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# Medication administration by caregiving youth: An inside look at how adolescents manage medications for family members

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## ABSTRACT

**Introduction:** Children take on the role of family caregiver throughout the world. No prior published research exists surrounding the particular circumstances of the task of medication administration and management by these youth, which was explored in this study.

**Methods:** A series of focus groups were conducted using semi-structured interviews of 28 previously identified caregiving youth ages 12–19 years old who live in the United States. Data analysis followed guidelines of conventional content analysis.

**Results:** The following categories emerged about youth caregivers handling medications: 1) tasks involve organizational and administrative responsibilities; 2) youth have varying degrees of knowledge pertaining to these medications; 3) most share responsibility with other family members; 4) they lack formal education about their responsibilities; 5) multiple challenges exist relating to this task; 6) managing medications is associated with emotional responses; and 7) possible safety issues exist.

**Conclusions:** These responsibilities represent a unique hardship and merit support and research from the medical, healthcare, legislative, and public health communities, among others.

## 1. Introduction

Caregiving youth, also known as youth caregivers or young carers as they are variably termed in different countries, are a worldwide reality. These youth provide care to family or household members for a variety of reasons: chronic physical or mental illness, disability, substance misuse, and/or other health condition(s) (Aldridge, 2018; Bleakney, 2014; Cass et al., 2011; Fives, Kennan, Canavan, Brady, & Cairns, 2010; Kavanaugh, Stamatopoulos, Cohen, & Zhang, 2016). Their responsibilities range from assisting in both personal and medical care to managing the majority of household duties.

The global prevalence of this phenomenon is difficult to pinpoint for two major reasons: 1) lack of standardization across countries, in terms of both definition (i.e. what determines caregiving) and age (e.g. in the U.S. ages 8–18 versus in Australia under 25 years) (Becker, 2007) and 2) the ‘hidden’ nature of young caregiving because of the stigma associated with illness or because the family is concerned that authorities will get involved and separation will ensue (Aldridge, 2018; Pakenham, Bursnall, Chiu, Cannon,

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& Okochi, 2006). While there may be some potential benefits to children from taking on caregiving responsibilities such as increased maturity, better preparation for adulthood and feelings of pride about their role (Rose & Cohen, 2010), the literature also shows that the requirements of this role can have a negative impact on caregiving youth academically, psychosocially, developmentally, and physically (Aldridge & Becker, 1993; Aldridge, Cheesbrough, Harding, Webster, & Taylor, 2016; Cass et al., 2011; Cohen, Greene, Toyinbo, & Siskowski, 2012; Fives et al., 2010; Kavanaugh et al., 2016).

Caregiving tasks are often divided into two categories. The first is Activities of Daily Living (ADLs), such as bathing, dressing, toileting, feeding, diapering, and assisting with mobility. The second is Instrumental Activities of Daily Living (IADLs), which includes handling finances and appointments, housework, transportation, translating, keeping company, meal preparation, using medical equipment, and managing medications. Medically related tasks are unique from other caregiving tasks because, if done incorrectly, can be life threatening. Medication management includes using judgement, such as when a dose is missed, along with a range of responsibilities such as organizing multiple medication schedules, measuring doses of medications, and physically administering medications through varied routes such as eye drops, nebulized solutions, physical placement of pills into care receiver's mouth, and injection of medications, each of which requires complex organizational and sometimes technical skills. Adult caregivers have reported that among the complexities the most stress provoking involved keeping multiple prescriptions filled, managing variable doses of medications, and remaining constantly vigilant for problems (Travis, Bethea, & Winn, 2000).

Clearly these varied responsibilities require different levels of knowledge and understanding. This distinction has been made by organizations that regulate home healthcare delivery. For example, the Florida Agency for Healthcare Administration (AHCA), which regulates tasks in home health, has determined that oral medications can be managed by an unlicensed home health worker, but recognizing the advanced skills needed for injection of medication, requires that this be done by a trained professional (Agency for Healthcare Administration [AHCA], 2016). Yet families, without the benefit of qualified trained health workers in their homes, take on these complex skills on a daily basis. As another example, local authorities in the United Kingdom, the most outspoken region in the world about young carers with research and campaign originating there (Aldridge & Becker, 1993, 1996; Keith & Morris, 1995), carry out young carers' assessments evaluating the appropriateness of caretaking for the person in question (Children and Families Act 2014). Inappropriate or excess care is defined as anything that will have a detrimental impact on the young carer, and administration of medication is definitively listed as an inappropriate responsibility ("Care & Support Statutory Guidance", 2016).

Studies reporting various types of care work have shown that approximately one third of youth caregivers in the US and half of young carers in the UK assist their family member(s) in general and nursing care which includes medication administration (Assaf, Siskowski, Ludwig, Mathew, & Belkowitz, 2016; Dearden & Becker, 2004; Hunt, Levine, & Naiditch, 2005; Kavanaugh et al., 2016). Qualitative studies show that young carers in Ireland reported administering medication as young as 10 years of age (Fives et al., 2010), and young carers in the US reported drawing up insulin as young as 5 years of age (Jacobson & Wood, 2004). However, this research team has not identified any previous studies that explore the issue of medication management by children. Thus, this qualitative study was undertaken to gain insight into the children's reported experiences and perceptions surrounding their responsibility related to medication management.

## 2. Methods

### 2.1. Study design

A qualitative research methodology, conventional content analysis, was used to collect data from focus groups. Focus groups are often used for examining perspectives of individuals who have a shared experience, but who might find it easier to articulate that experience if expressed collectively or in response to others (Kitzinger, 1995). Using groups with children and youth as the research method can empower participants to have confidence that their perspective is valuable (Carey & Asbury, 2012).

### 2.2. Participants

Participants of this study were school children ages 12–19 years enrolled in the Caregiving Youth Project of the American Association of Caregiving Youth<sup>®</sup>. Enrollment eligibility for the Caregiving Youth Project is based on high levels of caregiving responsibilities and weekly time spent in caregiving. The American Association of Caregiving Youth is a nonprofit organization headquartered in Boca Raton, Florida, with a mission of identifying and addressing the multitude of unrecognized issues of youth caregivers. The organization's model direct services program, the Caregiving Youth Project, works in partnership with The School District of Palm Beach County, and annually serves more than 600 youth caregivers and their families through a Skills Building curriculum, counseling, support services, respite, academic support, family strengthening, and a variety of fun activities. Partnering with the American Association of Caregiving Youth for this research allowed direct access to this specific population of youth caregivers, who are often otherwise unidentified. The caregiving youth participants of this study were identified by American Association of Caregiving Youth records or staff as involved in their care recipient's medication management.

Initially, seven caregiving youth were recruited by Caregiving Youth Project staff members and one of the researchers via face-to-face interactions at an American Association of Caregiving Youth holiday party in which both children and families were present and could provide consent. However, because of logistical issues (ex., transportation), only two of these students participated in the study. The rest of the participants were recruited by Caregiving Youth Project staff members working directly with children at individual schools, and parents were contacted after initial identification to provide consent. For the focus group that was held onsite at a school after hours, participants were recruited directly by Caregiving Youth Project staff members at that site in order to minimize logistical

**Table 1**  
Demographic and caregiving related characteristics of participants (n = 28).

<b>Age in years (range, mean)</b>	12 - 19, 14.7
<b>Female</b>	20
<b>English only spoken at home</b>	18
<b>Self-reported racial/ethnic/country of origin group</b>	
Caribbean	11
African- American	7
Hispanic/Spanish speaking country	6
Caucasian	4
<b>Care recipient relationship <sup>a</sup></b>	
Grandparent	10
Parent	9
Sibling	5
Other (cousins, aunts/uncles, unrelated)	10
<b>Reported diagnoses of care recipient(s) <sup>b</sup></b>	
Neurologic related disease <sup>c</sup>	12
Diabetes	7
Functional decline/mobility loss	4
Asthma	4
Vision loss	4
Other	4

<sup>a</sup> Six children reported two care recipients.

<sup>b</sup> Seven caregivers report multiple diagnoses for care recipient(s).

<sup>c</sup> Includes ALS, paralysis, autism, multiple sclerosis, Parkinson's, spinal tumor.

barriers for participation. Each caregiving youth received a \$20 gift card for participation.

The Caregiving Youth Project is a school-based program, and for this reason children were grouped according to the structure of the local school system. A total of 28 caregiving youth from high schools (ages 15–19 years) and middle schools (ages 12–16 years) participated. Demographic and caregiver-related descriptors were extracted from American Association of Caregiving Youth records and are provided in Table 1.

### 2.3. Procedure

The Institutional Review Board at the university approved the study protocols. All youth caregivers gave written assent and parents/guardians provided written consent for participants under 18 years of age; caregiving youth who were 18 years or older provided their own consent. Four focus groups were held: two sessions with middle school caregivers and two with high school caregivers. All focus groups were moderated by the same researcher (MN), with a Caregiving Youth Project staff member present to provide a passive supportive and a non-participatory role. Comments from the staff member were neither coded nor included in the analysis. Three groups were conducted in American Association of Caregiving Youth offices on school holidays; the fourth session was held on site at a school after hours. Each of the four focus group sessions was comprised of 5–10 participants and lasted approximately 60 min. The sessions were audio-recorded and transcribed by an external transcription service.

Focus groups were conducted by the first author who, at the time of the data collection, was a third year MD/MPH student with no previous experience with or exposure to the population studied. Two other others (JB and CS) participated in the data analysis. JB is a pediatrician and has conducted research and advocacy about caregiving youth but has not interacted directly with study participants. CS is the founder and president of the American Association of Caregiving Youth and in that role has over a decade of experience working directly with and advocating for caregiving youth.

Identifying information was not asked of participants during the session, but some children provided their names during the recorded introductions. Speakers were identified only by number throughout the rest of the transcription. If names were included, they were redacted from the transcriptions prior to analysis.

### 2.4. Analysis

Transcribed content from the focus groups was analyzed using conventional content analysis as the general analytical approach. Conventional content analysis is used for topics for which there is little previously published in the literature and helps to describe phenomena (Hsieh & Shannon, 2005).

Initially, three researchers independently read through each of the four focus group transcripts. They devised a codebook based upon emerging themes which contained a definition of codes, guidelines for their application, and quotations from the data exemplifying the code usage. Two researchers (MN, JB) independently coded the transcripts using the codebook, and then compared coding for consistency and agreement. The third investigator (CS) served to resolve any differences until the data was coded definitively, a process which strengthened reliability by improving consistency between codes, and ensuring that coding categories were well justified in the context of the collected data. The initial codes were then consolidated into broader clusters, and the final phase of

analysis consisted of all three investigators identifying themes based on a broader review of the transcripts and the coding. The themes were then used to create a framework about caregiving youth's experiences with medication management based on the focus group input, which is presented below.

The qualitative data analysis software ATLAS.ti was used to organize and sort through data during the analysis phase. Importantly, this software does not conduct analysis nor draw conclusions itself. Rather, it allowed the researchers to more easily categorize codes, link quotations to those codes, and overall manage the data documents efficiently.

## 2.5. Materials

Each of the four focus groups was conducted using semi-structured interviews. The focus group guide was developed by the research team, including the president of the American Association of Caregiving Youth and in consultation with a pharmacist. The interview guide was created in order to better understand key topics surrounding medication management identified from the adult literature and from the experience of the experts in the field. The guide created an overall structure for the interviews while also allowing for naturally occurring discussion. Questions centered on topics including the caregivers' responsibilities, knowledge about the medications they are administering, and the challenges and feelings associated with the tasks. The focus group guide is provided in [Appendix 1](#).

## 3. Results

Seven key themes emerged revealing concepts reflective of the reality of children handling medication for family members. These themes are: 1) caregiver responsibilities related to medication management; 2) the process of receiving instruction; 3) extent of caregiver responsibility; 4) overall knowledge pertaining to medication and care recipients' health condition(s); 5) challenges related to handling and administering medication; 6) feelings associated with medication management and administration; and 7) safety concerns.

### 3.1. Caregiver responsibilities related to medication management

The participating caregivers discussed their responsibilities in supporting a full spectrum of tasks related to actual administration of medication, sometimes for multiple family members and/or in multiple households. Examples of tasks included transporting pills from bottle to care recipient; organizing medications into pillboxes and/or physically administering the medication (for example, masking a medication with food and/or placing a pill or liquid medication directly into their care recipient's mouth); determining if an as-needed medication should be administered; handling insulin for a diabetic family member with responsibilities extending to measuring and injecting the medication; and assuring compliance. One middle school caregiver demonstrated a range of responsibilities and stated:

"I [help] my grandma put the pills into the little pill thing, like [it] says Monday, Tuesday, Wednesday, Thursday, that thing. So I help her do that and then I do, I will measure it out and give her the insulin."

The majority of participants were responsible for multiple medications for their family member. Some handled medications for several individuals as well, with a few helping family members living in different households. For most, this was a daily duty. Some had specific schedules they followed, such as the following participant:

"No, I know when to give it 'cause there's different times. And we have this boxing [box thing] at Monday, Tuesday, Wednesday evening, morning, evening. And then I know what time to give it. Like for morning I'll give it at around 10. But I didn't do it this time 'cause I had to get ready to go here [focus group]. So my sister did it... And so then – then I get, for evening, I'm doing it at five – noon. I do it at 12. And at night I do it when he goes to bed."

Others gave medication on an as-needed basis, requiring them to discern when their family member either missed or required a dose. One middle school caregiver explained:

"Because when he's coughing, I guess when he's coughing even though it's not like a real asthma I just want to give him some medicine just to make sure, you know?"

Responsibilities for many of these children also included more extensive organization and preparation. One caregiver discussed the process of organizing the schedule of medications for his mother:

"I grab her phone because she always had it with her. So I'll put, she has to take her pills at least six times a day and there's three different types of pills so she takes, maybe over 20 pills each day. So I have to put, like this time the three pills, this time these 5 pills, this time these 2 pills or something."

### 3.2. The process of receiving instruction

Numerous youth caregivers noted that the care recipient taught them which medication to give and when. Many progressed from initially needing instruction on handling medication to being able to do so without assistance. One high school respondent noted:

“Sometimes when I was younger, I would – my mom has been doing it for a while. But when I was younger, she would get her own pills and stuff. So I would kind of just watch her. Now I know how to do it. And she's told me, get this type of pill.”

When the care recipient was unable to provide instruction, caregiving youth may have learned from other family members who shared the responsibility. This type of “team-effort” was a common finding among the youth in this study. As one middle schooler explained:

“My uncle has, because my uncle has had his diabetes since I was really little my mom knew that she wasn't going to be here all the time to always give him the thing, so she would bring me to work with her like show me how to do it so then I eventually learned how to do it when I was eight and I was really good at it so that's how I know how really good.”

Some children experienced more passive, non-structured instruction where they learned through years of watching others. Others relayed the sentiment of medication administration being ingrained in them due to years of responsibility, rendering them unable to characterize how exactly they learned, revealing that handling medication has “always been this way” and thus that they cannot remember a time before their responsibilities. One respondent stated:

“I grew up with it, kind of. So I just know, pretty much. It's not really something I learned.”

Other youth caregivers received instruction from someone in the medical field, including home health aides, nurses, pharmacists, and physicians. One caregiver explained:

“Because like I said, my mom can't do stuff by herself. So she has to have aides in the day. And there's this one aide ... She's been around since like, since the beginning and she's still with us. So I learned from her.”

Some child caregivers took on an active role when interacting with medical staff, taking notes about medications and asking questions for clarification:

“They – usually they ask my mom a lot of questions and I answer them for her. And she'll tell me what to say, and then I'll repeat it to them. And when they – when she – when they are telling her what to do with the medication that she's taking, they – I listen to that because they usually – they're usually talking straight to me. But they're also talking to her. Because they know she can't do it by herself, so they're looking at me ...”

Other youth received a combination of instruction processes, as below:

“I – my – when my mom got sick, I was three years old. And then I started watching people at a young age taking care of her and stuff. And they – and then when I turned six, my mom, she needed help more. And it was like, it was getting worse. And I got older. And then – what do you call it – she just, they taught me everything. And my brothers were already doing it. When my mom got sick, they were older than me so they were already doing it. And they would show me – 'cause if they would leave and I would be there by myself with my mom, they would show me what to do and everything. And then I kinda learned from there.”

### 3.3. Extent of caregiver responsibility

In response to an inquiry about the proportion of responsibility these children carry, participants revealed that often this is a shared responsibility with other family members and/or health professionals. A couple of examples are:

“I don't know. If it's not the aide, then it's me. And it's rarely my brother or my sister.”

“Since I don't know how to put the insulin in and I know he needs it, and my sisters are there, but usually they're really tired 'cause they have to go from school. But I'm just like, can you please do it? 'Cause I just really want him to get it. And so I pick – I practically just force them to do it.”

A few youth caregivers noted that while other family members carry certain responsibilities now, the task will be “passed down” to them in time. For example, when one participant was asked about giving insulin to her family member, she responded:

“Yeah. My sister does that. I don't know how to do that yet. But they said they're gonna teach me. Don't know when. But it's gonna happen I guess.”

Finally, there were several youth caregivers who identified themselves (by raising their hand) as the primary manager of medications in the family.

### 3.4. Overall knowledge pertaining to medication and care recipients' health condition(s)

In response to open-ended questions about their level of understanding regarding the medications and the conditions treated, there were differences in knowledge between older and younger caregivers; older youth caregivers generally possessed more advanced understanding of medication function than their younger counterparts. This is a notable difference from the remainder of the themes, which were similar for both age groups. Similarities as a whole for participants included tasks, manner of instruction, and demonstrated degrees of responsibility. The following quotations represent the spectrum of knowledge pertaining to medication

function, by grade level:

Middle school (ages 12–16 years) caregiver responses:

“One is to help them sleep, one is for throat cancer. One is to make sure that they don't, like whatever they eat doesn't come right back out. And then a few more, I just don't remember what they do.”

“The yellow one is for to get her strength back because she cannot walk anymore. And yes, I don't know what they do for her. I just know the yellow one.”

“I know the insulin keeps him alive. I don't know if the pills do, though. And the insulin, it helps to be good.”

High school (ages 15–19 years) caregiver responses:

“I think her medication is replacing her hormones that the body can't produce naturally anymore. That's really all I know.”

“I kind of give my brother either a sleeping pill or melatonin every night because he really can't sleep on his own because he's got a lot of energy.”

“I know that it helps balance blood sugar and it keeps it elevated. So if you don't take it, it won't balance, it will just get even higher. And then you can either have to go to the hospital or something.”

The degree of knowledge also varied between age groups in terms of understanding the care recipient's health condition:

Middle school (ages 12–16 years):

“I think she has scoliosis and some other thing. I don't know. But I – she takes, I think – I have no clue. I forgot what they call them. I forgot what it's called.”

High school: (ages 15–19 years)

“Another thing that's [hard] is since my grandfather he has diabetes also, he like buys a whole bunch of sweet, he's like I'm going to eat this cake or I'm going to eat this, like no you should take your medications, it's time to take your medication. So it's hard for me to stop him from eating sweets because to keep his you know blood sugar down so it won't go up really high.”

The researcher asked if the caregiving youth were able to recognize the intended effects of the medication they give to their family member. Responses varied, seemingly with the type of medication that was handled. If the medication treated pain or hyperactivity, respondents were more likely to note an effect. For medications that treat chronic diseases, the effects were more difficult to ascertain. Some respondents were unable to notice any effect and voiced a blind trust in the medication. The following quotes from high school caregivers demonstrated this spectrum:

“I can tell. Because if it's not, my mom will be in like agonizing pain and she can't walk.”

“I just think it's helping. If the doctors say they should take it, so it must be helping.”

A high school caregiver demonstrated the need to monitor his mother to ensure the insulin is taking effect:

“I would know, because I wait 10–20 minutes, and I'll see if she's getting better, and I'll ask her, are you feeling a little bit better? And I'll test her blood sugar also.”

### 3.5. Challenges related to handling and administering medication

Youth were asked about what challenges they faced related to medication management and administration. Several participants noted difficulty understanding instructions, either written or as instructed in person by a health care professional. One middle school caregiver explained:

“Some of the stuff that the doctor says is kind of complicated because he uses, because he says this thing and this thing but you have to do this and this and I'm just like wait, can you start over? And then he says it over and over until I actually get it.”

Another caregiver noted:

“It has all these weird sayings. And sometimes I can't pronounce it so I'm just like, OK. This is great.”

The most common challenge for these child caregivers was noncompliance by their care recipient. Participants reflected on numerous instances in which family members refused to take their medication. One high school caregiver who routinely injected insulin into his diabetic mother stated:

“I learned through tricks sometimes. She says she can do it, and sometimes she didn't do it. So I say, I'm going to watch you do it and make sure you do it. Sometimes she'll be stubborn.”

Others had family members who physically interfere with administration of the medication. One participant noted:

“Sometimes he just won't let me—he won't take it. He'll slap it out of my hands sometimes.”

A few of the youth had developed strategies to reduce noncompliance in their care recipient. For example, some frequently “check

in” with their family member to ensure the pill has been taken. Others find ways to mask the medication in food, as one would with a child. One middle school participant explains:

“... so we have to hide it because he wouldn't eat it ... we have to force them to eat it because he's like, if he doesn't eat it he's going to have reactions and all of that.”

Another difficulty ascertained from conversations with these youth related to dynamics within their families. Because the majority of these youth shared responsibility with other family members, the tasks occasionally became a source of family conflict. One child stated:

“There's only a permanent aide on the weekday. And sometimes the aides, they can't come. So then I worry about her. But – 'cause if I'm not there, my brothers, sometimes they get attitudes and they don't want to do anything and so then I kinda get – and it makes me upset. That they don't want to help their mom ...”

Finally, several participants recalled their family members experiencing side effects related to medication that posted a challenge. The majority who had dealt with adverse effects were not certain that the symptoms were a medication reaction, further highlighting the lack of knowledge these youth caregivers have related to their responsibilities. One middle school caregiver recalled a potential side effect experience:

“It happened – that happened to my mom before. She took this medication. Then she got hives. And then – what you call it – things bothering her. And I think she was – it was another allergic reaction. And she got hives on her body. And then so I called the – I called my grandma 'cause she lives down the street.”

Interestingly, although youth caregivers alluded to multiple challenges related to medication management, the overall sentiment was that the burden of handling medication is small, compared to the other caregiving responsibilities. When questioned if dealing with medications is a “hard” part of having a sick family member, almost every participant responded that it was indeed “easy.” When asked why that was, one participant responded:

“Because the manual labor is harder ... Yeah, feeding her and bathing her, and all that stuff. That's harder.”

### 3.6. Feelings associated with medication management and administration

Focus groups highlighted the emotional response of medication responsibilities on caregiving youth. A common emotional response noted in our participants was “worry.” This was demonstrated in a variety of ways such as concern for lack of compliance by their care recipient, worry about adverse reactions, anxiety surrounding administration instructions, and fear that if they are unable to be present the family member may not receive the medication. One participant shares a personal concern:

“My mom has to be on medication for the rest of her life because they took out her thyroid. So I don't know what happens if she doesn't take her medicine. Hopefully I don't find out.”

Another expresses a more logistical worry:

“Like what if the power goes out. What happens to the insulin?”

Another emotional response noted in participants was regret that they are “missing out” on other aspects of childhood and adolescence due to their medication responsibilities. Examples of this vary from educational to recreational activities. The following participant demonstrates this:

“Yeah, that's the hard part. Sometimes I want to leave, and she's like, no. Wait. And then sometimes, because I volunteer at a (...) clinic, and she's like. No, you can't leave yet. But I have to get my hours so I can certify. Either I miss my hours, or I give her the medicine.”

Several participants expressed a desire not to have medication responsibilities. When asked what would make things easier, one middle school caregiver replied:

“Someone else to do it because I would really like some sleep.”

Interestingly, youth in multiple focus groups requested a machine to administer medication in their place. One middle school caregiver described:

“I want a robot, like a robot that helps, you know it just gives you the medicine, make sure you're taking your medicine.”

### 3.7. Safety concerns

One theme that emerged from focus groups was that child caregivers may encounter unsafe situations as a result of medication responsibilities, whether or not they are aware of them, especially surrounding caregivers who handle insulin for diabetic family members. One high-school caregiver details his experience with sharps disposal:



“Yes. Just wrap them in paper towels and put it in the trash ... the big one outside. Just drop it there.”

#### 4. Discussion

This investigation explored the significant reality of medication administration by adolescents. For the first time, this documents actual responsibilities, training, and knowledge relating to this role as well as introduces some of the related potential challenges, emotional response, and other concerns. This study highlights areas in which support for caregiving youth who manage medications is urgently required and emphasizes the pressing need for further research about this phenomenon.

##### 4.1. Areas in which support is needed

Child caregivers take on tasks that require complex skills similar to ones documented in the adult caregiving literature (Look & Stone, 2018). Alsaeed, Jamieson, Gul, and Smith (2016) described that adult caregivers of patients with dementia take on tasks that require management skills in varied domains such as teamwork, organization, symptom knowledge, and medication knowledge and suggest that caregivers require support in accomplishing these varied tasks successfully. Given their developmental immaturity, it would seem that youth caregivers may especially benefit from supportive strategies.

Policies to increase home health care services, especially for youth caregiving families, would decrease the necessity for these children to have to manage otherwise adult responsibilities. There is no formal recognition of and/or entitled services for caregiving youth in the United States, unlike other countries such as the United Kingdom and Australia (Child & Family Act 2014; Young Carers Bursary Program, n.d.), and so official recognition on a national level would be an important first step for American caregiving youth like the ones described in the study. Even amongst countries with well-established support systems for caregiving youth, supports for this specialized task of managing medications are not specifically mandated and would be of use for children worldwide.

Clearer recognition and acknowledgement of youth caregivers by health care providers would also be beneficial both in recognizing the important contributions they make as well as in helping to identify those caregivers in need of services and support. The data from this study indicates that youth caregivers have substantial interaction with medical professionals. Though most learned medication specifics from the care recipient themselves, many participants reported nurses, aides, and doctors teaching them (both actively and passively) how to handle medication. Health care providers should routinely ask in a non-judgmental manner about who is responsible for carrying out the treatment plan being prescribed for care recipients of any age. Care must be taken when inquiring in order to have open and honest communication given the previously described concerns about disclosing the child's role.

In addition, identifying a child as handling medications could be indicative of other caregiving responsibilities and need for extra support. Hunt et al. (2005) found that child caregivers who perform ADL's for a family member are more likely to also handle medication for that family member, and Noureldin and Plake (2017) found an association between medication management and other caregiving related activities among adults caregivers. In light of this, health care providers should receive education about family caregiving so they can actively inquire about this issue during medical encounters. Once identified, the health care team can provide appropriate recognition for their contributions and partner with the child and family to seek opportunities to alleviate any potential burden on the child through referral to home health services and/or available supportive organizations. For communities without specific youth caregiving resources available, professionals can be creative in seeking support in their own community through existing youth development programs, disease specific agencies, and counselors, among others.

Until then, more tangible tools such as pill-boxes and reminder systems to manage multiple medication regimens with a variety of dosages could help to simplify the task for youth caregivers. This is supported by research by Lau et al. (2009) in which adult caregivers highlighted the importance of having written and verbal instructions. Several participants in this study used forms of technology to aid with reminders and organization and some expressed a desire for a “robot” to alleviate this burden. Adult caregivers, especially younger caregivers, also report interest in technology to alleviate caregiving burden, and medication management is the most common task for which caregivers are already using technology among studies of American caregivers (HITLAB, 2016).

It is well established that teenagers are typically tech savvy and those with resources are closely connected to smart phones, and devising strategies to utilize this tool could be of great potential benefit for adolescents managing medications. Best practice for use of these tools among adolescent self-management for disease including asthma, diabetes and cancer is still unclear, but this is an important area for consideration for adolescents providing medication management as a part of their caregiving responsibilities (Burbank et al., 2015; Fedele, Cushing, Fritz, Amaro, & Ortega, 2017; Majeed-Ariss et al., 2015). Additionally, a qualitative study evaluating the influence of a mobile application for diabetes management for teens and young adults suggested that such technology can help mitigate feelings of isolation, which could be another potential approach for supporting caregiving youth (Husted, Weis, Teilmann, & Castensøe-Seidenfaden, 2018).

Among adult caregivers, medical responsibilities, including injecting medications, were associated with higher stress levels and reports of poorer health as well as increased likelihood of impact on work due to caregiving. (National Alliance for Caregiving [NAC], & AARP Public Policy Institute [AARP], 2015). Expansion of and universal access to programs including emotional support, respite, and/or financial support such as the Caregiving Youth Project in the United States, the Children and Families Act of 2014 in the United Kingdom, and the Young Carers Bursary Program in Australia are crucial to promote well-being and to address the emotional response associated with caregiving as described by the youth in this study. This is supported by the work of Pakenham, Chiu, Brusnall, and Cannon (2007) which found that social support was the factor most strongly associated with the positive outcomes of affect, life satisfaction and lower levels of distress among child and young adult caregivers.



Safety issues around medication administration, and specifically sharps disposal, are a particularly important area for intervention. The FDA recommends that all sharps be disposed of in a container made of heavy-duty plastic with a tight-fitting, puncture-proof lid, with proper labeling (U.S. Food & Drug Administration, n.d.). The youth in our study did not follow these guidelines, which is consistent with other research that has documented this phenomenon (Gold & Schumann, 2007; Markkanen et al., 2015). This is an important public health issue that deserves attention, and caregivers administering insulin and other medications requiring sharps should be trained and provided the appropriate bins to implement proper disposal. This could be carried out at multiple levels including the prescribing physician, dispensing pharmacist, first responders, home health agencies, and medical supply companies.

#### 4.2. Areas for future research

This study has generated many topics for future scientific exploration. A first step includes research to further detail the specific responsibilities of these young people. A quantitative study to address questions such as the frequency of usage of certain medications and the prevalence of children who perform certain tasks would be an important next step. Additionally, the study participants ranged in age from 10 to 19 years, yet many stated that they began caregiving at even younger ages, and thus exploring a wider range of ages would be an important direction for future research. These caregiving youth reported the task of medication management to be easier than other more physical and potentially intimate caregiving responsibilities such as “manual” tasks and bathing. This suggests many other opportunities for future studies about youth caregiving in general, but is consistent with what has been reported by Lackey and Gates (2001). Further exploration into complex topics such as the impact of culture, family financial, and health insurance status on caregiving youth tasks are also important areas for research, especially given the diverse demographic characteristics seen with this study population. Finally, standardization of the definition of caregiving youth is important to understand this phenomenon across countries.

This study revealed varied levels of knowledge from caregiving youth about the medications and health conditions they handle. This difficulty with medication detail has been recorded in other research. Research on adult family caregivers reveals that many lack medication education and skills. In one study of caregivers for patients with asthma, only 17% of participants reported that they had been given “ideal” medication education by a provider (Frey, Fagnano, & Halterman, 2016a).

Furthermore, Novais, Duclos, Varin, Lopez, and Chamouard (2016) quantitatively analyzed knowledge and skills related to hemophilia treatment and found that one third of the caregiver participants did not know the type of hemophilia their family member had and less than half understood the mechanisms of the medication. In another study, Erickson and LeRoy (2015) examined a group of adult family caregivers and found that the ability to follow instructions about medication administration was directly correlated with the level of education of the caregiver. This implies that children, who, by nature of age, have limited education and therefore are at a disadvantage in terms of providing optimum medication management, are likely to have difficulties with this task. Indeed, in the current study the level of medically related knowledge appeared to coincide with the age of the youth caregiver. Since lack of education was a component of the emerged themes, it would be beneficial to study how best to provide basic education to any youth caring for a family member regarding medication administration, function, and potential side-effects.

Because of the identified frequent interactions of caregiving youth with healthcare professionals, development of appropriate, validated screening tools to identify caregiving youth could provide increased identification of children in caregiving roles by pediatricians and/or school nurses and provide an opportunity for referral to support and intervention services. Research to assess the awareness among health care providers about the existence and responsibilities of caregiving youth is also needed.

Further exploration of the emotional impact of being a youth caregiver, and ways to promote positive outcomes and mitigate potential negative consequences, is vital. In the decades since the first publication on this topic, it has been well documented that Adverse Childhood Experiences, including “household challenges”, have a negative impact on adult health including increased risk for heart disease, obesity, cancer, substance misuse, suicide, and adolescent pregnancy (Felitti et al., 1998; Gilbert et al., 2015). While not specifically designated as an Adverse Childhood Experience, caregiving is a relatively unexplored issue and some aspects could arguably be considered a traumatic experience for children. The limited research that is available about young adult caregivers (many of whom have been caregiving since childhood) as well as young adults who had been caregiving youth suggest that some are at increased risk for high levels of stress and/or depression (Greene, Cohen, Siskowski, & Toyinbo, 2017; Levine et al., 2005; Shifren & Kachorek, 2003). However, Lackey and Gates (2001) found that the recollections of adults who were caregivers as children included many positive feelings such as an appreciated sense of responsibility, closeness with the family, and pride at learning life skills at an early age, and Remtulla, Charles, and Marshall (2012) found that child caregivers did not differ from their non-caregiving peers in areas such as feeling burdened by their responsibilities or relationship with their parents. Better understanding of the long term impact of the emotional stress of medication management and overall responsibilities on caregiving youth, as well as identification of protective factors, is important to develop and provide better evidence-based services and support to these young people.

Finally, while the impact on the health status of care recipients whose medication administration is overseen by youth was beyond the scope of this study, this area also provokes the need for further investigation. The inability of caregivers to provide appropriate care through accurate handling of medications can have a negative impact on the health of care recipients. For example, Frey, Fagnano, and Halterman (2016b) studied adult caregivers of children with asthma, querying the parents' ability to name their child's medications and correlating this with health outcomes. Difficulty in remembering medication names was significantly associated with increased symptoms, use of rescue medications, and likelihood of children missing preventative medication doses.

## 5. Conclusion

Limitations of this study include the sample size and the fact that participants were all recruited from a population served by the Caregiving Youth Project and in a single geographic area and limit the ability to generalize the findings to the broader population of child caregivers. Nonetheless, strengths of this study, such as the first hand reports from a population of caregiving youth actively managing medications and the qualitative nature of the study allowing for in depth exploration these young participants' experiences, demand that those interacting with young people be mindful of this too often unrecognized issue. This study highlights the unique responsibilities and burdens associated with managing medications. These findings also emphasize the need for targeted supportive services to help children with actual caregiving tasks and to assure they are provided resources to allow them to achieve their fullest potential emotionally, academically, developmentally and provide suggested topics for areas in need of future research related to this relatively unexplored important topic.

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## Declaration of interest statement

Connie Siskowski, RN, PhD is the Founder and President of the American Association of Caregiving Youth for which she is paid a salary. She is a donor to the organization, sits on its Board of Directors and is an in-kind contributor of services. Her contribution as an author is above and beyond her formal job description and there is no expectation of remuneration for this work. Julia Belkowitz, MD, MPH has been a donor to the American Association for Caregiving Youth and is a member of the Advisory Council for the Caregiving Youth Project. The American Association of Caregiving Youth is a 501c3 non-profit corporation. The other authors have no other relationships relevant to this article to disclose.

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## Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.adolescence.2018.09.001>.

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