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“I Just Learned by Observation and Trial and Error”: Exploration of Young Caregiver Training and Knowledge in Families Living with Rare Neurological Disorders

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Abstract

Background Caregiver skill training and support programs are traditionally offered to adult caregivers, leaving out the over 1 million children and youth who provide care (“young caregivers”). Skill building and support programs are critical to caregiver and patient well-being and can be informed by the knowledge of current caregiver skill and support acquisition.

Objective Using data from three studies of neurological disorders, this paper provides initial data on how young caregivers acquire caregiver skills and training needed to inform young caregiver programs.

Method Mixed method data drawn from three studies of young caregivers in neurological disorders, Huntington’s disease (HD) and amyotrophic lateral sclerosis (ALS).

Results Youth (N=96), ranged in age from 8 to 20, care for a family member with HD or ALS, and involved in tasks ranging from assistance with walking (76%), toileting (32%) and administering medications (37%). The majority (N=59; 61%), received no training or guidance. When asked how they knew what to do, six main themes arose: (1) patient tells me what to do, (2) watching and observing, (3) common sense, (4) treating patient like child or self, (5) process of figuring it out, and (6) don’t know.

Conclusion Young caregivers in neurological disorders engage in numerous caregiving tasks with little formal guidance, despite a desire for training and education by adults and professionals. Reliance on various skill methods and lack of formal guidance, points to the need for health care professionals to develop education and training programs targeting this isolated and underserved population, improving the well-being of both caregiver and care recipient.

Keywords Young carers · Young caregivers · ALS · Huntington’s disease · Family caregiving · Caregiver training

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Background

Families provide primary care for chronically ill family members; including neurological disorders which require assistive devices, detailed medication regimens, and heavy lifting and transferring (Goldstein et al. 2006). Care tasks are often complicated and require skills, knowledge, and understanding of the impact on person living with the illness. Given the evidence of depression, physical toll, and isolation in family caregivers (Mockford et al. 2006; Gauthier et al. 2007), providing caregivers with skills and training may negate the potential negative consequences of care, and improve caregiver confidence. Yet, little research exists addressing training and education for caregivers. Critically, what is known about caregiving training targets adults only, ignoring the most vulnerable and isolated of caregivers,—children and youth.

Young Caregivers

Approximately 1.4 million children and youth—“young caregivers”—between the ages of 8–18 in the United States provide care to an ill family member (Hunt et al. 2005). Young caregivers are involved in care including bathing, feeding, toileting and managing complex assistive devices (Hunt et al. 2005; Shifren 2008). The small body of research on young caregivers highlights the impact of care on school performance (Siskowski 2006), mental well-being (Shifren and Chong 2012; Cohen et al. 2012), and details a lack of support (Shifren 2008; Kavanaugh et al. 2015). Complex care tasks and lack of support point to the need to create skill and education programs targeting young caregivers.

Caregiving Skills and Training

The provision of skill-oriented training (e.g., basic skills of moving and handling patients, facilitation of activities of daily living, and simple nursing tasks), reduces anxiety and depression in adult caregivers (Kalra et al. 2004). Moreover, training protocols specifically involving support show a decrease in caregiver depression and an increase in self-efficacy (Toseland et al. 2004), underscoring the need to integrate support in any care training. Yet few training programs exist.

In the absence of training, family caregivers often acquire caregiving skills through trial and error or informal instruction from other family members or care recipients (Paun et al. 2004). Given the complex and ever changing needs associated with care, the lack of skills and training may compromise not only the mental and physical well-being of the caregiver, but potentially that of the care recipient. Indeed, caregivers often experience adverse physical, psychological, social, and financial hardships for which they are generally unprepared (Shah and Wadoo 1994), and are at high risk for physical injuries, caregiver stress, and burnout (Gerdner et al. 1996; Schulz 2004).

The lack of caregiver training has immediate implications to young caregivers, most of whom are physically smaller and less skilled than their adult counterparts. Their developmental age may affect their ability to fully comprehend or even question the care they provide, with many youths providing care at an age where their ability to understand complex or even hypothetical situations is limited at best (Erikson 1963). Many young caregivers recognize the need for training and guidance, even actively requesting information about the disease, assistance with caregiving, and advice about how best to provide care (Kavanaugh et al. 2015). Specifically, young caregivers living in families with complicated

and rare neurological disorders such as Huntington's disease (HD) and amyotrophic lateral sclerosis (ALS), present complex and intense caregiving challenges.

Amyotrophic Lateral Sclerosis

Amyotrophic lateral sclerosis (ALS) affects nearly 3.9 persons per 100,000 each year (Mehta et al. 2016). Given the constellation of symptoms including weakness, swallowing impairment, breathing impairment, and loss of speech (Andersen et al. 2005), ALS is a complicated disorder to manage for the family caregiver (Tramonti et al. 2014). Providing physical care, managing symptoms, and attending to safety needs are a few of the ways family caregivers influence the well-being and overall quality of life (QOL) of the patient with ALS (Chio et al. 2005). Data from the ALS family study indicates 1/3 of families living with ALS have a youth assisting in patient care (Kavanaugh 2016), highlighting the existence of many children in youth in caregiving roles.

Huntington's Disease

Huntington's disease (HD) affects over 30,000 people in the United States (Huntington's Disease Society of America (HDSA) 2015). Involuntary movements, cognitive impairment, slurred speech, and a lengthy illness trajectory can be stressful and isolating for families (Aubeeluck and Moskowitz 2008). HD usually appears in one's thirties and forties, a time when many adults are having and raising children (Paulsen et al. 2001). Youth in these families are often engaged in numerous and complicated caregiving tasks (Williams et al. 2009), many of whom change over time and require guidance and skill as the disease progresses.

While it is clear youth are engaged in numerous complex tasks which would require skill, how young caregivers acquire knowledge and training of and for caregiving tasks is unknown. Knowledge of caregiving skill acquisition in youth is critical given the complexity of care required for these diseases, and the potential for caregiver burden. With no large-scale data from which to draw, this paper seeks to provide initial understanding of how youth acquire skills and training, informing the development of targeted skill and training protocols. The following data is presented from qualitative data within three studies of young caregivers living in families with neurological disorders (HD and ALS). The goal of this paper is to answer the following research questions: do young caregivers receive training in care tasks? If not, how do they know what to do?

Method

Study Design

All three studies were mixed method, incorporating qualitative questions embedded within quantitative surveys. The stress process model (Pearlin et al. 1990) serves as the framework for all three studies, allowing for detail of relationships between variables among the four primary domains of the model: (1) background, (2) primary stressors; (3) secondary role strains, and (4) psychological well-being (see Kavanaugh 2014). The qualitative questions were embedded to understand how youth acquire skills and knowledge pertaining to care.

Participants

Study participants (N=96) ranged in age from 8 to 20, and had a parent or family member with either HD or ALS. Participants were identified by their adult family member as engaging in caregiving activities prior to study enrollment. Parents of participants and participants 18 and over provided consent, while participants under the age of 18 provided written assent. The study was reviewed and approved by the Institutional Review Board of the researcher's university. The first was a study of young caregivers in families with HD (N=40) (see Kavanaugh 2014). The second was a small pilot study of young caregivers in families with ALS (N=18). This study was conducted in a large Midwestern state and utilized the same measures as those in the HD study. This study provided pilot data for the third, national study of families in ALS (N=38).

Data Collection

Data collection procedures for each study are provided in detail in Fig. 1. Given the isolation and difficulty accessing families living with rare neurological disorders, the researcher used three methods to collect data: (1) paper survey, (2) one-on-one interviews, and (3) phone interviews. All study participants were accessed through the chapters associated with the Huntington's Disease Society of America (HDSA) and the ALS Association (ALSA).

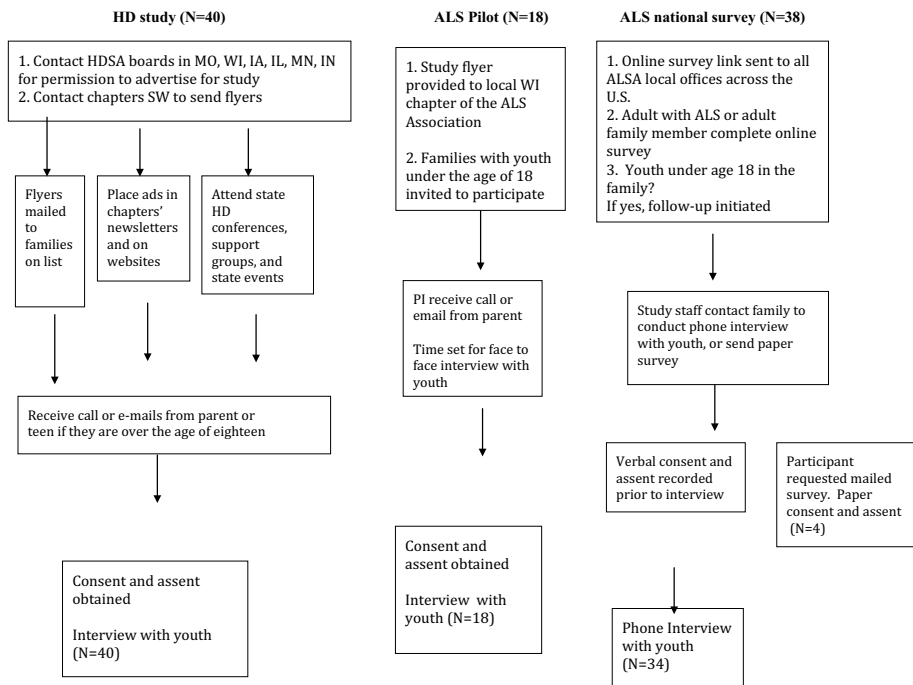


Fig. 1 Sampling and data collection flow chart

All interviews in the HD study and the pilot ALS study were conducted face-to-face with the researcher (N = 58). Data collected as part of the national ALS study was predominantly collected via phone interview (N = 34), with four youth completing the questions via paper. All phone and in-person interviews lasted between 35 and 45 min and involved only the youth and the interviewer, with no parent or adult present. All face-to-face and phone interviews were recorded and transcribed by an independent transcriptionist for accuracy. All youth were provided information about support contacts in their area, 24-h crisis lines, and were offered the opportunity to stop the interview at any time if they chose.

Measures

Data presented in this paper represents a small qualitative portion of the larger body of data from the interviews in each study. All of the data contained in this paper is original; the primary author takes responsibility for the integrity of the data and accuracy of data analysis. The HD descriptive data is published elsewhere (Kavanaugh 2014), with the ALS descriptive data forthcoming. To address caregiving skills and training, all participants were asked: (1) what caregiving tasks they participated in, (2) if they had received any training for the caregiving tasks (Y/N); (3) if they had received training, from whom, and (4) if they had not received training, how they knew what to do. Participants' responses to these questions are the focus of this paper.

Data Analysis

Quantitative Analysis

Descriptive statistics were used to describe the study sample. For a full description of the HD data, see Kavanaugh (2014). Given the exploratory nature of the training and skill questions and the lack of existing measures relating to young caregiver training and skill building, all questions specifically pertaining to training integrated both qualitative and quantitative inquiry.

Qualitative Analysis

The researcher used thematic analysis to identify and analyze patterns in the interview data, allowing for explicit theme development generated by the words of the young caregivers (Braun and Clarke 2006). Given the lack of data in this area, the focus of this analysis was not to impose any pre-determined themes, but rather to allow the respondents to describe how they learned to provide care in their own words. The researcher and an independent coder conducted the following steps of thematic analysis as outlined by Braun and Clarke (2006). First, each coder became familiar with the data by reading and re-reading the transcripts relevant to the open-ended questions and taking notes. Second, each coder independently began to systematically generate initial codes based on the data and the initial readings, taking care to use the explicit wording of the youth. Third, all codes were collated into potential themes. Fourth, themes were compared to the original list of codes, making sure nothing was missing. Fifth, the researcher and independent coder came together to compare their themes, discussing the defining characteristics of each theme and reaching agreement about the final themes and subthemes. Several strategies were used to enhance

analytic rigor and trustworthiness of findings, including audit trail, use of independent coders, and member checking, which was accomplished by bringing the data back to three participants to assess how accurately the themes matched their responses (Creswell 2007). The qualitative data is not meant to be generalized, rather to provide initial exploration in to an understudied, yet critical area.

Results

Quantitative Data

Background and Context

As detailed in Table 1, youth were predominantly female (65%), and ranged in age from 8 to 20. Participants primarily cared for parents (Father = 45%; Mother = 38%).

Caregiving Tasks

As shown in Table 2, participants across studies are involved in an average of 12 tasks. Tasks included: keeping family member company (92%), assisting with walking (76%), feeding (65%), dressing (50%), toileting (32%) and administering medications (37%).

Training

A total of 39% (N = 37) stated they had received some form of training or guidance, which they defined as 'being told what to do'. Only six participants indicated receiving training or guidance from an outside professional, who they identified as home health personnel. While 37 participants initially stated they had received training, after examination of the qualitative questions discussed in-depth below, several (N = 6) explicitly stated they actually did not have any training.

Qualitative Themes

The participants who stated they received no training or guidance (N = 59; 61%), were asked how they knew what to do. The data analysis resulted in six main themes of how these youth knew what to do: (1) patient tells me what to do, (2) watching and observing, (3) common sense, (4) treating patient like child or self, (5) process of figuring it out, and (6) I don't know.

Patient Tells Me What to Do

Eleven participants received guidance from their family member living with ALS or HD. This was described as brief guidance in the moment of care needed, instead of preparatory training. Several exemplary quotes highlight this type of guidance, including a 13-year-old male who stated, "I mean, my dad, always like, whenever he needs help, he tells me how to help him." Other participants in this group stated similar sentiments, including "He will tell me what he needs" and "If we're doing something not quite how she likes it, she lets us

Table 1 Caregiver descriptive

Characteristic	Overall		National		Pilot		HD	
	(N = 96, 100%)		(N = 38, 39.6%)		(N = 18, 18.8%)		(N = 40, 41.7%)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Caregiver age (years)								
8–11	20	21.3	15	40.5	5	29.4	0	0.0
12–14	25	26.6	11	29.7	6	35.3	8	20.0
15–19	37	39.4	11	29.7	6	35.3	20	50.0
20	12	12.8	0	0.0	0	0.0	12	30.0
Caregiver gender								
Female	62	65.3	21	56.8	10	55.6	31	77.5
Male	33	34.7	16	43.2	8	44.4	9	22.5
Relation to care recipient								
Mother	37	38.1	12	30.8	0	0.0	25	62.5
Father	44	45.4	19	48.7	10	55.6	15	37.5
Other	3	3.1	3	7.7	0	0.0	0	0.0
Grandmother	3	3.1	0	0.0	3	16.7	0	0.0
Grandfather	10	10.3	5	12.8	5	27.8	0	0.0
Caregiver education								
Elementary school	15	15.8	9	24.3	6	33.3	0	0.0
Middle school	28	29.5	16	43.2	6	33.3	6	15.0
High school	30	31.6	10	27.0	5	27.8	15	37.5
College	19	20.0	2	5.4	1	5.6	16	40.0
Not currently in school	3	3.2	0	0.0	0	0.0	3	7.5
Duration of caregiving duties (in years)								
1–3 years	49	57.0	20	54.1	8	88.9	21	52.5
4–6 years	23	26.7	13	35.1	1	11.1	9	22.5
7–10 years	12	14.0	3	8.1	0	0.0	9	22.5
More than 10 years	2	2.3	1	2.7	0	0.0	1	2.5
Hours per week care for family member								
1–10	54	64.3	27	79.4	8	80.0	19	47.5
11–20	7	8.3	1	2.9	1	10.0	5	12.5
21–30	10	11.9	3	8.8	1	10.0	6	15.0
31–40	3	3.6	1	2.9	0	0.0	2	5.0
41–50	4	4.8	1	2.9	0	0.0	3	7.5
More than 50	6	7.1	1	2.9	0	0.0	5	12.5
Is the youth the only caregiver								
Yes	11	13.1	1	2.6	1	6.7	9	22.5
No	82	97.6	37	97.4	14	93.3	31	77.5
How much responsibility do you have?								
A lot	38	40.4	16	42.1	7	43.8	15	37.5
Some	51	54.3	21	55.3	9	56.3	21	52.5
Almost none	5	5.3	1	2.6	0	0.0	4	10.0

Table 2 Caregiving tasks across groups

Task	Overall (N=93)		National (N=38)		Pilot (N=18)		HD (N=40)	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Grocery shopping	66	68.8	32	84.2	7	43.8	27	67.5
Cook meals by yourself	56	58.3	23	60.5	7	43.8	27	67.5
Help parent with appearance	42	44.2	21	55.3	2	12.5	20	50.0
Help parent undress/dress	48	50.0	22	57.9	7	43.8	18	45.0
Help parent eat	62	64.6	32	84.2	12	75.0	18	45.0
Help administer medications	35	36.5	19	50.0	4	25.0	11	27.5
Help parent toilet	31	32.3	19	50.0	4	25.0	7	17.5
Help parent bathe	18	18.8	11	28.9	2	12.5	5	12.5
Help to wipe mouth or with drooling	27	48.2	23	60.5	3	18.8	n/a	
Assist with respiratory equipment	24	25.3	15	39.5	7	43.8	2	5.0
Interpret, sign or other communication	31	55.4	22	57.9	10	62.5	n/a	
Help with Range of Motion or therapy	19	33.9	15	39.5	2	13.3	n/a	
Keep parent company	88	91.7	37	97.4	17	99.0	34	85.0
Help parent walk	73	76.0	26	68.4	14	87.5	31	77.5
Help parent transfer	46	82.1	30	78.9	16	98.0	n/a	
Help parent write	45	46.9	17	44.7	6	37.5	21	52.5
Help parent make phone calls	38	40.0	16	43.2	4	25.0	17	42.5
Drive parent places	30	31.3	8	21.1	4	25.0	17	42.5
Talk to doctor for parent	31	32.3	16	42.1	1	6.7	13	32.5
Work part-time	30	31.3	7	18.4	3	18.8	20	50.0
Pay household bills	10	10.4	4	10.5	0	0.0	5	12.5
Take care of siblings	40	40.8	23	60.5	7	26.9	16	38.1
Number of task (median (IQR))	N/A		12.5 (6.0)		9.0 (6.0)		12.0 (6.5)	

know. And we just all do our best.” (15-year old female). While “in the moment guidance” is important, the ability to make care adjustments is also critical due to the rapid disease progression in ALS.

Watching and Observing

A total of 15 youth described consistently watching and observing others provide care in the home, including the well-parent, caregivers, or other family members. Observing did not include any hands-on assistance with the person being observed, but rather required the youth to process and recall those actions without prior practice. This theme is illustrated by a 13-year-old male who shared how he learned to use a gait belt: “I mean, learning from observation because, like, when [the caregivers] use the gate belt, we learned cuz we never really used a gate belt before.” This quote describes being passively taught by observing others, instead of direct teaching. A 12-year-old also described watching, or observing, stating: “I look at how my dad does things, but no one really showed me anything.” Several participants added an element of recall and “noticing”, including a 17-year-old female who stated, “I watched my grandma, and I pretty much remember what she did.” A 16-year

old participant described taking notes and “noticing” things that needed to be done: “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.” All these quotes highlight a reliance on the youth to manage their own learning from other adults and persons living with the disease, as opposed to being directly taught.

Common Sense

The idea of common sense or what one “should” do when faced with a particular situation was another main theme. Five youth specifically stated they used “common sense” when providing care: “I just do. I don’t know. Most of it seems like kind of common sense” (15-year-old male).

“I mean, the things that I did do are pretty common sense. Your mom can’t eat food, you might as well make the food easier to eat” (13-year-old female). While the definition of ‘common sense’ in these quotes is unclear for all, when asked, one participant stated, “What you just know. You know what’s good for people. As long as it doesn’t kill them, you know” (19-year-old female). Another participant stated, “It just seemed like that’s what you should do” (15-year-old female). Finally, one participant explained it as follows, “No one ever told me how to do it. I just did it. I just tried to do it the easiest way” (18-year-old male).

Treat Patient Like Self or a Child

Seven participants either equated the care recipient to a child or to themselves, as children or youth. These participants identified a caregiving framework similar to self-care, rather than a specific set of skills for an ill family member. This is exemplified in a quote by a 13-year-old male, “It’s just things I do for myself.” While some activities are universal, many caregiving tasks are nuanced, leaving concern for how youth understand feeding and bathing from another point of view. This is demonstrated in a quote from a 15-year-old female: “Everyday, like, the washing, helping my mom take showers. It’s just like bathing myself, so.” To put it broadly, “That’s just what I usually do anyway” (18-year-old female).

Additionally, three participants compared their care recipient to a child, and identified caregiving tasks and responsibilities often associated with caring for children. This concept is exemplified in the following quotes. “I don’t know. I guess just, like, I ... I kind of treat him more like a child now” (16-year-old male) and “I kind of, you know, we pretty much treated him like a little brother I’d say. Like, his sister came over to help us and after 2 days she couldn’t do it.... she’s like, “He’s your father.” No he’s not, like, a father he’s like a child” (13-year-old male).

The skills inherent in these youths are closer to babysitting, as stated by a 13-year-old female: “I guess, I’ve babysat before and it’s almost like that honestly.”

Process of Figuring It Out

The “process of figuring it out” goes beyond training or being told what to do, focusing instead on the youth’s ability to “test” ways of doing and eventually identifying what works and what does not. Seven participants described this learning process as “trial and error” in the following quotes: “Trial and error really” (14-year-old); “I began at a really young age, so I just learned by trial and error.”

Those using “trial and error” also described the internal process stating, “I guess I use my own experience, I just do it, I guess I figure it out” (18-year-old), and “I just looked stuff up—no one told me what to do” (15-year old). This process of “figuring it out” can also extend beyond the individual caregiver and involve the entire family, as stated by a 12-year-old, “We figured it out at the same time—no one knew what to do.”

I Don't Know

When asked how they knew to provide care, 13 youth stated they did not know, even when asked to clarify. These youths seemed surprised to be asked and indicated they had not thought about it before; they just did what came naturally. A 15-year-old female stated, “Honestly I have never thought about it. I guess I don't know what to say, I just...I don't know”. These responses are exemplified in the statement by a 14-year-old male, “I really have no idea how I know, I just do it I suppose.” These are youth who just “do” and don't necessarily think through the process, highlighting concerns around caregiving knowledge and the need for guidance and supports in caregiving decision-making.

Discussion

Despite the growing body of literature around youth caregivers across the globe, and increased attention in the U.S. in recent years (Kavanaugh et al. 2016), we know little about *how* youth engage in care and what they may need to assist in that care, including training and skill development. This paper provides initial insight into how young caregivers currently receive training, detailing *how* youth may acquire caregiving skills and training, and *who* provides that training, vital to the development of young caregiver support development. All youth in the studies are deeply involved in a variety of care tasks including personal care and watching over a family member to ensure they do not fall, choke or have an accident. The care is time consuming, and requires knowledge of what to do next—specifically for those youth who find themselves home alone with the person with the disease. Many of the youth who did not receive any specific training stated that they relied on the care recipient to provide guidance on caregiving, which presents several potential issues. First, people living with an illness may have a difficult time expressing what they need, either verbally or figuratively, requiring them to effectively “step outside oneself”. This is difficult for many, but particularly difficult given the communication and cognitive challenges associated with neurological disorders such as HD and ALS, where requests may be misunderstood. Relying on the patient is further complicated by the number of youth who say they learned how to provide care by treating the patient as a child. While this theme indicates youth are potentially relying on skills developed from babysitting, providing care for an ill adult is not the same—given size and relational differences. Focus on the youth treating the parent as a child highlights the potential for parentification of the youth, or taking over the parenting role, in young caregivers (Bauman et al. 2006). While it is unclear whether all young caregivers can be described as *parentified*, or simply *caregivers*, providing training and skill development from another source, modeling how to do it, and what it looks like from the caregiver point of view might be a useful way to eliminate the potential parentification in young caregivers and lessen the strain on the patient to be the guide and trainer.

The high number of participants who identified “watching and observing” highlights the value of teaching and modeling correct skills and ways of providing care as well as the need for proper training and skill building protocols. While many youths described being able to watch and observe—thereby building caregiving skills—only two described watching a professional. Indeed, the majority watched a family member providing care, leaving gaps in understanding how the adult knew what to do and whether they were doing it correctly—and how this is translated developmentally to a youth. Reliance on passive observation illustrates a lack of active teaching by adults and an underlying assumption that the youth will “pick it up.” Future work in this area needs to assess how teaching and learning occur in the home, particularly for those youth who will be left alone for any period of time.

Additionally, in the absence of training, youth are also relying on their own knowledge or “common sense”. What common sense means is complicated, given varying developmental trajectories across ages and definitions of what may constitute “common knowledge.” Many youths described common sense as “just what you know”, without a clear understanding of *how* they know it, and how this “knowledge” differs from other youth. The discussion of common sense highlights the importance of *perception* in youth—how they perceive care in and of itself, as well as their understanding and application of the care needed. In youth living with illness in the family, perception of the illness can influence coping, both positive and negative, with the eventual outcome of the illness (French and Weinman 2008). Thus, it is important to assess how “common sense” in young caregivers helps them to understand caregiving for someone else’s illness, as they base their tasks on what they know of the disease and how to take care of someone. It is clear that youth are able to think through and process caregiving and caregiving tasks, as shown in the theme *process of figuring it out*. While thought process may build both confidence and self-efficacy, how the process plays out in youth who are in new or confusing settings and required to engage with tasks that may be beyond their developmental understanding. Indeed, reliance on personal experience is concerning given the overabundance of incorrect or poorly worded information available to youth, particularly on the internet.

Finally, the finding that many youths rely on “trial and error” shows that the youth are actively engaged in learning and testing skills and knowledge, which are critical to their development. However, trial and error can be concerning in the context of caregiving. Without guidance, they could inadvertently hurt themselves or the person with the illness. Many adult caregivers report using the trial and error process in their care (Paun et al. 2004), yet they have the capability to grasp more complex and hypothetical situations. Youth may not be able to “test” their way out of difficult situations, which may result in a negative outcome. Providing professional training, guidance and skill development allows youth to test and learn new ways of providing care in a controlled environment, without fear of harming their family member.

Practice Implications

The above data answered the initial questions of whether youth receive training, and in the absence of training, how they know what to do. Results show youth largely do not receive training, and rely on a variety of ways to know what to do. These results point to gaps in caregiver education, with the exclusion of youth caregivers. Knowledge that youth are involved in care with little training, can be used to inform training and skill interventions from a strength-based perspective, focusing on what these youths are doing well and how they process

information. Indeed, young caregivers want training and advice, and acknowledge fear of harming or hurting the patient without training (Kavanaugh et al. 2016). Moreover, young caregivers express a desire for support and engagement with “like” peers who are in similar situations with family members living with neurological disorders (Kavanaugh et al. 2017). Thus, developing youth caregiver training and education should include content as well as a peer support and engagement component, thereby lessening the feelings of being an “other” and “normalizing” the experience of being a caregiver. Skill building programs that use modeling from health care professionals in the context of “like” youth might be a useful way to not only develop skills and self-efficacy in caregiving tasks, but also increase social support.

Finally, the development of caregiver training and skill development has potential well beyond young caregivers in rare neurological disorders discussed in this paper. Young caregivers provide care across disorders and for varying length of time, requiring a variety of skills and education (Kavanaugh et al. 2015; Hunt et al. 2005). Results of this paper have the potential to inform and guide the creation of caregiving programs and trainings across disorders.

Limitations

This data represents the first known exploration of caregiving knowledge and training in the U.S. and should be seen as a first foray into an important and understudied issue, guiding program development and implementation. Given the exploratory nature, some limitations exist. First, the questions about training represented a small portion of the full interviews. While additional qualitative questions related to caregiver needs were asked and presented elsewhere (Kavanaugh et al. 2015), more in-depth questioning pertaining to the youth’s feelings about training and what type of training is desired should be the focus of future research to further inform targeted programming.

Second, the paper relied on different methods for data collection, potentially skewing or limiting responses, as people may report experiences differently on paper than in person. However, only four participants choose the paper option, lessening the potential for confusion. Finally, all respondents were obtained via disease based organizations, whose families may have received care and support for potentially many years. Individuals who do not interface with disease organizations may have limited access to professionals and opportunities around caregiving. Therefore, it is critical to ensure that future research and program development be promoted beyond disease organizations to the broader community to reach those families who may be more isolated than those represented in the current paper. Overall, the experiences described in these studies reflect similar experiences of young caregivers across disorders (Hunt et al. 2005), highlighting a common, shared experience among young caregivers. Caregiving training and skill development should transcend disease state, age, and gender as they are salient to all individuals charged with the care of another. Thus, these findings are relevant across caregiving populations and can be used as a base to further research and the development of training protocols for young caregivers.

Conclusion

Young caregivers in neurological disorders engage in numerous caregiving tasks with little formal guidance, relying on patients, common sense and trial and error. Previous research in this area highlighted young caregivers desire for training and education for the

often-intensive care provided. Thus, the lack of formal guidance points to a critical need for health care professionals to develop education and training programs targeting this isolated and underserved population, improving the well-being of both caregiver and care recipient. Therefore, it is incumbent on health care professionals to provide support and education with the goal of increasing well-being.

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Compliance with Ethical Standards

Conflict of interest The authors declares that they have no conflict of interest.

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