Child and Adolescent Social Work Journal (2021) 38:491–504
https://doi.org/10.1007/s10560-021-00783-8

How Far Have We Come? An Updated Scoping Review of Young Carers in the U.S.

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Accepted: 23 July 2021 / Published online: 10 August 2021

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 · 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 to 2015, reflecting the

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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) charting the data, (4) summarizing and reporting results, and (5) consulting with a known young carer expert to validate the overall review (Arksey & O'Mallley, 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 aged 18 and younger in both the U.S and internationally, and (2) the role they play 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 < 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 Fig. 1.

Results

From May 2015 to 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 United Kingdom, Australia, Pakistan, and Norway. Methodology varied, including six quantitative studies, three qualitative studies, and three mixed methods studies (Table 1).

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, 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, 2018, 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, 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 (Dondanville et al., 2019; Kavanaugh et al., 2016) stated ages 8–18, 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 et al. (2018), who included up to age 21, McDougall

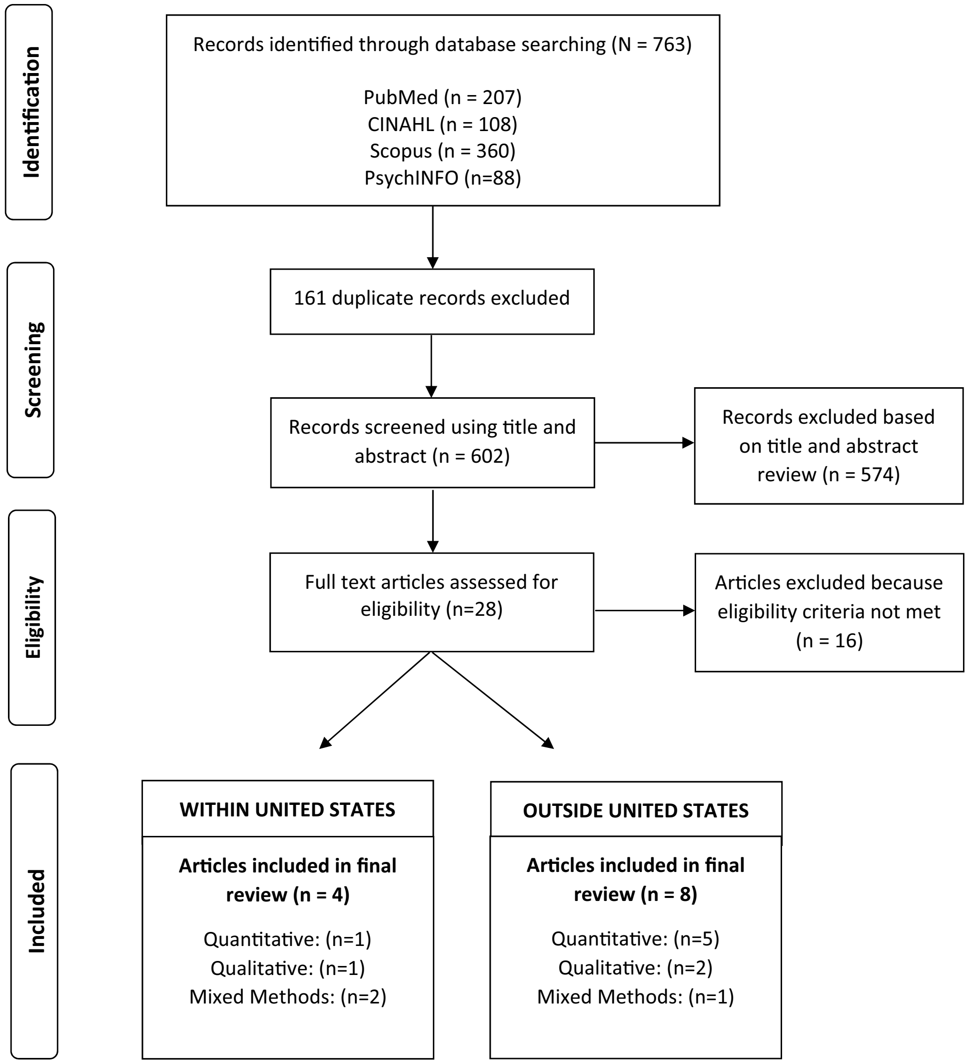

Fig. 1 PRISMA diagram of literature search-young carers 2015–2020

et al. (2018) who included up to age 25, and Metzing et al. (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 et al. (2017, 2018, 2020) and Metzing et al. (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

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	N = 396; sixth graders participating in CYP; mean age = 11 Male 38% Female 62% Hispanic 31% Haitian 17% White 17% Black 10% More than one, other or unidentified 21%	(1) To describe the participation, demographic and caregiving tasks among sixth graders 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 physical 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	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

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Kavanaugh et al. (2019) U.S.A. Social Work	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 and 18 providing care to ill family member	Mixed methods study; combining results from three previous studies Quantitative: demographics, caregiving skills, and training Qualitative: thematic analysis approach	(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 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 et al. (2020) U.S.A. Social Work	N = 38; aged 8–18; identified by family member with ALS as proving care Male 55% Female 45% White 76% Black 5.2% Hispanic 16% Native American 3.3%	(1) To identify and describe characteristics and perceptions of care from family and youth caregivers	Young caregivers: children and youth between age 8 and 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	Strengths: reverses assumptions that adults alone provide care. Results can be used to inform future research and programs Limitations: purposeful, limited sample. Sample is primarily White. Unclear whether parent was in the room during telephone interview Gaps/future research: future research and caregiver programs need to be adapted to target caregivers < 18 years old. Interventions for care that target a whole-family approach

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Outside the United States						
Nagl-Cupal and Prajo (2019) Austria Nursing	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	Strengths: shows that camps can make a significant contribution to giving young caregivers a feeling of normality and a break from their roles Limitations: 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 Gaps/future research: 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

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Gough and Gulliford (2020) U.K. Psychology	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 Male 43% Female 57%	(1) To determine whether children have different outcomes whether their parent has physical illness, mental illness, or substance abuse (2) To explore whether any factors are associated with the positive and negative outcomes	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	Quantitative study; cross sectional, explorative	(a) 10% of children reported negative outcomes at clinical level of concern (b) Half the children reported stress (c) Outcomes were not different across three groups of parents (d) Positive and negative outcomes were associated with caring activities, social skills and external locust of control	Strengths: linked data between parent and child, data comparing three parent groups. Use of well-established questionnaires Limitations: unknown inclusion rate. Many eligible people were excluded due to issues with provider reluctance to inform patient. Difficulties with participation due to illness Gaps/future research: need to explore how different types of caring activities impact outcomes. Providers must provide a better assessment of needs of young carers

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Kallander et al. (2017) Norway Medicine	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 activities (d) Social skills and external locust of control significantly impacted caring activities	Strengths: linked data between parent and child, data comparing three parent groups. Use of well-established questionnaires Limitations: unknown inclusion rate. Many eligible people were excluded due to issues with provider reluctance to inform patient. Difficulties with participation due to illness Gaps/future research: 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

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Kallander et al. (2020) Norway Medicine	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 male, 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	Strengths: large sample size, linked data between parent and child, broad recruitment, use of well-established questionnaires, few missing data points Limitations: skewed representability, no testing for co-morbidities in parents. No causal determinations can be made due to design Gaps/future research: 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

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Majeed et al. (2018) Pakistan Medicine	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	Strengths: adds to gap in research in low- and middle-income countries Limitations: small sample size, minimal ethnic diversity. Convenience sampling, limited generalizability. Inability to show causation Gaps/future research: 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 et al. (2018) Australia Psychology	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 (f) Challenges with feeling lost in the system and problems accessing support services	Strengths: focuses on the perspectives of young carers instead of just service provisions and policy Limitations: limited diversity of sample. Challenges in recruiting participants. Not a longitudinal study Gaps/future research: resources in a youth 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

Table 1 (continued)

References	Study population	Study aim (s)	Definition of young carers	Methods	Main findings	Strengths/limitations Gaps/future research
Metzing et al. (2020) Germany Nursing	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

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, 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, 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, 2020; McDougall et al., 2018). Indeed, Assaf et al. (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 et al. (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 et al. (2018) suggested screening for symptoms and culturally sensitive interventions that could help children cope. Kallander et al. (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 et al., 2016) and longitudinal designs (Gough & Gulliford, 2020). Additionally, all of the authors discussed the need for intervention research (Assaf et al., 2016; Dondanville et al., 2019; Gough & Gulliford, 2020; Kallander et al., 2017, 2018, 2020; Kavanaugh et al., 2019, 2020; Majeed et al., 2018; McDougall et al., 2018; Metzing et al., 2020; Nagl-Cupal & Prajo, 2019). In addition, Metzing et al. (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 to 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 et al. (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 et al. (2019) states the need for caregiver education that allows for engagement with "like peers" in similar situations, which informed the development of the YCare, a training and education program for young caregivers in neurological disorders (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 and Prajo (2019) states that political awareness is low for this population and there is a need to raise that awareness. Kallander et al. (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 et al. (2018) calls for more policy and a more sensitive and accurate portrayal of young carers in the media, 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 to 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.

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