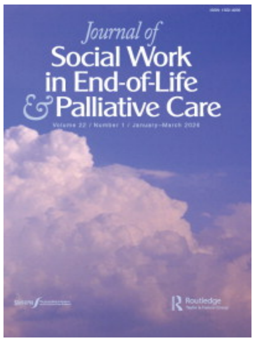

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RESEARCH ARTICLE

Living Outside the ALS Home – Everyday Experiences, Challenges and Needs of Adult Children with a Parent with ALS

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ABSTRACT
Adult children of a parent with ALS may be highly burdened and in need of support, but studies of their experiences and needs are scarce. The aim of this study was to explore everyday experiences, challenges and needs of adult children living outside the home of a parent with amyotrophic lateral sclerosis (ALS). The design was qualitative using Interpretive Description methodology and Sense of Coherence as framework. Focus group interviews were conducted with 16 adult children. Participants experienced changes in relationship and roles with siblings and parents when ALS moved into the family. Their parents' disease evoked a need for understanding ALS and its trajectory as the disease raised questions, concerns, and sorrow. Furthermore, having a parent with ALS led to strong and mixed emotions and dilemmas like bad conscience, self-blame, gratitude and closeness and wanting to be there but also not being able to bear witnessing the deterioration of their parent. Adult children experience profound challenges and needs related to their parent's disease. They need information and support from professionals and peers as they struggle to balance the demands related to ALS and everyday life with family, work and leisure. Professionals should provide support for this vulnerable group who appear highly burdened practically and emotionally by the situation.

KEYWORDS
Adult children; amyotrophic lateral sclerosis; everyday challenges; family caregivers; motor neuron disease

Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease characterized by progressive degeneration of upper and/or lower neurons that primarily affect people late in life (median age of onset is 65 years) (van Es et al., 2017). The degeneration of neurons leads to muscle atrophy, weakness and fasciculations which over time makes it difficult for the person to walk, talk, swallow, and breathe (van Es et al., 2017). People

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with ALS become increasingly dependent on help, care, and assistive devices such as electric wheelchairs, mechanical ventilation, and communication aids. About 30-50% of people with ALS develop cognitive and/or behavioral impairments, including impaired executive functioning and problems with social cognition, emotion recognition, and language (Benbrika et al., 2019; Goldstein & Abrahams, 2013). In 6-14%, the cognitive and behavioral changes develop into frontotemporal dementia (Benbrika et al., 2019). Median survival time from onset to death is 20–48 months (Chiò et al., 2009).

Caregiving in ALS is predominantly undertaken by family members, and the burden of caregiving is notably intense compared to other neurological diseases, probably because ALS often progresses fast and results in severe functional impairment early on in the disease course that in itself, as well as together with the potential cognitive and/or behavioral changes, results in a high demand for help from caregivers (Tramonti et al., 2019). ALS therefore usually affects the whole family (Malmström et al., 2023; Sommers-Spijkerman et al., 2022). Being a family caregiver of a person with ALS is a complex and multifaceted role that entails a unique set of challenges and strains (Aoun et al., 2013). ALS family caregivers are at increased risk of adverse effects on their wellbeing in every aspect of their lives, e.g. their health, quality of life, social relationships and economic security (Aoun et al., 2013; Burke et al., 2018; Galvin et al., 2016; Sandstedt et al., 2018; Schischlevskij et al., 2021).

Studies on family caregivers for people with ALS have generally focused on spousal caregivers or have combined data from adult children living away from home with spouses or have looked at young children (up until their mid-twenties) living within the household (Kavanaugh et al., 2020; Malmström et al., 2024). Spouses usually outnumber adult children in this research, thus, the experiences of adult children and their specific needs may not have surfaced when combined in samples with spouses. Studies of younger children show that they become involved in caregiving, experience changes in family relationships and family roles, and have a need for information and support (Lackey & Gates, 2001; Sommers-Spijkerman et al., 2022). It is unknown whether this also applies to adult children who live outside the home and may be more distant from the disease and their parents, at least in terms of geographic space. Adult children living outside the home may react differently, take on different responsibilities and have different needs as they are older than residing children and often have their own children, work and home to care for which may cause other dilemmas and challenges than those of (often retired) spouses or children living within the household. Findings from the general caregiver literature on people caring for both their aging parents and children of their own show that dual caring may be particularly burdensome and linked with high stress levels, personal burnout, work absenteeism, and depressive symptoms (Lei et al., 2023; Owsiany et al., 2023; Pashazade et al., 2024). Thus, adult children may potentially be highly burdened and could benefit from support as they grapple with the impending deterioration in their parent's condition and loss.

To our knowledge, only two studies have looked at adult children of a parent with ALS as a separate group. A small pilot study of the experiences of two mutual support groups, one for spouses and one for adult children, found differences in the discussion content of each group. Adult children talked about their feelings and how their role as caregivers was a reversal of their relationship with their parents. The prospect of their parents' death was also a common theme for the adult children whereas technical and practical aspects on how to take care of their partner and the hardship of finding time for oneself more often was the theme for spouses. This suggested that adult children and spouses may have different needs (Cipolletta et al., 2018). Another study of burden found lower, albeit still high, burden when the caregiver was an adult child of a patient with ALS compared to a spouse, providing further support for a difference in caregiver experience for adult children and spouses (Burke et al., 2018).

The aim of the present study is to explore the everyday experiences, challenges and needs of adult children living outside the home of a parent with ALS. Gaining an understanding of this may assist in developing support initiatives according to their specific needs.

Methods

Study design

This study was qualitative using the interpretive description (ID) methodology (Thorne, 2016, 2025) and the theoretical framework Sense of Coherence (SOC) by Aaron Antonovsky (Antonovsky, 1979, 1987). ID is an inductive applied research methodology that focuses on challenges and needs in clinical practice (Thorne, 2016, 2025). ID aims to enhance clinical practice through insights derived from research and translated to new knowledge that can be implemented into practice (Thorne, 2016, 2025). ID allows researchers to choose between methods that fit the study's aim (Thorne, 2019, 2025). SOC was used inductively to explore the participants' way of coping with life stressors like their parents' ALS disease and the consequences of it in relation to their everyday life (Antonovsky, 1987). SOC consists of the three concepts: comprehensibility, manageability and meaningfulness that, respectively, reflect the individual's way of thinking, acting and being in the world (Antonovsky, 1987) and shape their ability to navigate stress and maintain health in spite of stressful situations (Antonovsky, 1987; Lindström & Eriksson, 2005). SOC is a relevant framework to help understand the everyday experiences, challenges and needs of adult children and to gain insights into how they cope with these experiences, challenges and needs; Insights that are essential when designing health-promoting interventions for adult children.

This study was conducted at the Danish National Rehabilitation Center for Neuromuscular Diseases (RCFM) (RCFM, 2026). RCFM is a highly specialized hospital under the National Board of Health (The Danish Health Act, 2019). Approximately 3700 people with neuromuscular diseases (NMD) including ALS are registered with RCFM. Approximately 450 of them have ALS (RCFM, 2026). Through multidisciplinary teams, consisting of nurses, physicians, physiotherapists, occupational therapists, psychologists, social workers, family therapists and sexuality counselors, RCFM provides life-long rehabilitation for people with NMD nation-wide, either in the patients' homes or at the two clinics (RCFM, 2026). RCFM works closely with the person with NMD, their family, and professionals in the health, social, and educational system to foster the best possible circumstances for the person with NMD (RCFM, 2026).

Recruitment and data generation

A convenience sample strategy was applied (Thorne, 2025). Participants were invited to participate in a focus group interview by posting information about the study and how to contact the researcher in RCFM's Facebook group and the Facebook group of the Danish Foundation for Neuromuscular Diseases, Muskelsvindfonden. In general, only people who are referred to RCFM are members of the Facebook groups. Relatives of those referred to RCFM can also be members. Attempts were also made to recruit members from two support groups for adult children of parents with ALS run in a face-to-face format by the Danish Foundation for Neuromuscular Diseases. Participants were eligible if they were ≥18 years old, had or had had a parent or bonus parent with ALS, lived outside the ALS home, and were able to understand and speak Danish. Only people from the two Facebook groups contacted the first author. In total, 25 adult children made contact. Seven were unable to attend on the required dates for the interviews and two were excluded as they were unsure of their parent's diagnosis. For the remaining participants, their parent's ALS diagnosis was known to two of the researchers from work as healthcare professionals in RCFM. Thus, a total of 16 adult children participated: four males and 12 females (Table 1). In line with ID methodology, this was considered a large and varied enough sample to obtain an insight into the experiences, challenges and needs of adult children, being well aware that complete data saturation may not be reached and that additional variation may be possible (Malterud et al., 2016).

Table 1. Characteristics of the adult children.

	n (%)
Sex	
Male	4 (25)
Female	12 (75)
Age, median (range)	
24–30	5 (31)
31–37	4 (25)
38–45	3 (19)
46–53	4 (25)
Parent with ALS	
Mother/bonus	7 (44)
Father/bonus	9 (56)
Status of parent with ALS	
Living	9 (56)
Deceased	7 (44)

Between the 18th and 19th of January 2023, two online focus group interviews were carried out by the first and second author via Microsoft Teams. Nine adult children participated in the first interview and seven in the second interview. The group composition was mixed in terms of sex and status of their parent (living or deceased). Each focus group lasted 1½ hours. A semi-structured interview guide inspired by the theory of SOC was used (Table 2) (Antonovsky, 1979, 1987). The questions focused on the participants' experiences, challenges and needs in everyday life as adult children of a parent with ALS. Interviews were digitally recorded and conducted in Danish with quotes subsequently translated into English. The research group consisted of three females from RCFM: one researcher (occupational therapist, MA in educational psychology, PhD), one ALS counselor (registered nurse), one researcher and clinical psychologist (MSc Psych, PhD), all with expertise in ALS and its impact on family relations.

Analysis

Data was analyzed inductively guided by the four steps suggested by ID (Handberg & Lunde Jensen, 2021; Thorne, 2016, 2025). The SOC theory served as a guide throughout the analysis that helped to unfold, elaborate, and interpret how the participants coped with their everyday lives, challenges and needs when having a parent with ALS. Furthermore, the SOC inspired the development of themes as well as the interpretation of the relationships between them (Antonovsky, 1979, 1987; Braun & Clarke, 2019, 2021).

The analysis was completed through an iterative collaboration process, meaning the four steps were revisited and critically evaluated throughout (Handberg & Lunde Jensen, 2021; Thorne, 2025). First, the interviews were transcribed and read while making initial codes. The aim of this process was to obtain an initial impression of the data as a whole and to identify patterns related to the study's aim. All authors then met to discuss the initial codes and the content found in the data. The focus was on looking for

Table 2. Interview guide for adult children who have or have had a parent with ALS.

Welcome and introduction to the aim of the interview

Hello to all of you and welcome. First, thank you very much for being here today and for your willingness to share your experiences and perspectives on being an adult child of a parent with ALS. All of you here represent a unique story of how ALS influenced your life, and some have shorter or longer experiences of the ALS trajectory. All stories are of great interest to us, so please share whatever you would like to help us understand and support other adult children who in the near future will be in a similar situation as you or as you have been in.

The aim of the interview is to explore how ALS affects your everyday life, which challenges and needs the disease may have caused you as adult children living on your own. Based on your experiences and stories, we will develop a targeted intervention to support adult children who have parents living with ALS.

Introduction of participants

Please introduce yourselves; stating your name, age, how long your parent has lived with ALS, how close you live/lived to your parent, and how often you see/saw or speak/spoke with each other.

Opening Questions

I will like you all to complete the following sentence: *As an adult child of a parent with ALS, my greatest challenge has been…*

Could each of you try to describe what currently weighs most heavily on you as an adult child of a parent with ALS?

Would anyone like to comment on each other's experiences?

Challenges

What other challenges have you experienced as an adult child of a parent with ALS?

Have you experienced any difficulties in your relationship with your parent with ALS? Please elaborate

Have you experienced any changes in your relationship with your parent with ALSe? Please elaborate

How have you balanced your parent's needs with your own needs?

What have you done to take care of yourself along the ALS trajectory?

What has been difficult about taking care of yourself?

Needs

What needs have been unmet for you as an adult child during the ALS trajectory? (support, information ect.)

What thoughts and concerns would you like/have liked to share with others?

Has this been possible?

What consequences has ALS had for you?

What consequences has ALS had for your close family?

Recommendations for others

What do you think is important to inform other adult children of a parent with ALS about in a future support intervention?

If you were to give someone in a similar situation to yours one good piece of advice about self-care, what would it be?

What do you wish you had done differently, looking back?

What have you learned about yourself through the ALS trajectory?

Design of a future support intervention for adult children of a parent with ALS

If you were to participate in such an intervention; Would you prefer/have preferred face-to-face or virtual meetings?

How long would you like/have liked each meeting to last?

Over how long a period would you like/have liked the support intervention to last?

How often would you like/have liked to meet with other adult children (peers)?

How many peers would you feel comfortable meeting and sharing your experiences and concerns with?

Anything else that you would like the intervention to accommodate?

Closing questions

Would you be interested in participating in a support intervention like this?

Is there anything you would like to add?

Thank you for sharing your story og preferences

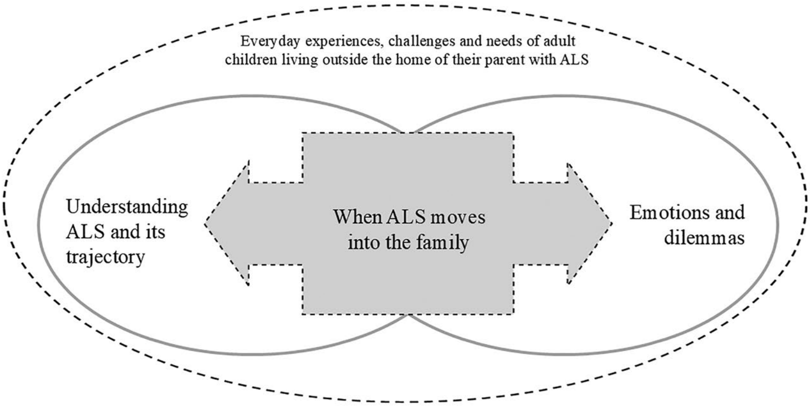
similarities and relations within data. If disagreement occurred and could not be resolved through discussion, the first author made the final decision. Based on these discussions, the codes were refined and organized into data segments in clusters or meaning units that reflected similar properties as the analytical process progressed. All the data were then uploaded into the software system Nvivo14 to help organize and compare data (Nvivo14 Windows, 2025). Then, moving beyond the self-evident, the first author reread all the data, focusing on uncovering general relationships and patterns. While engaging in ongoing discussions with the third author, the data were subsumed under descriptive labels and grouped and colored to help identify sub-themes through a constant comparison of specific elements related to the study aim. Afterwards, interpretation and critical appraisal of the relationships within the data was made to understand and interpret its meaning. This procedure revealed the relevance of thematic options that led to the primary categorization. Finally, the first author condensed and drafted the main messages arising from feedback and discussions on key insights, their hierarchies, and relations within the data. This was then qualified and coauthored by the third author through joint critical discussions, the results of which are displayed in a final categorization structure in Figure 1 (Thorne, 2016, 2025). A coding tree is presented to visualize the analysis process (Table 3).

Ethics

This study adheres to the COREQ checklist (Tong et al., 2007), the declaration of Helsinki (World Medical Association, 2013) and was not under obligation to notification to the Central Danish Region Committee on Health Research Ethics (File no.1-10-72-6-23). Written consent was obtained from all participants before data collection. To secure confidentiality, participants were referred to using only age as a descriptor.

Results

Three themes emerged from the analysis, all of which are interrelated and influence each other: when ALS moved into the family, understanding ALS and its trajectory, and emotions and dilemmas (Figure 1). When ALS



Note. The initial triggering factor that changed the participants' everyday lives and family relations was 'when ALS moved into the family' which caused a need for 'understanding ALS and its trajectory' as well as strong 'emotions and dilemmas'. There was a dynamic and shifting movement between the themes. The dotted lines indicate that the emotions and dilemmas experienced by the adult children may subtly penetrate and influence family relationships and how ALS is coped with (the consequence of ALS within the family), for instance, when participants have different needs or preferences to siblings or their parents. Also, the level of participants' understanding of ALS and its trajectory seemed to penetrate into family relations and influence the role the participants were able to take within the family such as how and what they could talk to their parents about.

Figure 1. Everyday experiences, challenges and needs children living outside the home of their parent with ALS.

Table 3. Coding tree, analytic steps illustrating how codes and themes were extracted.

Phase 1: Initial codes	Phase 2: Thematic categories	Phase 3: Core analytical themes	Phase 4: Illustration of findings
Changed roles and relationships between parents and siblings	Role shifts and relational strain	When ALS moved into the family	Visual figure displaying the relationship and hierarchy within the themes (Figure 1)
Role reversal and emotional distance	Protective and avoidant behaviors		
Parental coping strategies	Shared vs. conflicting coping		
System navigation and coordination			
Practical and structural burden	System complexity overload		
Information about the disease	Information needs and timing	Understanding ALS and its trajectory	
Support gaps and professional help			
Need for shared understanding	Unmet need for support		
Own reactions, emotions, and needs	Emotional burden	Emotions and dilemmas	
Moral pressure, self-judgment, insufficiency	Psychological overload		
	Balancing everyday life		
Expectations (own and other's)	Prioritization dilemmas		
Balancing work, family, and leisure	Self-care		
Emotional strain. Preventing burnout	Self-neglect leading to burnout		

moved into the family was the initial triggering factor that changed the participants' everyday lives and evoked challenges and needs. This life event evoked a need for understanding ALS and its trajectory and, at the same time, resulted in strong and mixed emotions and dilemmas that the participants had to comprehend, manage and cope with in their everyday lives. There was a dynamic and shifting movement between the themes.

When ALS moved into the family

Findings showed that ALS influenced family dynamics and the participants' relationship to the parent with ALS, the healthy parent and siblings. Participants reported that ALS had changed the ways they interacted with family members, which activities they engaged in, and many reported looking after their parent with ALS just like their parent had looked after them as children. The participants stressed how they consciously, from the outside, witnessed the fairly quick and total physical deterioration of their parent with ALS and the psychological deterioration of their healthy parent who, besides losing their partner, had to take over on a lot of responsibilities and tasks, became highly burdened and distressed. "I think you lose both of your parents a little bit - because we used to be very close, but because we only talk about the disease and because she's very affected by it and it's difficult to talk about anything else, I think it's affecting my relationship with both my mother and father". (36 years old). It seemed as if ALS influenced the participants' relationship with both parents as the disease overshadowed and negatively influenced the meaningfulness of close family relations. They felt that focus was mostly on the parent with ALS and that the healthy parent's well-being received too little attention. The participants had great concerns about the health of the healthy parent and how difficult it was to support and manage the health of both parents. One stated how she had had a difficult conversation with her mother with ALS on behalf of her healthy father, who she felt obliged to help, as he was otherwise alone:

> I get a phone call from my dad, and it's actually the first time I have talked to him about this, and he says to me, 'I would really appreciate if you would talk to mom, because she gets so angry with me when I suggest we stop the ventilator (invasive home mechanical ventilation)'. I think that's a huge thing to ask of me… 'It has come so far now, that we'll have to stop the ventilator, don't you think?'… But nobody's helping him either. He's all alone in this. (31 years old)

The participants took on many caregiving chores as they felt a responsibility to help and reduce the burden and suffering from their healthy parent. However, doing so was ambiguous as they on the one hand wanted to help their healthy parent by minimizing their burden as some participants feared losing both parents, but on the other hand they sometimes felt trapped between their parents' different needs, values and preferences. They stressed how ALS dominated most conversations in the family with discussions about logistics, practicalities, making decisions in time and coordinating chores such as who is taking care of the parent with ALS during holiday seasons, who is contacting external sources of support (e.g., the municipality or hospital departments), who is organizing personal assistance or other forms of support with the adult children taking on many of these chores. This occurred at the expense of spending valuable time together as a family and with their loved one they were about to lose. "ALS steals so much from a relationship – the relationship you have with the person with ALS, but also with my mother because everything is about practical things, routines and frustrations, and it takes your focus off the person who is affected by ALS." (33 years old)

ALS occupied everyday life, took time and caused insecurity and frustrations within the family as it was difficult to comprehend and manage the continuous actions and adaptations needed as the disease progressed. Some of the younger female participants experienced losing their parent with ALS who could no longer comfort them when the parent experienced difficulties in or ceased communication. Generally, the inability of the parent with ALS to talk and share points of view created an unequal relationship between the participants and their parents. In addition, there seemed to be a tendency for participants and parents to withhold information from one another or avoid discussing difficult aspects of the disease to spare each other from sorrow, concerns, and/or anger.

> It's difficult to talk about the difficult and ugly things related to the disease, and I don't want to make her sadder than she already is. At the same time, it makes me

> even more sad and more desperate thinking about the future and her wishes for the future with the disease because she won't talk about it. She never brings it up, and she immediately shuts down the conversation when we try to open it. (25 years old)

These considerations evoked feelings of loneliness and frustration among the participants as they did not want to burden their parent with ALS with their feelings or bother them about ordinary problems related to everyday life. It seemed that the participants tried to keep focus on the parent with ALS and not on themselves with the aim of staying strong. They listed topics on tough issues that they wished to talk about, e.g. Percutaneous Endoscopic Gastrostomy (PEG), mechanical ventilation, and genetic testing, but underlined that it was easier to address and handle practical issues than to have sensitive, but nevertheless important, conversations. They emphasized the importance of sharing thoughts and talking together within the family, but also the importance of acknowledging and respecting differences in reactions, needs and preferences.

The participants described how they were affected by their parents' ways of coping with ALS e.g. when parents held back, suppressed or neglected information as it caused sorrow among the participants, and they felt distanced from their parents. The participants talked about the past pre-diagnosis, and how their relationship used to be with the parent with ALS. This evoked feelings of longing and sorrow over the loss of their parent's former self and their former relationship with their parent whose physical and mental presence had changed considerably due to the often rapid progression of ALS. "I already feel like I've lost my mother because I don't get the version of her now that I've had all my life, when we could just talk and talk, and she would help me make decisions about my life." (25 years old). Not only did ALS affect the relationship with both of their parents, but also their siblings. Findings showed that siblings sometimes used different coping strategies and had different needs e.g. in terms of talking about ALS and their feelings or trying to suppress them. "I've got an older brother who's still a bit in shock and can't quite take it in… We're just very different in how we deal with it. I really want to talk about it, and he can't bear to talk about it, and this thing, I think it's difficult to be in right now". (49 years old)

The participants were all willing to talk about ALS and their feelings, whereas some participants mentioned how their siblings, who were not participating, would have found it very difficult. They explained how they had or took on different responsibilities regarding the disease trajectory and care of the parent with ALS and how various factors seemed to influence this such as having a helping personality, traditional gender roles, being the oldest or youngest in the sibling group or having a background in healthcare.

> I had to say out loud what my own needs were in all this, where my mother's needs were of course first and foremost, and I was also one of the first to drop everything and go home to help, if that was what was needed. And then I think, it was really difficult for me because I'm the little one at home, so all the practical stuff was taken care of by my older sister, and I was kind of like, what's my role in all this, how can I contribute? (24 years old)

Some explained how their role and responsibility in the disease trajectory was related to how close by or far away they lived from their parent compared to their siblings with those who lived close by having 'easier' access to the parent than a sibling living far away. Some participants also shared how they used to be the person within the family who took care of others and thus also ended up taking on this role in this situation. These differences in coping strategies, needs and chore-taking put pressure on sibling relations and changed the relationship and communication between siblings from before ALS entered the home. Participants talked about the interrelatedness between their roles as siblings and how one would be more burdened when the other took time off from caregiving. This meant that participants sometimes failed to understand the need of their siblings to take time off as they became overburdened themselves.

> It wore on my relationship with my sister because we had a silent agreement that, of course, we would both be there for my mother… If my sister backed out because she wanted to make herself a priority, I felt that I had gotten a raw deal in having to take care of things. I think it had a negative effect on our relationship because the disease and the coordination of it was the center of everything we talked about. (44 years old)

Most participants described increased tension and frustrations with their siblings as a result of the many demands and coordination required that was not always shared or handled, but some participants described developing closer ties with their siblings as a result of going through this strain together. The participants who had experienced a closer relationship to siblings during the ALS trajectory, stressed that this was due to deep conversations on sensitive topics which had united them in a different way than before ALS as they now had a strong common aim of supporting both parents and each other through the disease trajectory.

Understanding ALS and its trajectory

As ALS moved into the family, this immediately evoked a need among the participants to understand the disease and its trajectory and that the need for information differed among participants in the study. Some participants preferred 'dose-based' information while others preferred to have the entire disease trajectory outlined at the time of diagnosis as a way of comprehending and managing the new uncertain situation. Some wished for more professional information and greater guidance than given. “I could really use someone who is used to handling and navigating this, who can say ‘it’s ok, listen, this is how it is when we visit your father, this is what’s going on” (31 years old). Getting personal advice and guidance from someone with knowledge about ALS was expressed as a helpful way of maintaining a sense of coherence and navigating their parents’ disease trajectory. Although the timing needs of the information seemed to differ from individual to individual, there was a general preference for information to come from parents, professionals and peers with personal experience with ALS as participants expressed that no one else could grasp or imagine what it was like, not even if they had personal experience with other devasting diseases like cancer. One of the participants expressed the following regarding who, besides professionals, to obtain information from: “Someone who had lived with the disease longer, who could give you the lowdown on the disease – who was also a relative – and how you should respond to various things and stuff like that” (29 years old). It also appeared that the participants had a desire for information about ALS to help them comprehend and develop a common language about ALS in the family. This was seen as important to enhance communication within the family. They spoke about being prepared to talk about ALS-related issues including difficult topics to make informed decisions and to be able to make timely plans instead of lagging behind. Their questions centered around ALS and future concerns on what, when and how the disease progressed and how their parent would end up: “I actually think it’s great that we can address the things that are super uncomfortable and difficult to talk about – because it’s our reality – and if you keep putting it off, I think it only becomes harder. I really like that you can get help from professionals with specific and difficult conversations.” (49 years old)

Although uncomfortable conversations were sometimes put off or avoided, they were also an inherent part of the participants’ lived reality. There seemed to be an appreciation of receiving help from professionals to facilitate these conversations as professionals enabled them to navigate and cope with sensitive issues more constructively. They also emphasized other areas in which they lacked knowledge e.g. how to navigate the healthcare system, information on assistive devices, guidelines on having helpers in their parent’s home, and who to contact if they needed psychological support. Some participants had already thought of ideas on how to reduce these knowledge gaps. For example, the development of apps or event planners that illustrate different ALS impacts, suggest action steps, and present potential stakeholders to contact.

Something that, in particular, caused concerns and was difficult to comprehend were changes in the behavior of their parent with ALS. Some participants gave examples of how their parent had changed and behaved differently showing no interest in their family life, having no empathy for other people's situations and ways of reacting. One participant described her mother's changed behavior and lack of empathy like this: "She never asks about me or how I'm doing anymore, she used to ALWAYS ask and be curious about me and would help me get through stuff by talking about it and offer advice and guidance" (25 years old). Participants lacked information about cognitive and behavioral changes in ALS and stated that talking about changed behaviors with their parents was not easy. During the interviews, the participants supported each other by acknowledging each other's experiences and providing examples of their own experiences of egocentric or suspicious behaviors that their parent with ALS had exhibited. The participants shared their frustrations about the behavioral changes being an additional symptom to the physical deterioration that they had to comprehend and manage as if the physical deteriorations were not enough. They found it hard to understand the behavioral changes and how to cope with these. Some of the participants stated being uncertain about whether the changed behaviors reflected their parent's way of coping or were actual cognitive and/or behavioral deficits.

Emotions and dilemmas

The findings also outline emotions and dilemmas that the participants faced in their everyday life as adult children living outside the home of a parent with ALS. ALS indirectly affected their lives with family, friends, work and leisure and had major impact on their emotional state and well-being.

> I've been through an emotional crisis which cost me my job. I have a very different relationship with my mother now, we've lost what we had. It's difficult for me to hold on to other relationships. I constantly worry and often cry when I'm alone. I've had to grow up very quickly and be an adult to my own mother. (25 years old)

The emotional burden of being an adult child seemed to be so severe that it extended beyond the family sphere, disrupting occupational stability, everyday functioning and compromising the participant's capacity to maintain roles outside the family. Additionally, there appeared to be a sense of grief that was not only related the parent's disease but also to the changed relationship between the participants and their parent. The participants' lives had changed because of ALS and was described as a balancing act between having to take care of their own children, family and work meanwhile wanting and longing to spend as much time with their parent with ALS as possible while they still can: "My stomach hurts and I find it hard to be anywhere and nowhere, and where am I in all this and what is the right thing to do?" (49 years old)

They felt an obligation to look after their professional work but struggled to balance this while looking after their parent. Those who had a family of their own had their partner take over on responsibilities at home with the children, but felt guilty about this and worried about the consequences for their partner. Nonetheless, this released time for them to visit their parent with ALS. Many participants who had children themselves also worried about their own children's wellbeing and said they found it difficult to balance what information and how much information their own children should receive about their grandparent's disease and the future trajectory. The participants reported constantly being forced to make tough decisions and priorities in life which evoked dilemmas such as taking care of practical issues or their own children vs. spending time with their parent with ALS. They seemed to place their own needs at the bottom of the list at the expense of their own health. They said that it was difficult to call their parents as they feared being questioned about when they intended to visit them again and therefore some reconsidered it before calling to reduce the potential confrontation. They reported contrasting feelings such as wanting to be there for their parents as much as possible whilst at the same time finding it was hard to endure all the demands as well as face reality and the physical deterioration of their parent with ALS. ALS was referred to as exhausting and tough, and some participants described this as the reason for them not wanting the trajectory to drag out. Some felt relieved when their parent with ALS had passed away.

> My own needs and my selfcare was at the bottom of the list because there was of course my own family: my husband, my children, my mother, my sister, all that, and then there was my job … it wears you out, and I have to admit that the day we said goodbye to my mother, I was incredibly relieved – yes, it made a great difference. Those years were tough. (44 years old)

There seemed to be a dilemma amongst some participants between wanting it all to end as their parent was heavily impaired and, in some ways, already 'gone' meanwhile not wanting it to end, as this would be the point of no return and a final farewell. For some participants, the trajectory had lasted for years and was described as 'one long goodbye' as they knew from diagnosis that there was no cure and therefore had prepared themselves for the inevitable loss. The participants had paused their own lives and dreams to a minor or larger degree during the ALS trajectory as a way of prioritizing and surviving everyday life as an adult child.

> We (siblings) couldn't go on vacation together like we used to all the time … because we couldn't be away at the same time if something would happen to my mother. So,

> there were some years where a lot of things were on standby, but then in her last year, or two last years, we started doing things again, we were telling ourselves that 'we have to do things again, we don't know how long this is going to take'. (44 years old)

ALS evoked strong and mixed emotions like sorrow, anxiety, worries, frustrations, loneliness, powerlessness, deprivation, selfishness, bad conscience as well as feelings of closeness, and gratitude for a slowly progressing ALS or gratitude for their parent dying after a short disease duration. Assertions from some participants that the strong emotions had left long-lasting effects on the participants caused other participants who had not yet lost their parent to think that recovering post bereavement would be time consuming and tough. The bad conscience seemed to be linked to the intention of wanting to be everywhere but not being able to live up to such expectations. They wanted to provide the best support and care for their parent with ALS and described how they often felt that they failed to accomplish this. This caused self-blame and sadness.

> Whether you do enough, and it's hard to know whether you do the right thing. And that's because we have the same person who doesn't say a lot. Is it the right thing to do when you take your time to do other things and when you have your own family who you should also take care of and all that? Sometimes it's hard for me to know whether I do the things my father really wants me to. What are the needs you're trying to meet? (33 years old)

A 'deeper' reflective struggle to make sense of the caregiving and, the obligations toward their family and personal life existed. For example, ambiguity was revealed about whether caregiving actions were oriented toward their parent's actual needs, the participants' sense of duty, or broader social expectations of what a 'good' son or daughter should do. This ambivalence placed the participants in uncertainty with unclear roles and an emotional burden as they had to make decisions about how to balance and prioritize all their everyday activities including the support for their parents without knowing what was the right or best thing to do.

It seemed that the adult children possessed a role as fellow-travelers from a distance, because they no longer lived at home with the parent with ALS but still experienced being highly affected by the situation with little support: "I was alone with everything that happened during the disease trajectory. My biggest challenge was that there was no dialogue. Even when I tried to reach out for help, there was no help. Not from psychologists, not from anyone else". (31 years old)

This role meant that the participants were not naturally a part of the parents' daily life and thus found it hard to keep track of their parents' health and needs. They were not all invited to hospital meetings, meetings with municipality departments regarding assistive devices and/or personal support or multidisciplinary rehabilitation meetings with RCFM and therefore experienced getting filtered information from their parents which made it difficult for them to feel updated, calm and safe. Participants were unsure as to where they could find professional support for their needs and asked for guidance that focused on their needs, challenges and feelings. Individual and group-based psychosocial support were suggested by the participants as interventions that would be helpful. They explained how meeting peers who have a parent with ALS or had lost a parent to ALS would enable them to connect and support each other in ways that nobody outside an ALS trajectory would be able to. When asked directly about what would be useful and the format of such support, they elaborated how ongoing group meetings at monthly intervals would be likely to provide them with helpful support given that the group consisted of few attendees so that each person would have time to speak. Listening to others as well as ventilating by speaking were both considered important. Online meetings were preferred by most participants due to logistic barriers and an already busy schedule. However, some expressed a wish for being able to also meet face-to-face now and then as this was considered to make room for more informal chats.

Discussion

This study reported on the experiences and consequences of ALS for adult children not living in the ALS home. This study's findings suggest that adult children of a parent with ALS may take on a substantial caregiving role in relation to their parent with ALS. Their particular roles may overshadow all aspects of life including their family relations and emotional state, and they navigate with little of the needed information and support. Caregiving appeared to be all-consuming, disrupt family lives and to change relations with the person with ALS. This has also been previously reported in the ALS caregiver literature (Cipolletta & Amicucci, 2015; Galvin et al., 2016; Pagnini et al., 2010; Sommers-Spijkerman et al., 2022). Other studies have reported how there may be little space for valuable family time and self-care for caregivers during the ALS trajectory (Galvin et al., 2018, 2020; Katz & Gur, 2024; Larsson et al., 2022; Winther et al., 2020). These findings suggest that adult children may experience many of the same challenges as spousal caregivers despite living outside the ALS home.

The adult children experienced worries not only regarding their parent with ALS but also the healthy parent. It is a common finding in the ALS literature that family caregivers may be overwhelmed by the ALS situation and in need of greater help from formal services than is currently provided in most countries (Anderson et al., 2019; Andrén & Elmståhl, 2008; Burke et al., 2015; Cipolletta & Amicucci, 2015; Galvin et al., 2018; Knudsen &

Nikolajevic-Pujic, 2026; Olesen et al., 2022). The present findings indicate that the consequences of a lack of adequate support to spouses may influence adult children who become overburdened with caregiving chores and concerns about both parents. The only other study of burden in adult children likewise found adult children to be highly burdened by ALS, albeit slightly less than spousal caregivers (Burke et al., 2018). As the number of adult children included in Burke et al. (2018) and the present study were both small, this should be investigated further. However, the findings fit well with research from the general caregiver literature that show that people caring for both their aging parents and their own children may experience high stress levels and personal burnout (Lei et al., 2023; Owsiany et al., 2023; Pashazade et al., 2024).

Becoming entangled in disagreements between their parents and receiving little information from healthcare professionals and their parents to comprehend, navigate, and manage this, seemed to add to the burden of the adult children and contribute to psychological distress even in families who were close before ALS came into the family. Based on this, it is important that health professionals recognize adult children as caregivers, and that health professionals do not assume that families are able to discuss sensitive topics without professional guidance and information even when families are close-knit. Difficulty in family communication and decision making in end-of-life care has been documented elsewhere (Foley & Hynes, 2018; Wallace, 2015). Factors that have been linked with poor communication are role changes, the influence of multiple family members and having to make multiple decisions during the disease process (Wallace, 2015), factors which were all described by the adult children in the present study. Poor communication in families has been linked with greater distress, and poorer adjustment to terminal illness and to being a potential barrier for timely and appropriate treatments (Foley & Hynes, 2018; Wallace, 2015), consistent with the assertions by the participants. These findings highlight the importance of addressing family communication. Healthcare professionals including social workers may play a role in this by making information available and promoting meaningful communication within the family through the introduction of conversation tools such as Dignity Talk that contain conversation prompts for palliative patients and their families (Guo et al., 2018) or through the introduction of patient-centered decision-making support tools (Hogden & Crook, 2017). Developing digital tools such as an app that may guide adult children and their parents should also be considered as suggested by the adult children in the present study.

Information may be provided by a range of different professionals within the healthcare and social systems as the adult children's need for information did not only relate to the disease itself but also aspects such as how to navigate the healthcare system, information on assistive devices and personal help and assistance for their parents. That adult children have a clearly expressed need for information about ALS and the disease trajectory as a means to manage the situation resembles findings from a study on children living at home with a parent having ALS or another chronic physical disease (Lackey & Gates, 2001). The authors argued how it was imperative that children received adequate information on what was going on with their parent, were included in decision-making, and received access to adequate support systems (Lackey & Gates, 2001). However, the consequences of receiving or not receiving this information and support was not investigated, and the results may have been affected by poor recall as it was a retrospective study of adults recounting their experiences as young caregivers. Furthermore, it is unclear what role living within the house-hold versus outside the household may play for our findings. One may speculate whether being a 'fellow-traveler' from a distance results in an increased need for information for adult children as they are not able to witness the daily state of their parents, unlike home-dwelling children and spouses, but this will need to be explored.

Given the profound impact of ALS on the whole family, it is important that healthcare professionals focus on the entire family unit during the disease course. Inviting adult children to participate in medical consultations and other meetings related to ALS should be considered. Some families may also benefit from shared psychological counseling or family therapy. In support of this, the findings showed that the adult children often wanted to talk about ALS and the prognosis but that this was sometimes avoided because of discomfort and fear of burdening each other. This aligns with a recent study on communication between parents and children who live within a family with ALS which found that avoidant communication may stem from both parents and children who may both have an underlying fear of upsetting one another (Sommers-Spijkerman et al., 2024). Likewise, studies of younger children (including children of parents with ALS) show that parents may be inclined not to involve their children in difficult disease situations due to a wish to protect their children (Carter et al., 2014; Kean, 2007; Sommers-Spijkerman et al., 2022). It is possible that parents may have similar concerns regarding adult children, but it is also possible that parents do not share information for other reasons such as wanting to preserve autonomy in decision-making. Generally, studies on family communication at end-of-life show that both patients and caregivers desire more family communication, but hold back to protect each other (Gawinski et al., 2021; Wallace, 2015). Unfortunately, communication between ill parents and adult children is an understudied area (Gawinski et al., 2021). A qualitative meta-synthesis on young people's experiences of a parent's critical disease concluded that an early supportive approach of information and involvement of them would be far more protective than ignoring them as relatives during a parent's disease trajectory (MacEachnie et al., 2018) and should, thus, also be considered for adult children. How best to do this while supporting close family ties and respecting parental wishes should be investigated. In the present study, information and support were especially valued by the adult children when coming from peers with personal experience or healthcare professionals with knowledge of ALS. Peers and healthcare professionals may serve as potential role models for the families on how to cope with and talk about sensitive issues, and they may provide valid sources of understanding. Peer-support initiatives in chronic illness including ALS delivered in face-to-face or online formats have shown such advantages (Kirkegaard, 2022; Olesen et al., 2023, 2024; Watson, 2019). It is possible that adult children may benefit from family peer-support interventions as adult children seemed to benefit from a mutual support group in a previous study and wanted to continue being in contact with each other (Cipolletta et al., 2018). This was, however, a small pilot study of a support group for adult children only and needs to be replicated in a larger study. There appears to be no other studies that have investigated peer-support groups for adult children. Adult children in the present study specifically asked for support meetings to be online because they considered this most feasible to fit in with their busy schedules.

An early supportive involving approach to adult children would probably also benefit sibling relations as those who had developed closer ties to their siblings attributed this to having had deep conversations about sensitive topics. A study on family dynamics within dementia demonstrated the important role that siblings can play in sharing the caregiving load and, like the present study, how the caregiving load is rarely balanced or fair as there is always one person in the family who carries the heaviest load (Smith et al., 2022). These findings point to the importance of talking about how to share/divide the caregiving role and what expectations siblings may have of one another. As sibling dynamics prior to diagnosis were not assessed in the present study, it cannot be excluded that problematic sibling relations prior to diagnosis influenced sibling relations expressed by the adult children. It is possible that differences in coping strategies, needs and chore-taking reflected well-known personality and family patterns. Nonetheless, irrespective of relationship dynamics prior to diagnosis, the present findings clearly show that the ALS diagnosis and caregiving tasks seemed to place extra strain on sibling relationships.

ALS not only influenced the adult children's relationships with their parents and siblings, but also with their own children, work and leisure. The finding that caregiving and chores related to ALS may result in competing chores, the downscaling of other chores and setting aside one's own needs as experienced by the adult children in the present study is well known from the caregiver literature including ALS (Galvin et al., 2018) as is the experience of worries about the person with ALS, caregiver-related guilt and bad conscience related to never knowing whether you are doing the right thing (Galvin et al., 2016). Our study shows that this also accounts for adult children living outside the household. It was easier for the adult children to cut down on family chores than work, placing an extra burden on their own partners who had to take over on responsibilities at home with the children, potentially spreading the burden to their partners and young children. The consequences of this for their partners and young children are currently unknown and should be investigated further. Many of the adult children were concerned about their own children and expressed a need for advice on how to support them.

What may distinguish the adult children from caregiver spouses is the loss of a parent figure and the complete role reversal of having to take care of their parent. This and the emotions related to it was also one of the most talked about issues in a mutual support group for adult children with a parent with ALS in a former study (Cipolletta et al., 2018). The adult children reported strong emotions, and how the emotions, related to the loss of their parent, influenced them for a long time after bereavement. For how long cannot be asserted based on the present study, but previous research has found that emotional consequences for ALS family caregivers may be long-lasting (sometimes for years) after bereavement (Knudsen & Nikolajevic-Pujic, 2026; Martin & Turnbull, 2001). However, these studies mainly included spousal caregivers. The strong and ambivalent emotions and dilemmas experienced by the adult children underlines the importance of offering psychological counseling to adult children, which they were not all currently offered. Peer-support in a group only for adult children may create a safe space for voicing psychological distress and 'forbidden', but often common and natural thoughts such as wanting it all to end (Olesen et al., 2023, 2024). Peer-support groups may also be an important way to provide some form of support to adult children when parents are not willing to engage in family conversations with health professionals.

Strengths and limitations

A strength of the study is the use of semi-structured focus group interviews to explore the adult children's nuanced and contextual experiences. The interviewer was careful to ask each participant about their perspectives to limit bias from some participants being more outspoken (Roller, 2020). The group interviews were conducted online to enable recruitment of participants from across Denmark, but the data may have been affected by the lack of physical interaction and limited ability to observe body language of group members. Nonetheless, measures were taken to ensure a safe and comfortable environment for sharing. The sample size of 16 is reasonable for a qualitative study, although we acknowledge that there may potentially be more variation to be found, and we, thus, encourage more studies into the experiences of adult children (Malterud et al., 2016). These participants represented a broad spectrum of adult children in terms of age and living with or having lost their parent to ALS. The sample also varied in terms of sex, albeit with slightly more females than men, and the results should be interpreted with this in mind. We can also not rule out the risk of sample bias related to recruitment strategies as people who signed up via Facebook may have been more proactive or be more affected by their parent's ALS or may also have been those less affected who had the time and energy to participate. Some of our participants emphasized how their siblings would not have liked to share their experiences openly with strangers, suggesting that there may also be bias in relation to this. Additionally, participants were not recruited from formal support groups who are used to sharing their experiences of being adult children of a parent with ALS. Furthermore, the authors cannot rule out potential recall bias as some of the participants had lost their parent to ALS and provided retrospective experiences.

Lastly, it should be noted that this study's findings represent perspectives from Danish adult children, and therefore they may only be comparable to countries with culture and healthcare systems like the Danish.

Implications for social work

Social workers may play a crucial and fundamental role in making adult children of a parent with ALS visible, legitimizing their emotional burden, and helping them comprehend, navigate and cope with the dual responsibility of caring for a dying parent while caring for their own lives and, potentially own children. Adult children often occupy an outside position as they are not living at home and therefore are often not acknowledged as caregivers, yet they carry substantial emotional, practical and moral responsibilities. Social workers must therefore recognize this group as distinct and overlooked caregivers with unmet support needs. Social workers should ask families affected by ALS explicitly who in the family are emotionally affected or involved and contact them directly to acknowledge them as part of the family and assess difficulties and support needs. Adult children may struggle with anticipatory grief, helplessness, guilt, and emotional overload while trying to balance their everyday life with caregiving, work, and family responsibilities. Social workers should offer individual conversations that focus on the abovementioned issues and normalize emotional contradictions and dilemmas. If necessary, they should refer adult children to psychological or specialized counseling. Furthermore, they should help adult children clarify and set boundaries around what they realistically can and cannot take on. They should provide guidance on work-related rights such as flexible work arrangements, compassionate leave or caregiver leave options, and validate the importance of rest, leisure and spending time with their own children as protective and not selfish choices. Lastly, they should facilitate family communication and role negotiation as ALS often disrupts family roles and communication and increases frustration, tension, and misunderstandings among family members, including siblings. By providing clear, honest and timely information to adult children and their families about likely disease progression, future care needs, end-of-life considerations and encouraging families to talk about difficult issues, they may help reduce individual and family-related concerns, frustrations and emotional strains. This should be adjusted to the individual family needs. As findings showed adult children would value an opportunity to share experiences with peers in groups, social workers may also establish and facilitate such groups.

Conclusions

This study depicts everyday experiences, challenges and needs of adult children living outside the home of their parent with ALS. Everyday lives and family relationships changed substantially when ALS moved into the family. When a parent is diagnosed with ALS, it seems to automatically evoke a need for understanding ALS and its trajectory as it raises questions, concerns, and grief. Adult children living outside the ALS home may struggle with strong emotions and dilemmas which they tend to navigate with little information and support. Adult children of a parent with ALS seem to struggle to balance their everyday life with family and work whilst also longing for and having caveats about being close to their parent with ALS because of the progressive nature of the disease. Professionals should provide support for this vulnerable group who appear highly burdened practically and emotionally by the situation, their caregiving role and the future loss of their parent. These findings should be used to develop and target a future rehabilitation initiative for adult children who have a parent living with ALS. Due to the profound challenges and needs among adult children and the lack of professional support, it is imperative to raise awareness of this unsupported group of relatives who experience needs both in relation to caregiving, family relations and communication as well as psychological distress.

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Data availability statement

The data that support the findings of this study is not openly available due to reasons of sensitivity but may be available from the corresponding author upon reasonable request.

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