotes for Qualitative Themes and Subthemes

Theme 1: Being A Young Carer	
I Try Not to Make It A Huge Part of My Life: Feelings Regarding the Role	Probably after I found out, I started doing things, like, more just to make things easier for her. I don’t really think of it as, like, a chore. Like, I’m not upset that I have to do it because I just feel like, you know, I was a baby, she took care of me. She did everything for me, so it’s just like giving back what she did for me. So I don’t really think of it as a bad thing. (Samantha, age 20) I just, I don’t really think about it. It’s not an option I have or wanna have. I just, I do it if he wants something or my mom needs something; I’m at their beck-and-call, so. (Jane, age 20) I mean, the fact that my mom has Huntington’s disease and that I’m a care-giver isn’t a main part of my life. And so I just try not to make it a huge part of my life… I feel like in every family there’s always something, you know, that’s not normal or, or just wrong. Or there’s something bad, you know, that every family has to deal with and Huntington’s disease is ours. Some people’s moms have cancer. Some people’s parents have a problem with alcohol or are separated or something like that, you know? Ours just happens to be Huntington’s disease. (Matthew, age 19) I’ve been living with it since I was in elementary school. So I grew up with it. So it seems a part of my natural life that I’ve just had to learn dealing with. It doesn’t seem like any, like, ah, unusual stress or strain or undue, like, worries or anything like that. (Matthew, age 19) I like taking care of my mom. (Jennifer, age 16) I guess. I’m happy to do it though. I guess what I’m doing just seems kind of trivial compared to what she’s going through, so. (Sarah, age 13) It makes me feel good helping her and everything. (Maria, age 16)

	there's always the darker side of your growing up and this disease in your mom has impacted your entire life. And you sit there and as a child it, you might think that these thoughts are beyond yourself. But you sit there and you're like, "Why does this have to happen to my family?" And so sometimes when you help your mom, you sit and, "Why am I fueling what gave the disease to me?" (Michael, age 17) It felt good to do something. (Thomas, age 13)
I Just Did It: Learning to Be a Caregiver	The things I did were kind of basic, so. Everyday, like, the cleaning obviously was easy and washing, helping my mom take showers every once in a while. It's just like bathing myself, so. (Jennifer, age 16) It really just came naturally. Um, some of it was from watching my mom, 'cause she helped out a lot too. Um, but a lot of it just kind of came naturally as well. (Madeline, age 20) I guess just picking up on little things she needed help with. Noticing. Oh, she has problems remembering this. I'm gonna write it down, and stuff like that. (Ellie, age 17) It just seemed like that's what you should do. I mean, yeah. I, like, try and let him be independent as much as I can, but just there's some things that he can't do, that he needs help with. (Jacob, age 15) I just learned I guess. She just tells me to do it, and I do it (Katie, age 14) I knew what to do most of the time, but as a kid when your parent has Huntington's disease you don't know what to do all of the time. (Michael, age 17) Just know. You know what's good for people. As long as it doesn't kill them, you know. (Hallie, age 17) [I] just did it. (Wendy, age 16)

	I had to help her with things, like, taking showers and when she was trying to get rehabilitated in the house after she came back from the hospital from a few months, it, I had to do some of the things that I do with Marian. So it's kind of similar in that way (Susan, age 15) Just kind of, kind of just past experiences helping, just normal things around the house and stuff like that. I just kind of, um, kind of do it by myself (Jane, age 20) I mean, learning from observation because, like, when the care-givers, care-giver uses the gate belt, and we never really use a gate belt. But, yeah. That was just something we did as a family kinda (Matthew, age 19) I just do. I don't know. Most of it seems like kind of common sense. (Sarah, age 13)
People Don't Know How Hard It Is: The Burden of Caregiving	The only time you could escape was when I had to go to school. And then you'd come back home and then you'd watch him again. (Abigail, age 20) I just didn't wanna go home, but there was, like, nowhere else I could go. (Isabelle, age 20) A lot of times I get fed-up with my mom and I realize I really shouldn't. It's not her fault, but it's just really hard sometimes…It's just a hard situation to deal with. Sometimes I still do feel, man, this isn't easy. (Mark, age 17) It's almost unfair because, like, my friends don't have to help their parents. Like, their parents help them instead. (Katie, age 14) Like, if I had to choose between letting her live with me or putting her in a nursing home, I would put her in a nursing home. I love her, but I don't wanna take that on. (Carmen, age 17) It definitely gets hard sometimes (Susan, age 15) I told you it makes me feel good helping her and everything. But it was also, like, a big, big, like, toll on my part, like, in school and everything. (Maria, age 16)

	I guess just that it’s a lot harder than a lot of people see. And especially being seventeen it’s, there’s enough stuff going on with school and friends and all that, that as much as I love my mom, and I love being able to help her, some days it’s a little much. (Ellie, age 17)
I’ve Always Had to Deal with It: Coping with the Role	I’ve always had to deal with it, so I don’t really need ways to cope as much as other people do. But, I mean, just getting out sometimes helps a lot. You know, not having to always be in the midst of Huntington’s disease. (Mark, age 17) I think I cope with it pretty well because, since she’s lived with it for so long, she knows how to deal with it too. So, it’s not all on me or my mom. (Susan, age 15) I would probably just be outside a lot…Yeah, just to be away from her, yeah, with my friends and everything. (Maria, age 16) Singing is my main one ‘cause singing is my life. Or I write, like, I keep a journal, and I do that a lot. And then I have people, like, my boyfriend that’ll listen to me vent about anything. And I have a couple really close friends that are the same way. (Ellie, age 17) I always dealt with it on my own. I was one of those kids that if you go on a three hour car ride I’d be the one looking out the window and not speaking. And usually what my thoughts consisted of was about Huntington’s disease. But I think the meditation such as that is what has given me the mindset that I have today. So, coping with it, meditation. (Michael, age 17)
Theme 2: Dealing with It	
I Kinda Missed Out on all the Kid Things:	I’d be trying to do my homework and I’d have to go in my room and, like, shut the door or go in the basement…So I’d just stay at school in the library until, like, 4 and then I’d come home later. ‘Cause it was like, “I’m not gonna get this done at home. He’s gonna be doing something. (Abigail, age 20)

School and Peer Relationships	When I’d come home from work he’d be up, and I couldn’t get any of my homework done because he wanted me to help him, whatever he was doing. It was hard on my GPA. (Isabelle, age 20) [At school] where there’s just kids like you and its normal. You can be normal. (Isabelle, age 20) It keeps me from doing other stuff or stuff that I want to do. (Katie, age 14) I guess [it impacted] social abilities in grade school…Because we went to, like, every weekend and, like, junior high is when the girls started having a bunch of sleepovers and I never, ever could go to anything. And so I didn’t have friends in grade school… It was lonely and alienating in grade school and high school (Hannah, age 20) I wouldn’t like having people over, you know. So, if people were hanging out or if people needed, like, to meet up somewhere I wouldn’t ever bring them over. (Matthew, age 19) I, I didn’t wanna help her that much because I was a kid and I did wanna go have friends and play outside and stuff. I mean, I have friends, but like, I never got to hang out with them as much. (Jennifer, age 16) It’s good to be responsible and stuff, but I kinda missed out on all the kid things that I, that you normally go through as you’re growing up. I was more of, like, one of the adults at the age of what, like, thirteen? (Jennifer, age 16) It seemed like every time I try to study for a test she would be in her mood, so that was kind of hard to [study]…I did, like, okay on the test sometimes. (Allison, age a20) Um, I think almost, it almost helped it because, ah, I – if that sounds strange – it makes me want to do better in school I think because I can control that… If I, I can’t fix that my dad has Huntington’s, but I can do all that I can in school so that I can do better and make a difference when I get out of school by doing my best in school. (Wendy, age 15)

It’d Be Nice if Someone Asked Me How I Was Doing: Feeling Unheard and Alone	None of my high school friends had anything like that, so it was like, it felt like I was, like, an outcast. Like, eh. They, they didn’t understand. (Abigail, age 20) It felt like none of my teachers really understood though. Like, I was sleepy every day in class. They never asked me why. (Isabelle, age 20) Teachers, um, don’t know about it and that’s hard just like it is with friends. Because, like, sometimes we expect adults to know more than the kids do and they don’t. (Susan, age 15) I kind of need a friend who supports me more with it because a lot of my best friends just don’t get it and that’s hard. (Susan, age 15) I’d say some of the time they understand, but, like, they can’t – if you think about it they can’t really fully understand ‘cause they’ve never really been through it. I mean, so you, you’re getting your feelings out to that friend, but deep down you know that they, they’re really not gonna feel the way you feel and understand it ‘cause they’ve never been through it. (Jennifer, age 16) I told my friends about it ‘cause it’d be nice to talk to someone, but they didn’t really do anything. So then I’d tell them about it ‘cause, you know, then I didn’t have to, like, worry about it so much. And then they’d be like, “That’s too bad. Thanks.” They know, but they don’t understand. So I just don’t bring it up anymore. (Abigail, age 20) My aunt, she drove me home to college once and all she did was tell me how bad she felt for my mom the whole time. And I’m like, “What about me?” Like, the whole time she’s saying, like, “I feel so bad for your mom. She’s under all this stuff.” I’m like, “Um . . . like, I’m dealing with it too.” She didn’t say . . . she’s just going on and on. I’m just like, “Hey, I’m just sitting right here.” (Isabelle, age 20) It’s tough. That’s honestly why I’m doing this study. ‘Cause nobody kind of really ever acknowledges that teenagers are involved or kids. (Isabelle, age 20)

	Just recognize that I do it. That’s, you know. Just, it’s not easy. (Carmen, age 17) I don’t really need any help. But, like, if someone says, “How’s your mom doing,” I’ll say, “Oh, she’s doing all right.” But maybe it’d be nice if someone asked me how I was doing. Like, ‘cause I will have an answer. (Carmen, age 17) I need to know that people care. I need someone to talk to. Um, I need someone to distract me, and I need someone to push me. (Jane, age 20) Be there for me. That’s about it. (Hallie, age 17) I guess just be more understanding because a lot of people don’t understand it. It’s like . . . one thing I’ve really noticed is if my friends, if I say I can’t do something they’re just like, “Okay, what are you really doing?” ‘Cause they don’t think I can always say, “I’m helping my mom with this.” So they think that I’m using that as, like, an excuse when in reality I’m not. So I guess that’s the main thing. Just be more understanding about everything with it. (Ellie, age 17)
I Need to Know That People Care: Importance of Social Support	I’d ask people for advice, like, and they wouldn’t, they’d just kind of like, you know, distance themselves. Like, you know, they didn’t wanna get involved. So it was kind of like, like, you know, most of it was in high school, so I’d tell my friends what was going on or what was happening and, like, “What would you do?” or something. And they’d be like, “Oh, I don’t know. I gotta go home.” (Abigail, age 20) People always say they wanna help, but then, you know . . . we don’t really ask for their help just because we don’t really know how they could help. Because, like, people from church are always, like, “Let me know if you need anything” or whatever. And it’s like, “I don’t really know what we need” you know? (Abigail, age 20)

	I've got a pretty good support system. I think it's good that, 'cause I don't have to use it that often. But if I did use it a lot one of two things would happen – either it would strengthen a lot or it would weaken a lot. So me not using it is good because it's there when I need it. (Mark, age 17) Everyone's pretty supportive. I haven't had anyone that just kind of like, "Ah, too bad." You know? So they're all good…..like, so that's really nice. Just people like that who are willing to, like, help. And I, a lot of my friends do that. (Brenda, age 18) I did have one friend though that would stay with me, like, every night, like, on school nights and everything….We're just really close. We still are really close, and she always would help me. I feel like, she didn't really understand, but, like, she took the time to try to understand. (Jennifer, age 16) Support groups and stuff like that would be nice. Because it basically does feel like I am on my own taking care of my mom. (Ellie, age 17) Most of my friends even now a days are pretty understanding. I mean, I'm sure they don't completely comprehend everything that it involves with, what a person, even your mom has Huntington's disease. But never are they rude about it. And they're always just, "Okay, yeah." Supportive, you know, kind of blankly supportive. Because, like I said, they can't really understand. (Michael, age 17) I could have asked [for help], but no one seemed to care. (David, age 13) My mom makes it as easy on me as she can, so she has to do so much with Dad. She tries to make my life as normal as it can be. (Wendy, age 15)
It's Changed Me A Lot: Personal Growth	It's just kind of inspired me to just keep going no matter what life throws at you. Just, you keep going, and you take it, and you use it, and you go on. (Jane, age 20) I've felt like it's really made me a lot more mature because I've pretty much, like, raised myself since I was, ah, like in eighth grade. Like, anything school related, anything at school I had to fill out, I had to do myself…And like, anything, like, health insurance or any medical records, like, I'm on it. Like, I know how to do all of that. I

	know how to, like, pay all my own bills and, so that's how I see it. So I have benefited that way. Just, like, being able to know that, like, I'm strong enough I guess to, like, take care of her and also, like, grow from it. That's kinda nice, yeah. (Brenda, age 18) I'm not completely happy with it. But I do feel like what happened to me, like, made me stronger and, I don't know. I feel like I can do more things. I have more confidence. (Jennifer, age 16) I've matured at a super-early age mainly because of Huntington's disease. So I've learned to cope and deal with this kind of stuff, but other people haven't. And other people are already fragile. Like, there are already really fragile people that have to – nothing wrong with them – they're just emotionally unstable and then something like this happens to them and it can be bad. So, I guess, if there was a way for me to provide support for other people and know that I'm helping out with them, then that would be good. (Mark, age 17) It's made me become more responsible. I became adult. I came, I became more of an adult at a younger age I feel like 'cause I got, I had to be responsible and stuff. 'Cause if you think about it, I couldn't, like, get, like, my, like, the medicine thing I couldn't just give my mom whatever medicine and then her get sick or something. And taking care of my sister, so yeah, that's respons . . . I feel like I've became more responsible and grown-up faster than the normal person. (Jennifer, age 16) It molded me into the person that I am today I should say. Because it's a motivation moreso than a downer now. (Isabelle, age 20) I would say that as a young child I had always thought that my life would have been better off had my mom not had Huntington's disease. I could have been a normal kid, you know, with normal teenage problems. But with such factors as my mom actually did have Huntington's disease and I saw her "degrade" (you know, air quotes) over a course of ten years through my entire life it forced a sense of maturity upon me, I would say, that most children don't have to acquire until, you know, life slaps them in the face when they get out on their own. And without that certain experience about my mom having Huntington's disease I definitely wouldn't be the person that I am today. (Michael, age 17) It's hard but there's always something to smile about. Always stay positive. (Hallie, age 17)

	It definitely makes you grow up…I've always the dream of, like, going back in time, like, as I am now, and telling me, like, how far I've come. (Wendy, age 16)
Theme 3: Facing the Uniqueness of Being a HD Caregiver	
We're Just A Normal Family: Stigma and Isolation Surrounding HD	No one really knows what to do exactly do with Huntington's 'cause it's different for everybody… People always say they wanna help, but then, you know . . . we don't really ask for their help just because we don't really know how they could help. (Abigail, age 20) He would never, ever get dressed ever. He'd just wear his underwear all day. And one time, um, he got the mail in his underwear. And my mom, my friend's mom saw that and I never got to play with that person again. (Isabelle, age 20) I used to have a problem with that when I was really little because it was kind of embarrassing and . . . now most of my friends know about it and they're obviously, they're not judgmental or anything. Yeah, when I was little I was more worried about it, yeah. (Mark, age 17) I guess just one of the things that's toughest to get along with is social awkwardness. Like, She just doesn't, I guess she doesn't have the ability to get along with people as well as she used to… I don't think she's as aware of it, but she's just, like, she doesn't understand personal space anymore or volume of conversation, things like that. (Carmen, age 17) We're a normal family. There's, you know, nothing different about us than, um, you know the family next door; we just have different issues that we deal with. (Jane, age 20) Don't treat her like an alien, like, some total other being. Just act like she's a normal person. (Sarah, age 13)

	There's not anything you can really do to help. There's like, 'cause there's so many people that'll be, like, "I wanna help." It's like, well you really can't, like, unless you're, like, here taking care of my mom kind of thing. (Brenda, age 18) One time we went out to eat and she, like, choked on chips and stuff. It was kind of, I felt really bad for her 'cause she got really embarrassed and stuff. And everyone was laughing at her. It made me really mad. (Jennifer, age 16) Just try to understand how it is with Huntington's. Um, maybe study it enough so that they know what it is so they can understand what we're going through, you know, my family's going through. (Wendy, age 15)
I've Never Known That Person: Parent Child Relationships	It's gonna be, like, weird and stuff if I have to, like, help her get changed and everything 'cause I just don't see my mom being like that. Like, I see her as being really independent and doing everything for herself 'cause that's just how she's always been. (Samantha, age 20) I don't know. I don't . . . I never really talk to him about things and when he did listen I don't think he really, like, he'd think of other things, not listening to me. We never had, like, a heart-to-heart ever, like, never in my life. We never really talk or anything. He was just kind of like Dad, and we didn't, he was there but he wasn't, like, a father-figure. (Abigail, age 20) I grew up with it, so I kind of, you know, we pretty much treated him like a little brother I'd say. Like, "Don't do this." 'Cause he always wanted to do something and break something of ours. And like, he always wanted to do stuff like a kid would wanna do it. His sister came over to help us and after two days she couldn't do it. And she was telling us how to treat him and stuff, saying "He's your father." No, he's not, like, a father he's like a child. Like, my mom always says, like, she has three kids and all this kind of stuff. (Isabelle, age 20) My family members, like, my, my relatives, like, my grandmas and my aunts and stuff on both sides of the family, they don't understand what's going on. Like, they'd always go, like, "Oh, I remember Dennis. You know, he was, he's like, this. Your dad's like this, your dad's like this." I'm like, "No, he's not." They all think

	he's the Dennis they knew. But it's like, I've never known that Dennis. It's kind of annoying to hear their stories I'd say. But they don't get it. Like, they're still stuck in the past of what he used to be like. (Isabelle, age 20) I can't remember my mom before Huntington's disease at all. Well, I mean I can remember really small stuff, like, her feeding me and stuff like that. But I can't really remember who she was or anything. (Mark, age 17) I kind of treat him more like a child now. Our relationship's gotten closer. Um, we've gotten closer since he's been diagnosed. He has a lot more fun with us. He's a lot goofier. He's kind of stress-free. I mean, he just, he doesn't let, um, you know he doesn't have to worry about bills or going to work, dealing with the boss, um, so he just kind of really just gets to be himself and, which is awesome. And I wouldn't give anything in the world for that. (Jane, age 20) She can be more irritable. Although it's, it's a slow progression. I can only kind of remember her beforehand. I mean, nicest person ever before. (Matthew, age 19) It's like, when I would talk to her it'd be, like, talking to, like, a seven-year-old sometimes. (Maria, age 16) To care for her I think I kind of need more of a relationship with her. 'Cause, like, I said, before I, like, her symptoms started at, like, fortyish, that's what my dad said. And that's when I was born. She had me when she was forty. So, never really got to know her. My brothers just say that I got, like, the short end of the stick 'cause they, like, knew her and everything and I didn't. So I feel like if I would have had a relationship with her to bond it would be easier to take care of her. But I feel I just have more resentment than anything, so that's harder. (Caitlin, age 18) No, [she doesn't understand me] 'cause I don't think she knew us well enough after she was, when she started being symptomatic was, like my third year in school, so. (Wendy, age 16) It's just been hard for me because I never really had that emotional bond or connection towards her. (Caitlin, age 18)

It's Hard Knowing I'm Almost Powerless: Acknowledging End of Life	I try not to picture her, like, getting super sick and terrible. Well, not terrible, but like bad that she would need [end of life medical care]. Like, I just don't like picturing that, so I just don't really think about it. (Samantha, age 20) Sometimes I don't always like to talk about that 'cause sometimes I just don't like to think about it. (Erin, age 12) I asked him when he found out he had cancer if he was scared or not. He said he was. I was surprised he said that 'cause he's always pretty, um, go-with-the-flow kind of thing. So I was kind of shocked. And everyone else was like, "Why would you ask him that?" I was like, "I was actually wondering if he was or not. (Isabelle, age 20) If something were to happen…I know she has told us that she wants a "do-not-resuscitate" bracelet, so that's important. I've pretty much come to accept it especially since we're probably not too far away from my mother moving into a nursing home. Probably a couple of years I'd put it…It was emotional but not overwhelming. And I did get it. It was more like a sober realization. Like, a maturing kind of thing. That was kind of part of the whole thing of accepting Huntington's disease. (Mark, age 17) It's hard knowing that I'm almost powerless and that I can't do much to help her because there is no cure. And there's supplements, there's medicine that takes away the fatigue and stuff like that, but it doesn't . . . she's still going to die. And that's, like, sad but you have to come to terms with it too. Otherwise you can't help her at all. (Susan, age 15) It gets hard sometimes. Not actually helping him, but watching him decline, watching him progress. Um, it's hard hearing, you know, when, you know, friends come over and see him and they'll, you know, make comments like, "Oh, I didn't realize, you know, how much he's progressed." Or, um, "That he was actually gonna, you know, be that far along." Um, not that I don't recognize that, it's just kind of like a wake-up call. It's almost like, well, yeah, now that you brought it up, it's . . . I mean, 'cause I don't like thinking about it. I don't like looking at him and being like, "Oh, wow. You know he's, you know, at this stage and this is gonna, this is probably what's gonna come next." And, um, I don't like focusing on that. (Jane, age 20)

	She said don't put her in a nursing home and make sure that I have a good life. Try and live it to the fullest. (Emma, age 12) Sometimes it can kind of be, you know, depressing, but I'm a pretty matter-of-fact person, you know. Like, and if I can't avoid something then I'm not going to worry about it, you know? Um, just like, also, like, you know, I realize my mom's probably gonna die, I don't know, within a couple years or a few years, or she'll be put in a nursing home anyways, but . . . you know I'm fine with that 'cause that's what Huntington's does. (Matthew, age 19) I don't know how to describe it. Kinda made me really upset because, yeah everybody's gonna die, but like my mom is gonna die, like, more than likely way before the average person. And, like, I don't know. Like, dealing every day, like, knowing that each day she's, like, getting worse and worse . . . it just . . . I don't know. It makes me . . . upset and yeah, stuff like that. (Jennifer, age 16) When you're a first-grader you don't exactly realize the gravity of the situation. Ah, I don't know. I knew it was serious. Of course, it's something that's carried with me my entire life as I still remember the occasion. She didn't really talk about it much after [telling us]. I mean, it was part of her life and it was evident and you didn't really have to speak of it because it was there and prominent. (Michael, age 17)
I Wanna Know How Much Time I Have Left: Genetic Risk	I always worry about having Huntington's. So for like, you know, right now is, like, a big time to, like, think about my future and everything. (Abigail, age 20) I worry about, like, you know, having kids and, like, my job – like, you know I wanna be a nurse. So I'm like, you know, how far can I get before something happens. And, you know, and then I don't want anybody to find out and then I'll get fired or whatever, you know. So just stuff like that. Like, you know, like, you know, people want me to get tested so I can just forget about it all and stop worrying about it 'cause you know, they're like, "Oh, well if you have it then you know you have it. You can prepare. But if you don't have it then you can forget about it." And it's just like, I don't know. Like, I just . . . it's like too much to think about right now. (Abigail, age 20)

	My mom doesn’t want me to get tested yet. She’s like, I’m too young. She says I’m not emotionally stable for it. But I wanna get tested so I can plan my life out. A few years ago I wouldn’t have said that. I probably wouldn’t have said I wanted to get tested. {What changed?} kind of have a paradigm shift. Like, I was really depressed about it and, like, if I thought about it I’d get really depressed. And now it’s like . . . I don’t know. Like, I have a boyfriend now and I really, like, I wanna know how much time I have left to spend with him and everything. So I wanna know, like, where we’re gonna live and, like, what I should be, how long I should stay in school for. Like, what I should go for. I’d change, I’d, like, plan my college major and everything. And I gotta figure out how much time I have and, like, think of a career that didn’t . . . like, I couldn’t go to be a doctor – waste all my life in school. (Isabelle, age 20) My timeline was after high school, going into college, after I’d been accepted and gotten all the, everything cleared away I was gonna get tested. Now I’m not sure, but I’m pretty sure I wanna get tested before I get out of college. Knowing that it’s probably, the same things gonna happen to me. I still wanna know. Especially if I, like, when I start a family I wanna know (Mark, age 17) Um, I’d like to know because that would let me know how I’m gonna plan my future. Um, because I’m probably never gonna have kids if I do. Um . . . and, you know, if I have it, that will just let me know that I have to live my life out to the fullest before then. Um, and if I don’t have it, well, then I know that, um . . . I’m gonna have to be a, help my family out the best I can. (Matthew, age 19) It makes me feel guilty. Because I can’t get the disease and she has it. (Sarah, age 13) When I look at it, since I have a chance of having it ‘cause my mom had it . . . she of course is a carrier since she had it. I don’t know. Sometimes I think about what it’s gonna be like if I have it. And how my life is gonna change. But I don’t really let it affect me. I worry more about how my mom’s doing and what I can do to make things better for her now. (Jennifer, age 16)

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CHAPTER 5

CONCLUSIONS

This study focused on the exploration of the manifestation of parentification among young carers of persons with Huntington’s disease. The following section provides a) a summary of this body of work, b) a discussion of implications for future research and practice, and c) a summary of the study strengths and limitations.

Overview of Chapters

Chapter 1: Introduction

As described in the first chapter, Huntington’s disease is an illness that impacts a variety of different motor, cognitive, and psychological functions resulting in debilitating symptoms that progress until death (Huntington's Disease Society of America, 2011). Because diagnosis and the subsequent symptoms occur at an age where children are most likely in the home and because the disease trajectory often lasts the entirety of a child’s time living at home, children in families with Huntington’s disease often adopt a caregiving role (Kavanaugh, Noh, & Zhang, 2016). While this role is usually that of a secondary, informal caregiver, it still has the potential to lead to consequences such as parentification because these children are taking on the roles and responsibilities typically carried out by an adult (Blum & Sherman, 2010; McNamara & Rosenwax, 2010).

In addition to the difficulty caring for a parent with Huntington's disease, there is also the impact that the genetic risk of the illness imposes on these children (Walker, 2007). These children have a 50% chance of inheriting the illness of the parent that they are providing care for and if affected they are facing a terminal diagnosis and witnessing first-hand the devastating disease effects that they too may be experiencing. These realities can understandably complicate the caregiving experience (Dondanville et al., 2019; Kavanaugh, 2014). While parentification is a potential consequence of acting as a young carer, it is important to note that parentification is not solely negative. There are both positive and negative outcomes that can result from parentification, so it should not be viewed as purely pathological (Earley & Cushway, 2002; Hooper & Doehler, 2012). Further, parentification is a multidimensional concept that is unique to the individual experiencing it and the context that they find themselves in (Khafi et al., 2014; McMahon & Luthar, 2007; Williams & Francis, 2010). Therefore, how it manifests in specific individuals and contexts varies.

Chapter 2: Review of Literature

As outlined in chapter two, little is known about parentification among young carers, especially in the context of Huntington's disease, and young carers in general, especially in the United States. The difficulties regarding research in this population relates to a) the lack of a consistent definition of young carers, b) the limited research base of which most of the studies are exploratory in nature, and c) the low awareness and acknowledgment provided to this population, resulting in their exclusion from research, interventions, and policy (Leu & Becker, 2017; Kavanaugh et al., 2016).

This chapter contained two manuscripts, the first of which provided an update to a 2015 scoping review of U.S. research on young carers by identifying young carer research since the original review to assess progress in better serving young carers' needs and identifying persistent gaps for future research (Hendricks et al., 2020b). This review found that despite a previous call to action, few tailored interventions have been developed to prevent or mitigate potential negative outcomes related to the caregiving role, and a need for further research and global policy development (Hendricks et al., 2020b). The second manuscript described a concept analysis, to provide a better understanding of the phenomenon of parentification in young carers through a description of its antecedents, attributes, and consequences (Hendricks et al., 2020a). The resulting conceptual framework serves as not only as a foundation of understanding that specifies potential targets for intervention development, as well as modifiable outcomes, but also served to improve knowledge of young carers and to help justify future research, programs and policy (Hendricks et al., 2020a). This conceptual framework also served as a guide for the analysis conducted for this body of work.

While there has been research conducted related to parentification and young carers, as well as research related to young carers of persons with Huntington's disease, no research has explored how parentification may manifest among young carers in the context of Huntington's disease. To help fill this gap, this body of work aimed to explore how parentification manifests among young carers of persons with Huntington's disease.

Chapter 3: Methods

This study utilized a directed content analysis approach to perform qualitative analysis of secondary data. The data consisted of the transcripts from interviews with 28 individuals who all had a parent diagnosed with Huntington's disease exhibiting symptoms and self-identified as assisting their parent and family due to that diagnosis (Kavanaugh et al., 2015). Participants were recruited through the HDSA (Kavanaugh et al., 2015). The sample was made of up of primarily female participants (78.6%) and had a mean age of 16.6. Most reported acting as a young carer for 1-3 years (53.6%) with an average of 25.4 hours of care provided per week. The interview transcriptions provided not only the responses to the three open ended questions, but also elaborated responses to the closed ended questions which utilized a combination of Likert scales and true/false questions.

The directed content analysis approach called for the use of the parentification among young careers conceptual framework (Hendricks et al., 2020a) to guide the initial coding structure, while also allowing for the emergence of potential new categories (Hsieh & Shannon, 2005). After construction of a formative categorization matrix to serve as an initial guide to coding, the process of coding proceeded normally through converting meaning units to codes and then grouping those codes in the themes and sub-themes based on similarities and differences (Assarroudi et al., 2018; Bengtsson, 2016; Erlingsson & Brysiewicz, 2017). The themes and subthemes resulting from analysis of the data were then compared to the categories outlined in the formative categorization matrix to assess similarities and differences (Assarroudi et al., 2018; Hsieh & Shannon, 2005).

Chapter 4: Results

The results of this body of work, included as a manuscript, show that young carers in the context of Huntington's disease experience many of the attributes and consequences outlined in the parentificaion conceptual framework among young carers. The results demonstrated that their peer relationships and school performance were impacted by the caregiving role, the importance of social support, their feelings of fairness and obligation regarding their role, the relationship between the child and the care receiver, their education related to the caregiving role, and their potential for personal growth in the form of maturity and responsibility (Hendricks et al., 2021). While this study is unable to definitively say that these children were or were not experiencing parentification, it is evident from the data that they were experiencing aspects of the phenomenon as outlined in the conceptual framework (Hendricks et al., 2021).

Unique findings emerged from the data that were not originally reflected in the guiding framework. This is likely because these experiences are unique to young carers of a person with Huntington's disease. These emergent themes and subthemes dealt with the genetic risk of the illness, the discussion of end of life that is part of the Huntington's disease caregiving experience, the change in the relationship between the parent and child as a result of Huntington's disease, and the stigma and embarrassment surrounding Huntington's disease (Hendricks et al., 2021). An emergent theme that should be included in future iterations of the general framework of parentification among young carers is the concept of caregiver burden (Hendricks et al., 2021). While some of the potential consequences associated with caregiving burden were included as consequences in the original framework, inclusion of caregiver burden as an attribute of parentification in future iterations of the framework may be indicated

Implications

As with all work in the population of young carers, the first implication of this body of work is for healthcare providers, educators, and society as a whole to acknowledge that there are children providing care to individuals with chronic illnesses such as Huntington’s disease. For clinicians who are treating an adult with a chronic illness, such as Huntington’s disease, it is important to consider whether or not they have a child, as that child may be contributing to the caregiving going on at home and consequently, may benefit from support and education related to that role. As educators, it is important to acknowledge that if a parent of a student has a chronic illness, such as Huntington’s disease, the child may be taking on roles and responsibilities outside of the norm for a child and that it may have an impact on the child’s ability to participate in school related activities and their peer relationships. As a society, it is important acknowledge that children of ill parents may be taking on a caregiving role and to help eliminate the stigma and isolation they may feel as a result of their parents having an illness such as Huntington’s disease, but also to allow the child to feel that they can reach out for assistance if they find that they need it.

In the future, more research should be conducted to explore young carers in different disease contexts. Additionally, research is needed to explore the impact of the caregiving role on young carers over time through longitudinal research. To date, there are limited studies exploring the impact of the caregiving role and its consequences on a young carer’s adult life. Additionally, much of the research to date is exploratory in nature. Future research should focus on testing and implementing interventions to help young carers whether by minimizing the outcomes related to parentification or by helping to determine which factors may moderate or mediate outcomes. As a whole, researchers can make an effort to include children under the age of 18 in their studies looking at caregiving, and likewise the support and resources provided to adult caregivers could also be extended to those under the age of 18.

Strengths & Limitations

A strength of this body of work is that it provides a foundation to be built upon through continued research. Studies focusing on parentification among young carers are severely limited, especially in the context of specific illnesses or conditions. This body of work serves as an example for the exploration of parentification in areas that are previously unstudied. Another strength of this body of work is that it utilized a sample made up of children of a variety of different ages ranging from 12-20. Similarly, it included children at various points along the caregiving continuum, whether their parent was in the early stage of Huntington's disease or the late stage. This allowed for a broader picture of the caregiving experience in the context of Huntington's disease.

Limitations of the present study primarily deal with the fact that secondary data was utilized. Because the data was collected at an earlier timepoint, it was not possible to alter the data that was collected. Therefore, the data was not necessarily ideal for the aims of the study as questions pertaining specifically to parentification in young carers and its various attributes and consequences were not always asked of participants. Furthermore, because the data was collected at a prior time point, findings of the current study may not reflect of the context surrounding participants in the present day (Ruggiano & Perry, 2019). For example, the impact that the COVID-19 pandemic has had on young carers of persons with Huntington’s disease is not something that would be reflected in the data. Related to design, because the present study is an exploratory, qualitative study, cause and effect cannot be proven. Therefore, the present study is unable to definitively state that the young carer role in the context of Huntington’s disease causes parentification or that parentification causes the consequences discussed.

Conclusion

Being a young carer of a person with Huntington’s disease is an experience that is difficult for children as they are often taking on adult roles and responsibilities without any lessening of their own age-appropriate ones. In time, this role of young carer may result in consequences such as parentification. This body of work explored how parentification may manifest in young carers in the context of Huntington’s disease through a secondary qualitative analysis of transcripts from a sample of 28 children aged 12-20. Collectively, this body of work illustrated that young carers in this context experience many of the attributes and consequences outlined in a conceptual framework for parentification among young carers, but that there are unique aspects of being a Huntington’s disease carer that were not included in this framework. These findings contribute to the overall knowledge of young carers, especially in the context of Huntington’s disease, and bring to light important considerations for future research, support, and policy aimed at this population.

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