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RESEARCH ARTICLE

What, how and when do families communicate about ALS? A qualitative exploration of parents' and children's perceptions

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Abstract

Objectives: In families with a parent diagnosed with amyotrophic lateral sclerosis (ALS), children's adaptation depends among others on how their parents communicate with them about the disease and its trajectory. The aim of this study was to explore parents' and children's perceptions of ALS-related family communication. **Methods:** A qualitative analysis using a conventional content analysis approach was applied to interview data previously collected from 21 parents (8 with ALS) and 15 children (age 13–23 years) about their experiences living with ALS. **Results:** Three themes emerged from the interviews: communication topics, styles and timing. Communication topics include facts about disease and prognosis, feelings, care and equipment, and the end. Although most parents perceived the familial communication style concerning ALS as open, the interviews revealed that both parents and children sometimes avoid interactions about ALS, because they do not know what to say or how to open the dialogue, are afraid to burden other family members, or are unwilling to discuss. Communication timing is directed by changes in the disease trajectory and/or questions of children. A family-level analysis showed that ALS-related family communication is sometimes perceived differently by parents and children. **Conclusions:** The study provides a better understanding of what, how and when parents and children in families living with ALS communicate about the disease. Most families opened the dialogue about ALS yet encountered challenges which may hamper good familial communication. Through addressing those challenges, health-care professionals may facilitate better communication and adaptation in families with a parent with ALS.

Keywords: amyotrophic lateral sclerosis, motor neuron disease, communication, qualitative research

Introduction

Amyotrophic lateral sclerosis (ALS), including progressive muscular atrophy (PMA) and primary lateral sclerosis (PLS), transforms the everyday lives of those affected, as well as their families. Healthcare professionals and numerous medical equipment come into their homes, parents and children take on caregiving tasks, family dynamics are disrupted, and families have to find new ways to spend time together (1–3). Families face the challenge of continuously adjusting their lives –

cognitively, emotionally and behaviorally – to a new situation. This process of adjusting is referred to as resilience or adaptation and is critical to maintain a good quality of life (4). Previous work suggests that one key to adaptation lies in how families interact about the disease trajectory (5–12). Familial communication about the disease is of particular importance for children's adaptation. Timely and open communication between parents and their children about diagnosis, prognosis and treatment may prevent children from creating misconceptions about the disease, help them give

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meaning to the situation, prepare them for possible outcomes (e.g. caregiving role, loss of parent), and improve children's psychosocial functioning (6–9,13–15). To be able to support parent-child communication about ALS, it is crucial to understand how parents with ALS and their co-parents communicate with their children about the disease trajectory, prognosis and end of life of the parent with ALS and what challenges they may encounter. To date, parent-child communication has received only little attention in the field of ALS (1,16). The aim of this study was to explore perceptions of disease-related family communication among parents and children living in families with a parent diagnosed with ALS.

Methods

This paper provides a secondary analysis of previously collected data from interviews with 8 parents with ALS, 13 well parents and 15 children (age 13–23 years) from 16 different families (1). Sample characteristics and procedures have been published elsewhere (1). The current study extends the previously published paper by Sommers-Spijkerman et al. (1) by taking an in-depth focus on emergent issues around family communication.

Interview transcripts were screened in its entirety by AS and MSS seeking data reflecting parents' or children's perceptions of ALS-related communication. Relevant data were analyzed in NVivo 12 using conventional content analysis (17). After a preliminary review of the data, AS and MSS developed a coding scheme which was discussed with AB and MSK. Codes were revised and refined upon multiple reviews of the data. MSS coded all transcripts with the final coding scheme. Coded sentences or passages were checked for consistency by AB and MSK. Finally, MSS, AB and MSK rearranged and combined codes into themes and subthemes. Themes were analyzed at the level of parents ($n=21$), children ($n=15$) and families ($n=8$). For each theme, 1) parents' and children's perceptions of ALS-related family communication were explored and 2) perceptions of parents and children from the same family were compared.

Results

Interview data on ALS-related family communication were clustered into three themes: communication topics, communication styles and communication timing (see Figure 1 and Table 1).

Communication topics

Both parents and children indicated that ALS-related communication commonly focused on

giving the facts about diagnosis and prognosis (e.g. muscles get weaker and stop working, there is no cure). Other topics included *acknowledging and sharing feelings* and *preparing for care and equipment* (e.g. preparing children for emergencies, explaining medical aids and equipment). *Discussing the end* was only mentioned by a few parents and not by children.

Communication styles

The interviews revealed that the majority of parents perceive their communication style as *open and honest*. Nonetheless, some parents and children seem to *avoid* interactions about ALS, either in general or specific (sensitive) topics such as euthanasia or heredity, because they 1) do not know how or feel no room to open this conversation, 2) do not know what to say, 3) are afraid to burden other family members (i.e. parents, children or siblings), or 4) feel uncomfortable. Which communication style parents/children adopt seems to depend on multiple factors such as personality, parental comfort, the topic of communication and the age of the children.

Communication timing

While most parents opened the dialogue about ALS immediately or briefly after receiving the diagnosis, some parents already started this conversation prior to the diagnosis to prepare their children for the anticipated bad news. The interviews revealed that parents re-open the conversation following hospital visits, when anticipating adjustments in the home situation (e.g. new equipment), when noticing disease progression or aggravation of symptoms in the parent with ALS (*waiting for changes*), and when children start asking questions (*waiting for questions*).

Comparing perceptions at family-level

A comparison of parents' and children's perceptions at family-level revealed that, within some families, certain aspects of ALS-related family communication are perceived differently by parents and children. For example, within some families, parents perceived the communication within the family to be open whereas children perceived the communication as closed. Table 2 provides examples of corresponding and conflicting perceptions per theme.

Discussion

This study showed that families with a parent diagnosed with ALS have conversations about the facts, how they feel, care and equipment and/or the end, using both open and avoidant communication styles, and primarily precipitated following

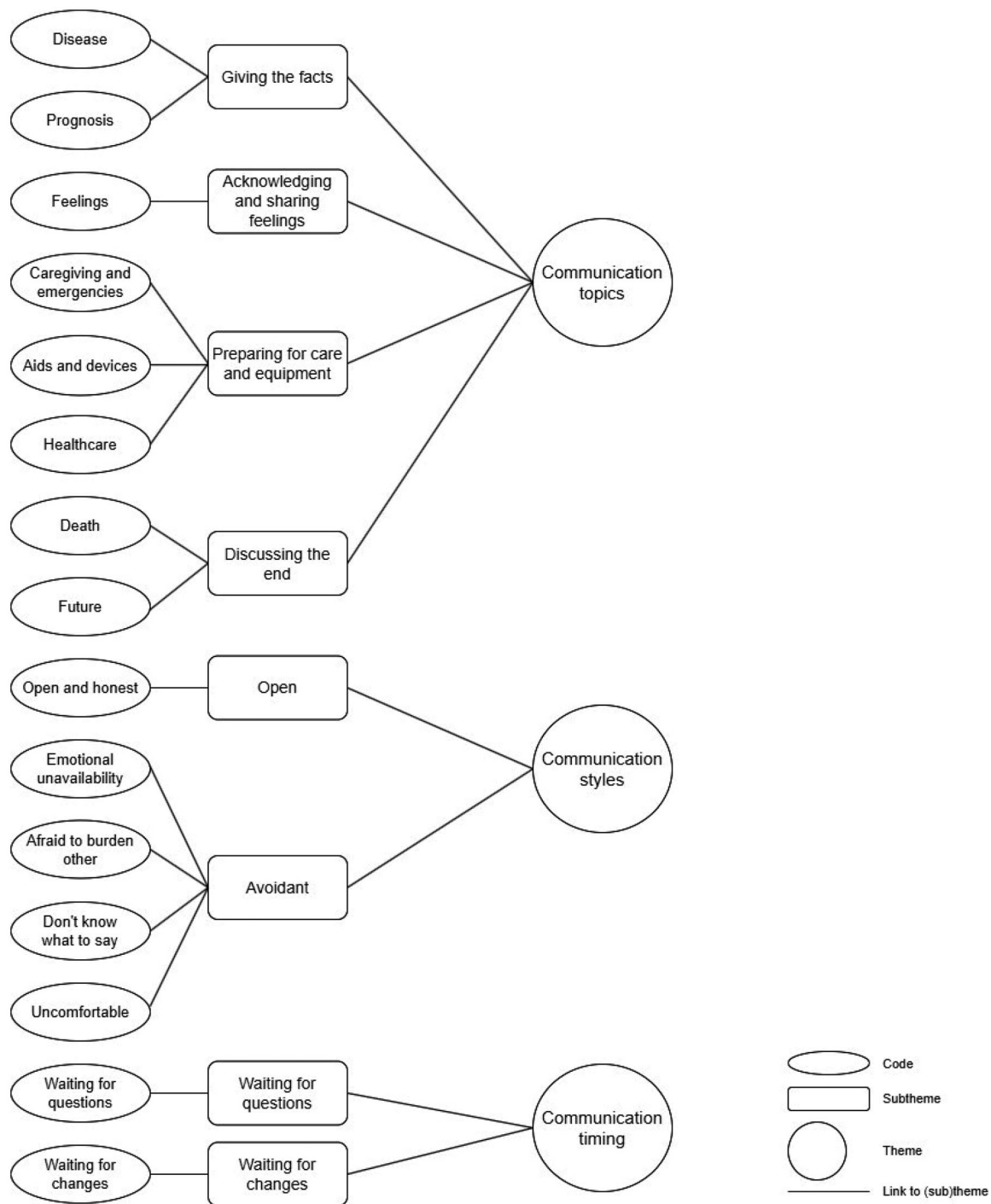


Figure 1. From codes to (sub)themes.

developments in the disease trajectory and/or when the child raises questions.

The interviews suggest that the content of ALS-related conversations from parent to child is primarily focused on providing factual or practical information about the disease and care trajectory, and to a lesser extent on psychosocial aspects. To help their children manage everyday life with ALS and prevent them from potential future problem behaviors, it is important that parents not only inform or educate their children about ALS, according to their child's developmental stage, but also give their children room to express the many

emotions they may be experiencing, including anger, sadness, grief and anxiety (1,6,18). Professionals may create awareness among parents about the importance of talking about feelings, and encourage parents to discuss their own feelings as well as to allow their children to express theirs.

In line with previous studies in other palliative diagnoses (1,6–8,13,14), the present study shows that open family communication may be hindered when family members do not know what to say, do not know how to open the dialogue, or are unwilling to discuss. Interviews with parents and children suggest that avoidant communication is

Table 1. Overview of themes and subthemes identified from the interviews.

Themes	Subthemes	Definitions	Example quotes – Parents	Example quotes – Children
Communication topics	Giving the facts	ALS-related topics which are addressed in family interactions	<p>“We talked to them about this straight away, how serious it is and the statistics we heard during the diagnosis interview: an average of three years, 80 percent die within 5 years, etcetera. So we talked about this from the very beginning”.</p> <p>“The eldest knows that Daddy’s arms and legs are not well and that that is why they are not working properly and that his mouth is sick and that that is why he can’t talk or eat properly. She also knows that the doctor does not yet have a medicine to make him better”.</p> <p>“We said: ‘You know about daddy’s arm that it’s not working properly. The doctors looked at it again today and they saw that it is a disease and that daddy’s arm can’t get better. They have also seen that the disease can also spread to other parts of his body’”.</p> <p>“They [children] came with questions or they were sad and then there is always some fear or something in that sadness and we tried to respond to that”.</p> <p>“If, for example, I am sad or my husband is sad, we explain why that is. We explain this very clearly and I think she understands”.</p> <p>“The children notice that you are sad. You don’t really want to show it, but it is what it is. That is sometimes difficult. But we also told the children ‘If you want to cry, you can cry, it doesn’t matter’”.</p> <p>“I have made it quite clear, if I can no longer talk and I choke, for example, that if I give a signal, he [son] can call 112 if he is alone here”.</p> <p>“There are so many aids and situations in the house. And we involve them [the children] in all of these. We let them figure it out, open it up, experiment with it, so that they also become familiar with it”.</p> <p>“My husband is tube-fed, so she [daughter] also knows that he has a tube in his stomach which feeds him. She also knows that he is ventilated at night. So then he gets a mask on and that is because his lungs aren’t working well. I don’t know if she knows what lungs are, but that this also has to do with the disease. There are caregivers in the house for a large part of</p>	<p>“We don’t talk about it that much, but I just know that it is a muscle disease and that your muscles fail and that things can fall out so that you can die. That your muscles actually stop working”.</p> <p>“In the evening they told me what it was and that he would eventually die of it and that it would take about 4 years. That he would end up in a wheelchair”.</p>
		Parents provide their children with information about the diagnosis and prognosis.	<p>“Sometimes we sit together with the family and think: Where are we now? What does that mean? What do you think? How do you feel about that?”</p> <p>“I can talk to my sister one-on-one, so my sister is very helpful to me. We can say a lot to each other, how we are feeling and what is going on in the family and whatever happened the day before and how we feel about it”.</p> <p>“That’s what my mom told me: ‘If daddy is choking you should know he’s trying to breathe through his nose, but if he isn’t managing, try to tell him to breathe through his nose. And try to go a little over his back’”.</p> <p>“He has a ventilator now and we had to get used to putting it on him. [We learned how to do it] just from home care and from my mother. When he [father] was still able to do it himself, he explained it to me”.</p>	
	Acknowledging and sharing feelings	Family members acknowledge and share emotions, worries and thoughts about the ALS situation.		
	Preparing for care and equipment	Parents inform their children about the required care and equipment.		

(Continued)

Table 1. (Continued).

Themes	Subthemes	Definitions	Example quotes – Parents	Example quotes – Children
	Discussing the end of life with their children.	Parents discuss death, dying or end of life with their children.	<p><i>the day to take care of him, so she knows that they are there to help daddy”.</i></p> <p><i>“We’ve indicated every time that daddy’s lungs are getting worse, so daddy’s breathing is getting worse and so it is possible that sometime daddy will go to sleep and won’t wake up again and die, because his lungs no longer work. So in that week [that the euthanasia took place], we kind of prepared them, because we knew it was coming. And the evening that he was going to die, we made a point of telling the girls to say goodbye”.</i></p> <p><i>“You sometimes talk about death. We are now in a phase where you’ve actually already addressed and discussed a lot of things, but to keep bringing these things up. I find that difficult sometimes. You can’t keep talking about the imminent death or what it will be like when their father is gone”.</i></p>	
Communication styles	Open	The ways parents talk and interact with their children about ALS-related topics share information, feelings or experiences.	<p><i>“It’s a very open topic. It is discussed a lot, often just in the normal course of everyday activities”.</i></p> <p><i>“We have said from the beginning that the children can know and see and do everything. And if they don’t want to know, that’s fine too, but we do offer them everything. If something happens or if things change or whatever, we let them know everything”.</i></p> <p><i>“We share everything with the children. I think we are very open about that sort of thing. And I think there’s nothing worse than withholding things”.</i></p> <p><i>“We did discuss things like a euthanasia request with our general practitioner. That’s something we’re not sharing yet”.</i></p> <p><i>“Because this disease is so intangible, it’s difficult to imagine that I might be in a wheelchair next year. But it could also be three years from now. And that’s a long time for children. I can’t really explain that. It may happen or it may not”.</i></p> <p><i>“My life is usually too busy and too hectic. They [children] tend to go to their father and he just listens to them and tries to find a solution. I don’t have time for that. I’m just really too busy with everything”.</i></p>	
	Avoidant	Resistance of parents or children to talk about ALS-related topics.		<p><i>“If something is bothering me, I don’t like to tell our dad, because then I know he will cry and he can’t help having this disease”.</i></p> <p><i>“We don’t actually talk about ALS at all, because I don’t like it and neither does our dad”.</i></p> <p><i>“We are not really a talkative family. My mother is rather introvert and my father tries to stay strong for us, so we don’t really talk to each other very much”.</i></p>

(Continued)

Table 1. (Continued).

Themes	Subthemes	Definitions	Example quotes – Parents	Example quotes – Children
Communication timing	Waiting for changes	When parents open the conversation about ALS opened when there are (expected) developments in the disease or care trajectory.	<p>“I still remember that when we came out of the hospital [daughter’s name] came out of school. She saw straight away that something was wrong, you can’t keep that to yourself. So we just told her straight away”.</p> <p>“If something is no longer possible, I discuss it”.</p> <p>“If the medicines change again or something like that, I usually involve my oldest children”.</p> <p>“They [children] will eventually draw their own conclusions. If everything stops at some point, then one day you will die. Yes, that’s right. And that’s the moment to say something about that”.</p> <p>“At some point there was the question: ‘Why can’t dad walk anymore?’. And then you actually explain how the muscles work. And then it was: ‘Will we have to go in a wheelchair too? Maybe we won’t get muscles anymore’. Then you have to tell them about that. At a certain point [name of partner]’s speech got worse, so you have to explain that too. You keep taking them with you a few steps at a time”.</p> <p>“We try to be honest and give concrete answers to all her questions, but not to make too much of it. So not telling more than she is asking”.</p>	<p>“If Mum has been to the hospital then it’s about whether things are going well or less well and then we talk about it for a while”.</p> <p>“Every time there is something new about him [father with ALS], he will tell us”.</p>
	Waiting for questions	The conversation about ALS is opened at times when the children express needs or questions.	<p>“When I ask how he got on in the hospital, he always tells everything. If I ask, he will share it”.</p> <p>“If my father has an appointment at the hospital and he requires a new treatment, then we are not always aware of that. Then we have to actually ask about it ourselves”.</p>	

Table 2. Family-level analysis.

Theme	Corresponding perceptions – example quotes	Conflicting perceptions – example quotes
Communication topics	Parent – “ <i>I do have conversations with the children about how they are doing</i> ”. Child – “ <i>Sometimes we sit together with the family and think: where are we now? What does that mean? What do you think? How do you feel about that?</i> ”	Parent – “ <i>We told [name of daughter], the eldest, in particular, that there are a lot of things that we don’t know, that the disease can progress differently for everyone. [...] We didn’t tell then that he would die from it. We did tell her that he would gradually get worse</i> ”. Child – “ <i>They told me what it was and that he would eventually die from it and that it would take about 4 years. And that he would end up in a wheelchair</i> ”.
Communication styles	Parent – “ <i>We are very open as a family</i> ”. Child – “ <i>They also explained to me that if I had questions I could always contact them and I actually do that. [...] If I have questions, I don’t look them up, I ask mom and dad</i> ”.	Parent – “ <i>Sometimes, when it has been really intense, I don’t share that. It would have to be really intense for me not to share it. I usually share everything with the oldest children</i> ”. Child 1 – “ <i>We are actually left out of a lot of things</i> ”. Child 2 – “ <i>We are not really a talkative family. My mother is rather introvert and my father tries to stay strong for us, so we don’t really talk to each other very much</i> ”.
Communication timing	Parent – “ <i>We had already prepared the children that it could be a very bad result for daddy. So we had also explained to the children what the disease was</i> ”. Child – “ <i>They [parents] had already been told that there was a high chance of ALS, so we were already a bit prepared</i> ”.	Parent – “ <i>They are involved when my husband goes [to the hospital] for an examination for the ventilator or something. [...] We do have conversations about that, not so much about ALS anymore, but about the things that come with it. If the medicines change again or something like that, I usually involve my oldest children again</i> ”. Child – “ <i>If my father has another appointment at the hospital and he requires a new treatment, then we are not always aware of that. Then we have to actually ask about it ourselves</i> ”. Child 2 – “ <i>My mother said the lung specialist is coming again and your father will be fitted with a respirator, for example</i> ”.

often due to an underlying fear, such as the fear to burden or upset other family members, the fear to say things that may not happen or the fear for (not being able to answer) questions. When families are not open, it is important to identify and address those underlying fears that withhold family members from being open to each other. Professionals may also help parents open the dialogue with their children through initiating family conversations and showing families how they can openly and respectfully talk to each other about ALS, including sensitive topics such as the inevitable end of life of the parent with ALS.

Finally, interview findings indicate that the conversation about ALS is re-opened multiple times along with developments in the functioning of the parent with ALS, the home situation and/or the child, suggesting that it is a dynamic and continuous process. ALS care professionals can play a critical role in maintaining continued open communication within families, through regularly assessing if things are changed and if (more) information or support is needed, especially when sensitive topics are to be addressed. It is crucial that the support offered is family-centered. Each family has its own dynamics, communication patterns, norms and values which may influence how parents and children talk about ALS (6). Differences in communication needs and preferences may not only exist between families but also within families, as reflected in the family-level analysis. Thus, first and

foremost, professionals may want to encourage parents to inquire and listen and attend to the communication needs of their children (13).

Limitations

The present study poses two major limitations, toning down the potential impact and generalizability of the findings. The interview data used were collected for a previous study (1), which 1) did not primarily aim to address family communication about ALS as a result of which data saturation could not be achieved for all themes, and 2) did not assess cognitive and behavioral functioning of parents with ALS which is likely to impact on how families talk about ALS.

Conclusion

This study provides further insight into what, how and when families communicate about ALS. Although families generally open the dialogue about ALS, they encounter challenges which may hamper good familial communication. Through addressing those challenges, healthcare professionals may facilitate timely and open ALS communication within families which is deemed essential for families’ and especially children’s adaptation to life with ALS. Cultural differences, how families talk about the imminent death of the parent with ALS and the role of cognitive and behavioral

impairments in family communication about ALS remain important topics for future research, as well as what types of support parents need to feel well-equipped to discuss ALS and its practical, social and emotional impact with their children.


Declaration of interest

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