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# What do people affected by amyotrophic lateral sclerosis want from health communications? Evidence from the ALS Talk Project

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## Abstract

**Introduction/Aims:** Health communication is central to effective, supportive amyotrophic lateral sclerosis (ALS) clinical care. Guidance for ALS communication is limited, focuses on diagnosis disclosure, and frequently relies on expert consensus and/or reviews. Patient-based evidence is needed to guide ALS health communication. We investigated how the experiences of ALS patients and family caregivers can inform effective communication practices from diagnosis to end-of-life.

**Methods:** Data were drawn from the ALS Talk Project, an asynchronous, online focus group study. Seven focus groups and five interviews (105 participants) were conducted. Data were qualitatively analyzed using directed content analysis and the constant-comparative approach.

**Results:** We found four primary themes: communication content, communication circumstances, information sufficiency, and communication manner. Data indicate participants relied on clinicians for medical information but also wanted practical information; health communication should attend to the circumstances within which conversations occur; information must be sufficient for individual needs, without overwhelming; and an empathetic, direct, and honest manner facilitated trust. Participants identified communication challenges and strategies to improve communication across major themes, including stepwise approaches and conversations tailored to individuals and their heterogeneous disease experiences.

**Discussion:** Healthcare professionals should discuss patient/caregiver communication preferences early in the therapeutic relationship, co-develop a communication agreement, and update the agreement in response to changing needs and disease progression. This will foster regular discussion of information needs and promote

**Abbreviations:** AB, Alberta; ALS, amyotrophic lateral sclerosis; ALS Talk, ALS Talk Project; AOFG, Asynchronous Online Focus Group; BC, British Columbia; HCP, healthcare professional; NB, New Brunswick; NS, Nova Scotia; ON, Ontario; PwALS, people (person) living with ALS; QC, Quebec; HCP, healthcare professional.

National/International meetings: Parts of the material in this article were included in a poster (2021) and platform (2022) presentation at the ALS Society of Canada's Annual Research Forum (Toronto, Ontario, Canada).

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timely discussions of challenging topics, including advance care, while giving patients and families a sense of control. Findings may have implications for other neuromuscular disease and/or seriously ill populations.

#### KEYWORDS

amyotrophic lateral sclerosis (ALS), family caregivers, health communication, patients, physician-patient relations

## 1 | INTRODUCTION

Health communication<sup>1</sup> in clinical settings is fundamental to the therapeutic relationship between healthcare professionals (HCPs) and patients,<sup>2</sup> especially patients affected by serious illnesses,<sup>3,4</sup> such as amyotrophic lateral sclerosis (ALS).<sup>5,6</sup> Clinical care for people living with ALS (PwALS) focuses on improving survival and quality of life through multidisciplinary care, including symptom management, nutritional support, and respiratory care.<sup>7-9</sup> Meeting the communication and information needs of PwALS and their family caregivers (collectively, people affected by ALS) is central to effective, supportive clinical care.<sup>6,10-12</sup>

Published communication guidance focuses on diagnosis disclosure.<sup>13-15</sup> Consensus-based documents recommend regular discussion of life-sustaining therapies and end-of-life care,<sup>9,13,16</sup> and recent publications offer recommendations for discussing prognosis<sup>17</sup> and edaravone treatment.<sup>18</sup> Many communication recommendations, however, are based on expert consensus, literature reviews, and/or extrapolation from other life-limiting diseases. There has been limited investigation of the perspectives of PwALS and family caregivers,<sup>19,20</sup> who are in the best position to inform communication practices that will meet their ongoing needs.

We report findings from the ALS Talk Project (ALS Talk), an asynchronous, online focus group (AOFG) study involving PwALS and family caregivers. AOFGs accommodate participants with disability-related travel barriers, using augmentative and alternative communication aids, living distant from research centers, and/or navigating caregiving responsibilities.<sup>21-24</sup> They are suitable for investigations of potentially sensitive topics and facilitate individual expression, reflection on others' experiences, and discussion of different or shared perspectives.<sup>25,26</sup> Previously we drew on ALS Talk data to examine support from ALS health charities<sup>27</sup> and coping in the early months of the COVID-19 pandemic.<sup>28</sup> Here we ask: how can the experiences and/or perceptions of people affected by ALS inform effective health communication practices throughout the ALS disease course?

## 2 | METHODS

ALS Talk was approved by the University of Alberta's Research Ethics Board (Pro0008471). All participants provided informed consent. Here we analyze unpublished data on health communication.

### 2.1 | Participants and recruitment

We purposively recruited PwALS and family caregivers in Canadian provinces with the largest populations (British Columbia [BC], Alberta [AB], Ontario [ON], and Quebec [QC]), and in two small provinces (New Brunswick [NB] and Nova Scotia [NS]). Participants were recruited via ALS multidisciplinary clinics, national and regional ALS Societies, and the Canadian Neuromuscular Disease Registry.<sup>29</sup> Participants had an ALS diagnosis<sup>30</sup> confirmed by an ALS specialist physician, or were a family member providing current or past care for a PwALS. Participants were over 18 y of age, able to communicate in English, and had Internet access. All qualifying volunteers were invited to participate. PwALS/caregiver pairs were not required.

We recruited between July 2019 and January 2020, seeking 15 participants/AOFG. We conducted separate AOFGs for PwALS and caregivers living in BC, AB, and ON. Due to low enrollment in QC, NB, and NS, PwALS from these provinces participated in a single AOFG; caregivers were invited to participate individually in an audio-recorded interview. There was no interaction between the seven AOFGs. Groups in AB and ON ( $n = 4$ ) started on January 7, 2020; groups in BC and QC/NB/NS ( $n = 3$ ) started on March 11, 2020.

### 2.2 | Design and data collection

Participants interacted in moderated, asynchronous discussions on the secure itracks Board™.<sup>31</sup> itracks offered text, video, and/or audio-based input options in a threaded Web forum structure. Participants answered questions and engaged in discussions at their convenience, from any location with Internet access, using their own devices, and via a Web browser or the itracks app.

Informed by a pilot project,<sup>32</sup> we developed an eight-topic/16-wk discussion guide. We identified redundancies in the early weeks of the AB and ON AOFGs. Discussion questions were restructured to ensure data integrity and consolidated into a seven-topic/14-wk discussion guide for the BC and QC/NB/NS AOFGs (Table S1). Topics focused sequentially on health communication throughout the disease course and were introduced biweekly. We added weekly topic-specific questions to promote further discussion. We notified participants by email when new questions were posted to the platform. Participants were required to post an initial response before they could read and respond to other group members or to moderators. All questions were optional. Questions remained open for input from posting to the end of the study.

AOFGs were actively moderated by trained research associates (S.K.G., W.L.). Moderators asked probing questions to encourage further input, clarify meaning, and/or encourage group interaction. Participants shared their perspectives in response to questions, moderator probes, and in discussions with other group members.

We adapted questions from the AOFG discussion guide for semi-structured interviews with caregivers in QC/NB/NS. An experienced interviewer (S.K.G.) conducted audio-recorded interviews in May 2020. All participants chose to interview via telephone rather than conferencing software.

### 2.3 | Analysis

itracks automatically generated transcripts from text-based data. A professional transcriptionist transcribed video responses to AOFG questions, and audio-recorded interviews. S.K.G. verified the transcripts. NVivo 12™ software facilitated data organization, theme identification, and coding. S.K.G. and W.L. developed a codebook based on a preliminary reading of the data. Subject experts (W.S.J., T.B.) reviewed the codebook. Data were analyzed according to four primary emerging themes. After initial coding, we identified and coded subthemes. We analyzed data using directed content analysis<sup>33</sup> and the constant-comparative approach.<sup>34</sup> Coders were trained on 10% of the data together and resolved discrepancies through discussion to consensus. After refining the codebook with expert input from W.S.J., coders then independently coded another 10% of data to evaluate intercoder reliability (Kappa coefficient, 0.96)<sup>35</sup> before coding the remaining data. We used descriptive statistics to summarize participant characteristics. Numeric data are not included when reporting qualitative results.

## 3 | RESULTS

Participants discussed their experiences and perspectives related to past, current, and future ALS health communication. They frequently discussed AOFG questions from the perspective of their loved ones (either PwALS or caregivers) and/or of patients and caregivers as a unit of care. Hence, data reflect the experiences and perspectives of people affected by ALS. Four primary themes emerged: communication content, communication circumstances, information sufficiency, and communication manner (Table 1). Participants identified communication challenges and strategies to improve health communication across these themes.

### 3.1 | Demographics

We analyzed data from 105 participants (52 PwALS; 53 caregivers). Participating caregivers included spouses, partners, siblings, and adult children of PwALS. One hundred people participated in the AOFGs (Table 2). Three caregivers and one caregiver/PwALS pair participated in interviews. Interviews ranged from 80 to 100 min.

**TABLE 1** Primary themes

Themes	Illustrative quotations
Communication content	<ul style="list-style-type: none"> <li>When making a decision about my treatment, especially new therapy, I will turn to the specialists that are overseeing my care. They have the knowledge and clinical experience ... they also have knowledge about my specific health condition/ progression. (P48, PwALS)</li> </ul>
Communication circumstances	<ul style="list-style-type: none"> <li>Communication is more than words. It is also about alleviating fears and worries around this disease by doing all that can be done to make the patient as comfortable as possible with what they have to live with. Demonstrations of whatever needs to happen is very positive communication for both me and my husband... It can be something as simple as the clinical nurse putting her hand on my husband's knee when she was talking to him in the first visit. (P54, caregiver)</li> </ul>
Information sufficiency	<ul style="list-style-type: none"> <li>There is a fine line between giving information about what is going to happen and how to handle it, and scaring the heck out of everyone involved. (P118, caregiver)</li> </ul>
Communication manner	<ul style="list-style-type: none"> <li>Both the ALS clinic and my family doctor have been supportive, caring, and thankfully honest. (P19, PwALS)</li> </ul>

### 3.2 | Theme 1: Communication content

Although participants used the Internet extensively to meet their information needs, they valued professional expertise and viewed medical and clinical information provision as a key role for HCPs. Information needs included ALS-related pathophysiology, symptoms, available and emerging therapies, progression and prognosis, and end-of-life care. Participants valued information from HCPs about research participation, and complementary and alternative therapies.

Participants also placed high value on practical information, including symptom management and accessing community support systems. While participants relied on HCPs for information about the medical aspects of symptom management, they wanted more information about the day-to-day challenges of living with ALS. They reported that the Canadian ALS Societies play a role in addressing this information need. Participants identified a lack of information from HCPs about psychological and/or mental health support, but they expressed mixed views about whether the health team should address social or interpersonal issues (Table S2).

#### 3.2.1 | Delivery strategies

Three content delivery strategies meet the needs of people affected by ALS. First, HCPs should share background information, including rationale for tests or recommendations, and potential outcomes of

**TABLE 2** Characteristics of ALS Talk AOFG participants<sup>a</sup>

Characteristic	PwALS (n = 51)		Caregiver (n = 49)		Total (n = 100)
<b>Gender</b>					
Women	19	37%	38	78%	57
Men	31	61%	8	16%	39
No response	1	2%	3	6%	4
<b>Province</b>					
Alberta	15	29%	17	35%	32
British Columbia	10	20%	16	33%	26
Ontario	17	33%	16	33%	33
Quebec/New Brunswick/Nova Scotia	9	18%	0	0%	9
<b>Age (y)</b>					
18–29	0	0%	3	6%	3
30–39	1	2%	3	6%	4
40–49	4	8%	10	20%	14
50–59	10	20%	15	31%	25
60–69	21	41%	10	20%	31
70+	14	27%	5	10%	19
No response	1	2%	3	6%	4
<b>Onset site (of self or family member with ALS)</b>					
Limb	34	67%	31	63%	65
Bulbar	10	20%	8	16%	18
Do not know	3	6%	5	10%	8
Other	2	4%	2	4%	4
Prefer not to answer	1	2%	1	2%	2
No response	1	2%	2	4%	3
<b>Time since diagnosis (of self or family member with ALS)</b>					
1–3 y	35	69%	32	65%	67
4–6 y	11	22%	12	24%	23
7+ y	4	8%	2	4%	6
Prefer not to answer	0	0%	1	2%	1
No response	1	2%	2	4%	3

<sup>a</sup>Demographic data for five interviewed participants not available.

investigations, therapies, and decisions about symptom management. Second, HCPs should first provide general information and progress to discussion of the individual's situation. Third, participants highlighted the effectiveness of information delivered iteratively, in small batches, and with increasing detail over time.

### 3.3 | Theme 2: Communication circumstances

The conditions surrounding communication critically influenced participants' experiences. The timing of communication, who initiates conversations, use of information resources, and access to HCPs were important to people affected by ALS (Table S3). Although not as prominent in the data, participants emphasized the importance of having someone close to the PwALS at appointments. Participants were also concerned about effective communication between HCPs both within and external to the clinic.

#### 3.3.1 | Timing

Participants highlighted the “right” time to receive information or discuss difficult topics. Perceptions of timing were influenced by personal dispositions and the disease course. Time to reflect on information was an important theme. Further, time functioned as a proxy for care quality, with efficient access to appointments being equated with high-quality care.

#### 3.3.2 | Initiating conversations

Participants wanted to be in control of health communication and valued self-initiated discussions. However, they also valued HCP expertise and felt unsupported if they were solely responsible for pursuing information. Participants suggested HCPs should proactively provide

opportunities to discuss specific topics and/or leverage physical changes to initiate conversations.

### 3.3.3 | Information resources

Participants valued HCP-provided information resources, such as paper handouts, illustrations, and/or Web links. They appreciated consulting and re-visiting these trusted resources when and as needed. Information resources supported and enhanced face-to-face health communication.

### 3.3.4 | Access

HCP contact information, including phone numbers or emails, supported health communication. Out-of-office access built trust in HCPs. A lack of access engendered feelings of abandonment.

## 3.4 | Theme 3: Information sufficiency

Communicating the “right” amount of information was important to participants. Most wanted either just enough information to meet their current needs (“enough for now”), or they preferred as much information as possible about current and potential future needs (“more is better”) (Table S4). A slightly higher proportion of PwALS than caregivers expressed an ‘enough for now’ approach; an equal proportion of PwALS and caregivers made statements indicating ‘more is better’. A few participants, both PwALS and caregivers, shared specific instances where they or their loved one did not want information. Perceptions of information sufficiency changed over time and with disease progression. Participants highlighted the role of HCPs in monitoring and responding to changing perceptions of sufficiency.

### 3.4.1 | Information overload

Many participants, particularly PwALS, reported information overload during diagnosis disclosure and, for some, at clinic visits. Strategies to mitigate overload at medical appointments included advance preparation of topics and/or questions for discussion with HCPs, bringing a support person, taking notes, and reviewing HCP-provided information resources following appointments. Strategies for HCPs included providing information resources and visit summaries.

## 3.5 | Theme 4: Communication manner

Participants strongly endorsed direct, honest communication. This facilitated trust in HCPs. At the same time, participants presumed that HCPs should demonstrate empathy. Communication behaviors demonstrating this demeanor included listening, responding to questions,

offering explanations, and unrushed time at appointments. Finally, HCPs should focus on individual patients and/or families, calibrating their communication manner to individual dispositions and people's heterogeneous ALS experiences (Table S5).

## 3.6 | Caregivers

Caregiver-specific themes focused on having timely and sufficient information to support caregiving. Caregivers wanted one-on-one communication with HCPs and many were proactive in seeking information. For example, “I wish [my spouse] would ask questions as I don't feel I can with him present. I feel certain that, as symptoms progress, I will reach out to these professionals with questions” (P88, caregiver). Some participants, both PwALS and caregivers, identified a need for support and information resources tailored to the needs of caregivers.

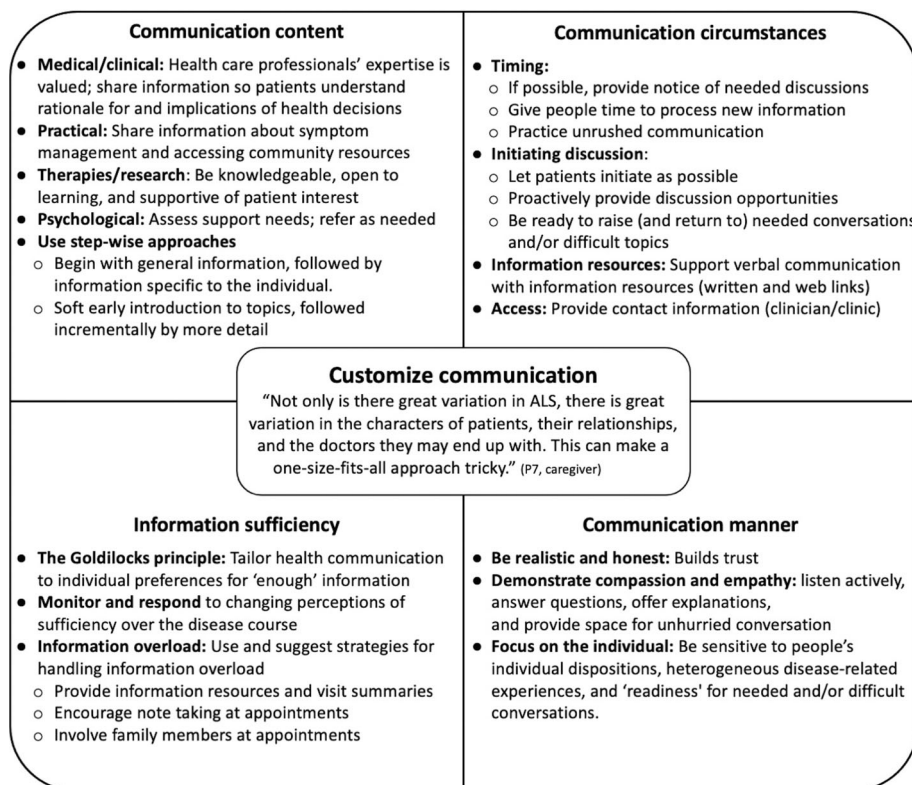
## 3.7 | Ongoing challenges

We identified four communication challenges (Table 3). First, participants reported poor communication during the ALS diagnostic journey, particularly prior to referral to specialized ALS clinics. Important themes included a lack of transparency during investigations and communication reluctance. Second, while participants understood that “ALS is pretty much unique for each patient” (P70, PwALS), many were frustrated by HCPs who appeared to avoid topics by citing disease heterogeneity. The third challenge was communication about prognosis and disease progression. Participants wanted explanations to include both general and personal prognosis. Finally, conversations about advance care were

**TABLE 3** Communication challenges

Themes	Illustrative quotations
The diagnostic journey	<ul style="list-style-type: none"> <li>It is like you are tossed between doctors/specialists like a hot potato, and nobody wants to tell you what they suspect is wrong. (P74, PwALS)</li> </ul>
Disease heterogeneity	<ul style="list-style-type: none"> <li>This was definitely one of the most frustrating aspects...whenever we asked a question about the future, we were always given the answer ‘everyone's progression is different, so we do not know’. (P61, caregiver)</li> </ul>
Prognosis and progression	<ul style="list-style-type: none"> <li>The question of prognosis is a difficult one and should be talked about frankly. The fact that it is such an individual thing, and everyone will have a different timeline is disconcerting for some, but just giving an average is wrong as well. (P118, caregiver)</li> </ul>
Advance care	<ul style="list-style-type: none"> <li>[HCPs] obviously would have the most information and have been involved in the advanced care of others. It is important to learn all of the options before the decisions need to be made. (P40, PwALS)</li> </ul>

**FIGURE 1** Recommendations for communication content, communication circumstances, information sufficiency, and communication manner.



challenging for both participants and HCPs. Although participants expressed varying preferences for the timing and initiation of these conversations, they valued compassionate, fulsome discussion of end-of-life choices.

### 3.8 | How to improve health communication

Participants made recommendations for improving communication content, circumstances, sufficiency, and manner (Figure 1). However, communication preferences differed among participants. Participants described their preferences and discussed the challenge of meeting varying communication needs. They recommended that HCPs and people affected by ALS discuss and identify communication preferences early in the disease course. HCPs should then tailor their communication to individual patients and families, with the understanding that they will raise and return to required conversations and difficult topics as needed. Participants believed that regular discussion of information needs would provide opportunities for asking questions and for HCPs to initiate needed discussions.

"At each clinic visit, the health professionals can say 'here are some things that you need to start thinking about'...Or, 'at our last visit, we started talking about X, have you had any further thoughts/questions?'...This at least starts the conversation and the thought process with an option for follow up." (P61, caregiver)

## 4 | DISCUSSION

Health communication is central to the experience of PwALS and caregivers, with profound impact at all stages of clinical care. Participants confirmed a reliance on online information seeking.<sup>36-39</sup> Nonetheless HCPs were a critical and preferred information source.<sup>37,39,40</sup> Our analysis reinforces the need for more information about the day-to-day challenges of ALS and psychological support.<sup>41-43</sup> This suggests that HCPs should facilitate the integration of care between medical and community settings. This may include referral to ALS health charities,<sup>27</sup> and/or facilitating connections between multidisciplinary clinics, community health and social care systems,<sup>44-46</sup> and palliative care.<sup>11,47-49</sup>

Our analysis also draws attention to how information is communicated,<sup>50</sup> supporting empathic, compassionate, and honest communication.<sup>11,12,50,51</sup> However, participants highlighted additional critical features: health communication must attend to the circumstances within which communication occurs, and it must be sufficient for patient and caregiver needs, without overwhelming.

We now discuss communication strategies that integrate the primary elements of communication highlighted by this investigation and respond to people's individual dispositions and heterogeneous ALS experiences.<sup>6,11,50,52</sup> We propose the adoption of personalized communication agreements that will facilitate and guide health communication throughout the ALS journey.

## 4.1 | Communication strategies

### 4.1.1 | Be prepared to discuss substantive medical and clinical information

People affected by ALS rely on HCPs for medical and clinical information as they confront complex decisions and make sense of the chronic and terminal aspects of ALS.<sup>53</sup> For example, study participants valued HCPs' capacity to explain symptom management and therapies within the broader contexts of disease trajectory, quality of life, and end-of-life decisions.<sup>54–57</sup> HCPs should also be prepared to explain and discuss topics covered in existing guidelines and reviews,<sup>8,9,58</sup> even though these are intended for expert audiences.

HCPs need to be attuned to patients' information preferences<sup>11,50,52,59</sup> and navigate their potential reluctance to communicate difficult information about diagnosis, prognosis, and end of life.<sup>5,17,53,60,61</sup> HCPs' knowledge and expertise is a critical resource for PwALS and caregivers. It facilitates understanding of health information from medical and non-medical sources,<sup>18,36</sup> helps PwALS and caregivers feel supported,<sup>12,62</sup> and builds patient trust and ownership of decisions.<sup>63,64</sup>

### 4.1.2 | Stepwise approaches

Similar to recommendations for diagnosis disclosure,<sup>15,65</sup> our analysis suggests that stepwise approaches will promote effective, sensitive health communication throughout the ALS disease course. Findings suggest two complementary approaches. HCPs should communicate general information about a topic, for example mechanical ventilation or enteral feeding, early in the disease course. This facilitates consideration of challenging issues before providing a personalized perspective<sup>66–68</sup> when initiated by patients and/or caregivers or when required by symptom progression. Second, health information provided iteratively, in small batches, and with increasing detail over time, will facilitate information processing,<sup>12</sup> help address prognostic uncertainty,<sup>69</sup> and respond to changing needs and progressing illness.<sup>70,71</sup>

Stepwise communication approaches should be supported by written information, including online resources and HCP contact information. Such approaches help patients and caregivers understand health information, cope with complex medical challenges, and build trust in HCPs.<sup>72–76</sup>

### 4.1.3 | Communication agreement

We propose that PwALS' and, secondarily, caregivers' communication needs and preferences be discussed early in the therapeutic relationship,<sup>11,46</sup> followed by the development of a personalized, adaptable communication agreement. Agreements should include preferences for communication content, circumstances, sufficiency, and manner, as well as when and how to initiate conversations about

future transitions,<sup>77</sup> including stepwise communication approaches. Communication agreements should be revisited and updated in response to patient needs, disease progression, and/or the cyclic decision-making experienced by PwALS.<sup>78</sup> A formal communication agreement animates recommendations for individualized communication,<sup>11,15,17,46</sup> and a systematic, structured approach to communication.<sup>79</sup>

Communication agreements should guide clinical encounters. They will help HCPs understand and accommodate individual dispositions, heterogeneous experiences, and emotional readiness for new and/or difficult discussions.<sup>11,46,48,80</sup> Attention to communication as a topic at each clinical encounter will foster regular discussion of information needs and promote timely discussions of challenging topics, including symptom management and advance care.<sup>49,71,81,82</sup> At the same time, a communication agreement will shape patient and caregiver expectations and foster a sense of control within the therapeutic relationship.<sup>51,83,84</sup> This sense of control may be achieved by prioritizing of patients' communication preferences and by developing trust in clinicians who will sensitively initiate and return to difficult topics as needed.<sup>51,85</sup>

## 4.2 | Limitations

There are limitations to this study. First, with ALS onset peaking at 65 y of age<sup>58</sup> and evidence for an age-related digital divide,<sup>86</sup> sampling and study results may have been influenced by requirements for online interaction. Although a high proportion of Canadians are Internet users,<sup>87</sup> Internet access is inconsistently distributed across rural areas in Canada.<sup>88</sup> This may have limited participation. Second, the study was conducted in a high-income country<sup>89</sup> with a publicly funded health system. This may have shaped participants' expectations for health communication. Third, as with all qualitative research, findings may not be directly generalizable to other populations, including those in other jurisdictions and non-English speaking populations.

## 4.3 | Conclusions

General neurology and ALS research identifies communication skills as a priority for clinicians.<sup>5,48,50,90,91</sup> Our analysis furthers this body of research by identifying what and how information should be communicated. We confirm health communication as central to clinical care for people affected by ALS<sup>2</sup> and answer the call to make actionable recommendations and guidance to support clinicians caring for ALS patients<sup>46,92</sup> Based on evidence from patients and caregivers, we provide strategies that can be adopted into clinical practice to improve health communication from the time of first symptoms to advance care planning. In particular, we recommend that clinicians and patients co-develop an adaptable communication agreement that is responsive to personal preferences, sensitive to individual circumstances, and will guide health communication throughout the disease course.



Further research is needed to develop this patient- and caregiver-based evidence into clinical communication guidance, and to develop and evaluate a communication agreement template that might be used effectively in clinical practice. We identified unmet participant need for information about psychological support. Given the sparse literature on psychological interventions adapted to the needs of this population,<sup>93-95</sup> this area requires attention from both clinicians and researchers. Finally, this investigation of health communication throughout the ALS disease course may have implications for other neuromuscular disease and/or seriously ill populations.

#### AUTHOR CONTRIBUTIONS

**Shelagh K. Genuis:** Conceptualization; investigation; writing – original draft; methodology; validation; writing – review and editing; formal analysis; project administration. **Westerly Luth:** Conceptualization; investigation; methodology; validation; writing – review and editing; software; formal analysis; project administration. **Tania Bubela:** Conceptualization; writing – review and editing; methodology. **Wendy S. Johnston:** Conceptualization; investigation; funding acquisition; methodology; writing – review and editing; supervision.

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#### CONFLICT OF INTEREST STATEMENT

None of the authors has any conflict of interest to disclose.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### ETHICAL STATEMENT

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

#### ETHICS APPROVAL AND PATIENT CONSENT STATEMENTS

The ALS Talk Project study was approved by the University of Alberta's Research Ethics Board (Pro0008471). Informed consent was obtained from all participants.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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