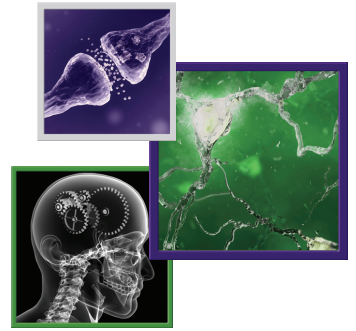




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Skill, confidence and support: conceptual elements of a child/youth caregiver training program in amyotrophic lateral sclerosis – the YCare protocol



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Practice points

- Approximately 1.4 million children and youths between the ages of 8–18 years provide care to a family member in the USA ‘young carers’, including bathing, feeding, toileting and medication management.
- This pilot study assessed a novel caregiving training and support intervention for ‘young carers’ under 19 years of age, who provide care for a person living with amyotrophic lateral sclerosis (ALS) – the YCare protocol. In particular, the study addressed the following broad aims: participants in the YCare protocol will show improved self-efficacy in care tasks after receiving the training; and participants can identify self-care goals and behaviors toward the development of self-management as caregivers.
- The YCare protocol, guided by the tenets of the Individual and Family Self-Management Theory, seeks to improve young carer confidence and support through a peer-engaged, multidisciplinary model. The model was developed and tested for feasibility by a multidisciplinary team of allied health providers with expertise in ALS, including physical therapy, speech language pathology, occupational therapy, respiratory therapy, neurology and social work.
- This pilot study utilized pre/post surveys with young carers engaged in the YCare training and support protocol, with youth who had not previously received the YCare training. Participants were between the ages of 8 and 19 years, were of any gender and had a family member with ALS. Caregiving tasks were assessed using the general Multidimensional Assessment of Caring Activities (MACA-YC18).
- This study found that young carers received inconsistent training prior to engaging in the YCare protocol, with most training focusing on less complicated and normative household tasks.
- Study results indicate a significant increase in confidence with several care tasks, providing preliminary evidence of the efficacy of a training protocol inclusive of multiple care tasks, critical to persons living with ALS. Benefits of training were also reported to include that the day had changed the young carers perceptions of care, and meeting ‘like’ peers.
- Results of the pilot YCare intervention underscore the need to assess how young carers feel and respond to new tasks when receiving support from developmentally similar peers.
- Further studies are required to assess the applicability of the findings of this pilot study to a broader group of participants.

Aim: Pilot study of a novel caregiving training and support intervention for children and youth <19 years, who provide care for person living with amyotrophic lateral sclerosis. **Materials & methods:** Youth (n = 19) between the ages of 8–19 years, participated in skills training and support program (basic care, feeding/communication, assistive devices and social support). **Results:** Participants reported significant increase in confidence in tasks, including communication systems and respiratory equipment. Participants identified goal setting and creating behaviors to reach those goals. Benefits of training included that the day changed their perceptions of care and meeting ‘like’ peers. **Conclusion:** Results of the pilot YCare intervention underscores the need to assess how young caregivers feel and respond to new tasks when receiving support from developmentally similar peers.

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Keywords: amyotrophic lateral sclerosis • caregiving training • caregiving youth • family carer • self-management • young caregiver • young carer

Approximately 1.4 million children and youth between ages 8–18 years in the USA provide care to a family member [1], including bathing, feeding, toileting and medication management. These 'young carers' are asked with the same caregiving as adults, it is unknown how these youth acquire the skills needed to provide care and support as caregivers, including those who care for family members with complicated neurodegenerative disorders such as amyotrophic lateral sclerosis (ALS).

Amyotrophic lateral sclerosis

Affecting breathing, communication and movement, persons with ALS eventually become fully dependent for care, primarily tasked to the informal family caregiver [2,3]. Caregiving research typically targets the adult caregiver, yet approximately a third of families living with ALS in the US rely on a young carer to provide care and help manage the numerous and complicated assistive devices [4]. Across disorders, young carers have difficulty attending and performing in school [5], managing depressive symptoms [6] and relating to and receiving support from non-caregiving youth [7]. Moreover, data from young carers in Huntington's disease and ALS found almost 70% of young carers engaging in numerous tasks with little to no training, instead, 'winging it' and 'using common sense' [8]. These data underscore the interconnectedness of emotional and social impact of care, and lack of support and skill, in a vulnerable and isolated caregiving population.

Yet what might improve skill while providing support for young carers is unclear, as no known published reports of combined targeted interventions exist with young carers. Given the intensity and frequency of care provided by young carers, one avenue – peer engaged caregiving skill training – may improve care confidence and support while providing an opportunity for youth to craft ways to manage their own well-being and engage with other youth. Skill-oriented programs improve caregiver wellbeing while increasing caregiving self-efficacy in adults [9], highlighting the opportunity for caregivers to manage their own well-being, gain support and develop caregiving skills. Yet, how young carers develop personal goals and implement behaviors to manage caregiving tasks, care self-efficacy and their own well-being is unknown.

Self-management

The Individual and Family Self-Management Theory (IFSMT) [10] has not been applied to young carers, despite its emerging application to adult caregivers. Shown in [Figure 1](#), specific domains of the IFSMT model include: context focusing on the risk and protective factors associated with young carers, complexity of disease process, caregiving tasks, caregiving skills and ability to self-manage; concepts in the process domain include ALS disease knowledge, self-efficacy, skill acquisition, goal setting and social support of peers; proximal behaviors of the study address the continued engagement of youth in self-management goals and ensuing behaviors and patterns of applying skills and support to continued and changing care; distal outcomes focus on the health-related quality of life of the youth.

Inherent in self-management theory, goal-setting involves the caregiver creating a strategy or plan for managing their own well-being in the context of care. These goals vary, and are developed by youth, reflecting a developmentally appropriate opportunity to state their own goals and identify well-being management behaviors. A focus on self-management and skill building is especially important for young carers with ALS given the complexity of care and care devices. Self-efficacy entails perceived confidence in performing care tasks and is inherent in the process of self-management [10]. Self-efficacy has been examined in adult caregivers, highlighting the relationship between elevated self-efficacy, caregiver mood and improved patient well-being [11]. Providing task-specific skill training combined with peer support for young carers may increase their self-efficacy and confidence in caregiving and help guide their overall self-management and goal setting, while receiving support from peers. Indeed, young carers want and actively seek out engagement with 'like' youth so as not to be labeled as 'other' by non-caregiving youth [7].

YCare protocol

The YCare protocol, guided by above tenets of the IFSMT [10], seeks to improve young carer confidence and support through a peer engaged, multidisciplinary model. The model was developed and tested for feasibility by a multidisciplinary team of allied health providers, including physical therapy, speech language pathology, occupational therapy, respiratory therapy and social work [12]. All providers have expertise in ALS, and work in

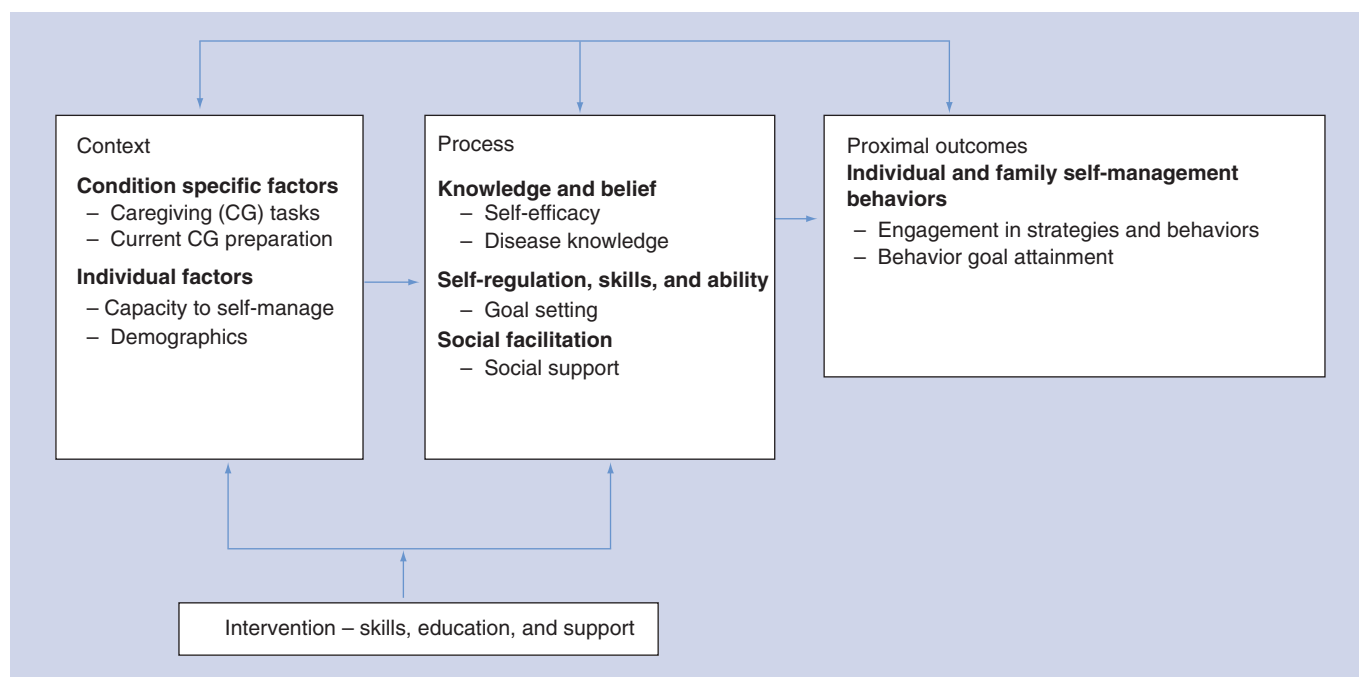


Figure 1. Adapted Individual and Family Self-Management Theory (Ryan & Sawin, 2009) [10].

an ALS Association certified ALS Multidisciplinary clinic and/or a chapter of the ALS Association. In order to conduct the YCare protocol, all providers received training in the YCare model and the structured four-step ‘teach back’ method. The teach back method has been used widely within clinical settings to help persons understand their own health and care needs [13]. In YCare, teach back is used to instill confidence in the context of guidance and peer support. The YCare model follows four specific steps led by the allied health professional: talk about the task and ask whether youth have participated in the task with their family member; show how to do the task; have youth try the task, with guidance and supervision from the professional; and ask the youth to teach back the task to the group, providing feedback if needed. At the end of each module, the professionals facilitate a debriefing session with the youth, identifying what tasks they liked and feel confident about, and what tasks still make them uncomfortable or unsure.

Data from the feasibility tests [12] supported several initial premises: allied health professionals with expertise in ALS can deliver the training; families will engage with the training to bring their children/youth, who will participate; and fewer tasks are easier to digest for the youth.

As shown in Table 1, the YCare training protocol includes four modules, established during an iterative process of professional identified care tasks addressed in clinical practice, and those tasks youth identified as stressful in prior ALS research [12]. Modules include: basic care (transferring and dressing) module, facilitated by the physical therapy and occupational therapy professionals; speech and feeding module, facilitated by the speech language pathology professionals; assistive devices (communication, BiPAP, and power chair) module, facilitated by the respiratory therapists and assistive technology specialists; and young caregiver support, facilitated by the social work professionals, which included a supportive debrief in between each module. Each module in the YCare protocol was delivered in small peer groups of 4–6 participants and lasted 50 min in duration. Each group consisted of similar ages (i.e., under 13 years, over 13 years) when possible.

This paper presents pilot data from pilot tests of the YCare protocol, addressing the following broad aims: young carer participants in the YCare protocol will show improved self-efficacy in care tasks after receiving the training; and youth participants can identify self-care goals and behaviors toward the development of self-management as caregivers.

Table 1. YCare day breakdown.		
	Group 1 (8–12 y/o)	Group 2 (13–18 y/o)
Introduction (9:00am–9:45am)	Introduction and Icebreaker; pre-test	Introduction and Icebreaker; pre-test
Room	Main room	Main room
Facilitators	Social work	Social work
2 MIN TRANSITION TO BLOCK 1		
Block 1 (9:47am–10:35am)	Basic care Task 1: Transfer/gait training Task 2: Rails, raised seats, and shower Task 3: Dressing	Speech communication and feeding skills Task 1: Communication strategies Task 2: Preparing food textures Task 3: Cueing patient for swallowing
Room	Room 1	Room 2
Facilitators	Physical therapist/occupational therapist	Occupational therapist/speech therapist
10 MIN BREAK; DEBRIEF OF BLOCK 1, TRANSITION TO BLOCK 2		
Block 2 (10:45am–11:35am)	Speech communication and feeding skills Task 1: Communication strategies Task 2: Preparing food textures Task 3: Cueing patient for swallowing	Basic care Task 1: Transferring Task 2: Rails, raised seats, and shower Task 3: Dressing
Room	Room 2	Room 1
Facilitators	Occupational therapist/speech therapist	Physical therapist/occupational therapist
10 MIN BREAK; DEBRIEF OF BLOCK 2, TRANSITION TO LUNCH		
LUNCH (11:45am–12:25pm)	Lunch	Lunch
Supportive discussions	Main room	Main room
TRANSITION TO BLOCK 3		
Block 3 (12:30pm–1:20pm)	Assistive Devices Task 1: Bilevel Positive Airway Pressure (BiPAP) Machine Task 2: Electric wheelchair Task 3: Speech Generating Device (SGD)	Assistive Devices Task 1: Bilevel Positive Airway Pressure (BiPAP) Machine Task 2: Electric wheelchair Task 3: Speech Generating Device (SGD)
Room	Main room	Main room
Facilitators	VENDORS	VENDORS
10 MIN BREAK; DEBRIEF OF BLOCK 3, TRANSITION TO BLOCK 4		
Wrap Up (1:30pm–2:00pm)	Wrap-up	Wrap-up
Room	Main room	Main room
Facilitators	Social work	Social work

Materials & methods

Study design

Pilot study utilized pre/post surveys with youth engaged in the YCare training and support protocol, with youth who had not previously received the YCare training. The study was approved by the study PI's Institutional Review Board. Participants under 18 signed assents, while parents and participants over 18 signed consent.

Recruitment

Participants were between the ages of 8–19 years, from any gender and had a family member with ALS. Participants were recruited from two chapters of the ALS Association (Upper Midwest and East coast). Chapter staff received YCare information to send to families via email, newsletters and clinics shown in Figure 2. A total of 19 youth participated between two pilot tests of the YCare protocol.

Data collection & analysis

The YCare protocol was implemented during two ALS research and family advocacy conferences, conducted by chapters of the ALS Association. The training was administered in conjunction with the conferences to increase attendance and address possible barriers to participation and access, allowing parents to attend the meetings while youth attended the YCare training. Two data collection points were included in the pilot protocol: baseline (before the training began); and immediately after the training.

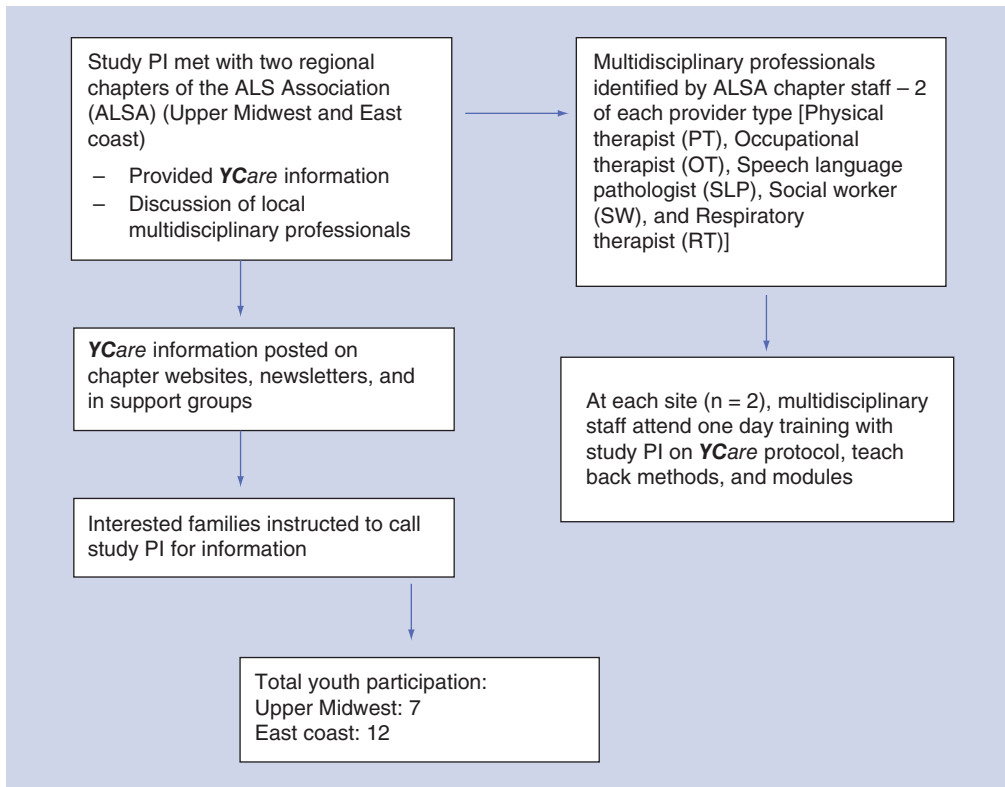


Figure 2. Recruitment and training procedures.

Measures

Demographics

Age in years, education level (0 = elementary, 1 = middle, 2 = high school, 3 = college), ethnicity and gender.

Caregiving tasks

Caregiving tasks were assessed using the general Multidimensional Assessment of Caring Activities (MACA-YC18) [14]. The scale assesses the extent to which young caregivers are involved in caregiving duties and how often they have performed each task (0 = 'never' to 2 = 'all the time') in the past month. The scale was adapted by adding tasks specific to ALS symptoms and care needs, not captured in the general MACA scale (pilot alpha = 0.78).

Caregiving training

For each task identified in the above MACA-YC18 list, a Yes/No question was asked whether the individual had received prior training.

Goal attainment/behavior

An exploratory two-item measure asking how strongly they agree/disagree (0 = strongly disagree, 5 = strongly agree) that they have the ability to identify a goal to manage or 'take care of' their own well-being, and create activities that help them reach their identified goal. An additional question asked to rate the importance of creating such goals to manage being a caregiver (0 = not important at all, 5 = very important). Goals varied by person, and were specific to their own belief about goals, thus no validation exists.

Well-being behaviors

Exploratory single item created to assess how often they were able to engage in the above identified behavior (1 = daily, 2 = weekly, 3 = monthly, 4 = never).

Caregiving self-efficacy

For each task identified in the MACA-YC18, youth were asked to rate their level of confidence in completing the task. Responses ranged from (1 = not at all confident to 4 = totally confident; Alpha = 0.90). No known self-efficacy scale exists targeting young carers, thus self-efficacy was measured using the above scale for each task identified in the MACA-YC18 [15].

Social support

Social support was measured using a scale developed for the study as part of prior qualitative research with young carers. The measure was created using qualitative responses from youth when asked what support they need. The measure contained 12 statements about support from peers and adults, asking youth to state support across different groups.

Qualitative exploration

At the end of the YCare day, youth were asked broadly what they ‘got’ out of the training. Youth wrote these out on colored post-its and placed on the YCare wall.

Data analysis

We conducted descriptive analyses of key variables. Continuous and categorical variables are summarized as mean \pm standard deviation and frequency and percentage. Pairwise t-tests were conducted to address whether youths will demonstrate improved confidence scores after participating in the YCare training, a main objective of the study.

Results

Demographics

Shown in Table 2, n = 19 participants ranged in age from 9 to 19 years old. The majority of participants were male (n = 13). All care recipients were male, fathers (n = 15), grandfathers (n = 2) or uncles (n = 2). Participants were primarily white/Caucasian (n = 16) and included Hispanic (n = 2) and African-American (n = 1) backgrounds.

Caregiving tasks

Shown in Table 3, participants engaged in housekeeping (n = 17), preparing meals (n = 16), caring for younger siblings (n = 8), toileting (n = 8), dressing (n = 10), transferring (n = 10), administering medication (n = 7), assisting with respiratory equipment (n = 7) and communication devices (n = 10). Participants spent an average of 16 h per week providing care.

Prior training

Training was infrequently provided across tasks, with the most common training addressing household chores (cooking n = 10; and cleaning n = 8). Minimal training was provided for care tasks, with youth indicating having received guidance with feeding (n = 10), transferring (n = 8) and toileting (n = 6).

Caregiving confidence/self-efficacy

Shown in Table 4, results show a significant increase in confidence with several care tasks, including communication systems, where participants increased their confidence score from pre- to post-training (standard error [SE] = 0.32; $p < 0.01$). Moreover, participants increased their confidence in using respiratory equipment ($p = 0.039$) from pre to post by a full point, 1.0 (SE = 0.44; $p < 0.05$). Additionally, results show a significant increase in confidence with using a power chair ($p = 0.031$) across all participants, increasing their confidence score from pre to post by 0.88 (SE = 0.37; $p < 0.05$).

Goal setting

A majority of participants (n = 15) stated they can develop goals and reach those goals to manage themselves and being a caregiver. A majority (n = 13) stated that setting goals to manage their own well-being was important. Participants management goals ranged from ‘to feel good’, to ‘helping out more, stressing less’ and ‘spending time with friends’. Youth identified behaviors including ‘talking to family and friends’, ‘playing sports’, ‘writing in my

Table 2. Caregiver demographics.

Characteristic	n	Total (n = 19)	
			%
Caregiver age (years)			
8–11	9		47.37
12–14	5		26.32
15–19	4		21.05
20	1		5.26
Caregiver gender			
Female	6		31.58
Male	13		68.42
Relation to care recipient			
Father	15		78.95
Grandfather	2		10.53
Uncle	2		10.53
Caregiver education			
Elementary school	9		47.37
Middle school	5		26.32
High school	4		21.05
College	1		5.26
Hours per week caring for family member			
1–10	9		47.35
11–20	7		36.84
21–30	2		10.49
31–40	1		5.26
Race/ethnicity			
White/Caucasian	16		84.21
Asian-American	1		5.26
Hispanic	2		10.53

journal’ and ‘getting away when I can’. Across age, older youth (over 14, n = 5; 25%) were more able to identify goals than their younger counterparts.

Well-being behaviors/activities

Depending on the behavior identified, participants felt they were able to engage in the behavior at least weekly, with several (n = 7) stating they could do the behavior daily.

Social support

Pre training, youth felt they had people to help them provide care (n = 14), yet only half (n = 9) felt they did not have friends who understand them. Others (n = 8) felt that they cannot talk to their friends about ALS and wished there were more kids who they could talk with about ALS (n = 10).

Qualitative exploration

Youth identified several important outcomes of the training. First, participants highlighted the benefits of hands-on training. The majority of the youth (n = 12) noted that the ‘hands-on’ was better than just being told what to do. In the words of a 13-year old, ‘it is nice to know people with good knowledge to let you try’ to guide them as they learned the tasks. Second, many youth (n = 8) described a change in perception of care, by learning the correct way to do a task, as noted by a 12-year old who said ‘transfers are way easier than I thought’ and a 16-year old who stated that ‘they had no idea low tech communication was, everywhere, and easy’. At last, almost all (n = 17) noted the importance of meeting new people, specifically peers who they can connect with, and did not have prior to

Table 3. Caregiving tasks.

Task	Total (n = 19)	
	n	%
Cleaning house	17	89.47
Grocery shopping	15	78.95
Work part time – financial help	6	31.58
Cook meals	16	84.21
Take care of siblings	8	42.11
Talk to the doctor	9	47.37
Use communication equipment	10	52.63
Help with respiratory equipment	7	36.84
Power chair	8	42.10
Help dress/undress	10	52.63
Help bathe	2	10.53
Help with appearance	8	42.11
Help feed and cut food	13	68.42
Help walk around	9	47.37
Help get in and out of bed	10	52.63
Help toilet	8	42.11
Help wipe mouth/drool	7	36.84
Help administer medications	7	36.84
Keep company	18	94.74
Make phone calls	10	52.63
Assist with writing	8	42.11

Table 4. Confidence change pre/post.

Tasks	Pre		Post		Pre/Post		
	Mean	STD	Mean	STD	Mean	SE	p-value
Using communication equipment	2.22	1.06	3.17	1.30	0.94	0.32	0.009
Helping dress/undress	2.28	1.23	2.50	1.43	0.02	0.39	0.579
Prepare food	2.67	1.18	3.28	1.07	0.61	0.37	0.119
Use power chair	2.12	1.11	3.00	1.54	0.88	0.37	0.031
Transfer bed and chair	2.29	1.23	2.50	1.20	0.22	0.42	0.601
Assist with toileting	2.24	1.35	2.18	1.38	-0.06	0.22	0.791
Use respiratory equipment	1.94	1.88	2.94	1.345	1	0.446	0.039

STD: Standard deviation.

training, and professional adults who ‘understand’ the care experience and provide information about the disease and caregiving. In the words of an 11-year old, YCare helps him ‘know what is going to happen in the future’.

Discussion

Results of this pilot study provides data on a novel training and support protocol for young carers in ALS. Despite the high number of reported caregiving and household tasks, young carers received inconsistent training prior to engaging in YCare, with most training focusing on less complicated and normative household tasks. The lack of prior training in complicated tasks and use of assistive devices highlights potential inconsistencies in familial expectations of youth involvement in care [8]. While acknowledging youth involvement in caregiving, many adults resist youth participation in further caregiving research, stating that ‘they did not want them [youth] to have to think

about it [care provided]'. This desire to 'protect' youth may extend to training in care tasks. Families with illness may self-isolate, heightening the potential for burden and lack of skills in young carers, leading to minimal access to training and guidance. In addition, social isolation may indicate skill-isolation and anxiety in care provision, a potential long-lasting impact on patient and caregiver well-being.

The change in confidence scores in the present study provides preliminary evidence of the efficacy of a training protocol inclusive of multiple care tasks, critical to persons living with ALS. Youth are involved with complicated assistive devices yet have not been trained or guided in their use, despite social assumptions that youth belong to a 'tech savvy' generation and know how to use technology. Participants in this study are dealing with devices that are often attached to, and actively in use by, family members – including parents. Fear and anxiety of harm may lessen the youth's ability to fall back on current tech knowledge and increase likelihood of harm to patients. These experiences underscore the importance of providing training targeting specific care needs. Indeed, after only one day, youth reported the largest improvement in areas where they had minimal prior training; using respiratory equipment and power chairs.

Participants found value in sharing the experience with 'like' peers, who are also involved in care, as well as receiving training from professionals who allowed them to try out and experience the tasks. The need to share the care experience with peers is critical, and reflected in data from a youth summer camp for families with illness. Campers identified the need to engage with 'like' youth in a supportive environment [7], much like the participants in YCare who clearly identified that a valuable outcome of YCare was the new interaction and support from youth. Given the relative isolation felt by young carers, it is hoped that participating in YCare will go beyond skill and confidence building, and lay the groundwork for long-term peer support from other young carers.

This data represent the only known evidence that young carers can identify goals and behaviors to manage their own wellbeing, but crucially, that they see managing their well-being as important. Caregiving is difficult, stressful and more than simply completing a task. Thus, it is important to note that youth are able to identify ways they can care for themselves and their family member, underscoring the perceived value of self-care in a vulnerable population. Of particular interest in our study was the difference in goal setting between older and younger youth. Older youth were able to identify goals better than younger youth. While this finding may be reflective of developmental progress, the results underscore the need to deepen our understanding of what 'self-management' is and how the concept is interpreted by children and youth of all ages. That said, the number of youths who identified behaviors and frequency for behavior implementation is a vital finding – supporting existing data that caregivers understand that caregiving goes well beyond completing a task, and acknowledge the value in finding ways to manage their own wellbeing. These are crucial findings for caregiving science and programming, and one which must be replicated in larger studies to assess long-term self-management goals and behaviors.

Implications

Implications exist for a broad range of healthcare professionals, in ALS, and other disease states. Youth are deeply involved in care, and can benefit from professional guidance and training in care tasks when provided the opportunity. Study results indicate youth can and will develop greater self-confidence with care tasks, including assistive technology, when properly engaged in an environment that encourages hands-on exploration and inquiry, while providing peer-engaged support for the youth. Moreover, home healthcare providers can engage youth in their home environment, even briefly, and provide structured guidance on how to assist and provide care for their family member.

Future testing of YCare will involve larger samples and involve multiple data points post-training, with additional data addressing: sustained peer supports over time; specific training needs of participants; and long-term effects on health-related quality of life.

Limitations

As a pilot study, several limitations exist. First, engagement by parents can be difficult given the time-intensive life with ALS and difficulty with transportation to events. In the first pilot, despite emails and calls to all families associated with the local ALS chapter and an easily accessible location, five families participated. Future application of the protocol will include transportation for youth and trainings held at different locations to increase participation. Second, families were wary of sharing that their child participate in care tasks. To alleviate these reluctant feelings, we will consider provision of more detailed information to families, with ensured access to study PI for questions and inclusion of several points of contact prior to the training. At last, all persons with ALS were male family

members. The sample was convenience, yet how the lack of diversity in care recipient gender may impact findings, it is important to include females in future projects.

Conclusion

Given the uncertain support in the US healthcare system for all caregivers, we do not anticipate that young carers will cease providing care; indeed, this care may increase as the population ages. The YCare training and support program is not only feasible but has clear implications for self-efficacy, skill development and building support among an isolated caregiving population. These implications may extend across disorders, particularly those requiring assistive devices (traumatic brain injury, stroke, amputation, etc). The modular nature of YCare lends itself to adaptation with other disorders and should be tested accordingly. YCare provides a critical intervention in a peer-supportive environment, underscoring the need to assess how young carers feel and respond to new tasks when receiving support from developmentally similar peers.

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No writing assistance was utilized in the production of this manuscript.

Ethical conduct of research

The authors state that they have obtained appropriate institutional review board approval or have followed the principles outlined in the Declaration of Helsinki for all human or animal experimental investigations. In addition, for investigations involving human subjects, informed consent has been obtained from the participants involved.

References

- Hunt G, Levine C, Naiditch L. *Young Caregivers in the US: Findings from a National Survey*. National Alliance for Caregiving and the United Hospital Fund, MD, USA (2005). www.caregiving.org/data/youngcaregivers.pdf
- Chio A, Gauthier A, Calvo A, Ghiglione P, Mutani R. Caregiver burden and patients' perception of being a burden in ALS. *Neurology* 64(10), 1780–1782 (2005).
- Aoun SM, Bentley B, Funk L, Toye C, Grande G, Stajduhar KJ. A 10-year literature review of family caregiving for motor neuron disease: moving from caregiver burden studies to palliative care interventions. *Palliat. Med.* 27(5), 437–446 (2013).
- Kavanaugh MS, Cho CC, Howard M, Fee D, Barkhaus PE. US data on children and youth caregivers in amyotrophic lateral sclerosis. *Neurology* 94(14), e1452–e1459 (2020).
- Siskowski C. Young caregivers: effect of family health situations on school performance. *J. Sch. Nurs.* 22(3), 163–169 (2006).
- Cohen D, Greene JA, Toyinbo PA, Siskowski CT. Impact of family caregiving by youth on their psychological well-being: a latent trait analysis. *J. Behav. Health Serv. Res.* 39(3), 245–256 (2012).
- Kavanaugh MS, Noh H, Studer L. “It’d be nice if someone asked me how I was doing. Like, ‘cause I will have an answer”: exploring support needs of young carers of a parent with Huntington’s disease. *Vulnerable Child Youth Studies* 10(1), 12–25 (2015).
- Kavanaugh MS, Cho CC, Howard M. “I just learned by observation and trial and error”: exploration of young caregiver training and knowledge in families living with rare neurological disorders. *Child Youth Care Forum* 48(4), 479–492 (2019).
- Toseland RW, McCallion P, Smith T, Banks S. Supporting caregivers of frail older adults in an HMO setting. *Am. J. Orthopsych.* 74(3), 349–364 (2004).
- Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: background and perspectives on context, process, and outcomes. *Nurs. Outlook* 57(4), 217–225 (2009).
- Hendrix CC, Landerman R, Abernethy AP. Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers. *West J. Nurs. Res.* 35(5), 590–610 (2013).
- Kavanaugh MS, Howard M, Banker-Horner L. Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS. *Soc. Work Health Care* 57(1), 1–12 (2018).
- Ha Dinh TT, Bonner A, Clark R, Ramsbotham J, Hines S. The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: a systematic review. *JBI Database System Rev. Implement Rep.* 14(1), 210–247 (2016).
- Joseph S, Becker S, Becker F, Regel S. Assessment of caring and its effects in young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child Care Health Dev.* 35(4), 510–520 (2009).

15. Steffen AM, Mckibbin C, Zeiss AM, Gallagher-Thompson D, Bandura A. The revised scale for caregiving self-efficacy: reliability and validity studies. *J. Gerontol. B Psychol.* 57(1), P74–P86 (2002).