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Living with a parent with ALS - adolescents’ need for professional support from the adolescents’ and the parents’ perspectives

NINA MÅLMSTRÖM, BIRGITTA JAKOBSSON LARSSON, STEFAN NILSSON, JOAKIM ÖHLÉN, INGELA NYGREN, PETER M. ANDERSEN & ANNELI OZANNE

Abstract

Aim: The aim of the study was to qualitatively investigate the adolescents’ need for professional support when a parent has amyotrophic lateral sclerosis (ALS) – from the adolescents’ and the parents’ perspectives. Methods: A total of 37 individual semi-structured single interviews with 18 families were conducted, including 11 adolescents aged 8-25 and 26 parents, 13 with ALS and 13 co-parents. Data was analysed using qualitative content analysis. Results: Both adolescents and parents described the adolescents as needing professional support but found it difficult to articulate this need. However, the results indicate that the adolescents needed help in bringing manageability into their lives due to the uncertainty of living with the illness in the family. It was therefore essential to ensure that the adolescents were not forgotten in the disease context and that their needs for being involved as well as for obtaining information and understanding, was addressed. The importance of offering the adolescents support early was emphasized, but also of actively helping the families to master challenges in their everyday life. Support adapted to each family’s unique situation and preferences was desired, as the adolescents’ need for support seemed to be individual, disease-dependent and varied during different phases. Conclusion: Given the adolescents’ need for information and understanding, healthcare professionals must actively work to reach the adolescents as early as possible. It is crucial to ensure that the adolescents are given the opportunity to be involved based on their own conditions, as well as to support the families to strengthen their communication.

Keywords: Amyotrophic lateral sclerosis, motor neuron disease, adolescents as relatives, family support, qualitative content analysis, neurophysiology, clinical trials, ethics

Introduction

People with amyotrophic lateral sclerosis (ALS) increasingly need help in everyday life. The family is often involved in this support while witnessing how the ill person is deteriorating and eventually dies (1,2). Caring for a family member with ALS can be demanding and burdensome. Younger age and a lack of social support have been associated with higher burden while adequate social support can work protectively (3,4). However, the disease may disrupt the family's life situation (3,5), and especially in families with young carers, these family members risk social isolation (6). This makes support from healthcare professionals (HCP) important (7,8) and according to the guidelines patients with ALS and their families should be cared for by a multi-professional team (9).
Adolescents living with a parent with a life-threatening condition are a particularly vulnerable group, given their phase of development and dependent position (10). This can result in stressful experiences and an increased risk of developing ill health and long-lasting physical, cognitive, emotional, and behavioral problems (11,12). Previous research focusing on adolescents of parents with ALS shows negative impacts on their well-being (5). They rate symptoms of anxiety, depression, and self-loathing, as well as shame, guilt, and emotional stress as worse than a control group (13). Adolescents providing care for a parent with ALS also report poorer sleep and higher usage of medication compared to non-caregivers (14).

A lack of professional support for adolescents caring for a parent with ALS has been identified (2), but research examining how they should be supported by professionals is limited. The aggressive and rapid course that is specific to this disease may make it different from other serious diagnoses for which previous research has examined adolescents’ need for support while living with an ill parent. To our knowledge, only one study has explored the support needs in families where a parent has ALS, but with a focus on strengthening parenthood (5). To promote or maintain the health of these adolescents, more knowledge is still required about their specific need for professional support. The aim of this study, therefore, was to qualitatively investigate the adolescents’ need for professional support when a parent has ALS - from the adolescents’ and parents’ perspectives.

Materials and methods

Study design

This study had a qualitative, descriptive, and interpretive design. This article reports a secondary aim of a larger project with the purpose to improve support for families where a parent has ALS - from the perspective of the adolescents, parents with ALS, co-parents, and HCP. The consolidated criteria for reporting qualitative research (COREQ) 32-item checklist was used to report the research (15).

Participants

The recruitment of participants was conducted via the ALS teams at three University hospitals in different regions across Sweden. A purposive sampling was applied to recruit adolescents and parents who met the inclusion and exclusion criteria. The inclusion criteria were patients who had been diagnosed with probable or definite ALS according to the El-Escorial WFN (16) at least six months earlier as well as their partner/former partner with whom they had children in common and their children. The adolescents had to be between the ages of 8 and 25, and fully or partly live together with the parent with ALS. In addition, the patient needed to be treated by an ALS team and have sufficient communication ability to be able to participate in an interview. The exclusion criteria were patients who had dementia or severe cognitive impairment and co-parents that the patient did not want to include. Adolescents that the parents did not want to include as well as adolescents whose parents did not consider them to be in a sufficiently good mental state of health were also excluded.

In this study, the term “adolescent” is used to refer to children as well as adolescents and young adults. Adolescence can be described as a phase of brain development beginning around the age of 6–8, before visible signs of puberty, and continuing for two decades (16). In addition to research on the maturity of the brain, the wide age range among the participating adolescents was relevant because clinical experience shows that adolescents in this age range often support their parents for everyday life to function (frequently referred to as “young carers”) (17).

Data collection

The patients were asked face-to-face or by telephone for interest in participation by the nurse, research nurse, or physician at the ALS team. If positive response, the researcher informed the patient by telephone about the purpose and implementation of the study and asked for consent to contact their partner/former partner and children. Approval from both parents was required before contacting the children. Data on how many potential participants chose not to participate is missing. Data for 37 individual single interviews were collected between December 2020 and April 2022, by the first (NM) and last author (AO), as well as by a research assistant. None of them clinically cared for the participating families.

A semi-structured interview guide was used with questions adapted to the different participant groups, i.e. the parents with ALS, co-parents, and adolescents who were further divided into three groups based on age. The topics of questions asked were: received or offered and wanted support for the adolescents and parents in connection with diagnosis as well as over time; possible future support needs; the involvement of potential supporting actors. Examples of questions were: “What is important for healthcare/school/authorities to think about when they talk to you/your child?” and “What can the healthcare/school/authorities do to make your family’s life situation easier?” Five of the interviews were conducted face-to-face in the participants’ homes and 32 were conducted by telephone, based on the participants’ preference which may have been affected by the ongoing
covid-19 pandemic. The interviews lasted between 15 and 99 min (median = 40.5 min), were audio-recorded and transcribed verbatim. The researchers estimated the parents’ physical function using the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R) (18).

Data analysis

Data were analyzed by qualitative content analysis (QCA), focusing on similarities and differences between different parts of the text (19,20). After repeated reviews of the material, the text was divided into meaning units followed by condensation. The condensed meaning units were subsequently formed into codes, which in the next step were abstracted and sorted into different subthemes (21) by using NVivo software (22). The subthemes were then abstracted into themes and finally, an overall theme was generated. The analysis was mainly conducted by NM, but with continuous reconciliations and reflections together with BJL and AO to enhance trustworthiness. The authors moved back and forth between parts of the text as QCA is not based on a linear process. The formulation of the themes and the presentation of the results were continuously discussed within the research group until a consensus was reached.

The team of researchers had methodological experience with QCA as well as clinical experience in meeting persons with ALS and their relatives and palliative care. A pediatric nurse was also involved.

Ethical considerations

The study has been approved by the Swedish Ethics Review Authority (Dnr 2019-03861). Oral and written informed consent was obtained from all participants, and from both children and parents if the child was under the age of 15.

Results

The study sample comprised 37 participants from 18 families with 11 adolescents, 13 parents with ALS, and 13 co-parents (Table 1).

Bringing manageability into the adolescents’ life of uncertainty

The main theme, “bringing manageability into the adolescents’ life of uncertainty”, was expanded from three themes: “making the adolescents’ needs visible”, “forming a protective social network”, and “strengthening the family”. These themes were sustained by an additional eight sub-themes; “involving and interacting with the adolescent”, “obtaining information and understanding”, “knowing where to turn”, “having someone to talk to”, “meeting others in similar situations”, “involving the school”, “bringing the family together”, and “giving practical support” (Tables 2 and 3). To bring manageability into the adolescents’ lives, their need for professional support had to become more visible. The families should be strengthened in managing their life situation together, whereby professional support could have a protective effect.

Making the adolescents’ needs visible

While everything revolved around the disease, the adolescents’ need for professional support was overshadowed, and it was essential to make them more visible through “involving and interacting with the adolescent” and “obtaining information and understanding”.

Involving and interacting with the adolescent.

The adolescents wanted to be involved in discussions about their parent’s condition, the development of the disease, and possible future scenarios, despite most having non-existent or little contact with the healthcare. The parents likewise emphasized the importance of involving the adolescents, but sometimes experienced difficulties in suggesting it to their child. However, not involving the adolescents could also be an active choice by the parents in an attempt to protect them.

The adolescents’ need to be involved seemed to vary during the different phases of the disease and was described as particularly great in connection with the diagnosis. Healthcare provision was considered to have a significant role in ensuring their involvement, above all in families where the disease progressed rapidly. Both adolescents and parents requested an active initiative from the ALS team in gathering the entire family at an early stage. Directly inviting the adolescents was highlighted, especially among parents with older children. Accompanying the parents to hospital appointments was believed to make the situation less unfamiliar for the adolescents, which some parents thought could increase their children’s sense of control. However, some adolescents expressed reluctance to visit the hospital and thus desired other kinds of opportunities to be involved.

The adolescents did not want HCP to treat them differently from others, while the importance of listening, showing respect, and understanding was emphasized. The parents had similar preferences. HCP’s ability to find a balance between maintaining hope and being honest was appreciated. Honesty was described as fundamental but being aware of the family’s approach to the disease and weighing words accordingly was also important. However, confidence in healthcare capability to appropriately interact with the adolescents was high overall.

Obtaining information and understanding.

Both adolescents and parents highlighted the importance of providing the adolescents with information about the disease to obtain a better
understanding of the situation. Information was usually received from the parents, which some adolescents considered sufficient. Others expressed a need for a medical explanation from healthcare services and to be allowed to freely ask questions. Several parents also requested that opportunity, while others thought they should have sole responsibility for imparting this information to their children.

The level of information provided to the adolescents seemed to be based on their age, receptiveness, and progression of the disease. However, even parents with older adolescents sometimes withheld information from their children. Some parents had chosen a more open approach from the outset, while others preferred to gradually share some facts. In the absence of information, several adolescents tried to increase their

Table 1. Self-reported descriptive characteristic of the participants.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Adolescents (n = 11)</th>
<th>Parents with ALS (n = 13)</th>
<th>Co-parents (n = 13)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average age (SD)</td>
<td>18.5 (4.5)</td>
<td>52.5 (5.6)</td>
<td>54.3 (10.1)</td>
</tr>
<tr>
<td>Age range</td>
<td>8–25</td>
<td>35–66</td>
<td>41–60</td>
</tr>
<tr>
<td><strong>Civil status (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fully living at home with the parent</td>
<td>7</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Partly living at home with the parent</td>
<td>4</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Married to/cohabiting partner of the other parent</td>
<td>–</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td>Divorced from the other parent</td>
<td>–</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>Occupational status (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>7</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Full-time/self-employed</td>
<td>3</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Part-time/temporary employed</td>
<td>1</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Job seeker/in labor market policy measures</td>
<td>–</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Retired</td>
<td>–</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td>On sick leave</td>
<td>–</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>No answer</td>
<td>–</td>
<td>–</td>
<td>1</td>
</tr>
<tr>
<td><strong>Diagnosis (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familial ALS</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>Sporadic ALS</td>
<td>–</td>
<td>9</td>
<td>–</td>
</tr>
<tr>
<td>Don’t know</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>No answer</td>
<td>–</td>
<td>2</td>
<td>–</td>
</tr>
<tr>
<td><strong>Time from diagnosis of the patient to interview (n)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;1 year</td>
<td>–</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>1–2 years</td>
<td>4</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>2–4 years</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4–6 years</td>
<td>–</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>6–8 years</td>
<td>–</td>
<td>1</td>
<td>–</td>
</tr>
<tr>
<td>8–10 years</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>≥10</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>No answer</td>
<td>2</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>ALSFRS-R</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean sum score (SD)</td>
<td>–</td>
<td>31.2 (12.5)</td>
<td>–</td>
</tr>
<tr>
<td>Range sum score</td>
<td>–</td>
<td>9–45</td>
<td>–</td>
</tr>
<tr>
<td><strong>Children in the family</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of children (SD)</td>
<td>2.5 (1.8)</td>
<td>2.9 (2.4)</td>
<td>1.7 (0.5)</td>
</tr>
<tr>
<td>Age range of the children</td>
<td>8–28</td>
<td>2–35</td>
<td>8–28</td>
</tr>
</tbody>
</table>

*The higher ALSFRS-R score, the more retained physical function.  
**These data are intended to depict the variation in the ages of the children and adolescents in families where only the parents or some of the adolescents participated.

Table 2. Overview of main theme, themes, and sub-themes.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Bringing manageability into the adolescents’ life of uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Themes</strong></td>
<td>Making the adolescents’ needs visible</td>
</tr>
<tr>
<td><strong>Sub-themes</strong></td>
<td>Involving and interacting with the adolescent</td>
</tr>
<tr>
<td></td>
<td>Obtaining information and understanding</td>
</tr>
<tr>
<td></td>
<td>Meeting others in similar situations</td>
</tr>
</tbody>
</table>

The higher ALSFRS-R score, the more retained physical function. These data are intended to depict the variation in the ages of the children and adolescents in families where only the parents or some of the adolescents participated.
### Making the adolescents’ needs visible

**Involving and interacting with the adolescent**

That they (HCP) talk to you as if you were... yes, but that you’re allowed to participate as if you were one of the adults in the family, because that’s still the role you’ll take later. You’ll still take responsibility and be involved in the whole situation.—Adolescent aged 21 (participant 1)

I’m just thinking that they (the children) need to be invited and, well, they would need to attend their father’s appointments. The repeated ones. Because it’s a way to, what to say, perhaps start to recognize the situation yourself and feel that you have some control.—Co-parent (participant 2)

I’ve had a hard time thinking about doctors and things like that, I think about exam rooms, and I don’t think that’s good for the children. Then it’ll be like sitting in an office and that something will be required of the children. So if you can meet under other conditions. (…) So, no, I don’t know how to do it. There are children’s wards and... You can have coffee breaks and... —Parent with ALS (participant 3)

**Obtaining information and understanding**

So, of course, you would have liked someone telling you, but you haven’t been part of the ALS investigation, you haven’t been involved in any information like that. Well, yes, it would have been easier if you knew more about how to handle different things.—Adolescent aged 20 (participant 4)

So, there were many nights of googling, you wanted to find out... find out more.—Adolescent aged 20 (participant 5)

The children know that Mum’s weak in the arms and that she has a muscle disease, but not the extent of it in any way. (…) No, we have chosen not to tell them because... we didn’t see any reason for them to go around and think about it, because it’s not yet so tangible. (…) So, it has really been something like, some strategy there to... protect them from that, from... so to speak, the final consequences.—Co-parent (participant 6)

### Forming a protective social network

**Knowing where to turn**

I find that a bit difficult because I don’t really know where to turn. (…) I’m not depressed and in need of help in that way, but it’s just that I’ve a different life, and sometimes it’s hard. (…) It’s a bit difficult to know where you fit in. Because really, there’s nothing wrong with me. It’s just that I’m a relative or whatever they call it. So, I think it’s a bit difficult to know where to turn.—Adolescent aged 17 (participant 7)

So it’s heavy for healthcare. But someone just has to, someone also has to take responsibility for the children, if the parent isn’t capable of doing so. And I think you should assume that the parent never has the ability, in such a difficult situation.—Parent with ALS (participant 8)

It was very unclear, I had to try to find out a lot myself: Where should I turn to myself? Where should I turn for my daughter? Because it was, the healthcare aimed at my daughter’s mother, there was a lot of focus on her. (…) Yes, more actively for the relatives around, I feel that. I do.—Co-parent (participant 9)

**Having someone to talk to**

She (the psychologist) has been a fantastic... help. It has been very good, and I still go to her now and... have sort of gotten help with the stuff, the personal stuff that I thought was the most troublesome. (…) So now when I see her, I usually talk about my mother and our family relationships and such. It’s great to have such a... well, room to vent.—Adolescent aged 18 (participant 10)

What I’ve missed from the beginning, was someone giving them (the adolescents) that support and calling regularly and talking to them and... and someone who gave them advice on how to handle situations. Some tools for how they should think, so that it’ll not be so difficult.—Parent with ALS (participant 11)

I don’t want to go far away, or that it’ll affect the school and things like that and my free time because I need to... I don’t want to do something for just an hour and then go home again. So, it would probably have been easier if it (support conversations) was available nearby.—Adolescent aged 18 (participant 7)

**Meeting others in similar situations**

If his condition had been worse, I think I would have appreciated support groups or discussion groups, that you could go to and meet people in the same situation. (…) Then there would probably have been a greater need to discuss how it really feels to move away from home when your father is very ill.—Adolescent aged 21 (participant 1)

They’ve asked if we want to meet others who have parents with ALS, but like around here, as far as I know, there aren’t that many people of my age who have a parent with ALS. So, I’ve kind of, I haven’t really seen any purpose in it before. But sometimes I wish I could talk to someone who understands.—Adolescent aged 17 (participant 7)

From the children’s perspective, you see that... just to be able to share thoughts. And to witness: “Well, others do it in this way”. It’s possible to play cards with the father, yes, because the assistant can hold the cards, or you can arrange it like that.—Co-parent (participant 11)

**Involving the school**

So those (the school) who know about it, they treat me like anyone else. And I think that’s nice. There’s nothing special about me or anything.—Adolescent aged 14 (participant 12)

And then you wish that they (the student health team) would be present every day, because our son doesn’t know which day he will be sad. He may not always be sad every Tuesday or Wednesday. He might be sad on a Friday, but then maybe the counselor’s on maternity or sick leave.—Co-parent (participant 13)

Meet and treat me exactly as you do with the rest of the students. No special treatment should be given at the school.—Adolescent aged 17 (participant 14)

I think it’s important that the school think about showing understanding, and that you might feel very bad at the beginning and that you can get a little respite.—Adolescent aged 21 (participant 4)

Maybe (would have liked to talk to someone at school about the life situation) Erm... that we... that it’s hard, that I think it’s a bit hard sometimes and things like that.—Adolescent aged 8 (participant 15)

(Continued)
understanding by searching the internet, which concerned some parents who wished they had access to more general age-appropriate education materials.

**Forming a protective social network**

Having a good social support could be crucial for the adolescents in trying to deal with their difficult life situations. It was important to ensure access to a protective professional network to facilitate their “knowing where to turn”, “having someone to talk to”, “meeting others in similar situations”, and “involving the school”.

**Knowing where to turn.** Both adolescents and parents described a need for professional support, but the tendency of the disease to take over everyday life to such an extent meant there was no time for them to reflect on what support they wanted. There was uncertainty about where to turn for help, and better information about support options was requested. Struggling with their own emotions meant not all parents were able to go through the process of seeking help for their children, which reinforced the importance of support being actively offered by healthcare. Some felt that the ALS team focused on the ill parent and missed the family’s support needs, while others thought that the team provided optimal support.

**Having someone to talk to.** The adolescents highlighted the importance of having a support contact who did not have a personal connection to the family but equally described feeling ambivalent about having support conversations. Likewise, several parents considered it essential that their children had the opportunity to talk to a professional but sometimes experienced difficulties in getting them to accept this help.

Some adolescents had had supportive conversations with the ALS team, while others had turned to other institutions. Several adolescents had neither had any supportive conversations nor been offered one. There were also parents who declared that they had not passed the team’s offer of support, as they did not feel their children needed it. The adolescents’ need for supportive conversations was highlighted as depending on the individual, the phase of their parent’s disease, and any existing informal support.

The importance of accessibility was emphasized, as illustrated by the team’s offer of support sometimes being refused due to the distance to the hospital. Some parents suggested digital solutions to facilitate access or make it easier for those who found it difficult to talk to a stranger in a physical meeting. Another suggestion was to organize supportive activities instead of having traditional conversations.

**Meeting others in similar situations.** Some adolescents wanted to meet others in similar situations to share experiences and to feel a sense of belonging, while others found this uncomfortable. Several parents found there was a strong focus on the disease in support groups and therefore actively dissuaded their children from attending, for fear of worsening the situation. In other families, there was a great demand for peer support among both adolescents and their parents, but no alternatives seemed to exist. Support groups had also been canceled during the Covid-19 pandemic.
Additionally, some co-parents stated it was difficult for the rest of the family to meet others in similar situations if the parent with ALS did not want to talk about the disease.

The importance of age-appropriate groups was also highlighted, but opinions differed as to whether the groups should only target children of parents with ALS. Besides creating a sense of community, some parents believed that meeting others could help their children identify possibilities in everyday life by witnessing how other families had dealt with certain issues. Additionally, there were suggestions for combined support groups including children and parents.

**Involving the school.** The school’s involvement in the adolescents’ life situation appeared to vary, depending on their age, preferences, and the progression of the disease. Having the school as a free zone could be a reason for not sharing the information. Other adolescents emphasized the importance of the school being aware of the situation to increase understanding and adaptation. At the same time, they did not want to be treated differently from other students. The parents were often of a similar opinion.

Both adolescents and parents described positive experiences of involving the school, which was perceived as doing its utmost to support the adolescents. However, resources were not always sufficient, and establishing new support contacts when changing schools could be complicated. Some parents cited the general lack of knowledge about ALS as a barrier to receiving support from the school and requested better collaboration with the ALS team as well as education materials.

**Strengthening the family**

Strengthening the family to master the challenges of living together with ALS was important to the adolescents and could be achieved through “bringing the family together” and “giving practical support”.

**Bringing the family together.** Both adolescents and parents wanted healthcare to take a more holistic view of the family. Changed family dynamics due to the disease were described by some adolescents, who believed that group therapy sessions could bring the family together again. They wanted to support in finding methods to facilitate more open communication within the family, which some co-parents also brought up.

Table 4. A summary of the adolescents’ and parents’ views of possible support in bringing manageability into the adolescents’ life of uncertainty.

<table>
<thead>
<tr>
<th>Main theme</th>
<th>Themes</th>
<th>Sub-themes</th>
<th>Adolescents’ and parents’ views of possible support</th>
</tr>
</thead>
</table>
| Making the adolescents’ needs visible | Involving and interacting with the adolescent | - Active invitation from healthcare  
- Involved in discussions  
- Meet under other circumstances (e.g. home visits, children wards, coffee breaks, etc.)  
- Appropriate interaction from healthcare | |
| Obtaining information and understanding | Information about the disease  
- Ask healthcare questions  
- Medical explanation  
- Age-appropriate education material | |
| Forming a protective social network | Knowing where to turn | Information about support options  
- Professional support conversations  
- Digital solutions  
- Supportive activities | |
| Having someone to talk to | Age-appropriate support groups  
- Combined support groups | |
| Meeting others in similar situations | Free zone function  
- Supportive school environment  
- Education material for the school | |
| Involving the school | Bringing the family together | Family-oriented meetings  
- Family follow-ups  
- Family communication support  
- Possibility-focused approach  
- Preparation for the future | |
| Giving practical support | Increased practical support  
- Respite from the disease context  
- Holistic family view  
- Support from authorities and municipalities | |
Additionally, adolescents and parents called for routine follow-ups of the family situation.

A more possibility-focused approach from healthcare was stated as being desirable in supporting the families’ togetherness. Support was also requested in preparing for the future together. Although adolescents and parents were aware of the uncertainty of the disease, they felt having examples of different conceivable scenarios could make their family situation more manageable.

**Giving practical support.** There was a need to be able to do more things as a family, both with and without the parent with ALS, but the disease was perceived as an obstacle. Some families described practical support from healthcare, authorities, and municipalities as sufficient, while others experienced it as quite opposite. Among the latter, extensive practical support was called for, both in helping care for the ill parent and in doing the daily housework to ease the burden on the rest of the family.

Both adolescents and parents considered the opportunity for recreation essential, and some wanted support to ensure that the adolescents could participate in activities outside the home. Getting a break from the disease context while staying at home was also mentioned and consequently, the importance of offering suitable respite accommodation for the parent with ALS.

Adolescents and parents wanted authorities and municipalities to improve their general knowledge about ALS and take a more holistic and understanding view of the family situation, as the decisions of the authorities affected the whole family.

A summary of the adolescents’ and parents’ views on the support that can meet their needs is provided in Table 4.

**Discussion**

The results show a need for professional support for the adolescents of parents with ALS that can help them bring manageability into their lives of uncertainty. Professional support can be crucial for the adolescents by making their needs visible, ensuring a protective network around them, and strengthening the families to master the challenges of living with the disease together.

The results may not differ significantly from that of previous research on adolescents’ need for professional support when a parent has a life-threatening disease. A similar need for informal, emotional, and social support has been articulated before (5,6,10,12,23). However, our findings particularly reinforce the importance of reaching out to the adolescents and actively offering them individually adapted support. Participation is a prerequisite for good processes, and it is thus essential that the adolescents are asked right from the beginning, but also over time, how they want to be involved.

Although the adolescents expressed a need to be involved, the results highlight a lack of contact with healthcare. Previous research indicates that healthcare is primarily based on the adults’ perspective (10,23), while the adolescents are often forgotten (2). Additionally, the HCP’s offer to contact the adolescents and provide them with information is sometimes declined by the parents. Given the rapid deterioration that characterizes ALS, it is particularly crucial that healthcare adopts a more active approach to reach out to the adolescents as early as possible.

The findings emphasize the adolescents’ need to get respite from the disease context. Breaking up stressful situations and heavy thoughts with stimulating activities can be vital for the adolescents’ well-being (24), and equally, the process of moving in and out of grief has been described as an important protective mechanism (25). Our results also indicate the school has an important function as a free zone, which has been shown among children whose sibling receives palliative care as well (26). A supportive school environment may be valued and crucial (5), but the general lack of knowledge about ALS complicates support. Increased cooperation from healthcare in educating all parties involved could potentially make a difference.

The importance of a holistic view of the family is evident from the results. In families with younger children, the need for practical support may in some cases be greater, but it is conceivable that the need in families with older adolescents can be just as high. Being a young carer of a parent with ALS is demanding (2,6) with experiences of having their own life interrupted. To reduce this burden, increased practical support can be crucial.

Given the individual need for support, which also seems to vary during the different phases of the disease, it is important to meet each adolescent at their own level and on the premise of the family’s unique situation, using a person-centered approach (27). As the adolescents’ needs may not always be articulated, HCP must assist in identifying them. Communication tools to stimulate the adolescents to reflect on and express their needs could be useful, for example, the Carer Support Needs Assessment Tool (CSNAT) (27,28). The need for support to facilitate more open communication within the family is also highlighted in the results. Likewise, previous research shows the importance of strengthening the parents in their parental roles and in family communication (5).

In conclusion, clearer guidelines for professions that meet these families are required, and special training in identifying adolescents in extra need of help is particularly important. Further, it is also essential to examine more closely parents’ reluctance to involve
their children in care, as well as to increase their awareness of the protective effect of participation.

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Declaration of interest

The authors report no conflicts of interest. The Declaration of interest.