‘Intensive palliative care’: a qualitative study of issues related to nurses’ care of people with amyotrophic lateral sclerosis at end-of-life

Palliative Care & Social Practice

2023, Vol. 17: 1–13

DOI: 10.1177/26323524231170881

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Abstract

Background: Amyotrophic lateral sclerosis (ALS) is currently an incurable and fatal disease, which often comes with a high symptom burden at the end-of-life stage. Little is known about nurses’ experiences in this context.

Objective: To explore the experience of nurses caring for people with ALS at end-of-life.

Design: A qualitative multiple-case study design.

Method: Individual semi-structured interviews were conducted between February and August 2022 with nurses from Quebec, Canada, who had provided care to at least one person living with ALS at the end-of-life in the past 12 months. The content analysis method was used for data analysis and within-case and cross-case analyses were conducted, as well as comparative analyses according to the type of position held by the participants that determined the cases: (1) home care, (2) hospital and (3) palliative care home.

Results: Participating in the study were 24 nurses: 9 were from home care, 8 from hospitals and 7 from palliative care homes. Five main themes were identified: (1) identifying the end-of-life period, (2) communication issues, (3) supporting the need for control, (4) accompanying in the fight culture and (5) the extent of the need for care. A sixth theme was also added in order to report the need expressed by nurses to improve their care of patients living with ALS at end-of-life.

Conclusions: Although nurses’ experiences varied among the different settings, the study identifies the pressing need for better education and, above all, more resources when caring for a person living with ALS at end-of-life. Future research should explore the experiences of other members of the healthcare team and test interventions designed to improve the quality of life and end-of-life of people living with ALS.

Keywords: case study, end-of-life, Lou Gehrig’s disease, nursing, palliative care, qualitative research

Received: 24 February 2023; revised manuscript accepted: 3 April 2023.

Background

Amyotrophic lateral sclerosis (ALS), a degenerative disease affecting the motor neurons, is characterized by symptoms affecting the motor and respiratory systems.[1] The disease has an estimated average prevalence of 4.4 per 100,000 people worldwide, according to a meta-analysis published in 2020, and the number has been steadily increasing since 1959.[2] Despite advances in research to develop curative treatments, the disease currently remains incurable, with an estimated median survival of 36 months from the onset of the first symptom.[3]

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The end-of-life period for people living with ALS is often accompanied by breathing difficulties, severe dysphagia, sialorrhea, dysarthria and paralysis.[1] This high symptom burden, which threatens the quality of end-of-life, requires almost constant support from relatives and members of the healthcare team, including nurses.

The only identified study looking specifically into nurses' perspectives on their care of people with ALS at end-of-life used a postal questionnaire to explore the difficulties encountered by Japanese nurses in providing home care to this population.[4] The problems the participants faced related to communication with the person with ALS, due to progressive dysarthria, and difficulty adjusting by the person and their relatives, due to the rapid progression of the disease.

As nurses are important members of the interdisciplinary end-of-life care team, it is essential to better understand their experience in providing end-of-life care to people living with ALS. This experience includes their own needs, which must be explored in order to improve the quality of care they provide.

The purpose of this study was to explore the experience of nurses when caring for people with ALS at end-of-life. The specific objectives were as follows:

1. To explore the characteristics of nurses' care of people with ALS at end-of-life.
2. To identify the needs of nurses in providing quality care to people with ALS at the end-of-life.

It should be noted that while palliative care is an important component of care for people living with ALS from the time of their diagnosis,[5,6] this research focuses on end-of-life care. For the purposes of this study, end-of-life care has been defined as care provided within 3 months of death.

Theoretical framework

The research is based on the Palliative Care Nursing Self-Competence Scale proposed by Desbiens and Fillion.[7] It consists of 10 domains that determine competence in palliative care nursing, which are presented in Table 1.

Table 1. Domains of the Palliative Care Nursing Self-Competence Scale.[7]

1.	Physical needs – pain
2.	Physical needs – other symptoms
3.	Psychological needs
4.	Social needs
5.	Spiritual needs
6.	Needs related to functional status
7.	Ethical and legal issues
8.	Interprofessional collaboration and communication
9.	Personal and professional issues related to nursing care
10.	End-of-life care

For the study, both the physical needs domains were merged together, as were the psychological, social and spiritual needs domains, thus leaving a total of seven domains. This framework influenced the development of the research objectives, the content of the interview guide, and it guided the data analysis.

Method

A qualitative multiple-case study design proposed by Stake[8] was chosen. The method is grounded in a constructivist paradigm,[9] as this form of case study allows for an in-depth exploration of a complex phenomenon that is understood to be interpreted in relation to the context that influences it. In this study, cases were defined according to the nurses' workplace, since this has a significant impact on how care is organized. The three cases in this study involved multiple nurses in each of three settings, representing the most common places of death for people living with ALS:[10,11] (1) home care, (2) hospital and (3) palliative care home. Sometimes called hospices, palliative care homes in the province of Quebec, Canada, are places, often run by a community organization, that exclusively offer end-of-life care, similarly to hospital-based or long-term care palliative care units.[12] Consolidated criteria for reporting qualitative research (COREQ) was used to guide and report this study.[13]

Table 2. Inclusion criteria.

1.	Having provided care to at least one person living with ALS at end-of-life in the past 12 months
2.	Being a nurse in Quebec, Canada
3.	Working in a hospital, home care or a palliative care home

ALS, amyotrophic lateral sclerosis.

Sample

As proposed by Stake[14] for case studies, a purposive sampling method was used to recruit nurses from the various work sites. The inclusion criteria are found in Table 2.

Recruitment was conducted between February and August 2022, using social media to share the recruitment poster on the pages of Quebec organizations related to palliative and end-of-life care or nursing. Paid advertisements on Facebook were also used with the same recruitment poster. A snowball approach completed the recruitment. Monetary compensation (CAN$20) was offered following participation.

Data collection

A sociodemographic data questionnaire was used to document the participants' profile and work environment context. A journal was also used by the interviewer to record methodological decisions, memos, and reflections after each interview. A single semi-structured individual interview format was chosen for the data collection to provide a structure flexible enough to allow participants to address unanticipated topics when necessary, while still addressing certain predetermined aspects.[15] The interviews averaged 49 min in length and were audio recorded and transcribed with anonymization of the verbatim. No one else beside the interviewer and the participant were present during the interview. They were conducted by the first author, who had previous experience in qualitative interviewing. She identifies herself as a cisgender woman. Three participants were already known to the interviewer through a professional relationship.

An interview guide (Supplementary Material A) was used. Due to the province-wide recruitment area and the still-changing pandemic context at the time of the study, the interviews were conducted virtually. To allow for consideration and analysis of differences in the types of positions held by participants (palliative care or non-palliative care) within cases, participant codes were identified by a suffix corresponding to their position.

Data analysis

A descriptive analysis of sociodemographic data was conducted. Data from the semi-structured interviews were analysed using NVivo 1.0 software, following the content analysis method of Miles *et al.*[16] Using an iterative process, the method includes two cycles of coding. The first consists of assigning a code representing a unit of meaning for each passage of the verbatim and then classifying these codes under one of the seven themes of the Palliative Care Nursing Self-Competence Scale.[7] In the second cycle, a pattern coding is performed, in which the codes emerging from the first cycle are condensed into conceptual categories.

This step allowed for within-case and cross-case analyses to be conducted, as well as comparative analyses according to the type of position held by the participants, which is consistent with the multiple-case study design.[8] The principal investigator led the analysis. A matrix was then designed and discussed with the research team, to confront ideas, clarify themes and ensure the intelligibility of themes and categories.

Results

A total of 24 nurses participated in the study: 9 from home care, 8 from hospitals and 7 from palliative care homes. With an average age of 41 (range, 26–64 years old), all nurses worked day or evening shifts and half held a specialized palliative care position. In terms of their most recent degree, palliative care home nurses tended to have more advanced education: most had a graduate degree (microcredentials) and none had a college degree as their last degree, contrary to the nurses in other settings. The sociodemographic characteristics are shown in Table 3. Additional sociodemographic characteristics are also available in Supplementary Material B. The decision to stop recruiting was made when the team determined that theme comprehensibility and depth were sufficient. The quotations presented are translated from French.

Five main common themes were identified: (1) identifying the end-of-life period, (2) communication issues, (3) supporting the need for control, (4) accompanying in the fight culture and (5) the extent of the need for care. Discrepancies between cases appear in the corresponding theme. A sixth theme was also added in order to report the needs expressed by nurses to improve their care of patients living with ALS at end-of-life.

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

Participants reported difficulties in identifying the beginning of the end-of-life phase, which made it difficult to support people with ALS and their relatives, especially when decisions about care needed to be made or when questions about clinical status arose. These difficulties were attributed, at least in part, to the clinical picture, which could vary greatly from one form of the disease to another, and from one person to another.

Also, the differences in symptomatology between ALS and other, better-known terminal illnesses created uncertainty in the nurses about identifying a possible end-of-life. Indeed, the presence of symptoms or treatments associated with imminent end-of-life in patients with other terminal illnesses, such as severe cachexia or dysphagia, or the use of a bilevel positive airway pressure (BiPAP) respiratory devices on an ongoing basis, sometimes several weeks before death, led to confusion in identifying the end-of-life in people with ALS:

> You know, everyone has a different trajectory, no matter what the disease is, but my impression is that the ALS trajectory is different for everyone too . . . and it's like impossible for me to say, 'Well there's this much time left or there's that much time left . . .'. [. . .] You know, I mean, there are symptoms that my oncology patients have that make me think they're not going to last long. My ALS patients are the same but they're not at the end-of-life. (Nurse 1, home care)

Despite these greater difficulties in identifying the end of life, some signs were reported by participants, including respiratory deterioration, increased difficulty in managing bronchial secretions and the constant need to adjust medication, especially to manage dyspnea and secretions, without being able to reach a new stability:

> In terms of medication management, when it comes to having to adjust, adjust, adjust [. . .], I think that's when you come to the point where you say, now, we're nearing the end. (Nurse 13, home care)

Four nurses noted that, in retrospect, de novo identification of difficulty digesting enteral nutrition (tube feeding) was the warning sign leading to death, be it in the form of a higher-than-usual gastric residual volume that persisted, or reflux of gavage back into the mouth. Those with these signs all died within days of their being identified.

According to the nurses, a strong fear of dying from suffocation or in a state of respiratory distress was quite common among people with ALS, sometimes leading them to decide not to die at home or to request physician-assisted medical aid in dying, which is legal in Quebec, Canada:

> We wondered if she was going to change her mind about receiving medical aid in dying, because [not meeting her grandson] was a huge source of grief for her, but she was really, really afraid of suffocating to death, so she kept her date. (Nurse 15, palliative care home)

To support people with this fear, nurses relied mainly on educating people about medication that helps reduce the sensation of dyspnea and about the availability of the distress protocol should respiratory distress occurs. It should be noted that a distress protocol is routinely prescribed for terminally ill patients in Quebec; it is used in emergencies such as respiratory distress or haemorrhage to induce temporary sedation and can be administered by nurses or, for people at home, by a trained relative:[17]

> Often re-explaining medication management to them because morphine affects breathing too. Sometimes people forget that, so it's about repeating it, reteaching it, and reassuring them. You know, some people are afraid to take morphine for breathing, but it helps so much. So, it's about reassuring them, removing the fears and false beliefs if you will. (Nurse 13, home care)

Finally, the care needed in the last few hours of life was not considered different for people with ALS, compared to other types of end-of-life care.

Table 3. Sociodemographic characteristics.

Characteristics	Home care (%), *N* = 9	Hospital (%), *N* = 8	Palliative care home (%), *N* = 7	Total (%), *N* = 24
Age				
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

ALS, amyotrophic lateral sclerosis.
[a]In Quebec, Canada, the requirement for nursing is either a technical college degree or an undergraduate university degree.

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

Many people living with ALS presented severe or complete dysarthria in the last few weeks of their lives. Many were also unable to use their limbs, so they could not operate a tablet or point to letters or pictograms, for example. Communication and understanding needs became a major challenge for healthcare teams, which had an impact on the clinical assessment and support of people living with ALS at end-of-life. However, these communication barriers particularly affected psychosocial assessments and related interventions, which left many nurses feeling helpless:

> Well, there's also the psychological side with the person, but there are barriers all the time, because of communication problems. You know? What is a good therapeutic approach to take with someone who doesn't communicate 100% verbally? That's what gets complicated too, because you can't understand them. (Nurse 5, home care)

While some nurses were content to refer to the social worker or psychologist on the healthcare team, where available, others were very involved in this aspect of care because they considered it important. These nurses were able to develop a measure of comfort with silence and to relate without the need for verbal communication in order to support their patients:

> I think that you don't need to talk to experience the transpersonal caring relationship. [. . .] You can experience sadness and pain without necessarily having to express it verbally. When we know that it's the spirit that's not OK, we deduce the rest and we feel the sorrow together. At the beginning of my training, it was important for me to do something, to say something, but with the passage of time, I realized that silence has its place in a therapeutic relationship. And now, I can say that I am really comfortable, completely comfortable, with saying nothing and simply existing in the presence of someone else and getting them to express their suffering in ways other than talking. (Nurse 16, palliative care home)

With communication issues making nurses unable to directly assess the capacity of people with ALS at end-of-life, this capacity was rarely questioned and was thus often assumed. These assessment difficulties caused ethical questions for nurses, in situations where they were unsure whether interventions the person with ALS had consented to, through a simple nod or blink of the eyes, were truly in accordance with their wishes or were instead in response to the needs or wishes of their relatives.

While communication issues sometimes made nurses feel helpless, they also had a positive impact on them, with many stating that their experience caring for people with ALS at end-of-life and with significant dysarthria had made them more aware of nonverbal cues in all care contexts. Finally, participants also emphasized the central role played by relatives in initially understanding the patient's needs and habits.

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

Participants repeatedly mentioned that adhering to a routine was important for many people living with ALS at end-of-life and for their relatives. This strict routine took the form of precise steps, in a specific order, and using a set technique, all of which should not be deviated from. While some nurses saw this need to maintain the same detailed routine as a rigid requirement without any basis, most nurses saw it as a means for people to maintain some control, in a situation where their autonomy was greatly impaired:

> And I remember she was a very . . . you know, one of these people, they've lost almost all control over their body, so they try to look for control somewhere. We understood that everything had to be placed exactly the way she wanted it. For example, I was trying to position the glass, with the straw in her mouth, and it was like 'no, more to the right', 'no, more to the left'. It really had to be put EXACTLY in the right spot. (Nurse 10, palliative care home)

Participants reported that the healthcare team's respect for the person's need for control was viewed as reassuring by the people living with ALS and their relatives, and it helped build trust with the healthcare team:

> Day by day, we learning a little bit more about the patient's routine, and day by day, she [the spouse] gave us a little more room, so she could free herself from the caregiver role and be the spouse again, if you will, to take some breaks. (Nurse 22, hospital)

In addition, when nurses succeeded in familiarizing themselves with the routine and followed it, it proved to be just as reassuring for the healthcare team, since it alleviated, among other things, the communication issues caused by the illness:

> She was someone who had extremely pre-established routines, so during the day, her partner knew her routine, and that's what made her feel much safer. At the same time, having this kind of routine also made the team feel more secure because, since there was a communication issue, it allowed everyone to understand a little more where we were heading. (Nurse 17, palliative care home)

Thus, supporting the need for control by respecting the person's routine had an impact not only on the person living with ALS at end-of-life but also on the relatives and the healthcare team.

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

Nurses reported having difficulty supporting people with ALS at end-of-life, or their relatives, when the person, their relatives or both did not perceive the person's deteriorating clinical condition, when they insisted on continuing care the nurses considered futile, or an activity of daily living that was no longer safe for them (e.g. eating a normal diet with severe dysphagia). Participants associated this behaviour with a denial of the disease's progression, which was encountered more frequently and more intensely among people living with ALS and their relatives than among people dying from other conditions:

> Her autonomy was very important to her, and it was decreasing more and more, so we tried to maintain it as much as possible. You know, she wanted to do everything. It was like she was still in her normal condition. Her mind hadn't reached the same stage as her body. (Nurse 3, hospital)

In response to such situations, some nurses wanted to avoid being the bearers of bad news. They refrained from talking to the individual or their relatives about the signs of deteriorating health that they observed and from suggesting interventions to address the deterioration:

> I would say that sometimes it takes weeks for the patient's acceptance to arrive, and also, I think, for us to accept that 'they're there'. Because I really think we want to fight with them. I think there's this pattern in our heads, and I would also like to say that, in terms of diet, for example, the step from 'normal' to 'bite-sized' is not so bad, but when you go from 'bite-sized' to 'minced', then the step seems to be HUGE, and no one wants to take it. It's like putting them [the patient] in front of a fait accompli. (Nurse 2, hospital)

In exploring the reasons for their discomfort in pointing deterioration specifically in people with ALS at end-of-life, or their relatives, the nurses attributed the phenomenon to the fight culture, which seems to drive them more than people with other terminal diseases:

> Well, I think it's the kind of battle she is leading that causes her grasp onto a great many things, which means that we can't do what we do with another patient who doesn't have the same condition. (Nurse 11, hospital)

That said, nurses in specific palliative care positions, regardless of the case, did not experience this discomfort, and most reported feeling comfortable with the difficult discussions related to deteriorating health and the need to adapt care accordingly.

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

The end-of-life care needs of ALS patients are such that one participant compared them to 'an intensive palliative care' (Nurse 3, hospital). Care related to tracheostomy, breathing apparatus, gastrostomy, tube feeding, management of respiratory secretions, mobilization, positioning, feeding, wound care, pain management, and the time needed to understand the needs of the person living with ALS were all part of the nurses' daily routines.

Some nurses commented on the rewarding nature of the care they were able to provide to people with ALS at the end-of-life. While complex and demanding, it allowed them to apply their skills and maximize the potential of their nursing role:

> I think that, yes, it's a terrible disease, but I think that we have the means – or the capacity – as nurses to do wonderful things with these patients as well: you just have to take the time. Of course, experience helps, but you have to take the time. (Nurse 16, palliative care home)

However, participants also described other realities: nurses taking sick days to avoid a busy shift, unit transfers of patients living with ALS due to an exhausted care team, requests from nurses' aides to be assigned to another unit and nurses going to work without wanting to:

> The other nurse who was there, she was a regular, and she knew [the patient] very well and had an excellent bond with her – to the point that [the nurse] eventually had to say, 'Listen, I know I'm specialized with so-and-so, but right now, I could use a break because it's a lot'. Yes, because as soon as [the patient] was on your team, it was going to be a busy evening for sure. (Nurse 14, hospital)

The lack of consideration for nurses by organizations was also raised. Participants stated that they were not heard when they expressed the need to adjust their nurse-to-patient ratio when a person with ALS at end-of-life was under their care. Thus, nurses caring for a person with ALS at end-of-life find themselves with a work overload that sometimes interferes with the quality of care for the people with ALS as well as the others in their care.

Some nurses involved in the admissions process to palliative care homes also disclosed an informal limit of one person ALS being admitted at a time to their facility. Fearing that caring for more than one person with this disease in that setting would be detrimental to the other people being cared for, or even to the person with ALS themselves, and that it would create or increase the burden on the healthcare team, people with ALS were not considered for admission when there was already a person with ALS in the facility.

Nurses in hospital case raised their ethical discomfort with the unequal time they have to give to people living with ALS at end-of-life *versus* their other patients, whether at the end-of-life or not:

> You know, I have no choice but to be with this patient, because he's the one who takes up most of my time. But my stroke patient, who is also being tube fed and is panicking because he doesn't understand the instructions even though his brain is working, I neglect him . . . So, I always neglect two or three of them because of the ALS workload. (Nurse 2, hospital)

Within the palliative care home case, the recognition that more care time is needed for ALS patients at end-of-life was seen as equitable, with the patient with the greatest need receiving the most care:

> Well, it's like, I saw this as fair. Not equal, you understand – it's not the same level of attention, but it's what the person needs. (Nurse 18, palliative care home)

Moreover, nurses working in palliative care homes said that their trust in their colleagues on their team considerably reduced the pressure they felt when they had to provide long periods of care to someone living with ALS at end-of-life. Finally, within the home care case, nurses felt that the visits to each patient at end-of-life were comparable in terms of time, regardless of the person's diagnosis.

Nurses' needs to improve their care

The issues raised by the participants allowed them to identify several needs, to improve the care they provide to people living with ALS at end-of-life. Table 4 summarizes those needs, which are three categories, namely, educational, clinical and organizational, and shown with the participants' justification for them. The table also specifies the case (home care, hospital or palliative care home) of the nurses that identified the need.

As regards educational needs, the nurses wanted to receive training on many aspects in order to better support patients and their families and to be able to answer their questions. With respect to symptoms and their treatment, the nurses emphasized their need for education on management of respiratory symptoms and the psychosocial assessment and support of patients with significant dysarthria.

As for clinical needs, access to clinical assessment and communication tools adapted to people living with advanced ALS was mentioned, to ensure quality of care. For example, the interviews highlighted the wide range of communication aids in use: rope-in-the-mouth call bell, vibration-controlled computer, electronic tablet, and so on. This made it difficult to navigate or to even know what is available for professionals not specialized in ALS or neurology. As such, nurses wanted an accessible registry of options available. The same

Table 4. Identified needs to improve care.

Need	Justification	Case
Educational		
Learn about the disease, its trajectories and symptoms	To better support patients and their relatives and to be able to answer their questions about the progression of the disease and the end-of-life trajectory	☑ Home care ☑ Hospital ☑ Palliative care home
Learn about management of respiratory symptoms (including secretion and BiPAP management)	To expand the knowledge of nurses, who felt they have only basic knowledge in an end-of-life situation for people living with ALS	☑ Home care ☑ Hospital ☑ Palliative care home
Increase knowledge about evaluation and support of psychosocial aspects in the presence of severe or complete dysarthria	To improve offered care and support	☑ Home care ☑ Hospital ☑ Palliative care home
Reflect about the approach to accompanying uncertainty and having difficult conversations	To be more comfortable when there is no answer to the person's or relatives' questions, or when the answer could confirm a deterioration or end-of-life	☑ Home care ☑ Hospital ☐ Palliative care home
Address ALS in initial education	To avoid being unprepared when making initial contact with a person living with advanced ALS for the first time	☑ Home care ☐ Hospital ☐ Palliative care home
Clinical		
Access to clinical assessment tools specific to people living with advanced ALS in the context of communication issues	To ensure comprehensive and systematic assessments of physical and psychological state of the person living with ALS	☑ Home care ☑ Hospital ☐ Palliative care home
Access to communication tools (pictograms, letters table, tablets, etc.)	To help establish a means of communication with the person living with ALS	☐ Home care ☑ Hospital ☐ Palliative care home
Access to adapted equipment	To facilitate and accelerate the adaptation of care when needed	☑ Home care ☑ Hospital ☐ Palliative care home
Access to detailed chart of the person's most frequent habits and needs, accessible in the room, including photos of positioning	To facilitate the continuity of care between teams and improve comfort	☐ Home care ☑ Hospital ☑ Palliative care home
Access to a professional with expertise in the end-of-life context of ALS	To have a resource for clinical issues	☑ Home care ☑ Hospital ☐ Palliative care home
Access to a written or web-based guide containing best practices for end-of-life care for people living with ALS	To reactivate knowledge among nurses who do not regularly provide end-of-life care to people living with ALS	☑ Home care ☑ Hospital ☐ Palliative care home
Organizational aspects		
Adjust the nurse-to-patient ratio for the nurse caring for a person with ALS at end-of-life	To promote quality and safety of care	☐ Home care ☑ Hospital ☑ Palliative care home
Have dedicated time for data collection on the person's admission	To promote a therapeutic relationship with the person and their relatives, as well as the effectiveness of care	☑ Home care ☑ Hospital ☐ Palliative care home
Promote healthcare team stability, while also respecting the needs for breaks	To promote a therapeutic relationship with the person and their relatives, as well as the effectiveness of care and the well-being of the team	☐ Home care ☑ Hospital ☑ Palliative care home
Admit people with advanced ALS to a large enough private room up front	To avoid transferring a large amount of material and having to reorganize established work methods	☐ Home care ☑ Hospital ☑ Palliative care home

ALS, amyotrophic lateral sclerosis; BiPAP, bilevel positive airway pressure.

is true about adapting other types of equipment, for example, a wheelchair when the patient is no longer able to support their head. Since nurses do not always have access to a physiotherapist or occupational therapist within a reasonable timeframe, nurses felt the need to be made aware of the range of options available, so they could address issues as quickly as possible to foster the patient's well-being.

Finally, organizational needs focused on staffing, dedicated time and an appropriate environment. Adapting the nurse-to-patient ratio was particularly important to participants, to provide safe, quality care to people with ALS and to other patients under their care. Some nurses were allowed accommodations in this regard, but it was often after negotiating – sometimes vigorously – with their manager.

Also, having dedicated time at admission was identified as important to allow the nurse to conduct a thorough initial assessment and adjust the care plan accordingly, *via* documenting the person's desired routine and, most importantly, ensuring quality of care.

Discussion

Our findings provide a better understanding of the issues nurses face when caring for people with ALS at end-of-life. The nurses describe various aspects to be considered when caring for these patients and their relatives, along with many educational, clinical and organizational needs to optimize the quality of their care. These findings highlight the unique characteristics of end-of-life care for people with ALS, including ethical and disease-related cultural aspects.

Clinical and research needs can be derived from the results of our study and are discussed here in relation to those results and the existing literature. The need for control of people living with ALS at the end-of-life, which was identified by the participants, has been addressed by Foley *et al.*[18] In their qualitative study of people living with ALS at all stages of the disease, 'control' in their relationships and demands on healthcare professionals was identified by people with ALS as a response to the multiple losses and significant lack of control experienced in all other areas of their lives. Control-oriented behaviours allowed people with ALS to remain grounded in the present and maintain a sense of normalcy. Our findings highlight that this control manifests strongly at end-of-life, through demands that nurses respect the routine of people living with ALS as much as possible.

The fight culture identified in our study has not been discussed much in literature. Nevertheless, a study from Guité-Verret and Vachon[19] on the experiences of women living with incurable metastatic breast cancer discusses the 'war metaphor'. It indicates a fighting posture, represented the women's strong desire to live, that is also contradictory since they sometimes consider themselves a 'receptacle' for a fight initiated by the doctors, from which they want to distance themselves. It would therefore be relevant to explore this fight culture among people living with ALS, as well as the impacts of this posture on their disease journey and well-being.

The results of our study described the scope and particular characteristics of the care to be provided to people living with ALS at end-of-life. This implies an organization of care and resources that must be rapidly re-evaluated and adjusted. The positive impacts of an adequate nurse-to-patient ratio[20,21] and workload[22] have been repeatedly demonstrated in many other contexts. Yet, the conditions in which nurses are regularly placed are far from conducive to quality of care or the well-being of patients living with ALS at end-of-life, their relative or the healthcare team. There even seems to be an informal form of discrimination in the admissions process for these patients. Albeit a well-intentioned way to provide quality care to some, it reduces others' access to quality end-of-life care. Coupled with the inequality of access to palliative and end-of-life care for non-oncology clients, which has already been well described in the literature,[23–26] many patients with ALS at end-of-life are currently experiencing injustice in healthcare, if not harm, because of their diagnosis. Thus, there is an urgent need to recognize the intensity of care that must be provided, increase the resources available to support relatives in home care and adjust the nurse-to-patient ratios. In this regard, it seems essential for managers to gain a better understanding of the experience of healthcare teams when providing care to a person living with ALS at end-of-life or in an advanced stage, in order to improve the quality of care provided by nurses. Better quality of care, in addition to improving end-of-life for

people with ALS themselves, would also help reduce the heavy burden on relatives.[27]

In addition to training nurses based on their identified needs, including about existing communication aids like eyetracking technology[28] for example, one other important aspect must be considered: most nurses caring for a person with ALS at end-of-life do so only occasionally. However, this frequency is expected to increase due to the rising incidence and prevalence of the disease.[2] As a result, applying new knowledge gained during continuous education can sometimes be delayed by several months. Therefore, it is important to better study methods to support the development, maintenance and reactivation of nurses' knowledge in this context.

Finally, also in terms of future research needs, it is essential to explore the experiences of other members of the healthcare team, to gain a more comprehensive view of interdisciplinary work.

Strengths and limitations of the study

This study adds to the knowledge about the nurses' experiences of caring for people living with ALS at end-of-life, through the use of in-depth interviews. The multiple-case study method also highlights the similarities and differences between care settings, thus allowing a better understanding of the issues faced.

In terms of limitations, recruitment was carried out mainly through social networks, thus excluding a pool of nurses who do not use this type of platform and probably reflecting a certain profile of nurses. Finally, the lack of nurses working the night shift also represents a limitation, since it is possible that the inherent characteristics of the work on this shift could have allowed other findings.

Conclusion

In addition to providing a better understanding of the experiences of nurses providing end-of-life care for people living with ALS, this study identified a critical need for more resources and for rethinking how care is organized. As the number of people with ALS will increase in the coming years, until a cure is found, it is imperative that we also increase our research efforts to improve the quality of life, end-of-life and quality of care available for these people and their relatives.

Declarations

Ethics approval and consent to participate

This research was conducted in accordance with the Declaration of Helsinki. The study was approved by the Research Ethics Board of Université du Québec à Trois-Rivières (CER-22-284-07.01). Free and informed consent was obtained electronically from each participant before the interviews.

Consent for publication

Not applicable.

Author contributions

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Acknowledgements

We would like to thank Confluence for the linguistic revision of this manuscript.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Competing interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Availability of data and materials

The raw data are not publicly available as this would jeopardize the confidentiality and anonymity of the participants and it is not part of the ethical approval obtained. If necessary, specific sections of the anonymized analysis matrix and verbatim could be shared individually, in French, upon reasonable request to the corresponding author.

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Supplemental material

Supplemental material for this article is available online.

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