

US data on children and youth caregivers in amyotrophic lateral sclerosis

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Abstract

Objective

An estimated 1.4 million young caregivers (<19 years of age) in the United States provide care to ill family members yet remain hidden from state and national caregiving programs and services, including amyotrophic lateral sclerosis (ALS) caregiving services. Given the intensive care needs and acuity of ALS, appreciation of the young caregiver experience within the family context may have a significant impact on patient and family quality of life. This article seeks to identify family and youth caregiver characteristics and perceptions of care through interviews with 38 youth caregivers and their families with ALS.

Methods

Online adult surveys and follow-up youth interviews were conducted with families with ALS across the United States in this cross-sectional study. Participants were accessed through chapters of the ALS Association. Both thematic content analysis and descriptive statistics were used.

Results

Youth caregivers (n = 38) ranged in age from 8 to 18 years and spent an average of 5 h/d providing care for an average of 12 tasks. Persons with ALS relied on youth primarily due to cost and identified complex feelings about relying on youth caregivers, including feeling like a failure, guilty, but proud.

Conclusion

Youth are intricately involved in all areas of caregiving in ALS. They are isolated and have little training or guidance in care, yet they are able to identify ways to manage their care burden. Results provide clear implications for health care professionals in designing best care and support practices for persons with ALS and their young caregivers.

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Glossary

ALS = amyotrophic lateral sclerosis.

Family caregivers in amyotrophic lateral sclerosis (ALS) experience depression, physical toll, and isolation¹ in ways that may not be salient in other nonfatal, slow-moving diseases or those that do not require complex care for short intensive time periods. Yet, one population of caregivers is completely overlooked in ALS, children and youth who serve as caregivers.

Approximately 1.3 to 1.4 million children and teens in the United States between the ages of 8 and 18 years (young caregivers) are involved in tasks ranging from household chores to toileting, bathing, dressing,^{2,3} and medication management,⁴ affecting their school performance⁵ and mental health⁶ and straining peer interactions.⁷ Many young caregivers feel overlooked, including by health care staff,² leaving them isolated and dealing with caregiving on their own,³ despite evidence that health care providers can have a positive influence on families affected by illness.⁸ Other disorders such as Huntington disease create anxiety and long-standing emotional difficulty for young caregivers⁹ but have an extended time with disease and relatively slow progression. This process is unknown in families with ALS. The present study provides initial data on families living with ALS who rely on a young caregiver (children or youth 8–18 years of age) to assist in care, incorporating the views of both the person living with ALS and the young caregivers. Our study research questions were the following: identifying previously unknown family-level characteristics associated with having a young caregiver; describing family perceptions of relying on children/youth for care; and detailing youth-level characteristics, including caregiving tasks and impact of care.

Methods

Study sample

The study sample includes 2 groups: adults at least 18 years of age diagnosed with ALS who have a child between 8 and 18 years of age in the family and youth 8 to 18 years of age identified by the adult as providing care.

Standard protocol approvals, registrations, and patient consents

Adults provided online consent and verbal audiotaped parental consent; youths <18 years of age provided verbal audiotaped assent. The present study was approved by the Institutional Review Board at the primary author's university.

Data collection

As detailed in the figure, recruitment was carried out over a 9-month period, entailing a multistep process to capture as many families from across the United States as possible.

Given the complexities of living with ALS, an online adult survey was the least burdensome and easiest process for people living with ALS (survey completed by themselves or with assistance from an adult in the home). All families who completed the survey were asked 2 screening questions at the end of the survey: (1) Do they have a child or youth 8 to 18 years of age in the family? (2) If yes, do they give us permission to interview the youth? Contact information was requested for youth interview follow-up. If permission and contact information were provided, a follow-up call was made to the family to arrange a time to obtain verbal consent/assent and to conduct a phone interview with the youth. All information stated clearly to complete the adult survey only if they had a child or youth in the family. However, numerous persons living with ALS but who did not have a child in the family completed the survey. These surveys were not included in the final analysis.

The adult survey was captured by Research Electronic Data Capture. Phone interviews with youth were audiotaped, transcribed, deidentified, and coded with a 3-digit code. The same 3-digit code was given to the adult-level data to link the two. A paper-and-pencil option was offered to encourage participation for those without computer access. A total of 4 families chose the paper option.

Measures

Family demographics

The online adult survey captured age, race/ethnicity, education, income, presence of and type of insurance, and marital and employment status.

Qualitative care questions

Persons with ALS were asked 2 open-ended questions: "What caregiving task does your child/youth do to assist you?" and "How does it feel to rely on your child/youth for care?"

Youth caregiving tasks were assessed from the youth perspective with the Multidimensional Assessment of Caring Activities.¹⁰ The measure was created and tested on samples of young caregivers across disorders (Cronbach $\alpha = 0.78$).

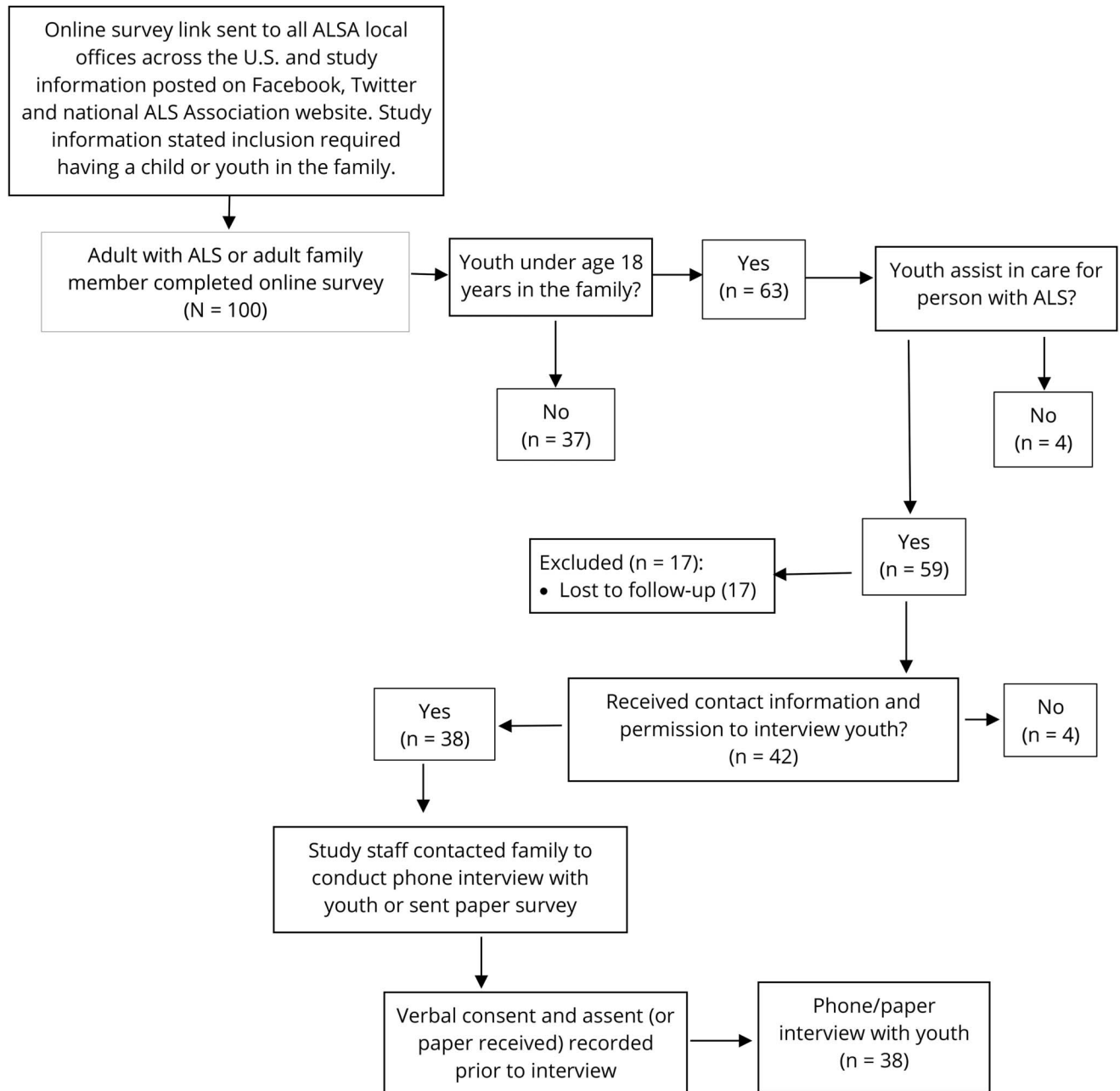
Caregiving impact

Caregiving impact was measured by the Young Caregiver of Parents Inventory,¹¹ a measure created and tested specifically on the young caregiver population (Cronbach $\alpha = 0.72$ – 0.88).

Coping with care

Youth were asked an open-ended question to describe any "task or activity they engage in to cope with or deal with being a caregiver."

Figure Sampling and data collection flow chart



ALS = amyotrophic lateral sclerosis; ALSA = ALS Association.

Data analysis

Given the exploratory nature of the present study, quantitative data were analyzed with descriptive statistics. Qualitative analysis used conventional content analysis to identify specific words and patterns that arose from multiple readings of the open-ended questions, rather than using a predetermined coding scheme.

Data availability

Any anonymized data will be shared by request from the principal investigator.

Results

A total of 100 families with ALS, representing 12 states across the United States, consented and completed the initial online survey. Of those, 63 identified having a child in the family 8 to 18 years of age. Of the 63 families with an identified child or youth in the family, 59 identified that a child/youth provided care. After loss of families to follow-up and families who identified a young caregiver but did not provide permission for the youth interview, a total of 38 interviews with youth were completed.

Family-level data

Table 1 details those living with ALS who had a youth providing care. Fathers represented half of those living with ALS, with the rest divided between mothers and other family members. The majority were white, with a median age of 46 years. Across the sample, the majority had at least a high school degree, while 13% had an advanced degree. Almost a third of the families had an income less than \$30,000,

Table 1 Persons with ALS identified young caregiver (n = 38)

	No.	%
Male	21	55
Female	17	45
Black/African American	2	5.2
White/Caucasian	29	76
Hispanic or Latino	6	16
Native American or Alaskan Native	1	3.3
Married	34	89
Divorced	1	3.3
Separated	2	5.2
Other	1	3.3
Grades 9–11 (Some high school)	1	3.3
Grade 12 (Completed high school)	6	16
Some college	12	32
College degree (BA, BS, etc)	14	37
Advanced degree (MA, MS, PhD, MD, etc)	5	13
Less than \$15,000	4	11
\$15,000–\$29,999	7	18
\$30,000–\$49,000	10	26
\$50,000–\$99,999	10	26
\$100,000 or more	7	18
Full time	5	13
Part time	3	8
Not currently employed	5	13
Unemployed/on disability	24	63
Medicare	23	61
Medicaid	10	26
Private insurance	18	47
VA	6	16
Currently receiving care from ALS specialist	28	74
Rely on family due to lack of funding for care	24	63

Abbreviations: ALS = amyotrophic lateral sclerosis; VA = Veterans Affairs.

yet almost as many had income over \$100,000. Average time since diagnosis was 4.8 years. Of note, the families who were lost to follow-up (n = 17) did not differ demographically from those who allowed the youth follow-up interview.

Treatment/insurance

Two-thirds of adults who rely on youth for care currently received treatment from an ALS specialist/clinic. Despite the presence of insurance, the majority relied on youth care due to cost and inability to pay for outside help.

Caregiving

Adults with ALS identified numerous tasks engaged in by youth, including feeding, assisting with transferring, dressing, showering/toileting, and managing assistive devices.

How it feels to rely on a youth

When asked how it felt to rely on a youth for care, persons with ALS described both positive and negative feelings, stating they felt “appreciative” (n = 5), as described by a father with ALS, “I appreciate that my kids see the value of taking care of me,” or “grateful” (n = 4), reflected in a quote by a father, “I can’t do much, so am grateful that I have the kids to help me out.” Yet the majority struggled with having a youth provide care, describing feeling “sad” (n = 6), “a burden” (n = 5), and a “failure” to their family (n = 3), as described by a quote from a mother, who stated, “It is hard to not to feel like a disappointment to my kids because they have to do so much to help me.” In addition, 8 adults described both positive and negative feelings, stating feeling both “grateful and guilty” for relying on a youth.

Youth characteristics

Background of the young caregiver

As detailed in table 2, youth ranged in age from 8 to 18 years. Youth caregivers were almost equally split between male and female. The majority lived with the person with ALS.

Caregiving tasks

Table 3 shows that youth participated in an average of 12 tasks for an average of 5 h/d. Tasks engaged include feeding, showering/bathing, and transferring from/to chair or bed. These tasks are reflected in the parent/family-level data, providing initial congruence between those identified by youth and those by the adult with ALS.

Impact of caregiving

Youth identified the need for more information about ALS (n = 26, 68%), a desire to connect with other youth their age to share about ALS (n = 19, 50%), and the difficulty in explaining ALS to their friends (n = 19, 50%). In addition, youth highlighted concern about talking about ALS with other family members (n = 15, 39%) and feeling guilty when they were not providing care (n = 24, 63%). Reflecting the positive and negative feelings of their family members receiving care, many youths acknowledged that providing care makes them feel good about themselves (n = 27, 71%).

Table 2 Young caregiver demographics

	No.	%
Male	18	47.4
Female	20	52.6
Age, y		
8–10	2	5.1
11–13	9	23.7
14–16	10	26.4
17–18	5	13.2
Race		
White/Caucasian	25	68
Black/African American	5	14
Native American or Alaskan Native	1	3
Other	6	16.2
Education		
Elementary school	9	24.3
Middle school	16	43.2
High school	10	27
College	2	5.4
Relationship to person with ALS (providing care)		
Father	19	50
Mother	12	32
Other	7	18.4
Aunt	2	
Cousin	1	
Grandfather	4	
Currently living with the person with ALS	30	79

Abbreviation: ALS = amyotrophic lateral sclerosis.

Coping with being a caregiver

The majority of youth identified and actively engaged in activities to deal or cope with being a caregiver ($n = 24$, 63%). Coping activities identified by youth included being active ($n = 12$), playing video games ($n = 5$), writing ($n = 9$), talking with friends ($n = 4$), and crying ($n = 5$).

Discussion

Children and youth <18 years of age are actively involved in caring for persons living with ALS. They engage in tasks ranging from feeding to toileting, yet they do so in relative isolation. By highlighting the role children and youth play in care, the present study reverses traditional assumptions that adults alone provide

care^{2,4,6,9} and provides implications for adapting long-standing research foci¹² and state and national caregiver programs solely targeting caregivers ≥ 18 years of age.¹³

Youth are more actively engaged with basic care skills than the complex assistive devices. While it remains unclear why, given the numerous devices in use with person living with ALS, one reason may rest in the lack of caregiver training and skills provided to young caregivers.¹⁴ With limited training and unclear skills, young caregivers may avoid or fear the more complicated devices, despite the intrinsic need for such devices in ALS. Given the high use of devices in this population, training and skill development may provide the guidance needed for youth to understand the devices, reduce the inherent fear of the devices used by family members living with ALS, and serve to improve patient quality of life, knowing that the caregiver is confident in the use of complicated equipment.

Adults with ALS and their youth caregivers showed congruence in care tasks undertaken by youth, as well as the positive and negative experiences of giving and receiving care. Congruence in the caregiver/care recipient dyad is not always present. Prior studies found disagreements frequent to the dyad, primarily in relation to the need for care and difficulty of providing care.¹⁵ In the present study, adults with ALS described feeling both grateful and guilty for having their child assist with care, much like the youth describing the “push and pull” of being a caregiver. These results are reflected in findings from a poll of young caregivers in the United Kingdom. Results showed that while 48% said that being a young caregiver made them feel stressed, 51% reported that they were proud of being a young caregiver, and 42% said that it made them happy. The positive and negative responses highlight the overall complexity of both being a caregiver and receiving care from a family member, particularly children and youth. Care interventions can be informed by these data, creating a whole-family approach targeting caregiver and care recipient. Assessing congruence or disagreement in the caregiver dyad is critical to the development of family-based interventions, a broader family-level acknowledgment of the role that youth play as caregivers, and shared understanding of what tasks are needed.

An important finding was the lack of support provided to young caregivers and their identified need for more information about ALS. These results highlight opportunities for health care professionals to engage families in discussions about youth caregivers, previously assumed to be too stigmatizing or unnecessary. When patients are seen in the clinic to assess home needs, a few probing questions can be added to assess care needs, including inquiring whether a child or youth engages in care. If so, how can professionals make sure the child and family are supported or in need of respite to reduce burden? Asking about care may help reduce the isolation felt by families and increase trust and engagement with health care professionals, as well as access to opportunities for respite and care services. Despite potential difficulty, these conversations are supported by data showing that youth and families are

Table 3 Youth care tasks

	Never		Some or all of the time	
	No.	%	No.	%
Household chores				
Clean house	4	10.53	34	89.47
Cook meals	15	39.47	23	60.53
Activities of daily living				
Help your family member dress/undress ^a	16	42.11	22	57.89
Help him/her shower/bathe ^a	27	71.05	11	28.95
Help him/her go to the bathroom ^a	19	50.00	19	50.00
Help feed him/her ^a	6	15.79	32	84.21
Help him/her take medication	19	50.00	19	50.00
Help family member with appearance ^a	17	44.74	21	55.26
Help to wipe mouth or with drooling ^a	15	39.47	23	60.53
Make phone calls for him/her	21	56.76	16	43.24
Help him/her write	21	55.26	17	44.74
Transferring				
Help him/her walk or get around house ^a	12	31.58	26	68.42
Help him/her get in/out of bed or chair ^a	8	21.05	30	78.95
Assistive devices/activities				
Interpret, sign, or use other communication systems ^a	16	42.11	22	57.89
Help with respiratory equipment ^a	23	60.53	15	39.47
Help them with range of motion or therapy exercise ^a	23	60.53	15	39.47
Other				
Keep your family member company ^a	1	2.63	37	97.37
Take care of siblings	15	39.47	23	60.53

^a Tasks also identified by adult with amyotrophic lateral sclerosis.

valid historians of care tasks, share a common understanding of the role they play, and need support in their caregiving role from a variety of health care professionals.

Families in the present study relied on youth for care due to cost of care. Indeed, the cost of care is increasing across disease populations, leaving many families unable to pay out of pocket for care.^{16,17} Understanding how families manage care is specifically critical for those with costly disorders such as ALS. If families rely on youth due to cost, what are the options for families without youth or other family members? This information can be used to inform how caregiving programs and funds are distributed and accessed by families in need, not only in ALS but across costly disorders. Moreover, these results support disease-based organizations in the development and implementation of targeted family-based programming focused on family support and respite provision.

Despite the clear burden of care, youth showed the ability to create and engage in personal coping activities to manage being a caregiver. Given the lack of current support programs for young caregivers, it is important to identify how youth caregivers personally deal with care and what they need to maintain a normal youth experience, specifically opportunities to engage with other caregiving youth. These data may be used to inform the development of targeted youth caregiver support programs, integrating tenets of self-management theory.¹⁸ Self-management and identification of behaviors to manage care have been studied in adult caregivers,¹⁹ yet there is a lack of data on whether youth are able to create self-management strategies as caregivers. The present study provides initial insight that youth can engage in self-care and coping behaviors and can attend to their own well-being, laying the groundwork for further exploration of how young caregivers care for themselves while caregiving for others.

Despite the potential for vital information from the present study, 4 families declined to have their child interviewed. When asked why they did not want to give permission for the interview, adults stated they did not want their youth to “discuss care” or “think about it,” despite previously stating their youth provided care. These responses highlight the delicate balance families maintain when discussing youth caregivers: acknowledgment of the youth’s role at the risk of potential social judgment due to relying on a child or youth or simply not wishing their child to grow up too fast because of having to think about ALS. Acknowledging this need, implications exist for providers to talk to families in a sensitive, constructive manner, assessing family-level needs, including children and youth as caregivers, across disorders. Indeed, the existence of young caregivers in a variety of populations, including but not limited to ALS, may highlight an unmet need for families and an opportunity for intervention and engagement by social and health care providers in developing whole-family approaches to family illness.

The data presented are exploratory, yet several limitations exist. Families living with ALS are clearly overwhelmed, making follow-up difficult. In our study, 17 families completed the online adult survey, identified youth as a caregiver, provided permission to interview youth, yet were lost to follow-up for the youth interview. While numerous methods were used to address potential loss (personal calls, e-mails, and mailings), the most effective method may require personal connections with families to build trust and flexibility to match the needs of these families. While this method increases cost and time, not available in the present study, personal connection may have increased sample size and follow-up access.

In addition, the sample is purposeful, limited to young caregivers of a family member with ALS and connected to chapters of the ALS Association. Therefore, these young caregivers and their families may be substantively different from others who do not have access to services through the ALS Association. In addition, the lack of random sampling procedure precludes the generalizability of the present study findings, and findings should be limited to the sample at hand. Finally, the sample lacks diversity; it is overwhelmingly white. Future research is needed to address the cultural and ethnic implications of caregiving by young caregivers. While these results detailed congruence on care tasks identified by young caregivers and adults, future data should delve into this finding to assess how these tasks are assigned and whether there was actual agreement.

Finally, it is unclear whether an adult was in the room when youth were competing the interview. While none were noticed during the telephone interview, it is unclear if they were in the background, which may have influenced youth responses.

Gaining the insight of youth caregivers in families with ALS is critical for a broader understanding of the family experiences in ALS but may lend itself to other complex and intensive neurologic disorders. Study results can be used to inform the

development of future collaborative youth caregiver research across disorders comparing and contrasting impacts of care on youth, to inform targeted support programs for youth caregivers and their families, and to create whole-family interventions. By providing support and guidance to the youth caregiver, we hope to lessen caregiver burden and increase the quality of life for all family members in ALS and beyond.

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Appendix Authors

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Melinda S. Kavanaugh, PhD	University of Wisconsin–Milwaukee	Collected study data; analyzed qualitative data; performed statistical analysis; crafted paper outline; involved in all phases; maintains oversight of all study data and research conduct; responsible for all journal communications during review process
Chi Cho, MA	University of Wisconsin–Milwaukee	Lead in quantitative data analysis, performed statistical analysis, edited paper sections
Megan Howard, MA	University of Wisconsin–Milwaukee	Coanalyzed qualitative data, edited paper, crafted references
Dominic Fee, MD	Medical College of Wisconsin, Milwaukee	Collaborated on study design and editing
Paul Barkhaus, MD	Medical College of Wisconsin, Milwaukee	Collaborated on study design and editing

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