

# What are the roles of carers in decision-making for amyotrophic lateral sclerosis multidisciplinary care?

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**Purpose:** Family carers of patients with amyotrophic lateral sclerosis (ALS) are presumed to have frequent involvement in decision-making for symptom management and quality of life. To better understand and improve decision-making, we investigated the range and extent of carer participation in decision-making. By focusing on the perspectives of ALS support carers, the study aimed to explore carer participation in decision-making, to identify carer roles, and determine the facilitators and barriers to carer participation in decision-making for ALS multidisciplinary care.

**Participants and methods:** An exploratory, in-depth study was conducted with eight carers of ALS patients from two specialized ALS multidisciplinary clinics. Carers participated in semi-structured interviews that were audio recorded and transcribed then coded and analyzed for emergent themes.

**Results:** Carers made a significant contribution to ALS decision-making. Their roles were: promoting the patient voice, promoting patient health literacy, and providing emotional support and logistical assistance. Facilitators of carer participation in decision-making were perceived to be: health professional endorsement of patients' decision-making style; access to credible information sources; evidence-based information from the ALS clinic, ALS support association, and health practitioners; supportive relationships with family and friends; spiritual faith; ease of contact with ALS services; and availability of physical and practical support for carers. Barriers to carer participation included: changes to patient communication and cognition; conflict between respect for patients' independence and patients' best interest; communication breakdown between patient, carer, and service providers; the confronting nature of disease information; credibility of Internet sites; carer coping strategies; lack of support for the carer; and the burden of care.

**Conclusion:** Carers enhance ALS patient-centered care through their participation in decision-making. They collaborate with patients and health professionals to form a decision-making triad within specialized multidisciplinary ALS clinical care. Nevertheless, health professional engagement with carers as collaborative partners is acknowledged to be a significant challenge.

**Keywords:** motor neuron disease, carer experience, patient-centered care, health literacy, health care triad, barriers and facilitators

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## Introduction

The presence of carers during medical appointments enhances patient-centered care and promotes patient autonomy in decision-making.<sup>1-4</sup> Carers, often family members or friends of the patient, participate in health care visits with patients who are elderly, in poor health, or who have high disease burden.<sup>2,5</sup> The value of carer involvement

in decision-making has been demonstrated in life-limiting conditions.<sup>3</sup> However, a recent review of decision-making in palliative care found limited evidence of carer participation.<sup>6</sup> While end-of-life studies reveal the difficulties surrounding end-stage care decisions, an examination of decision-making in progressive diseases highlights the challenges to decision-making throughout the disease trajectory. Accordingly, the study reported here focused on the life-limiting condition amyotrophic lateral sclerosis (ALS). Also known as motor neuron disease, ALS is a progressive multisystem disorder without a cure.<sup>7</sup> Treatments focus on symptom management and enhancement of patients' quality of life. Patients face deterioration of their physical and, potentially, cognitive and behavioral function.<sup>8</sup> Survival time averages between 2 and 3 years. Patients make numerous and complex decisions about symptom management and quality of life over the course of the disease.<sup>9,10</sup> Significant decisions include those concerning: gastrostomy placement for artificial nutrition and hydration,<sup>11</sup> use of invasive or noninvasive ventilation,<sup>12</sup> selection of equipment to assist mobility and communication,<sup>13,14</sup> modifications to the family home to accommodate the patient's changing physical needs,<sup>15</sup> and the transition to palliative care.<sup>16</sup> Due to the rapid progression of the disease, many symptom management options require discussion long before they are implemented.

To date, decision-making research in ALS has focused on patients' uptake of symptom management options and services.<sup>17,18</sup> Carer inclusion is recommended in specialized ALS multidisciplinary care,<sup>10,19</sup> but, to the best of our knowledge, there has been no investigation of the type and extent of carers' involvement in this model of care. Carer participation is shaped by the unique set of circumstances presented by ALS. As with cancer care, ALS patients frequently share decision-making with their carers and health professionals.<sup>20</sup> However, decision-making studies of ALS carer participation are limited to carers' perceptions of patient preferences, choices, and actions<sup>21,22</sup> or their involvement in surrogate decision-making.<sup>23</sup> Unlike in cancer care, ALS patients and carers are restricted to decisions about symptom management and quality of life, rather than choosing between curative and treatment options. The removal of hope from the decision-making equation means that models of decision-making used in cancer treatment are not directly applicable to ALS multidisciplinary clinical care. Likewise, the principles of end-stage and palliative management for cancer patients do not account for decision-making throughout the disease course.

"Patient-centered care" is the formation of partnerships between patients, families, and health professionals as a

responsive approach to the needs and values of patients.<sup>24</sup> This is enacted through patient-centered decision-making; that is, the exchange of information between patient and clinician and deliberation on available treatment choices, with the final decision resting in the hands of the patient.<sup>25</sup> Decision-making models rely on the participation of competent patients or their surrogates. Established models seek to improve the decision-making relationship between patients and health providers<sup>26</sup> but overlook the contribution of carers. ALS is known to have lasting impact on the carer's life throughout the disease course and after the patient's death.<sup>27,28</sup> Carers experience a high burden of care, which affects their physical, mental, and emotional health,<sup>29,30</sup> finances,<sup>31</sup> quality of life,<sup>32,33</sup> and social networks,<sup>34,35</sup> while adding stressors to the patient-carer relationship.<sup>36</sup>

As far as the authors are aware, the roles of carers within the ALS decision-making triad have not been evaluated and the carer viewpoint on ALS decision-making is unknown. Carer participation in ALS decisions provides an ideal case study of decision-making under difficult circumstances. By examining ALS carer involvement, we gain understanding of carer roles and the challenges to carer participation. An investigation of carer involvement in ALS decision-making provides a longitudinal view of decision-making under continually changing circumstances. Therefore, by focusing on the perspectives of ALS carers, this study aimed to explore carer participation in decision-making, identify carer roles, and determine the facilitators and barriers to carer participation in decision-making for ALS multidisciplinary care.

## Methods

By use of an exploratory study design, this investigation responds to the lack of research on the range and extent of carer roles and carer participation in ALS decision-making.<sup>37,38</sup> Semi-structured interviews allowed the interviewer to be responsive to each participant and their individual circumstances.<sup>9</sup>

## Participants and setting

Participants were recruited using convenience sampling.<sup>39</sup> Carers associated with two specialized ALS multidisciplinary clinics were invited to participate. One clinic was metropolitan based and the other was in a regional center. Both clinics offered access to neurology, allied health (comprising health and social care professionals), and palliative care services and were linked to gastroenterology and respiratory services. Members of the ALS support association attended both clinics. Twenty-four carers were provided with an information sheet

describing the project during clinic sessions. Carers who agreed to take part were later contacted to confirm their participation and enroll them into the study.

Eight carers participated, a response rate of 33%. The participant group presented a diverse range of carer relationships, circumstances, and experiences (Table 1). Five participants resided with their patient and two participants were caregivers for patients living in a residential care facility. The remaining carer and patient lived some distance apart, with the carer travelling regularly to provide support. All carers reported good health. The eight patients they cared for were in the advanced stages of ALS. Six patients experienced difficulty with both communication and mobility. One patient had normal communication skills and one remained independently mobile.

## Data collection and analysis

With reference to the literature, an interview guide (Table 2) was developed reporting carer participation in shared decision-making.<sup>21,40–42</sup> A list of topics was selected and reviewed for relevance to ALS care. The topics were further refined in consultation with two key informants<sup>43</sup> with clinical and research expertise in ALS, resulting in a list of ten open-ended questions. These questions were designed to elicit carer experiences with ALS decision-making and to determine their decision-making roles and the facilitators and barriers to their involvement. The help of facilitators was an aspect of carers' ALS decision-making experience that assisted their participation in decision-making, while barriers were those aspects that hindered their participation.

Data collection took place from May 2011 to May 2012. Human research ethics approvals were provided by the University of New South Wales and the participating health services. Six participants were interviewed in person, while

**Table 1** Carer demographics

Characteristic	Measure
Relationship to patient	Spouse = 5 Child = 2 Parent = 1
Duration of care (months)	Range = 6–96 Mean = 40
Age (years)	Range = 33–76 Mean = 56
Gender	Male = 3 Female = 5
Employment status	Working full time = 4 Working part time = 1 Not working/retired = 3

**Table 2** Interview guide

Theme	Question
Experience with ALS	1. Tell me about your experience when [patient name] was diagnosed.
Participation in decision-making	2. How did you access ALS services and information?
	3. What decisions have had to be made since the diagnosis?
	4. How were these decisions made?
	5. Who was involved?
Influences on decision-making	6. Has decision-making changed since the diagnosis?
	7. Do you feel that [patient name] has been capable of making these decisions?
	8. Has [patient name] ever wanted someone to make them on his/her behalf?
	9. What do you feel has influenced these decisions?
	10. What would you do differently?

**Abbreviation:** ALS, amyotrophic lateral sclerosis.

two chose to complete the interview questions by email. The researcher spent up to an hour with each participant, building rapport and explaining the study goals prior to the interview. The formal interviews lasted approximately 30 minutes and were audio recorded and transcribed. The transcripts were member checked;<sup>39</sup> that is, the participants were given a copy of their transcript to validate the transcription content. The validated transcripts were imported into NVivo 9 software (QSR International, Melbourne, Australia) in preparation for analysis. One author (AH) conducted the analysis, which was crosschecked by two coauthors (DG, PN) to reach agreement. As the numbers of sites and participants were low, data were pooled across the sites (presented further on).

The transcripts were analyzed using a systematic process of thematic analysis.<sup>44</sup> This enabled the identification of patterns within the data to reveal trends and relationships between the participants' statements.<sup>45</sup> Significant exemplars of the perspectives relating to carer experience in decision-making, the roles they filled, and the facilitators and barriers they perceived to their involvement in decision-making, were selected during the conceptual stage of the analysis. Each excerpt was assigned a code to summarize the meaning of the statement in context with other excerpts.

A total of 95 codes were identified from the data. Codes were then grouped by meaning, resulting in create twelve sub-themes. Each sub-theme was endorsed by between one and seven participants, containing between one and 34 statement references. For example, the sub-theme "relationship with health services" comprised 34 statements from

six participants. Sub-theme categories were further refined into four role themes and their associated facilitators and barriers. Exemplar quotes were selected from the participant statements to represent the themes. Quotes are presented by participant number to protect carer identities.

## Results

Respondents reported their participation in a range of decisions concerning patients' symptom management and quality of life. Decisions included: discussion of end-of-life preferences; palliative care placement; completion of advance care directives; uptake of home care packages; transition to residential care; insertion of percutaneous endoscopic gastrostomy (PEG); and selection of equipment to assist mobility, communication, and safety needs. Carers reported inclusion in information exchange and deliberation processes with the ALS multidisciplinary clinic health professionals. Respondents stated that they were involved in all aspects of their patient's care.

Four common carer roles emerged. Carers promoted the patient voice and patient health literacy, and provided emotional support and logistical assistance. Half of the carers reported participating in all four roles, while the remainder participated in three. All carers were involved in tasks to promote the patient voice and in offering emotional support. Commonality was evident in the facilitators to

carer participation in decision-making. Specific barriers were more individual in nature, but collectively conveyed the personal challenges surrounding the patient's declining condition (Table 3). The results are presented by carer role and the facilitators and barriers associated with that role. Barriers contain greater detail than facilitators, to reflect the way particular challenges are manifested in carers' personal experiences and circumstances.

## Promoting the patient voice

Carers promoted patients' own capacity for decision-making by supporting them to have their voices heard. Participants worked to promote the patient voice by: endorsing the patients' decision-making style, coaching patients through difficult decisions, and facilitating communication between patients and health service providers. Carers characterized patients as being independent, shared, or reliant decision-makers. No respondent had acted as a surrogate decision-maker. Three carers described the patients they cared for as independent decision-makers and viewed their role as supporting the patient to maintain their autonomy: "We've always kind of tried to leave it up to her, and help her and support her and maybe not even give advice, but just talk to her and say these are the options, and if she asks then help out" (C1).

Half of the carers took a shared approach to decision-making with the patient. For some, this meant deliberating

**Table 3** ALS carer decision-making roles and facilitators and barriers to carer participation in decision-making

Decision-making role	Carer task	Facilitators	Barriers
Promoting the patient voice	<ul style="list-style-type: none"> <li>• Support patient's decision-making style</li> <li>• Coach patient to make decisions</li> <li>• Facilitate communication between patient and health professional</li> </ul>	<ul style="list-style-type: none"> <li>• Health professional endorsement of patient decision-making style</li> </ul>	<ul style="list-style-type: none"> <li>• Changes to patient communication and cognition</li> <li>• Conflict between respect for patient's independence and best interests</li> <li>• Communication breakdown between patient, carer, and service providers</li> </ul>
Promoting patient health literacy	<ul style="list-style-type: none"> <li>• Source and synthesize information</li> <li>• Filter amount and content of information for patient or family</li> <li>• Provide information to patient</li> </ul>	<ul style="list-style-type: none"> <li>• Access to credible information sources</li> <li>• Evidence-based information from ALS clinic, ALS support association, health practitioners</li> </ul>	<ul style="list-style-type: none"> <li>• Confronting nature of disease information</li> <li>• Credibility of Internet sites</li> </ul>
Emotional support	<ul style="list-style-type: none"> <li>• Provide emotional support for discussion of patient's changing needs</li> </ul>	<ul style="list-style-type: none"> <li>• Supportive relationships with family and friends</li> <li>• Spiritual faith</li> </ul>	<ul style="list-style-type: none"> <li>• Carer coping strategies</li> <li>• Lack of support for carer</li> </ul>
Logistical assistance	<ul style="list-style-type: none"> <li>• Provide physical and practical assistance for patients to attend appointments</li> <li>• Coordinate services and appointments</li> </ul>	<ul style="list-style-type: none"> <li>• Ease of contact with ALS services</li> <li>• Physical and practical support for carer from family, friends, and health services</li> </ul>	<ul style="list-style-type: none"> <li>• Burden of care</li> </ul>

**Abbreviation:** ALS, amyotrophic lateral sclerosis.

the available choices with the patient until a decision, often consensus, was reached.

Other carers preferred to delineate final responsibility for the decision to the patient. They acted as a sounding board for the patient during the deliberation process. One patient was reported to be reliant on his carers for decision-making. A carer stated that family members would discuss forthcoming decisions with health professionals then present this information to the patient. The patient preferred that the carers made and implemented the final decision. In this case, the carers represented the patient's voice in discussion with health professionals, and then made a judgment based on the patient's best interest and their understanding of his wishes.

Three carers, from health care backgrounds, reported coaching patients who were reluctant to make decisions that were perceived to acknowledge their deteriorating condition. Respondents distinguished between supporting patient preferences and deciding what was in the best interests of the patient. They gave accounts of working with, and at times against, the wishes of the patient when the patient's safety was considered at risk. Examples included patients' compromised nutrition and hydration when gastrostomy was delayed and when patients resisted their increasing need for assistance and required the use of mobility equipment: "And then we got the right [walking frame]. He was assessed by the occupational therapist and physical therapist to see it was the right one. But he was denying. He was fighting for a long time. It wasn't easy" (C10).

Carers facilitated communication between patients and service providers. Six respondents assisted patients who were no longer able to use speech. One carer stated: "I tend to communicate with people via email because I get good responsiveness if I include everybody in one email, and everybody knows the same information, has the same picture" (C4).

Participants navigated a fine line between representing the patient voice and expressing their own views. This was made more challenging if the carer did not fully agree with the patient's choices. Promoting the patient voice during communication with health service providers required balancing respect for the patient's independence and choices with achieving the best possible health outcome.

#### Facilitators to promoting the patient voice

Carers' ability to promote the patient voice was facilitated when health professionals supported the patient's preferred decision-making style. Participants reported that patient

values and independence were respected by the ALS health professionals in discussions for care planning. Carers perceived that patient-centered care resulted when health professionals were able to accommodate into their care planning patients' difficulty accepting change in their condition.

#### Barriers to promoting the patient voice

Participants reported aspects of ALS that affected their relationship with the patient and challenged their capacity to promote the patient voice. These were: communication with patients who had lost their ability to speak; changes to the patient's cognition; and communication breakdown between the patient, carer and health service providers. Carers considered that communication difficulties and the patient's lack of insight placed strain on their relationship. This in turn increased the patient's reliance on the carer for support. Respondents perceived that, at times, patients resented this loss of independence.

Respecting the patient's independence and right to make decisions sometimes came at a cost. Barriers arose when supporting the patient's decision-making independence clashed with the best interests of the patient: "I could have overridden everyone and got guardianship and got him admitted to a nursing home. But this would mean that I am taking everything away from him. He has lost so much and I wanted him to make the decision" (C8).

One carer expressed concern about a lack of health professional support when the needs of the patient clashed with the best interests of the family. Others reported breakdown in communication between the patient, carer, and health services and between health service providers. Communication barriers resulted in delays to receiving equipment when services were unable to respond promptly to patients' concerns. Three carers identified difficulties communicating with health service providers in times of urgent need: "That offer of support was always there, and we felt really good about it. But then, when specifically we needed stuff, and needed the stuff quite urgently, it was lacking" (C1).

Promoting the patient voice to support patients' decision-making capacity was also hindered when service providers were unable to respond within the short timeframes imposed by ALS deterioration.

#### Promoting patient health literacy

"Health literacy support" was considered the sourcing, collation, and provision of information about ALS and associated health and community services to support and develop the decision-making capacity of the patient.

Participants identified seeking information for their own needs and on behalf of the patient. Carers cited information sources as being the Internet, the specialized ALS multidisciplinary clinic, the ALS support association, and medical practitioners. Two respondents from health care backgrounds reported consulting colleagues as an additional source of information. Participants reported frequently accessing the Internet to further their understanding of ALS. Half of the carers recounted investigating the disease more frequently than the patient. Two carers described researching ALS then filtering that information before providing it to the patient. Patients who did not wish to seek information for themselves relied on the carer to act as a conduit for disease-related information: “He didn’t want to know anything about it. So I’d wait until he’d go to bed, and then I get on the computer and look up the Internet” (C16). One carer, from a health professional background and familiar with the course of ALS, also described filtering prognostic information to protect family members. The carer sought to shield the family from the inevitable reality of the ALS disease trajectory.

It was difficult to discuss my knowledge within the family, because I felt it important for the well-being of some other family members who didn’t know what I knew, not to provide too much information ... I needed to seek my support externally from the family in an attempt to protect the family from the dire things that I knew were going to happen. (C4)

Two carers, both children of patients, relied on credible information sources to anticipate their parents’ prospective care needs. They emphasized the need to look ahead and plan for the next deterioration: “We were always very aware of what was going to happen and what was coming up, and we were trying to prepare for that before it happened” (C1). Evidence-based information from the specialized ALS clinic and the ALS support association, as well as research from their own initiative, assisted their planning.

### Health literacy facilitators

Health literacy was facilitated by ready access to credible information sources that carers could access to support patient decision-making. Carers were satisfied with the expert information they received from the clinic and the ALS support association. There were no information gaps identified.

### Health literacy barriers

Barriers to carer participation in health literacy support for decision-making arose from carers’ reactions to

Internet-based information. Several carers indicated discomfort with the confronting nature of disease information they found and the credibility of some information was called into question. Carers gave accounts of needing to discern between credible and non-credible websites. Non-credible sites offering false cures and treatments became a source of distress for carers. For example, one participant explained: “[The] Internet is a very good thing for everything these days but [it] can make so much damage” (C10). This respondent explained she had ceased seeking information from the Internet to preserve her sense of well-being. False hopes raised by non-credible information led to carers’ reluctance to invest further in health literacy activity: “I don’t want to go through this whole stuff ... going from having some hope [and] going to the very bottom, it’s too much. It’s better not to go” (C10). This carer now relied on the ALS clinic to provide updates on the disease and treatments as they became available. She preferred to receive, rather than seek, information from credible sources.

## Emotional support

Participants explained the emotional support they provided to patients for decision-making. Emotional support was given in response to patients’ reactions to physical and cognitive changes. Three carers reported helping patients to deal with their emotions following the onset of deterioration. Emotional support facilitated patient decision-making by allowing patients to discuss their changing needs when they were ready to do so. One carer described his mother’s response to physical change as a cycle of deterioration, emotional reaction, and adjustment:

It’s very much in steps the whole way along. We’d go well for a couple of weeks, and then ... something would deteriorate and she wouldn’t be able to cope with something and then 2, 3 days of just pure emotional outbursts ... Then she would accept it and adjust and we’d plateau again, until the next one. (C1)

Once patients had adjusted to the changes, they were able to discuss ways to manage their new limitations.

### Emotional support facilitators

Respondents identified two sources of support that facilitated their participation in decision-making. The first was the personal support they received to enable them to provide support to the patient. Carers drew support from their relationships with family members and friends. The second was the spiritual beliefs of carers. Two participants viewed

spiritual faith as contributing to their well-being. None reported accessing formal carer support services, such as counseling, available to them through the specialized ALS multidisciplinary clinics or the ALS support association.

### Emotional support barriers

Barriers to carer provision of emotional support for decision-making included the carer's choice of coping strategy and perceived lack of support. Many carers reported feelings of sadness, anger, and anxiety about the future. Participants described individual mechanisms for dealing with their situation. Some coping strategies may have created barriers to timely decision-making. These included carers' avoidance of the prognosis, by preferring to get on with life and not dwell on the future. The majority of spouse carers expressed the need to take one day at a time and not look too far ahead:

Well, typical Australian male, you sort of bury your head in the sand a bit and think of other things. But I never used to get depressed of a morning, but sometimes when I wake up now, I think, "Why don't I feel real flash?" ... You kind of think, it's not fair. Not for me, just not fair for her. So I sort of deal with it by just trying [to stay] the same. I think initially I dealt with it by saying I didn't believe it, and now I think, well she's changing, but it's very slow. (C6)

Carers preferred to address the patients' needs as they arose. Participants described early attempts by health professionals to address end-of-life planning as confrontational or inappropriate.

Two carers revealed conflict between themselves and patients that exacerbated the carers' sense of burden and loss of independence. One carer reported ongoing tension between herself, the patient, and the patient's extended family, which resulted in delays to decisions about residential care placement and PEG insertion. Participants perceived a gap between the emotional support they provided and the support they received.

### Logistical assistance

The fourth role carers undertook in decision-making was the provision of logistical support, which comprised physical, practical, and organizational assistance. Carers engaged with a range of health providers and facilitated interaction between themselves, the patient, and health professionals. Services included the specialized ALS multidisciplinary clinic, local allied health services, palliative care teams, care package providers, general practitioners, and residential care staff. Three-quarters of participants routinely accompanied

the patient to their specialized ALS clinic appointments and gave physical and practical assistance to ensure the patient attended and participated in clinic appointments. One participant commented:

The clinic here is very good. The thing that I liked about it is that you see all the different disciplines on the one day, so it's not five different visits to the hospital. Getting him out of the house is not easy. It's much easier to take a day off; it takes about 2 to 3 hours to get him out of the house. So this is much easier. (C8)

Carers coordinated patients' appointments with service providers. Respondents conveyed the importance of knowing which health professionals to contact when needs arose. They attempted to synchronize home-based services with hospital and clinic appointments in already busy schedules. Patients' need for logistical support increased as the disease progressed. Coordinating an increasing number of care services became more challenging as patients' mobility deteriorated. Two carers of patients in facility-based care reported greater responsibility for service coordination once the patient transitioned into care, particularly as the care facilities had limited experience of the needs of ALS patients. Cohabiting carers did not report encountering this issue. The two participants identified communicating with and coordinating a range of care providers as a significant part of the logistical assistance they provided. While not providing daily personal care, these carers continued to have levels of involvement similar to those of the other participants in all other aspects of care. Service providers changed with the transition from home to facility-based care and carers recounted bridging communication gaps between new and established service providers:

I think when he first went into the nursing home, it was working out the logistics of "who provides what" was difficult, because [the clinic] could provide him with equipment while he was at home, but not when he was in the nursing home. And then the ALS support association had to take over at that point, so the logistics of that stuff was difficult, but we sorted it. (C4)

The logistical support role thus involved extensive liaison between services and professionals. Carers worked to reduce disruptions and facilitate ongoing care.

### Logistical assistance facilitators

Six carers reported that their role was facilitated by ease of contact with health professional services that offered

information and advice on decisions under consideration. Carers were satisfied with the contact they received from health professional services. One participant identified the assistance she received from funded care packages as support that allowed her to continue working. Five carers received support from family members, friends, and health providers. This included physical assistance with patient care, such as washing and dressing, and practical assistance, such as meal preparation.

### Logistical assistance barriers

Carers identified the greatest challenge to providing logistical support as the burden of care they experienced. This had a negative impact on their capacity to participate in decision-making. The sense of burden was increased by limitations to the support the carer received for physical and practical assistance with the patient, respite care, and assistance with childcare. The level of burden experienced was unique to each participant's life situation and the needs of the patient. One carer identified a prolonged burden for a patient who lived in an incapacitated state for many years. The sense of burden was exacerbated when carers lacked support from the extended family or friends. Several carers reported difficulties balancing their caregiving responsibilities with maintaining full-time employment or caring for children and grandchildren. Work and family commitments influenced carers' availability to participate in activities that offered support to the carer, such as carer respite, or that supported decision-making, such as ALS support association information sessions.

Carers who lacked support from extended family or friends reported prioritizing the patients' needs over their other commitments. One carer described loss of control over many aspects of their life, including career development, finances, relationships with children, and socialization with friends: "I was having to find people to look after the kids; I was just on the run. I had no time to think" (C8). Tension in the patient-carer relationship and the frantic nature of caring for both patient and children affected the carer's capacity for prolonged deliberation of symptom management options with the patient. As a result, carers reported that decisions were delayed until they were better able to participate.

## Discussion

This study has shown that the roles of ALS carers extend beyond the physical, emotional, and logistical support found in other health care settings.<sup>3,4</sup> Carers in this study reported acting as conduits of information between patient and health

professionals and facilitating the deliberation of treatment options, a process that occurs outside the timeframe of a clinical appointment.<sup>3,46</sup> Our findings confirm the value of carer participation in patient decision-making found in cancer and palliative care settings.<sup>3,47,48</sup> However, the trajectory of ALS creates an intense and dynamic decision-making environment that differs from other terminal conditions. The role of the carer is uniquely shaped by the ALS disease and care circumstances.

The complexities of ALS and the challenges to timely decision-making for symptom management and quality of life necessitate a decision-making triad for ALS patients supported by carers and health professionals. Carers act not only as a support person for the patient, but also as a decision-making partner and care collaborator. This confirms findings of studies of older patients, in which carers promoted patient autonomy in decision-making through their active engagement to facilitate communication between doctor and patient.<sup>4</sup> The extent of the carer's participation in decision-making was determined by the patient's level of independence and autonomy, their preferred decision-making style, and their capacity to make decisions. Formal and informal systems of support influenced carer participation in the decision-making triad.<sup>34,49</sup>

This investigation points to gaps in our understanding of the roles carers fill within the broader field of ALS care giving. Health professionals have viewed carers as supporters and gatekeepers of the patient,<sup>50</sup> or, in some situations, as copatients.<sup>51</sup> However, one cancer study indicates that carers act as surrogate care managers in the absence of multidisciplinary care, bridging service information and coordination gaps to provide long-term care for patients.<sup>48</sup> ALS carers accessing nonspecialist services may also find themselves in this position.<sup>52</sup>

Further, this research offers a more nuanced account of health literacy support for patient-centered decision-making in ALS specifically and in end-of-life care more generally. Carers sought disease and service information more frequently than their patients<sup>53</sup> and then strove to assess, synthesize, and filter that information not only for the patient but also to other family members. These aspects of assessing, synthesizing, and filtering broaden our understanding of health literacy for decision-making. Definitions of "health literacy" imply these aspects<sup>54</sup> but do not appear to make them explicit. Differences between spouse and non-spouse carers were evident with respect to information seeking and forward planning. Carers who were children of patients sought disease trajectory information with which to plan



their parents' future care, while spouse carers preferred to take one day at a time.<sup>55</sup> These findings may assist health professionals in identifying carers' information needs and in planning a collaborative approach to decision-making.

## Impact of barriers

Diverse barriers to carer participation in decision-making reflected individual characteristics of the patient–carer relationship and the impact of ALS on the family as a whole.<sup>56</sup> Challenges arose from tension in relationships with the patient<sup>36,57</sup> and their extended family,<sup>31</sup> limited assistance for care giving,<sup>30</sup> and breakdowns in communication with health service providers.

One coping method carers used to deal with their situation may have hindered timely decision-making. Carers' desire to avoid dwelling on the future<sup>58,59</sup> has negative consequences for decisions that require advance planning.<sup>50,60</sup> The rapid progress of ALS combined with time-limited choices, such as PEG insertion, create a need for proactive decision-making.<sup>52,61</sup> Conflicts of interest between patients and carers<sup>59</sup> placed carers in the difficult position of prioritizing the patients' needs above their own and family and work commitments.<sup>52</sup> In addition, carers also found themselves in conflict about their respect for patient autonomy and independence versus the effective and timely decision-making advised by health professionals. Carers experienced the consequences of late decisions, such as difficulty maintaining patients' weight if PEG insertion was delayed, and so were caught in a double bind – they could either respect patient autonomy and live with poor health consequences or seek to override patient autonomy for improved quality, and possible length, of life.

Carer roles change as patients' needs become more complex.<sup>52</sup> Carers adjust to patients' continually changing needs or, in the case of slower disease progression, maintain support for heavily incapacitated patients over several years. Recent research suggests that carers view the cognitive and behavioral changes many patients experience as more stressful than the burden of physical care.<sup>62</sup> The impact of patients' cognitive and behavioral deterioration on ALS decision-making remains undefined<sup>50,63</sup> and thus represents avenues for further investigation.

## Clinical implications

Health professionals face significant challenges to directly engaging carers as collaborative partners in decision-making. Demanding clinic schedules and limited resources<sup>50</sup> combined with the physical and cognitive impact on ALS patients create

pressures on clinicians to optimize the time patients spend in a clinic appointment. Forming a decision-making partnership with carers adds to the clinical load and not all carers have the desire or capacity to participate in decision-making. For those who do, our findings suggest that carers may potentially take on roles that support and extend the work of clinicians.

The clinicians' duty of care is to the patient; nevertheless, the reality is that clinicians negotiate each case individually to identify and facilitate the carer's role and level of participation in patient decision-making. Conversely, many patients have carers who do not routinely attend clinic appointments but who are involved in many aspects of decision-making with the patient. Establishing a decision-making triad with carers presents ongoing challenges to the way health professionals work with carers and families<sup>56</sup> as well as how they view the roles that carers fill in patient-centered care. This creates opportunity to explore ways to improve patient decision-making in ALS care.

## Study limitations

This study required an exploratory approach and featured a small number of sites and participants. Small participant numbers and lower rates of response are commonly reported in studies examining aspects of end-of-life and ALS carer experience, due to the intense and emotionally charged commitment of caring.<sup>34,49,55,64</sup> While the proportions of spouse and non-spouse carers reflect those of larger international studies,<sup>65</sup> generalization to other settings needs consideration. Further studies to quantify carer participation may compliment this research. The qualitative methodology revealed that carers make a valuable and influential contribution to patient participation in decision-making. Large-scale studies may be useful to measure the influence of carer participation in decision-making in terms of patient choices, outcomes, and the timing of decisions. Comparative studies of accompanied and unaccompanied patients may reveal the effectiveness, challenges, and limitations of the ALS decision-making triad.

## Conclusion

Our findings raise the question of what constitutes patient-centered care in ALS multidisciplinary clinical settings. The decision-making triad highlights the complex clinical and emotional work that ALS health professionals perform. Negotiating with carers as well as patients increases the complexity of care, as the carer is engaged as much as the patient in the clinical process. This is a significant challenge for and an onerous burden on health professionals

in demanding health service environments. To achieve patient-centered ALS care, we need to find ways to accomplish this effectively.

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The authors report no conflicts of interest in this work. The authors alone are responsible for the content and writing of this paper.

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