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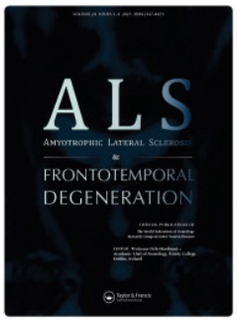

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RESEARCH ARTICLE

Amyotrophic lateral sclerosis (ALS) health charities are central to ALS care: perspectives of Canadians affected by ALS

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Abstract

Objective: Expert consensus guidelines recommend referral of people with amyotrophic lateral sclerosis (ALS) to ALS health charities for support. Limited research indicates that patients and families value interaction with these volunteer sector organizations. We investigated how patient support from Canadian ALS health charities (ALS Societies) is experienced by those affected by ALS, and whether patient-centered outcomes validate recommendations for referral. *Methods*: Data were drawn from the ALS Talk Project, an asynchronous online focus group study. Patients and family caregivers were recruited from regions across Canada. Seven groups met online for 14 weeks between January and July 2020. Seventy-eight participants made statements about ALS Societies. Data were qualitatively analyzed using directed content analysis and the constant-comparative approach. *Results*: Participants viewed ALS Societies as integral to the healthcare system. The Societies acted as patient navigators and filled perceived care gaps, including psychological support. They provided critical practical assistance, particularly equipment loans and peer support groups; comprehensive disease-related and real-life information; and personal connections. They facilitated knowledge of research, emerging therapies, and research opportunities. Delayed referral to ALS Society supports and information resources was a concern for some participants. *Conclusions*: ALS Societies provide patients with critical practical, informational, and emotional support and play an overarching role as patient/research navigators. Patient-centred outcomes support patient referral to ALS Societies. Communication about the services provided should be a standard component of clinical care, with choice of access left to individuals. Clinical conversations should be supplemented with information resources developed by these voluntary sector organizations.

Keywords: *Amyotrophic lateral sclerosis (ALS), health communication, organizations, nonprofit, patient navigation*

Introduction

Amyotrophic lateral sclerosis (ALS) is a fatal neurodegenerative disease characterized by rapid, progressive motor impairment, severe disability, and eventual respiratory failure (1). Median overall survival is 30 months after symptom onset with a 5–10% 10-year survival rate after diagnosis (2,3) and an incidence rate between 0.6 and 3.8 per 100,000 person-years (4). Disease modifying therapies provide modest benefit. Patient care interventions mitigate symptoms, leading to survival benefit, optimized function, and improved quality of life (2,5–7). Published guidance for communicating an ALS diagnosis recommends that health professionals refer patients and families to ALS health charities, also called patient organizations, for support (6,8,9). Evidence for such referrals is based on expert consensus, literature reviews, and/or extrapolation from other diseases (6). ALS health charities in Canada comprise the national *ALS Society of Canada* (10) and regional ALS Societies. We therefore refer to ALS health charities as *ALS Societies*.

These patient organizations are primarily represented in the literature as research funders and/or collaborators (11–13). Statements by ALS Societies indicate focus on research and advocacy,

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Table 1. Stated focus of selected ALS/MND health charities*.

ALS Health Charities	Stated focus	Website
ALS Society of Canada	"… we respond to the urgent unmet need for life-changing treatments by investing in high-quality research … and advocating for equitable, affordable and timely access to proven therapies. Responding to the tremendous need for current and credible ALS knowledge, awareness and education, we empower Canadians affected by ALS to navigate the current realities of ALS, be informed consumers of ALS information, and advocate effectively for change."	https://als.ca/
Motor Neurone Disease Association (England, Wales, and Northern Ireland)	"The MND Association focuses on improving access to care, research and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland."	https://www.mndassociation.org/
ALS Association (United States)	"By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure."	https://www.als.org/
Motor Neurone Disease Australia	"… the national peak body of state organizations that support those living with and impacted by Motor Neurone Disease (MND) … Our national and international networks help increase understanding of the disease and advocate for the needs of those affected. We fund world-class research for better treatments, improved care, and ultimately a cure."	https://www.mndaustralia.org.au/
MDN Scotland	"We deliver a number of vital services for people affected by Motor Neurone Disease in Scotland, including: Grants, Counseling, Benefits Advice and Advocacy. We also invest millions of pounds into ground-breaking MND research in Scotland and across the UK … we share best practice across the global MND community … We campaign and raise awareness to help improve the lives of people affected by MND"	https://www.mndscotland.org.uk/

*examples selected from English language websites.

as well as support for people living with ALS (PwALS) (Table 1). This latter focus – support given for the everyday management of ALS – has received very limited attention by researchers. For example, PwALS and family caregivers (collectively, people affected by ALS) rated neurologists more highly if they provided information about or referral to these volunteer sector organizations (14,15). Two small qualitative studies note valuable practical support received (16,17), with one study highlighting emotional support (17). In addition, a small number of articles suggest that effective delivery of care is enhanced by collaboration between multidisciplinary clinics and ALS Societies (18–20).

For this investigation we drew data from the ALS Talk Project (ALS Talk), an asynchronous online focus group (AOFG) study of health communication with PwALS and family caregivers. AOFGs accommodate physical disabilities including motor speech disorders (21–25), caregiving responsibilities (25,26), and/or geographical distance (25,27,28). AOFGs also facilitate investigation of both individual and shared experiences, providing opportunities for consensus development (29,30). Previously we drew on ALS Talk data to investigate the Covid-19 pandemic experiences of people affected by ALS (31). Here, we analyze unpublished data and investigate patient-centred outcomes from interaction with Canadian national and regional ALS Societies. PwALS and family caregivers are in the best position to validate consensus-based recommendations to connect PwALS with ALS Societies (6,8), and to improve understanding of how these organizations influence people affected by ALS. We ask: (1) How is support from ALS Societies for PwALS experienced and/or perceived by people affected by ALS? (2) Do patient-centred outcomes validate recommendations to refer PwALS to ALS Societies?

Table 2. Participants per ALS Talk asynchronous online focus group.

Province	People with ALS ($n = 51$)	Caregiver ($n = 49$)
Alberta	15	17
British Columbia	10	16
Ontario	17	16
Quebec/New Brunswick/ Nova Scotia	9	n/a

Methods

ALS Talk was approved by the University of Alberta's Research Ethics Board (Pro0008471). All participants provided informed consent. Research methods are described in greater detail elsewhere (31).

Participants and recruitment

ALS Talk sampling was purposive. To achieve a national sample, we recruited participants in Canadian provinces with the largest populations (British Columbia (BC), Alberta (AB), Ontario (ON), and Quebec (QC)), and in two smaller Atlantic provinces (New Brunswick (NB) and Nova Scotia (NS)). We partnered with ALS multidisciplinary clinic staff, the Canadian Neuromuscular Disease Registry (32), and national and/or regional ALS Societies to recruit participants.

Participants were over 18 years old, were able to communicate in English, and had a formal ALS diagnosis (33) or were a family member providing current or past care for someone formally diagnosed with ALS. PwALS/caregiver dyads were not required. We ran separate AOFGs for PwALS and family caregivers living in BC, AB, and ON. Due to low enrollment in QC, NB, and NS, we combined PwALS into a single AOFG and did not run a caregiver group. There were seven AOFGs in the study (Table 2).

Design and data collection

Participants interacted in moderated, AOFGs using the itracks™ platform (34), which offered text, video, and audio-based discussion in a threaded web forum structure. Participants accessed their AOFG using a web browser or the itracks™ app.

Discussion occurred over 14 weeks within each AOFG and focused on seven topics (Table 3). Topics were informed by a pilot project (35). They focused sequentially on communication throughout the ALS disease course, including, from first symptoms to ALS diagnosis, living with ALS changes, potential research participation, and end-of-life decisions. An optional topic was available in weeks 15–16. We introduced new topics biweekly and added weekly topic-specific questions to stimulate discussion. Discussion topics remained open from posting to the end of the study. We notified participants by email when we posted new questions. For each question, participants made an initial response before reading and responding, at their convenience, to other group members. All questions were optional. We encouraged participants to post at least weekly. There was no interaction between different AOFGs. Trained research associates (SKG, WL) actively moderated discussions, asking probing questions to encourage further input and group interaction. Participants shared their perspectives on the ALS Societies spontaneously as they discussed study topic areas and questions. Figure 1 provides an example of ALS Talk discussion questions that prompted discussion about patient support from ALS Societies. Where appropriate, moderators asked probing questions about participants' experiences with ALS Societies.

Table 3. Asynchronous online focus group discussion topics.

Topics	Weeks	Discussion description*
Intro		Register, 'welcome to the focus group', introductions
1	1-2	Communication around the time of ALS Diagnosis
2	3-4	Talking about ALS changes
3	5-6	Seeking information outside the healthcare system
4	7-8	Research participation; complementary and alternative therapies
5	9-10	Planning for future medical care
6	11-12	Conversations about death & dying
7	13-14	Improving ALS communication and support
Optional	15-16	Participation in observational research and data sharing

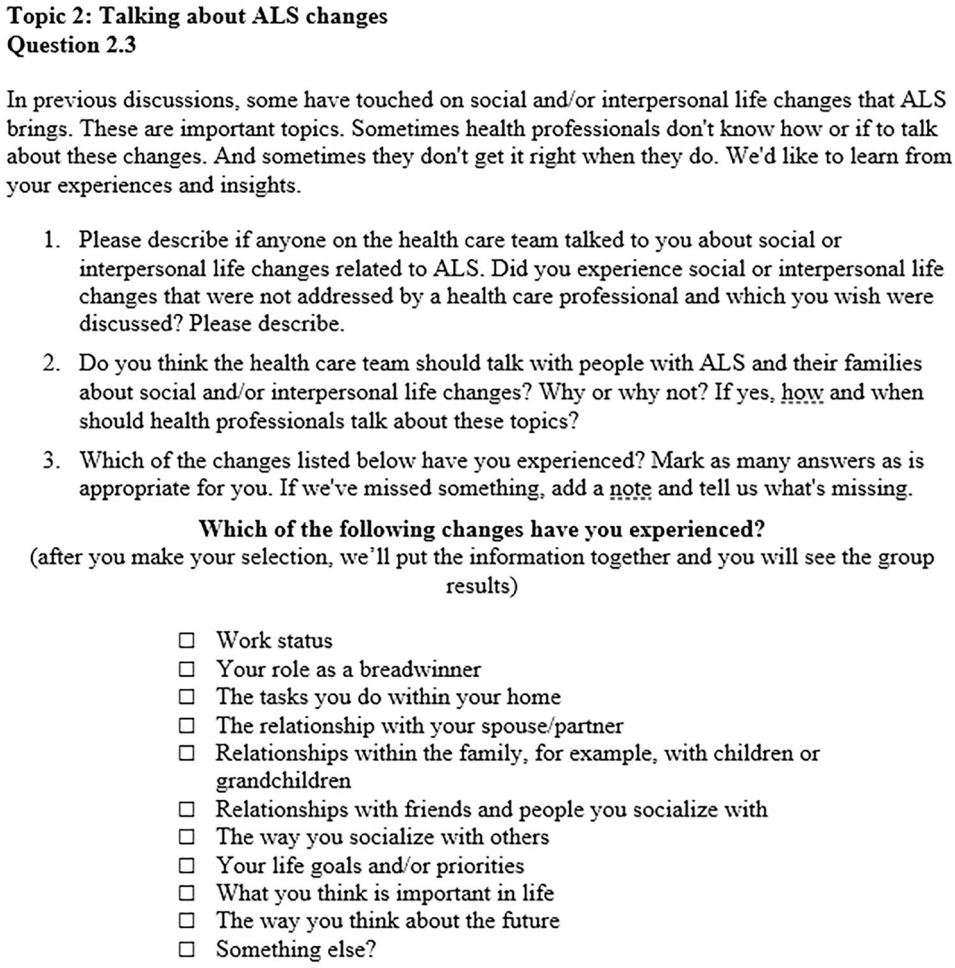
*We investigated participants' experiences with and perspectives on communication with health professionals about the discussion topics.

AOFGs started on January 7th, 2020 (AB, ON) and March 11th, 2020 (BC, QC/NB/NS). Data collection occurred between January and July 2020.

Analysis

itracks™ automatically created transcripts from text-based data. A professional transcriptionist transcribed video recordings. SKG verified transcripts. We used NVivo 12™ to facilitate data organization, identification of themes, and coding.

During initial data analysis, we identified statements about ALS Societies. We analyzed these using directed content analysis (36) and the constant-comparative approach (37). Following line-by-line reading, we developed a codebook representing primary themes (SKG, WL). An expert ALS clinician/researcher (WSJ) verified the codebook. Coders (MA, WL) received training on 10% of the ALS Societies data. During training, coders



Topic 2: Talking about ALS changes
Question 2.3

In previous discussions, some have touched on social and/or interpersonal life changes that ALS brings. These are important topics. Sometimes health professionals don't know how or if to talk about these changes. And sometimes they don't get it right when they do. We'd like to learn from your experiences and insights.

1. Please describe if anyone on the health care team talked to you about social or interpersonal life changes related to ALS. Did you experience social or interpersonal life changes that were not addressed by a health care professional and which you wish were discussed? Please describe.
2. Do you think the health care team should talk with people with ALS and their families about social and/or interpersonal life changes? Why or why not? If yes, how and when should health professionals talk about these topics?
3. Which of the changes listed below have you experienced? Mark as many answers as is appropriate for you. If we've missed something, add a note and tell us what's missing.

Which of the following changes have you experienced?
(after you make your selection, we'll put the information together and you will see the group results)

- ☐ Work status
- ☐ Your role as a breadwinner
- ☐ The tasks you do within your home
- ☐ The relationship with your spouse/partner
- ☐ Relationships within the family, for example, with children or grandchildren
- ☐ Relationships with friends and people you socialize with
- ☐ The way you socialize with others
- ☐ Your life goals and/or priorities
- ☐ What you think is important in life
- ☐ The way you think about the future
- ☐ Something else?

Figure 1. Example of ALS Talk questions prompting participant discussion of support from ALS Societies.

resolved discrepancies through discussion to consensus with input from SKG and WSJ. Coders independently coded another 10% of data to assess intercoder reliability, which achieved a Kappa coefficient of .95. MA coded the remaining 80% of the data.

Results

Discussion of ALS Societies occurred in all seven AOFGs and within all topic areas. The primary themes were: (1) ALS Societies are integral to the healthcare system, (2) ALS Societies provide critical practical and emotional support, and (3) ALS Societies connect people with ALS research. Participants were overwhelmingly positive about their experiences with ALS Societies, however some recommended improvements. Overall, the ALS Societies played a vital role in many participants' ALS journeys.

Demographics

Seventy-eight of one hundred ALS Talk participants made statements about ALS Societies. Participant characteristics are described in Table 4.

Theme 1: Integral to the healthcare system

Although participants understood that the ALS Societies are nonprofit, voluntary sector organizations and not licensed healthcare providers, they viewed the Societies as integral to the healthcare system. For example:

> *I consider the ALS Society to be part of the healthcare system … Their in-home visits by regional representatives and equipment loan pool, as well as their very complete and current information manual, puts them squarely in the health provider arena.* (P4, PwALS)

Participants commonly presented the ALS clinics and Societies as a unit providing ALS care. Similarly, on a national level, participants identified the ALS Society of Canada as closely associated with Health Canada in advocating for drug therapies ('Health Canada and the ALS society should be involved in getting these therapies' (P115, caregiver)). Participants also described the ALS Societies as health system navigators. They helped participants make sense of disease-related information received from health professionals. The ALS Societies also helped participants identify

Table 4. Participant characteristics.

Characteristics	ALS Talk Participants ($n = 100$)		**ALS Societies Participant subset** (78)	
Age				
18-29	3	3%	3	3.8%
30-39	4	4%	4	5.1%
40-49	14	14%	10	12.8%
50-59	25	25%	15	19.2%
60-69	31	31%	27	34.6%
70+	19	19%	17	21.8%
No response	4	4%	3	3.8%
Gender				
Female	57	57%	44	56.4%
Male	39	39%	32	41.0%
No response	4	4%	3	3.8%
Role				
Caregiver	49	49%	36	46.2%
PwALS	51	51%	43	55.1%
Residence				
Alberta	32	32%	25	32.1%
British Columbia	26	26%	22	28.2%
Ontario	33	33%	25	32.1%
Quebec/New Brunswick /Nova Scotia	9	9%	7	9.0%

Table 5. Theme 1: ALS societies are integral to health care.

Subthemes	Illustrative quotations
ALS clinic and Societies as a unit	• 'The Clinic and the Society have played a huge part in helping us anticipate what we will need as my husband's symptoms progress.' (P36, caregiver)
Health system navigators	• 'My husband and I had trouble navigating the support systems like homecare. The ALS society was helpful and now we have a homecare caseworker.' (P44, PwALS)
Filling gaps	• 'I think the neurologist who provided the initial diagnosis could have told me/us about anticipatory grief and suggested we get professional help to deal with it – telling us that the ALS Society has a Psychological Support Program.' (P130, caregiver)

missing information and the appropriate health professional to query. Moreover, the Societies facilitated understanding of the health system and access to health and community services. Finally, participants looked to the ALS Societies to fill perceived gaps in the healthcare system. In particular, participants highlighted a lack professional psychological and/or counseling services available through provincial health systems. For some participants, this gap was addressed by the ALS Societies, which provided information about accessing these services, direct referrals, and/or programmatic support (Table 5).

Theme 2: Practical and emotional support

ALS Societies were critical sources of practical and emotional support through their provision of supportive services, information, and personal connection (Table 6).

Supportive services

Participants discussed peer support groups and access to equipment loans. ALS Societies provided important emotional support, for example, support groups helped participants cope with the ALS diagnosis. Support groups also provided practical information about topics ranging from symptom management to home adaptations. Equipment loan programs provided a wide variety of free equipment that improved patients' quality of life and facilitated care in the home setting. Loans included eating and communication aids, as well as larger items such as wheelchairs and hospital beds. Participants highlighted proactive equipment advice and the timely delivery of needed equipment.

Information

Participants identified the ALS Societies as critical information sources and repositories. In particular, they highlighted the extensive and detailed information available in 'the ALS binder,' an information resource developed collaboratively by the ALS Society of Canada and regional ALS Societies. ALS clinics or local ALS Societies provided this manual to PwALS and families and it became a foundational information resource, an 'invaluable starting point' (P1, caregiver). Information from the Societies was also comprehensive, including both overarching and detailed information on a

Table 6. Theme 2: Practical and emotional support.

Subthemes	Illustrative quotations
Support Services	
Support groups	• *'Attending support groups was one of the best decisions we made. At the groups you hear the stories and get a lot of good ideas and perspective from others dealing with the same problems as you. There is a lot of comfort from the relationships you develop.' (P19, caregiver)*
Equipment loans	• *'The ALS Canada rep made sure that we got all of our equipment (wheelchair, commode, hospital bed, grab bar, suction machine for drooling, etc.) before it was needed, which was great.' (P84, caregiver)*
Information	
Foundational	• *'The Manual covers everything from the meaning of ALS to coping with ALS to disease Management to Equipment available thru ALS, and legal and financial issues.' (P61, PwALS)*
Comprehensive	• *'Early on we met with our regional manager from the ALS Society. She gave an overview of their services and equipment offerings. She also told us about the Direct Funding Program and suggested we apply early.' (P93, PwALS)*
Real-life	• *'I was totally surprised that they included symptoms I have dealt and not received any help with from any medical team. Some examples are frequent urgent urination, lack of ability to push out stools, feelings of being stuffed with food after eating not much, the need to hydrate to keep your mucous thin and why, laryngeal spasms, and many more.' (P114, PwALS)*
Personal connection	• *'The Society rep came to our house and sat with my mom to talk. It was nice to have that in-person contact, to know that we weren't alone. It really highlighted that ALS society was there to help.' (P54, caregiver)*

Table 7. Theme 3: Connecting people with research.

Subthemes	Illustrative quotations
Facilitating knowledge of research and emerging therapies	• *'The ALS Society is great with dissemination of the latest research outcomes – webinar on latest research available on their website, good source for updates.'* (P47, PwALS)
Communicating research opportunities	• *'ALS Society and the ALS Clinic should approach people personally to invite patients to participate based their interest in research studies.'* (P52, caregiver)
Fundraising and advocacy	• *'One of ALS Canada's biggest advocacy efforts is aiming to improve the [drug approval] process at both the federal and provincial levels.'* (P4, PwALS)

wide range of ALS-related topics. Moreover, Society representatives engaged in information-seeking on behalf of participants: 'Even if they didn't know something, they would help figure it out' (P29, PwALS). Finally, they were a primary source of real-life information about day-to-day life with ALS and the proactive steps needed to meet anticipated needs.

Personal connections

ALS Societies also established important personal connections and communicated empathetic understanding. Participants noted availability ('They're going to be available for you' (P11, PwALS)), continuity ('I received a call yesterday from the ALS Society checking how I was doing and what questions I had' (P67, PwALS)), individualized support ('The ALS Society [representative] arranged for a grief counselor to visit us' (P20, caregiver)) and honesty ('I appreciated her candor' (P24, PwALS)). Many meetings with Society representatives took place in participants' homes.

Theme 3: Connecting people with research

ALS Societies also informed participants about research (Table 7). Participants valued the Societies' role in facilitating knowledge of current research and emerging therapies. Most participants relied on the ALS Societies' websites, social media accounts, and/or newsletters for information about ALS research. Participants also viewed ALS Societies as authoritative sources of information about research participation. Participants were aware that PwALS may be ineligible for some research studies and that online information may be inaccurate. A number of participants stated that they wanted the ALS Societies to take an active role in directing PwALS to appropriate research opportunities.

Finally, participants were aware that the ALS Societies enabled research through fundraising and advocacy. Specifically, many participants expressed support for the Societies' fundraising activities. Due to the timing of data collection, some participants expressed concerns about the impact of the Covid-19 pandemic on in-person fundraising events, as well as the influence of economic uncertainty on donors. A small number of PwALS and family caregivers noted the advocacy role of ALS Societies. Participants wanted the ALS Societies to advocate to governments for research funding and the rapid approval of new ALS treatments. A few participants noted a public advocacy role. For example, 'The Society needs to educate the public about why they should care about the daily challenges of ALS' (P8,

caregiver). For many participants, the ALS Societies' annual 'Walk to end ALS' was an example of both fundraising and public advocacy.

Endorsements and recommendations

Participants were almost universally positive about the ALS Societies, for example: 'I can't say enough about how helpful they are' (P81, caregiver), and 'Our home is full of equipment on loan from the Society. It has saved us many thousands of dollars' (P33, PwALS). Although not prominent in our analysis, some participants expressed concerns about system barriers, specifically delayed referral to the ALS Societies by health professionals and delayed access the information resources provided by ALS Societies. One participant, for example, wrote: 'The time to get the ALS Society manual is the day of your diagnosis' (P114, PwALS). Some participants also wanted different support structures than those currently offered by their local ALS Society, especially related to peer support groups. A few participants expressed a preference for one-on-one rather than group support, and some expressed reservations about fundraising initiatives within support groups. For example, 'Fundraising distracts from the practical and emotional support' (P7, caregiver). Finally, some participants wanted further caregiver-focused support services: 'As great as the ALS Society is, I wish there was more for caregivers' (P54, caregiver).

Discussion

This investigation provides patient-centered evidence that validates recommendations to refer PwALS to ALS Societies. Findings support expert-based guidance (6,8,9) and research suggesting that delivery of ALS multidisciplinary care will be enhanced by coordination and collaboration between healthcare and voluntary sectors (19,20,38). We now discuss ALS Societies as integral partners with the healthcare sector in the delivery of care and services, information providers, and patient navigators.

While the benefits of ALS multidisciplinary care are well established (39–42), people affected by ALS need greater practical, social, informational, and psychological support (43). Our results indicate that ALS Societies play a central role in meeting these needs. Equipment loan programs and information resources fulfill critical, practical needs. Peer support groups provide practical insights and strategies for living with ALS, as well as important interaction with peers (44). Further, ALS Societies support some services that address psychological needs. However, our results suggest an ongoing need for psychological and/or counseling support (43,45–47) that is adapted to the specific needs of people affected by ALS (48,49).

The ALS Societies also play a central role as information providers. They reinforce information provided by health professionals, potentially increasing people's fluency with and acceptance of difficult medical information (50,51). They also supplement medical information by providing practical information focused on the day-to-day challenges of living with ALS. Moreover, the comprehensive 'ALS binder' facilitates information review and assimilation according to individual preferences and need. The prominence of this resource within our study supports other research indicating that written information helps people make sense of and cope with complex medical situations and challenges (52–56).

Finally, the ALS Societies play an overarching role as patient navigators (57–59). Although patient navigators are identified in the literature as individual health professionals or lay people with specific training (57,60–63) and most commonly associated with cancer care (64), our results indicate that Canadian ALS Societies perform the function of patient navigators for people affected by ALS. They provide disease and health system information (58,64–66); help people identify and overcome patient-level barriers to care (61,63–65,67); facilitate the integration of care between medical settings and community and social services (58,63,64,66,68); and provide individualized assistance (64,65,69,70). To this list of roles, our study adds research navigation, which is not identified as a role within the patient navigator literature. Our study participants looked to the ALS Societies for assistance in navigating the complexities of ALS research and emerging therapies. This patient-centred research role complements the role of ALS Societies as research funders and/or collaborators (11–13).

Limitations

Our study had practical and methodological limitations, despite robust sampling, research design, and methodological and interpretive rigor. First, participation in ALS Talk required internet access and the ability to interact online. ALS onset peaks at 65 years of age (1) and there is a well-documented age-related digital divide (71). This may have influenced our sample, with greater participation by people who are potentially younger and/or more comfortable with online interaction. Second, results primarily reflect experience with in-person support groups. Findings may not be applicable to online support groups. Third, our study was conducted in a high-income country (72) with publicly funded provincial health systems. This may have influenced the services and resources offered by the ALS Societies, as well as how these supports were experienced and perceived by participants. Fourth, among those reporting where they

heard about ALS Talk, about one third mentioned the ALS Societies. This may have biased the sample to include those with more favorable views. Finally, as with all qualitative research, results may not be generalizable to other populations, including non-English populations, and those in other jurisdictions.

Conclusions

This investigation suggests that ALS clinicians should be knowledgeable about the services and resources offered by ALS Societies or their equivalents. Communication about the suite of services and supports provided by ALS Societies should be a standard component of clinical care, leaving the choice of access to individuals. Health care providers should consider supplementing their clinical conversations with information resources developed by ALS Societies. Our participants highlighted the value of hard-copy information that could be consulted when and as needed. Directing people affected by ALS to online information provided by national ALS Societies (73–75) may provide a similar benefit.

Our results also have implications for policy. Canadian ALS Societies provide critical assistance in areas overlooked by or outside the mandate of the healthcare sector. This suggests that policy makers should reevaluate critical health services for PwALS. Support from governments and other health care funders may be warranted for services provided by the voluntary sector, especially since the absence of effective ALS therapies has positioned quality of life, including mental health, as central to patient care (1,6). The ongoing gap in psychological services requires the attention of policy makers and healthcare funders.

Our study represents a first examination of ALS Society patient support from the perspective of people affected by ALS. Further research is needed to evaluate ALS Society support for family caregivers. Research exploring the roles of similar organizations in other jurisdictions, including those with similar health systems, for example, most European countries, and those with blended private-public models, such as the United States, is also needed. Further research will enable a more nuanced understanding of health care provider perspectives on the value and role of ALS Societies, as well as the role of such organizations as information providers and patient/research navigators.

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Declaration of interest

No potential conflict of interest was reported by the author(s).

Data availability statement

The data that support the findings of this study are available from the corresponding author (SC) upon reasonable request.

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