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Original Article

Nurses' Experiences of End-of-Life Care in Amyotrophic Lateral Sclerosis: A Qualitative Multiple-Case Study

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Abstract

Amyotrophic lateral sclerosis (ALS) remains an incurable and ultimately fatal condition that frequently involves a heavy symptom load during the terminal phase. Relatively little is currently known regarding nurses' lived experiences in this setting. To investigate the experiences of nurses who provide care to individuals with ALS during the end-of-life period. Semi-structured individual interviews were carried out between February and August 2022 with nurses practicing in Quebec, Canada. All participants had cared for at least one person with ALS at the end of life within the previous 12 months. Data were examined using content analysis, including within-case and cross-case analyses, as well as comparative analyses based on the participants' practice setting that defined the cases: (1) home care, (2) hospital, and (3) palliative care home.

A total of 24 nurses took part in the study: 9 worked in home care, 8 in hospitals, and 7 in palliative care homes. Five primary themes emerged: (1) recognizing the end-of-life phase, (2) communication challenges, (3) supporting the desire for control, (4) accompanying patients within a culture of fighting the disease, and (5) the degree of care required. A sixth theme was incorporated to capture the nurses' expressed need to enhance the care they provide to patients living with ALS at the end of life. Although the nurses' experiences differed depending on the care setting, the findings highlight an urgent requirement for improved education and, most importantly, greater resources when supporting a person with ALS at the end of life. Future studies should examine the perspectives of other healthcare professionals and evaluate interventions aimed at enhancing the quality of life and end-of-life care for individuals living with ALS.

Keywords: Case study, End-of-life, Lou Gehrig's disease, Nursing, Palliative care, Qualitative research

Introduction

Amyotrophic lateral sclerosis (ALS), a progressive neurodegenerative disorder that targets motor neurons, manifests through symptoms that impair motor function and respiratory capacity [1]. According to a 2020 meta-analysis, the average global prevalence is 4.4 per 100,000 individuals, with rates rising consistently since 1959 [2]. Although substantial research efforts continue in pursuit of disease-modifying therapies, ALS is still considered incurable, with a median survival time of approximately 36 months from the appearance of initial symptoms [3].

During the end-of-life stage, individuals with ALS commonly experience respiratory distress, profound swallowing difficulties, excessive salivation, speech impairment, and extensive paralysis [1]. This intense symptom burden, which significantly compromises the quality of the final days, demands nearly continuous assistance from family members and healthcare professionals, particularly nurses.

The sole published study to specifically examine nurses' viewpoints on end-of-life care for people with ALS used a mailed questionnaire to investigate the challenges Japanese nurses face when delivering home care to this group

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[4]. The main difficulties reported involved communication barriers stemming from worsening dysarthria, as well as the struggle of both the patient and family to adapt to the disease's swift progression.

Given that nurses form a vital part of the multidisciplinary team responsible for end-of-life care, gaining deeper insight into their experiences when supporting people with ALS is crucial. This includes understanding their personal needs, which must be addressed to elevate the standard of care delivered.

This study aimed to examine the experiences of nurses caring for individuals with ALS at the end of life. The specific objectives were:

1. To examine the features of nursing care provided to people with ALS during the end-of-life period.
2. To determine the support needs of nurses to deliver high-quality care to people with ALS at the end of life.

It is important to clarify that, although palliative care plays a key role in the management of ALS from the point of diagnosis onward [5, 6], the present research concentrates exclusively on end-of-life care. In this study, end-of-life care is defined as the care delivered within the final 3 months before death.

Theoretical framework

This investigation relies on the palliative care nursing self-competence scale created by Desbiens and Fillion [7]. The scale comprises 10 distinct domains that outline the competencies required for palliative care nursing, as listed in **Table 1**.

Table 1. Domains of the palliative care nursing self-competence scale [7].

No.	Domain
1	Physical needs – pain management
2	Physical needs – management of other symptoms
3	Psychological needs and support
4	Social needs and relationships
5	Spiritual and existential needs
6	Needs related to functional ability and daily living
7	Ethical and legal considerations
8	Interprofessional teamwork and communication
9	Personal and professional challenges in nursing care
10	Care provided at the end of life

In the current study, the two domains concerning physical needs were combined, and the domains covering psychological, social, and spiritual needs were merged into a single category. This adjustment reduced the total to seven domains. The framework served as a foundation for shaping the study's objectives, designing the interview questions, and guiding the data analysis.

Materials and Methods

The research adopted a qualitative multiple-case study approach recommended by Stake [8]. This design is anchored in a constructivist perspective [9] because such case studies facilitate a comprehensive investigation of intricate phenomena that are shaped and interpreted through their specific contexts. For this project, the cases were established based on nurses' practice environments, as workplace settings play a major role in determining how care is delivered and organized. The three cases each consisted of several nurses working in one of the three primary settings where people with ALS most often die, as identified by Chhetri *et al.* [10] and Goutman *et al.* [11]: (1) home care, (2) hospital, and (3) palliative care home. In Quebec, Canada, palliative care homes—also known in some contexts as hospices—are usually community-run facilities dedicated solely to delivering end-of-life care, comparable to specialized palliative units found in hospitals or long-term care institutions [12]. Reporting of the study was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) [13].

Sample

Consistent with Stake's [14] guidance on case study research, purposive sampling was applied to select nurses from diverse work locations. The inclusion criteria appear in **Table 2**.

Table 2. Inclusion criteria.

No.	Criterion
1	Having delivered care to at least one person with amyotrophic lateral sclerosis (ALS) during end-of-life in the previous 12 months
2	Being a registered nurse practicing in Quebec, Canada
3	Working within a hospital setting, home care services, or a palliative care facility

ALS, amyotrophic lateral sclerosis.

Recruitment occurred from February to August 2022. A recruitment poster was circulated through social media channels on the websites and pages of Quebec organizations focused on palliative care, end-of-life support, or nursing practice. Targeted paid ads on Facebook using the identical poster were also employed. In addition, a snowball sampling technique helped expand the pool of participants. Each nurse who completed the study received CAN$20 in compensation.

Data collection

Participants first completed a sociodemographic questionnaire that collected information about their personal background and professional working conditions. The interviewer kept a reflective journal throughout the process, noting methodological decisions, emerging ideas, and personal observations after each session. Data gathering involved one semi-structured individual interview per participant. This interview style provided enough structure to cover essential topics while remaining open enough for participants to introduce new or unexpected themes [15]. On average, each interview lasted 49 minutes. All sessions were audio-recorded and then transcribed in full, with personal identifiers removed to ensure confidentiality. No other individuals were present besides the interviewer and the participant. The interviews were led by the first author, who brought previous experience conducting qualitative interviews. She identifies as a cisgender woman. Three of the participants had an existing professional acquaintance with the interviewer before the study.

An interview guide (Supplementary Material A) directed the conversations. Given that participants were recruited across the entire province and the study took place amid an ongoing, shifting pandemic, all interviews were conducted online. To support analysis of variations linked to participants' roles (palliative care versus non-palliative care positions) within each case, each participant's code was assigned a suffix indicating their specific position type.

Data analysis

A descriptive review of the sociodemographic information was performed. Data collected from the semi-structured interviews were examined using NVivo 1.0 software, applying the content analysis approach proposed by Miles *et al*. [16]. This method follows an iterative procedure that includes two coding cycles. During the first cycle, each portion of the transcribed text is assigned a code reflecting a specific unit of meaning, after which these codes are grouped under one of the seven domains of the Palliative Care Nursing Self-Competence Scale [7]. In the second cycle, pattern coding is conducted to condense and organize the codes from the first cycle into broader conceptual categories.

This procedure enabled both within-case and across-case examinations, along with comparisons based on the participants' professional roles, in keeping with the multiple-case study framework [8]. The principal investigator directed the analytical work. A summary matrix was then prepared and discussed with the full research team to debate interpretations, sharpen the themes, and ensure they were clear and coherent.

Results and Discussion

A total of 24 nurses participated in the study: 9 from home care services, 8 from hospital settings, and 7 from palliative care residences. Their average age was 41 years (range 26–64 years). All participants worked day or evening shifts, and half held specialized palliative care positions. Regarding their most recent educational qualifications, nurses in palliative care homes generally had higher levels of training: most held a graduate credential (microcredential), and none had a college diploma as their final qualification — unlike nurses in the other two environments. The sociodemographic profile is displayed in **Table 3**. Further sociodemographic details are available in Supplementary Material B. Recruitment stopped once the team determined that the themes had achieved sufficient clarity and depth. All quoted passages have been translated from French.

Table 3. Sociodemographic characteristics.

Characteristics	Home care (%) (n = 9)	Hospital (%) (n = 8)	Palliative care home (%) (n = 7)	Total (%) (n = 24)
		Age (years)		
25–35	3	1	2	6
36–45	5	4	2	11
46–55	1	1	3	5
56–65	0	2	0	2
		Gender		
Female	8	7	5	20
Male	1	1	2	4
		Position type		
Palliative	4	1	7	12
Non-palliative	5	7	0	12

Last completed degree [a]				
College	3	5	0	8
Undergraduate	6	3	3	12
Graduate (microcredentials)	0	0	4	4
Shift				
Day	9	3	4	16
Evening	0	4	3	7
Rotation (day-evening)	0	1	0	1
Estimated level of competence in end-of-life care				
Excellent	1	4	5	10
Good	5	3	2	10
Moderate	3	1	0	4
Low	0	0	0	0
Estimated level of competence in end-of-life care specific to ALS				
Excellent	0	1	1	2
Good	3	3	2	8
Moderate	4	3	4	11
Low	2	1	0	3

Abbreviation: ALS = amyotrophic lateral sclerosis.

[a] In Quebec, Canada, nursing practice requires either a technical college diploma or a university undergraduate degree.

Five main common themes emerged: (1) recognizing the end-of-life phase, (2) communication difficulties, (3) supporting the desire for control, (4) accompanying patients within a culture of fighting the disease, and (5) the overall extent of care needs. Differences emerged within the relevant themes. A sixth theme was added to document the specific needs nurses expressed for improving end-of-life care for patients living with ALS.

Recognizing the end-of-life: 'now, we're nearing the end'

Participants described challenges in determining when the terminal phase began. This uncertainty made it harder to assist people with ALS and their families, particularly when important care decisions had to be made or when questions about the patient's clinical condition arose. These difficulties were attributed in part to the disease's highly variable clinical presentation, which can differ substantially across its different forms and from one person to another.

In addition, the distinct symptom patterns seen in ALS compared with more familiar terminal illnesses created uncertainty for nurses when trying to identify the approach to end-of-life. Symptoms or treatments commonly associated with imminent death in other terminal conditions — such as severe cachexia, profound dysphagia, or continuous daily use of bilevel positive airway pressure (BiPAP) devices for several weeks before death — often led to confusion when assessing end-of-life status in ALS patients:

You know, every patient follows their own path regardless of the illness. Still, I feel the course of ALS is especially unpredictable for each person... and it's almost impossible for me to predict how much time remains... There are clear signs in my oncology patients that suggest limited time left, yet when my ALS patients show similar symptoms, they are still not at the end stage (Nurse 1, home care).

Despite these notable difficulties in identifying the terminal phase, participants highlighted several warning signs. These included progressive respiratory decline, increasing problems managing bronchial secretions, and the continuous need to adjust medications — especially for breathlessness and secretions — without achieving a new stable state:

When it comes to constantly having to tweak and readjust medications... that's usually the moment I realize we are approaching the end (Nurse 13, home care).

Four nurses observed in hindsight that newly emerging difficulties with tolerating enteral nutrition (tube feeding) served as a critical indicator preceding death. This could appear as persistently elevated gastric residual volumes or as feed refluxing back into the mouth. All patients displaying these signs passed away within days of the observation.

According to the nurses, a strong fear of dying from suffocation or severe respiratory distress was common among people with ALS. This fear sometimes led patients to decide against dying at home or to request physician-assisted medical aid in dying, which is permitted under law in Quebec, Canada:

We wondered whether she might reconsider her decision about medical aid in dying, since not being able to meet her grandson caused her deep sorrow. Still, her intense fear of suffocation kept her committed to the original date (Nurse 15, palliative care home).

To help address this fear, nurses primarily focused on educating patients about medications that can reduce the sensation of breathlessness and on informing them about the availability of a distress protocol in the event of an acute respiratory crisis. It should be noted that a distress protocol is routinely prescribed for terminally ill patients in Quebec; it is used during emergencies such as severe breathing difficulty or bleeding to induce short-term sedation and can be administered by nurses or, for home patients, by a trained family member [17]:

I often have to explain the medication plan again, reminding them that morphine also helps with breathing. People sometimes forget this, so it becomes necessary to repeat the information, reteach it, and offer reassurance. Some are hesitant to use morphine for breathing issues, but it really provides significant relief. The key is to calm their worries and correct any misconceptions (Nurse 13, home care).

Finally, the care required during the last few hours of life was viewed as essentially the same for people with ALS compared with other forms of end-of-life care.

Communication issues: 'getting them to express their suffering in ways other than talking.'

Many individuals living with ALS experienced severe or total loss of speech in the final weeks of life. Many were also unable to use their arms or hands, preventing them from operating a tablet or pointing to letters or symbols. As a result, meeting communication and comprehension needs turned into a significant obstacle for care teams. This had a clear effect on clinical evaluation and overall support for people with ALS at the end of life. However, the barriers particularly hindered psychosocial evaluations and related support efforts, leaving many nurses feeling powerless:

There is also the emotional and psychological aspect for the patient, but constant obstacles arise due to the communication difficulties. What is an effective way to provide psychological support to someone who can no longer speak clearly or at all? That becomes especially tricky because you cannot understand what they are trying to convey (Nurse 5, home care).

While some nurses preferred to refer these matters to a social worker or psychologist on the team when available, others took a more active role because they viewed this part of care as essential. These nurses learned to feel at ease with silence and to connect with patients without relying on spoken words:

I believe you do not need conversation to build a deep, transpersonal caring connection. You can share in someone's sadness and distress even if they cannot put it into words. When we sense that their spirit is struggling, we can often intuit the rest and sit with that sorrow together. Early in my career, I felt pressure to act or speak, but over time, I learned that silence has real value in a caring relationship. Today, I feel entirely at ease simply being present with someone and helping them convey their pain through means other than speech (Nurse 16, palliative care home).

Because communication problems prevented nurses from directly evaluating the decision-making ability of people with ALS at the end of life, this capacity was seldom challenged and was usually taken for granted. These assessment challenges raised ethical concerns for nurses, especially when they were unsure whether a simple nod or blink truly reflected the patient's wishes or was influenced by family members' preferences.

Although communication barriers sometimes left nurses feeling helpless, they also produced a beneficial effect. Many reported that caring for people with advanced ALS and severe speech difficulties had heightened their attention to nonverbal signals in every care setting. Finally, participants stressed the vital role that family members played in helping the team initially understand the patient's preferences and daily habits.

Supporting the need for control: 'that's what made her feel much safer'

Participants frequently noted that maintaining a consistent daily routine was highly important for many people living with ALS at the end of life, as well as for their families. This routine involved specific sequences of actions, performed in a fixed order and using a precise method that could not be altered. While a few nurses regarded this insistence on strict routines as inflexible and unfounded, most interpreted it as a way for individuals to retain some sense of control in a situation where their physical independence had been severely compromised:

I recall one woman who had lost nearly all control over her body, so she sought control wherever she could find it. We learned that every object had to be positioned exactly as she wished. For instance, when I tried to place the glass with the straw at her mouth, she would direct me — "no, a bit more to the right," "no, a bit more to the left." It truly had to be placed in that one exact position (Nurse 10, palliative care home).

Nurses observed that when the care team respected the person's need for control, this was reassuring to both the individual with ALS and their relatives. It also helped strengthen confidence in the healthcare providers:

Over time, we gradually became more familiar with the patient's daily habits, and day by day, her spouse began to trust us a little more. This allowed her to step back from her constant caregiving duties and be a wife again, permitting herself to take breaks (Nurse 22, hospital).

Furthermore, when nurses successfully learned and adhered to the established routine, it reassured the care team. Among other benefits, it helped reduce problems stemming from the patient's communication difficulties:

She had very fixed daily patterns. During the day, her partner knew exactly what those patterns were, and that familiarity made her feel much more secure. At the same time, having a clear routine helped the whole team feel more confident, because despite the communication barriers, everyone had a better sense of what was happening and where things were headed (Nurse 17, palliative care home).

In this way, respecting the person's need for control by honoring their routine benefited not only the individual living with ALS at the end of life, but also their family members and the healthcare team.

Accompanying the fight culture: 'her mind hadn't reached the same stage as her body'

Nurses described challenges in supporting individuals with ALS at the end of life, as well as their families, when the patient, their relatives, or both failed to recognize the person's worsening clinical status. This often involved insisting on continuing treatments or daily activities that nurses viewed as no longer beneficial or safe (for example, consuming a regular diet despite severe swallowing difficulties). Participants linked this behavior to a form of denial regarding disease progression, noting that it occurred more often and with greater intensity among people living with ALS and their loved ones than among those facing other terminal illnesses:

Her independence meant a great deal to her, and as it continued to decline, we did our best to preserve whatever remained. She wanted to handle everything herself and behaved as though she were still in her usual state of health. Her mind had not caught up with the condition of her body (Nurse 3, hospital).

Faced with such situations, some nurses preferred not to deliver difficult news. They avoided discussing the observed signs of decline with the patient or family and hesitated to recommend changes in care to manage the deterioration:

I would say it can sometimes take weeks for the patient to come to terms with the situation, and honestly, it takes time for us as caregivers to accept it, too. We often want to keep fighting alongside them. There seems to be an internal script we follow. For instance, moving from a normal diet to bite-sized pieces doesn't feel too drastic, but shifting from bite-sized to minced feels like an enormous leap, and nobody wants to make that change. It feels like forcing the patient to confront an irreversible reality (Nurse 2, hospital).

When reflecting on why they felt particularly uneasy about highlighting deterioration in ALS patients or their families compared with other cases, nurses pointed to a prevailing culture of fighting the disease. This mindset appeared stronger in ALS than in other terminal conditions:

I believe it's the intense battle she is waging that makes her hold on so tightly to many things. Because of that, we cannot approach her care the same way we would with a patient with a different condition (Nurse 11, hospital).

That said, nurses working in dedicated palliative care roles did not report this discomfort, regardless of the specific case. Most felt reasonably comfortable engaging in sensitive conversations about health decline and the need to modify care plans accordingly.

The extent of the need for care: 'intensive palliative care'

The end-of-life care demands for patients with ALS are so substantial that one nurse described them as resembling "an intensive palliative care" (Nurse 3, hospital). Daily responsibilities routinely included care related to tracheostomy, respiratory support devices, gastrostomy, tube feeding, secretion management, mobilization, positioning, feeding assistance, wound care, pain control, and the additional time required to understand the individual's specific needs fully.

Some nurses highlighted the fulfilling aspects of providing care to people with ALS at the end of life. Although the work was complex and physically taxing, it enabled them to fully utilize their expertise and realize the true potential of their nursing practice:

Yes, it is a devastating illness, but I also believe that, as nurses, we have the tools and ability to do meaningful, even beautiful things for these patients — provided we invest the necessary time. Experience certainly helps, but above all, you have to be willing to take that time (Nurse 16, palliative care home).

However, participants also described more difficult realities: nurses calling in sick to avoid particularly demanding shifts, transferring ALS patients to other units because the team was overwhelmed, requests from nursing assistants to be reassigned, and staff arriving at work with reluctance:

The other nurse on duty that day knew the patient very well and had built a strong connection with her. Eventually, she had to speak up and say, "I know I'm the one specialized in her care, but right now I really need a break — this is becoming too much." Whenever this patient was assigned to the team, everyone knew the shift would be extremely busy (Nurse 14, hospital).

Participants also raised concerns about insufficient organizational support for nurses. They reported that their requests to adjust nurse-to-patient ratios when caring for someone with ALS at the end of life were often ignored. As a result, nurses faced significant workload pressures that sometimes compromised the quality of care provided not only to the ALS patient but also to other individuals under their responsibility.

Nurses involved in admissions to palliative care residences mentioned an informal policy limiting facilities to admitting only one person with ALS at any given time. The concern was that caring for more than one such patient could negatively affect care for others in the residence, harm the ALS patients themselves, or place excessive strain on the healthcare team. Consequently, new ALS admissions were typically declined if another person with the disease was already present.

Nurses in hospital settings expressed ethical unease about the disproportionate amount of time they had to devote to ALS patients at end-of-life compared with their other patients, whether those patients were also at the end of life or not:

I have no real choice but to focus most of my time on this patient because his needs are so high. Meanwhile, my stroke patient — who is also receiving tube feeding and becomes anxious because he cannot understand instructions despite having a fully functioning mind — ends up being neglected. Because of the ALS workload, I regularly have to shortchange two or three other patients (Nurse 2, hospital).

In contrast, within palliative care residences, the understanding that ALS patients at end-of-life required more time was generally viewed as fair and appropriate — the person with the greatest needs received the most attention:

To me, it felt equitable. Not necessarily equal in the sense of giving everyone the same amount of time, but rather giving each person what they actually needed (Nurse 18, palliative care home).

Additionally, nurses working in palliative care homes noted that strong trust in their team members helped ease the pressure associated with providing extended periods of care to someone with ALS at the end of life. Finally, in the home care setting, nurses reported that the duration of visits for end-of-life patients was generally similar across diagnoses.

Nurses need to improve their care

The concerns expressed by the participants enabled them to pinpoint several requirements aimed at enhancing the care they deliver to individuals living with ALS at the end of life. **Table 4** summarizes these needs, grouped into three main categories—educational, clinical, and organizational—and includes the participants' rationale for each. The table also indicates the specific setting (home care, hospital, or palliative care home) from which each nurse who identified the need originated.

Table 4. Identified needs to improve care.

Category	Need	Rationale	Setting
Educational	Acquire knowledge about the illness, its progression, and associated symptoms	To enhance support for patients and their families and to confidently address questions regarding disease evolution and end-of-life stages	☑ Home care ☑ Hospital ☑ Palliative care home
	Develop competencies in managing respiratory issues (including secretion control and BiPAP use)	To broaden nurses' expertise, as many reported only foundational knowledge in end-of-life care for individuals with ALS	☑ Home care ☑ Hospital ☑ Palliative care home
	Strengthen understanding of assessing and supporting psychosocial needs in cases of severe or complete dysarthria	To improve the quality of care and support provided	☑ Home care ☑ Hospital ☑ Palliative care home
	Reflect on strategies for handling uncertainty and engaging in challenging discussions	To increase comfort when answers are unavailable or when responses may indicate deterioration or approaching the end-of-life	☑ Home care ☑ Hospital ☐ Palliative care home
	Integrate ALS-related content into initial training programs	To prevent a lack of preparedness during first encounters with individuals living with advanced ALS	☑ Home care ☐ Hospital ☐ Palliative care home
Clinical	Ensure the availability of clinical assessment tools tailored to advanced ALS, especially in the presence of communication barriers	To support a thorough and systematic evaluation of both physical and psychological conditions	☑ Home care ☑ Hospital ☐ Palliative care home
	Provide access to communication aids (e.g., pictograms, alphabet boards, tablets)	To facilitate effective communication with individuals living with ALS	☐ Home care ☑ Hospital ☐ Palliative care home
	Ensure access to appropriate and specialized equipment	To enable timely and efficient adaptation of care as needs evolve	☑ Home care ☑ Hospital ☐ Palliative care home
	Provide a detailed and accessible record of the patient's routine habits and needs (including positioning photos) in the room	To support continuity across care teams and enhance patient comfort	☐ Home care ☑ Hospital ☑ Palliative care home
	Ensure access to a specialist experienced in end-of-life ALS care	To provide support for complex clinical situations	☑ Home care ☑ Hospital ☐ Palliative care home

	Provide written or online guidelines outlining best practices for end-of-life care in ALS	To reinforce knowledge among nurses who infrequently manage such cases	☑ Home care ☑ Hospital ☐ Palliative care home
Organizational aspects	Modify nurse-to-patient ratios for those caring for end-of-life ALS patients	To ensure high standards of care quality and patient safety	☐ Home care ☑ Hospital ☑ Palliative care home
	Allocate dedicated time for information gathering at patient admission	To foster a strong therapeutic relationship with patients and families and improve care delivery	☑ Home care ☑ Hospital ☐ Palliative care home
	Encourage continuity within healthcare teams while also allowing adequate rest periods	To strengthen relationships with patients and families, enhance care quality, and support staff wellbeing	☐ Home care ☑ Hospital ☑ Palliative care home
	Assign individuals with advanced ALS to sufficiently large private rooms upon admission	To minimize the need for transferring equipment and reorganizing established workflows	☐ Home care ☑ Hospital ☑ Palliative care home

Abbreviations: ALS = amyotrophic lateral sclerosis; BiPAP = bilevel positive airway pressure.

Regarding educational needs, the nurses expressed a strong desire for targeted training on various topics to assist patients and their families better and to respond more effectively to their questions. In relation to symptoms and symptom management, they highlighted the need for further education on managing respiratory issues, conducting psychosocial evaluations, and providing support for patients with severe speech difficulties.

Regarding clinical needs, participants stressed the importance of access to assessment and communication tools specifically designed for people with advanced ALS to maintain high-quality care. The interviews revealed a wide variety of communication devices currently in use, such as rope-in-the-mouth call bells, vibration-controlled computers, electronic tablets, and others. This diversity made it challenging for non-specialist nurses — especially those outside ALS or neurology — to know which options existed or how to select the most suitable one. Consequently, nurses requested a readily available, centralized list or registry of available tools. A similar need was identified for guidance on adapting other types of equipment, for instance, modifying a wheelchair for a patient who could no longer hold their head upright. Since timely access to a physiotherapist or occupational therapist is not always possible, nurses felt it would be beneficial to be informed about the range of possible adaptations so they could resolve problems promptly and promote the patient's comfort and wellbeing.

Finally, organizational needs centered on adequate staffing levels, protected time, and a suitable care environment. Participants considered adjusting the nurse-to-patient ratio especially critical, as it would allow them to deliver safe and effective care to individuals with ALS and to their other patients. While some nurses were granted such adjustments, these were frequently obtained only after persistent — and sometimes intense — discussions with their managers.

In addition, protected time during the admission process was considered essential. This would enable nurses to perform a comprehensive initial evaluation, document the person's preferred daily routines in detail, and develop an individualized care plan that would ultimately support the delivery of high-quality care.

Our results offer deeper insight into the challenges nurses encounter when providing end-of-life care to individuals living with ALS. Participants described multiple factors to be considered when supporting these patients and their families, along with a range of educational, clinical, and organizational requirements to enhance care quality. The findings underscore the distinctive features of end-of-life care in ALS, including important ethical considerations and disease-specific cultural elements.

Clinical and research implications can be drawn directly from the study results and are examined below in the context of the existing literature. The strong need for control among people living with ALS at the end of life, as reported by participants, was previously explored by Foley *et al.* [18]. In their qualitative study involving individuals with ALS across all disease stages, "control" emerged as a key response to the numerous losses and profound lack of autonomy experienced in nearly every aspect of daily life. Control-oriented actions helped patients stay anchored in the present and preserve a feeling of normalcy. Our findings emphasize that this need for control becomes particularly pronounced at the end of life, often expressed through requests that nurses maintain the patient's established routines as closely as possible.

The culture of fighting the disease observed in our study has received limited attention in the literature. However, a study by Guité-Verret and Vachon [19] on women living with incurable metastatic breast cancer examined the "war metaphor." It described a combative stance that reflected the women's powerful will to survive, while also revealing a contradiction: the women sometimes viewed themselves as passive vessels in a battle primarily driven by their physicians, from which they wished to withdraw. It would therefore be valuable to investigate this fight culture more thoroughly among people with ALS and to examine how this mindset influences their disease trajectory and overall wellbeing.

The present study also illustrated the considerable scope and specific demands of care required by individuals with ALS at the end of life. This highlights the need to review and adapt care systems and resource allocation promptly. The benefits of maintaining an appropriate nurse-to-patient ratio [20, 21] and manageable workload [22] have been consistently demonstrated across various healthcare settings. Nevertheless, the working conditions routinely faced by nurses in this context remain poorly suited to delivering high-quality care or supporting the wellbeing of patients with ALS at end-of-life, their families, or the care team itself. An informal type of discrimination even appears to exist in the admission processes for these patients. While intended to protect care quality for some, it ultimately restricts access to appropriate end-of-life care for others. When combined with the already well-documented disparities in access to palliative and end-of-life services for non-cancer patients [23-26], many individuals with ALS currently face inequity — and sometimes outright harm — in healthcare simply because of their diagnosis. There is therefore an urgent need to acknowledge the intensive nature of the care required, expand resources to support families in home care settings, and adjust nurse-to-patient ratios accordingly. In this context, managers must develop a clearer understanding of the experiences of healthcare teams caring for people with advanced or end-stage ALS. Such insight would help improve the quality of nursing care. Higher-quality care would not only enhance the end-of-life experience for patients with ALS but would also alleviate the substantial burden placed on their relatives [27].

Beyond providing training that addresses the specific needs identified by nurses — including education on available communication aids such as eye-tracking technology [28] — another key consideration must be addressed. Most nurses care for a person with ALS at the end of life only sporadically. However, this situation is likely to change as the incidence and prevalence of the disease continue to rise [2]. As a result, the application of newly acquired knowledge from continuing education may be delayed by several months. It is therefore important to investigate effective strategies for supporting the acquisition, retention, and timely reactivation of nurses' knowledge and skills in this area.

Finally, from a research perspective, it is essential to examine the experiences of other healthcare team members to obtain a more complete picture of interdisciplinary collaboration in the end-of-life care of people with ALS.

This study contributes to the existing body of knowledge on nurses' lived experiences when caring for individuals with ALS at the end of life, achieved through detailed, in-depth interviews. The multiple-case study design further emphasizes both the commonalities and the variations across different care environments, thereby offering a clearer picture of the challenges involved.

Regarding limitations, participant recruitment relied primarily on social networks. This approach likely excluded nurses who do not use such platforms and may have yielded a sample that reflects only a subset of nurses. Additionally, the absence of nurses working night shifts constitutes another limitation, as the unique demands and characteristics of night work might have yielded different insights.

Conclusion

Beyond deepening our understanding of the experiences of nurses delivering end-of-life care to people living with ALS, this study revealed an urgent requirement for additional resources and a fundamental re-evaluation of care organization. Given that the number of individuals diagnosed with ALS is projected to rise in the coming years until a cure becomes available, it is essential to intensify research efforts aimed at enhancing the quality of life, improving end-of-life experiences, and elevating the standard of care for these patients and their families.

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References

1. Brown RH, Al-Chalabi A. Amyotrophic lateral sclerosis. N Engl J Med. 2017;377(2):162–72.
2. Xu L, Liu T, Liu L, Li W, Fang Y, Liu S, et al. Global variation in prevalence and incidence of amyotrophic lateral sclerosis: a systematic review and meta-analysis. J Neurol. 2020;267(3):944–53.

3. Hodgkinson V, Lounsberry J, Mirian A, McDermott CJ, Strong MJ, Kiss A, et al. Provincial differences in the diagnosis and care of amyotrophic lateral sclerosis. Can J Neurol Sci. 2018;45(6):652–9.
4. Ushikubo MP, Okamoto KP. Circumstances surrounding death and nursing difficulties with end-of-life care for individuals with ALS in central Japan. Int J Palliat Nurs. 2012;18(11):554–60.
5. Cheng H, Chan KY, Chung YKJ, Yuen JK, Li SY, Chan CL, et al. Supportive & palliative interventions in motor neurone disease: what we know from current literature? Ann Palliat Med. 2018;7(2):320–31.
6. Flemming K, Turner V, Bolsher S, Hulme C, McHugh A, Barclay S, et al. The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: a qualitative systematic review. Palliat Med. 2020;34(6):708–30.
7. Desbiens JF, Fillion L. Development of the palliative care nursing self-competence scale. J Hosp Palliat Nurs. 2011;13(4):230–41.
8. Stake RE. Multiple case study analysis. New York: Guilford Press; 2006.
9. Fearon D, Hughes S, Brearley SG. Constructivist Stakian multicase study: methodological issues encountered in cross-cultural palliative care research. Int J Qual Methods. 2021;20:16094069211015075.
10. Chhetri SK, Bradley BF, Gallagher P, Donaghy C, Hardiman O, Pender NP, et al. Choosing the place of death: empowering motor neurone disease/amyotrophic lateral sclerosis patients in end-of-life care decision making. Palliat Med. 2015;29(8):667–8.
11. Goutman SA, Nowacek DG, Burke JF, Labunsky K, McCarty S, Shefner JM, et al. Minorities, men, and unmarried amyotrophic lateral sclerosis patients are more likely to die in an acute care facility. Amyotroph Lateral Scler Frontotemporal Degener. 2014;15(5-6):440–3.
12. Ministry of Health and Social Services. Modalité d'encadrement des maisons de soins palliatifs. 2016.
13. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
14. Stake RE. The art of case study research. Thousand Oaks, CA: SAGE; 1995.
15. Brinkmann S. Unstructured and semi-structured interviewing. In: Leavy P (ed.). Oxford handbook of qualitative research. Oxford University Press; 2014. pp. 277–299.
16. Miles MB, Huberman AM, Saldaña J. Qualitative data analysis: A methods sourcebook. 4th ed. Thousand Oaks, CA: SAGE; 2020.
17. Godbout K, Tremblay L, Lacasse Y. A distress protocol for respiratory emergencies in terminally ill patients with lung cancer or chronic obstructive pulmonary disease. Am J Hosp Palliat Med. 2016;33(8):817–22.
18. Foley G, Timonen V, Hardiman O. Exerting control and adapting to loss in amyotrophic lateral sclerosis. Soc Sci Med. 2014;101:113–9.
19. Guité-Verret A, Vachon M. The incurable metastatic breast cancer experience through metaphors: the fight and the unveiling. Int J Qual Stud Health Wellbeing. 2021;16(1):1971597.
20. Driscoll A, Grant MJ, Carroll D, Dalton S, Deaton C, Jones I, et al. The effect of nurse-to-patient ratios on nurse-sensitive patient outcomes in acute specialist units: a systematic review and meta-analysis. Eur J Cardiovasc Nurs. 2018;17(1):6–22.
21. McHugh MD, Aiken LH, Sloane DM, Barnes H, Golden A, Griffiths P, et al. Effects of nurse-to-patient ratio legislation on nurse staffing and patient mortality, readmissions, and length of stay: a prospective study in a panel of hospitals. Lancet. 2021;397(10288):1905–13.
22. Margadant C, Wortel S, Hoogendoorn M, Bosman RJ, Van Gulik L, Wijnhoven B, et al. The nursing activities score per nurse ratio is associated with in-hospital mortality, whereas the patients per nurse ratio is not. Crit Care Med. 2020;48(1):3–9.
23. Kangtanyagan C, Vatcharavongvan P. No terminally ill patients with non-cancer received palliative care services during hospital admission: a cross-sectional study. Am J Hosp Palliat Care. 2023;40(5):492-9.
24. Lau C, Meaney C, Morgan M, Chan K, McCallum L, McKenzie M, et al. Disparities in access to palliative care facilities for patients with and without cancer: a retrospective review. Palliat Med. 2021;35(7):1191–201.
25. Rosenwax L, Spilsbury K, McNamara BA, Semmens JB, Holman CDJ. A retrospective population based cohort study of access to specialist palliative care in the last year of life: who is still missing out a decade on? BMC Palliat Care. 2016;15:46.
26. Seow H, O'Leary E, Perez R, Tanuseputro P, Barbera L, Earle CC, et al. Access to palliative care by disease trajectory: a population-based cohort of Ontario decedents. BMJ Open. 2018;8(3):e021147.
27. Linse K, Aust E, Günther R, Joos M, Storch A, Meyer T, et al. Caregivers' view of socio-medical care in the terminal phase of amyotrophic lateral sclerosis – how can we improve holistic care in ALS? J Clin Med. 2022;11(2):254.
28. Linse K, Rüger W, Joos M, Ziegler W, Müller HP, Abrahams S, et al. Usability of eyetracking computer systems and impact on psychological wellbeing in patients with advanced amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener. 2018;19(3-4):212–9.