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**Brief Communication**

# Asymmetry and Alignment: Physician Perspective on Patient-Based Evidence for Improving Health Communication

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**ABSTRACT:** We investigated the response of experienced amyotrophic lateral sclerosis physicians to patient-based evidence pertaining to health communication. Fifteen expert amyotrophic lateral sclerosis (ALS) physicians participated in an in-person focus group. Focusing on clinical feasibility and first-hand experience, participants discussed recommendations from people with ALS and caregivers for improving communication. Data were qualitatively analyzed using conventional content analysis. Findings demonstrated shared and differing perspectives, and communication challenges. Findings suggest a difference in perspective centered on how to achieve the shared goal of patient-centered communication. We discuss asymmetry between healthcare professional perspectives and patient-based evidence, and opportunities for alignment that will advance effective health communication.

**RÉSUMÉ : Asymétrie et alignement des points de vue des médecins au sujet des données probantes obtenues auprés de patients en vue d'améliorer la communication en matière de santé**. En ce qui concerne la communication en matière de santé, nous avons étudié la réaction de médecins expérimentés spécialisés dans la sclérose latérale amyotrophique (SLA) face à des données probantes obtenues auprès de patients. Au total, 15 médecins ont participé en personne à un groupe de discussion. En mettant l'accent sur la faisabilité clinique et leur expérience directe, les participants ont discuté des recommandations formulées par des patients atteints de SLA et des soignants pour améliorer la communication. Les données recueillies ont été analysées de manière qualitative à l'aide d'une analyse de contenu conventionnelle. Les résultats ont mis en évidence des points de vue communs et divergents, ainsi que des difficultés en matière de communication. Ces résultats suggèrent aussi une différence de perspective quant à la manière d'atteindre l'objectif commun d'une communication centrée sur les patients. Nous entendons ainsi discuter de l'asymétrie entre les points de vue des professionnels de la santé et les données probantes obtenues auprès des patients, ainsi que des possibilités d'alignement qui permettront de faire progresser une communication davantage efficace en matière de santé.

**Keywords:** Amyotrophic lateral sclerosis (ALS); health communication; patient-centered care; physicians; physician–patient relations

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Patients have become more engaged in decision-making and advocating for their needs and preferences. This has transformed communication between healthcare professionals (HCPs) and patients resulting in recommendations to tailor communication to individual patients, explore patient expectations, and elicit patient perspectives.[1–3]

Previously we conducted seven online, asynchronous focus groups investigating health communication as it is experienced and perceived by people living with amyotrophic lateral sclerosis (PwALS) and family caregivers (caregivers). PwALS and caregivers discussed and reflected on health communication throughout the disease course, including from first symptoms to ALS diagnosis, navigating ALS-related changes, and end-of-life decisions. They also discussed information seeking and needs and made recommendations for improving communication between HCPs and patients. Patient-based recommendations arising from this PwALS/caregiver study are published elsewhere.[4] Understanding and improving health communication, however, requires investigation not only of patient perspective but also of HCP perspective.[5]

Here we investigate the response of experienced amyotrophic lateral sclerosis (ALS) physicians to PwALS/caregiver recommendations for health communication. We ask: What is the response of HCPs to patient-based evidence pertaining to ALS health communication? And, how can effective health communication be advanced by HCPs' reflections on PwALS/caregiver recommendations?

This study was approved by the University of Alberta's Research Ethics Board (Pro0008471). All participants provided informed consent. Research methods for the PwALS/caregiver focus groups and patient-based evidence used in this study are described elsewhere.[4]

We recruited a sample of convenience from among experienced ALS physician attending an annual meeting (Meeting) for biomedical and clinical ALS research dissemination in Canada. We emailed invitations and information sheets about the 1-hour,

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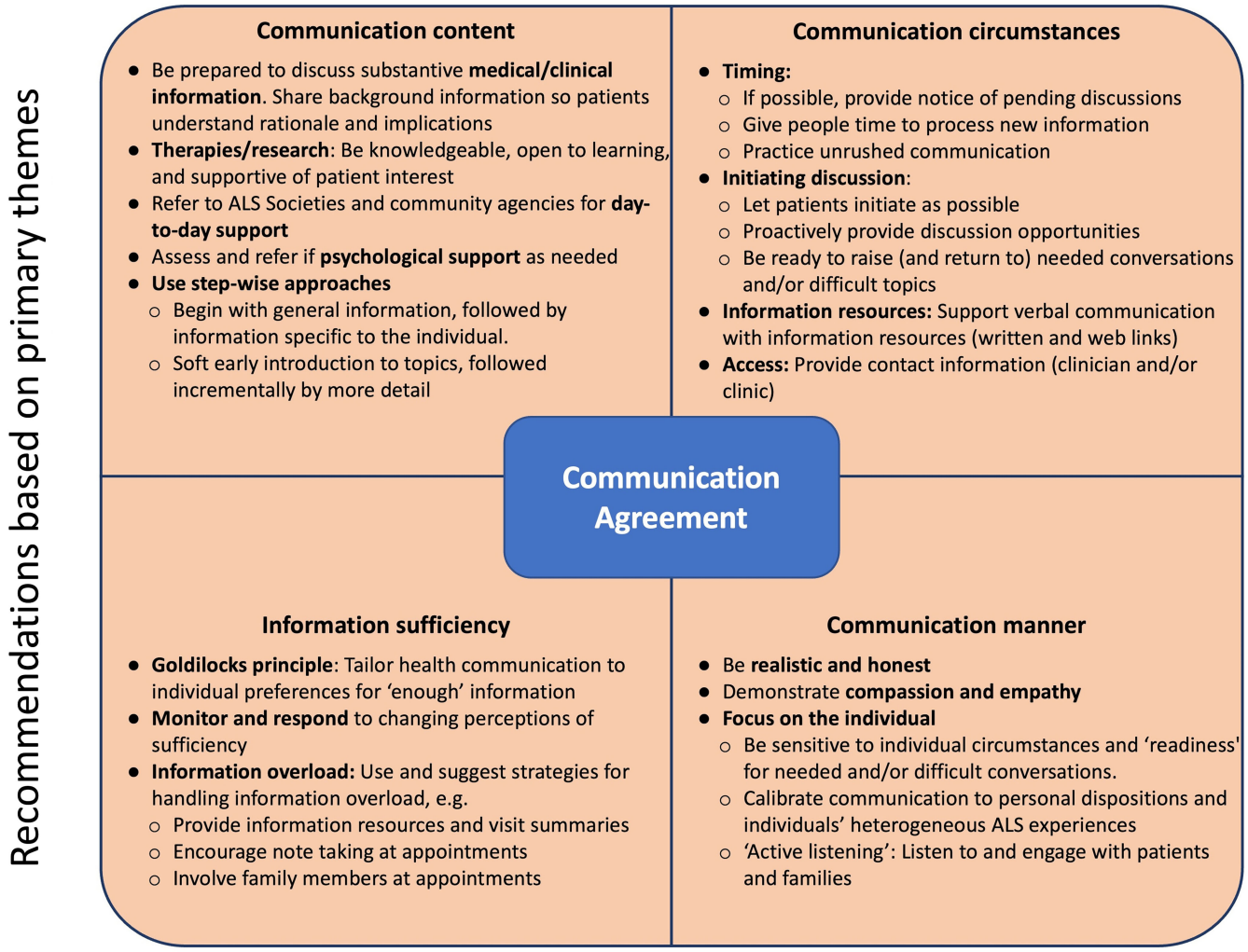



**Figure 1.** Example focus group discussion slide: summary of PwALS and caregiver recommendations for health communication. Slide adapted from Genuis et al. (2023).[4] ALS = amyotrophic lateral sclerosis.

in-person focus group (FG) to 28 ALS physicians from across Canada who were likely to attend the Meeting.

One week prior to the event, a summary of PwALS/caregiver recommendations [4] for health communication was emailed to consenting participants. The FG was held in a private conference room on May 6, 2023, prior to the Meeting's opening reception. The FG was audio-recorded; notes were taken by experienced research associates (SKG and WL) during the discussion. Participants were asked to reflect on slides summarizing published, patient-based recommendations for health communication [4] throughout the ALS disease (Figure 1) and consider if or how this evidence might be made actionable. A semi-structured discussion guide was used by the moderator (WSJ). The FG was conducted in English. To ensure participant anonymity within Canada's small community of ALS specialists, we did not collect demographic information.

The audio recording was professionally transcribed. The transcript was verified (SKG and WL) and qualitatively analyzed in NVivo 14™ using conventional content analysis.[6] The analysis was discussed to consensus by the authors. A summary, including themes, sub-themes, and illustrative quotations, was emailed to participants for member checking. Two participants responded, providing confirmation of the identified themes.

Fifteen active ALS specialist physicians participated. Of those invited to participate, five did not respond, five did not attend the Meeting, and four were unavailable at the designated time. Participants discussed PwALS/caregiver recommendations for ALS health communication and their personal experiences communicating with PwALS and caregivers. Three overarching themes emerged from the HCP FG data: shared perspectives, differing perspectives, and communication challenges. (Table 1)

*Shared perspectives*: HCPs affirmed PwALS/caregiver recommendations for tailoring communication to individuals, building trust-based relationships, and utilizing information resources. They also supported the importance of stepwise communication over the course of the disease, emphasizing the HCP's role in preparing PwALS for discussions or decisions pertaining to difficult topics such as enteral feedings or breathing support. HCPs also affirmed patient-based findings indicating that background information about tests or interventions is important for effective health communication. HCPs, however, emphasized the importance of exploring patients' motivations for seeking information and understanding patients' family and/or cultural contexts when sharing information.

*Differing perspectives*: Although strongly supported by patient-based evidence, HCPs were ambivalent about explicitly discussing PwALS/caregivers' communication preferences. Instead, study

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**Table 1.** Primary themes

| Themes | Illustrative quotations, HCPs | Illustrative quotations, PwALS/caregiver† |
|---|---|---|
| **Shared perspectives** | | |
| Individualized communication | *"You want a personal approach; you want to have individual approach."* (HCP8) | *"If our health professionals inform us all in the same way at the same time on this journey, they may be satisfying some and terrifying others"* (P58, PwALS) |
| Stepwise communication | "*Part of preparedness is gauging [the patient's] preparedness. It is also planning ahead . . . to say, 'I need them to be prepared for certain levels of information and so I'm going to lay the groundwork for that.'"* (HCP10) | *"A conversation about an emerging symptom, its associated equipment and/or supports would be helpful and again as the symptom gets closer to the point of need."* (P93, PwALS) |
| Background information | *"Sometimes patients do not know really what they're asking about. So I think, 'What do you really want to know?' Or, 'Why are you asking this?'"* (HCP9) | *"A discussion of how the [PwALS] would benefit from the equipment would be helpful . . . how progression will proceed without the equipment. Then an informed decision can be made."* (P52, caregiver) |
| **Differing perspectives** | | |
| Enacting patient-centeredness | *" . . . all the experienced ALS clinicians in the room probably use the art of medicine to the greatest degree when communicating with patients. And the art of medicine depends on reading the room, reading our patients, reading patients' prior experiences and trying to predict what kind of information the patient wants . . . our experience leads to that art of medicine."* (HCP6) | *"They [HCPs] have to reflect on the patient's wishes about knowledge of the illness and progression, therefore, that would be one of the first questions they should ask - What and how much do you want to know at this point of your illness?"* (P78, caregiver) |
| Navigating PwALS and caregiver differences | *"A lot of times I tell them, 'It's [the patient's] wishes.' And I suppose it comes across to the spouse as I'm teaching them – but I teach them that they have to respect the patient wish."* (HCP3) | "*Family influences me the most . . . They want me to be here to see grandkids grow and be a part of their lives . . . but they also understand my desire to leave when I believe it's time*." (P80, PwALS) |
| **HCP challenges** | | |
| Feasibility within clinical contexts | *"I am worried that we might be creating expectations that just are not possible . . . to have a completely unrushed 'I'll go at your pace, I will hold off on this, and we'll do it the next time.' That may not be possible in some clinics."* (HCP13) | *"If the patient isn't ready but their physical status is declining, then the conversations should be initiated to say, "over the next two weeks we need to discuss this further." Give the patient time to think ahead and understand."* (P124, caregiver) |
| HCP boundaries | *"We've [clinical team] talked about drafting a formal communication guideline for patients, mostly from a boundary perspective. Like, 'Yes, there's emails. Yes, there's phone numbers for every team member. But no, you cannot expect a response within five minutes.'"* (HCP7) | *"Perhaps the most valuable is that the ALS Clinic ensures that I have the email addresses and phone numbers of all the specialists I see, and invites me to contact them at any time if I have questions."* (P4, PwALS) |
| Responsibility for difficult conversations | *"We cannot always respect people's communication preferences. It doesn't matter how much a patient doesn't want to talk about a feeding tube. At some point, you have to talk about a feeding tube, because you need an informed decision to plan for surgery."* (HCP15) | *"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 starts the conversation and the thought process with an option for follow up."* (P59, caregiver) |

HCP, healthcare professionals; PwALS, people living with amyotrophic lateral sclerosis.
† PwALS/caregiver data are drawn from Genuis et al. (2023) [4].

participants emphasized their skills and experience, the "art of medicine" (HCP6), as the foundation for enacting patient-centered communication. For example, patient-based evidence indicated that individualizing communication should include asking PwALS and caregivers about their communication preferences, whereas HCPs focused on discerning and moderating communication to accord with unspoken needs:

> "This person who said, 'I do not think you can ever get too much information.' Patients sometimes come in saying that. Then you start talking about the different drugs and you think, 'Oh, they actually don't want to know this . . . They're not absorbing any of this." (HCP7)

HCPs also shared difficult experiences navigating PwALS' and caregivers' different communication needs and perspectives on care, particularly as related to advance care planning. Patient-based evidence from both PwALS and caregivers, however, suggested that even if PwALS and caregiver views differed, caregivers supported the patient's perspective.

*Communication challenges*: In response to PwALS/caregivers' recommendations for health communication, HCPs discussed increasing patient volumes, the limited number of ALS specialists, and a need for work/life balance. They highlighted three communication challenges: feasibility within clinical contexts, maintaining HCP boundaries, and their requisite responsibility for initiating difficult conversations as needed.

HCP affirmation of recommendations originating from PwALS and caregivers suggests that these recommendations are fundamental to patient-centered ALS care. Findings, however, suggest a difference in perspective centered on how to enact patient-centered communication within the time constraints imposed by clinical practice and the management of an unpredictable, rapidly progressive disease. In the following paragraphs, we discuss asymmetry between HCP perspectives and patient-based evidence, and opportunities for alignment that will advance effective health communication.

Findings draw attention to asymmetry between HCP and PwALS/caregiver approaches for achieving patient-centered

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communication. Patient-based evidence suggested that health communication should be shaped by patients' explicit communication preferences.[4] HCP participants, however, viewed patient-centered communication as a primary manifestation of the "art of medicine," a physician dependant construct emphasizing biomedical knowledge and careful management of patient–physician relationships, including health communication. While this emphasis on physicians' role may suggest an unequal distribution of power within the clinical encounter, it is not necessarily illegitimate.[7] PwALS and caregivers are challenged by complex medical decision-making within short time frames.[1] Although information and peer support may be sought online, PwALS and caregivers rely on and value HCPS who will sensitively initiate and return to difficult topics as needed.[8]

Further, HCPs highlighted practical time pressures that challenged their ability to adopt patient-based recommendations. A lack of time during complex clinical encounters, for example, may limit accommodation of PwALS/caregiver preferences for receiving information.[7] This draws attention to physician well-being in a context of limited ALS specialists and increasing workloads. However, despite participants' legitimate concerns about work–life balance, findings highlight important questions about patient-based evidence and how patient needs might be addressed.[9]

Health communication is optimized when there is alignment between HCP and patient perspectives.[3] Findings suggest opportunities for fostering this alignment. HCP focus on relationship building early in the disease course will promote mutual understanding and trust. This will reduce relationship trauma caused by ineffective early communication [1] and facilitate the complex decision-making experienced by PwALS and caregivers. Explaining the roles of team members who are involved in ALS patient care may also facilitate understanding of available support and create opportunities to outline HCP and clinic capacities and boundaries. This may help shape PwALS/caregiver expectations.

HCPs should also foster discussion of how patients want to approach difficult topics and decision-making.[7] Although these discussions will be shaped by physician skills and the timely introduction of difficult topics, talking about communication preferences will help foster patients' sense of control within the therapeutic relationship – a critical feature of care for PwALS.[10] A sense of control may be achieved by adapting communication to the expressed preferences of the individual patient and/or by fostering patient trust in HCPs.[7] Finally, HCPs should promote connections with community resources, such as ALS health charities, to maximize access to support and resources.

This study has four primary limitations. Data were derived from a single FG conducted in a high-income country with a publicly funded health system. Second, although member checking affirmed findings, the feedback was limited. Third, the perspectives of expert ALS physicians may differ from HCPs working with PwALS and caregivers in the community. Finally, as with all qualitative research, findings may not be generalizable to other populations or jurisdictions.

This investigation contributes to patient-centered communication by promoting better understanding of how perspectives may differ between physicians and those affected by ALS, and by outlining opportunities to foster alignment. HCP participants emphasized clinician skills and experience as a basis for effective health communication. They highlighted time pressures that challenge communication in the context of an unpredictable, rapidly progressing disease. Although asymmetrical power within clinical encounters may be unavoidable given the medical expertise required for ALS clinical care, opportunities for alignment between physician and patient perspectives are possible. These include early relationship building to promote mutual trust and understanding of physicians' responsibility to introduce difficult discussions as needed, as well as enhancing patients' sense of control through the timely exploration of how PwALS and caregivers want to approach difficult topics and decision-making. Findings may have implications for other neuromuscular disease and/or seriously ill populations.

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