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Priorities for Advancing Palliative Care for Amyotrophic Lateral Sclerosis: A Consensus Report From a Palliative Care for ALS Working Group in the United States

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ABSTRACT

Until there is a cure for amyotrophic lateral sclerosis (ALS), it is imperative that everyone facing this devastating illness receives care to alleviate symptoms and suffering and improve quality of life. Emerging evidence has demonstrated benefits of palliative care for people with ALS, but palliative care is not yet widely available or accessed by people with ALS throughout the disease course. The Palliative Care for ALS Working Group was formed within the International Neuropalliative Care Society, consisting of interprofessional ALS and palliative care clinicians, researchers, advocates, and patients and care partner representatives who are committed to improving palliative care for people living with ALS. The group engaged in a strategic planning process to determine what is needed to advance palliative care for people with ALS over the next 3–5 years. This report outlines the core recommendations from that strategic planning process. Recommendations are divided into five sections: (1) clinician education, (2) clinical service expansion, (3) research, (4) public awareness, and (5) policy change. The aim of this report is to provide ALS and palliative care clinicians, researchers, ALS advocacy organizations, and funders with a road map of priority areas where dedicated focus could significantly advance palliative care for people facing ALS, with the goals of relieving suffering and improving quality of life. The Palliative Care for ALS Working Group is making concrete steps toward these priority areas and will continue to serve as a convening and coordinating body for this work.

Abbreviations: ALS, amyotrophic lateral sclerosis; CAPC, Center to Advance Palliative Care; EPEC-N, Education in Palliative and End-of-Life Care for Neurology; INPCS, International Neuropalliative Care Society.

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Peer Review: This paper underwent peer review by the AANEM Clinical Publications Review Committee and review by the *Muscle & Nerve* editor. The objectives of this activity are to (1) Understand the current state of palliative care for people with ALS in the United States. (2) Assess what is needed in the coming years to advance the practice and our evidence base regarding palliative care for ALS. (3) Consider concrete steps that ALS and palliative care clinicians, researchers, advocates, funders, and other stakeholders can take to contribute to progress in this area.

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1 | Introduction

Amyotrophic lateral sclerosis (ALS) has profound impacts on physical, emotional, social, spiritual, and financial well-being throughout the disease course [1–6]. Many people with ALS suffer tremendously, and improving comfort and quality of life are high priorities among people living with this illness [7]. Palliative care is specialized medical care focused on improving comfort and quality of life for people facing a serious illness [8]. Palliative care, particularly when provided by an interdisciplinary team with specialty training, has been shown to have positive impacts on physical and emotional symptoms, quality of life, prognostic awareness, goal-concordant care, and care partner well-being for people facing a wide range of serious illnesses [9–14].

Emerging evidence suggests that palliative care can also improve outcomes for people with ALS specifically, including symptoms, quality of life, rates of advance care planning, and satisfaction with care [15–20]. Accordingly, people living with ALS and their care partners, as well as multidisciplinary ALS clinicians and guidelines committees, have called for increased integration of palliative care into ALS care, both through ALS clinicians addressing palliative care needs—such as symptoms, emotional well-being, and care planning—and through referrals to palliative care specialists when needs are pronounced, complex, or refractory [21–24].

However, per a survey reporting on 86 of 150 ALS clinics in the Northeast ALS (NEALS) Consortium, only 27% of clinics include palliative care specialists, and about half of people with ALS receive palliative care, typically in late stages of the illness or when needs are severe [1, 25]. Access to palliative care is also unequal across populations of people with ALS, with some geographic regions having few palliative care programs and some demographic groups accessing palliative care significantly less frequently than others [26–28]. In 2023, the Palliative Care for ALS Working Group was formed within the International Neuropalliative Care Society (INPCS) to advance knowledge and practice in this area [29]. In this report, members of this Working Group summarize recent literature and initiatives pertaining to palliative care for ALS; identify important gaps; and provide consensus recommendations about what is needed to improve the quality, availability, evidence, and impact of palliative care for people with ALS while simultaneously supporting ALS teams in addressing the palliative care needs of their patients as much as they can within the confines of their practice. The goal is to provide a road map of priority areas where dedicated focus could meaningfully advance palliative care for people facing ALS.

2 | Methods

The INPCS Palliative Care for ALS Working Group consists of interdisciplinary ALS and palliative care clinicians and researchers, members of ALS advocacy organizations, and patient and care partner representatives interested in advancing palliative care for ALS [29]. This group has grown steadily and, as of September 2025, it included 126 members. The Working Group held an in-person launch meeting in September 2023 to set shared goals and priorities; this was followed by monthly, hour-long video meetings during which the group members discussed clinical cases, topics relevant to the practice of palliative care for people facing ALS, and research studies and other projects focused on this area.

A subgroup of 27 members of the Working Group met in person again in September 2024 for a 4-h workshop to review existing literature about palliative care for people with ALS and to brainstorm what is needed to advance the practice of palliative care for ALS over the next 3–5 years. Ideas generated during the workshop were further refined through group discussions during Palliative Care for ALS Working Group meetings over the subsequent year, and a draft set of consensus recommendations was created. These draft recommendations were reviewed by an ALS patient-family advisory council to ensure that the perspectives of people with lived experience are represented. Ultimately, the group of authors finalized the consensus recommendations included in this report, which are intended to catalyze and focus future efforts to improve the evidence for, practice of, and access to palliative care for people with ALS. Recommendations are divided into five priority areas: (1) clinician education, (2) clinical service expansion, (3) research, (4) public awareness, and (5) policy change (Figure 1).

3 | Recommendations

3.1 | Clinician Education

Over the past decade, there has been a call for more palliative care training for neurology residents, fellows, and practicing neurologists [30–34]. Several of the seminal publications about the need for palliative care education for neurologists mention ALS as a prototypical neurologic illness that benefits from neurologists having skills to address patients' profound palliative needs. Despite this, gaps in palliative care education for neurologists persist [31, 33, 35–37]. More recently, there have also been complementary calls to increase education about neurology topics, including ALS, during palliative care training programs and for practicing palliative care clinicians [1, 38]. Here, too, gaps in education remain. For example, a 2025 survey study of ALS and palliative care clinicians found that ALS clinicians want and need education about palliative care, and palliative care clinicians caring for people with ALS want and need education about ALS [1]. Specific topics that palliative care providers want to learn more about include the ALS disease trajectory and prognostication, ALS disease-modifying therapies and equipment, and management of dyspnea and respiratory failure. Specific topics that neurology providers would like to learn more about include pain management, addressing spiritual/existential distress and care partner burden, advance care planning, and determining who is appropriate for palliative care versus hospice and how to refer them. Clinicians indicated a desire to learn through webinars, presentations at professional meetings, and on-demand online content and resources (Table 1).

There are currently a variety of educational resources to help ALS clinicians of all disciplines improve their knowledge and clinical skills in palliative care. These include Education in Palliative and End-of-Life Care for Neurology, VitalTalk, the Serious Illness

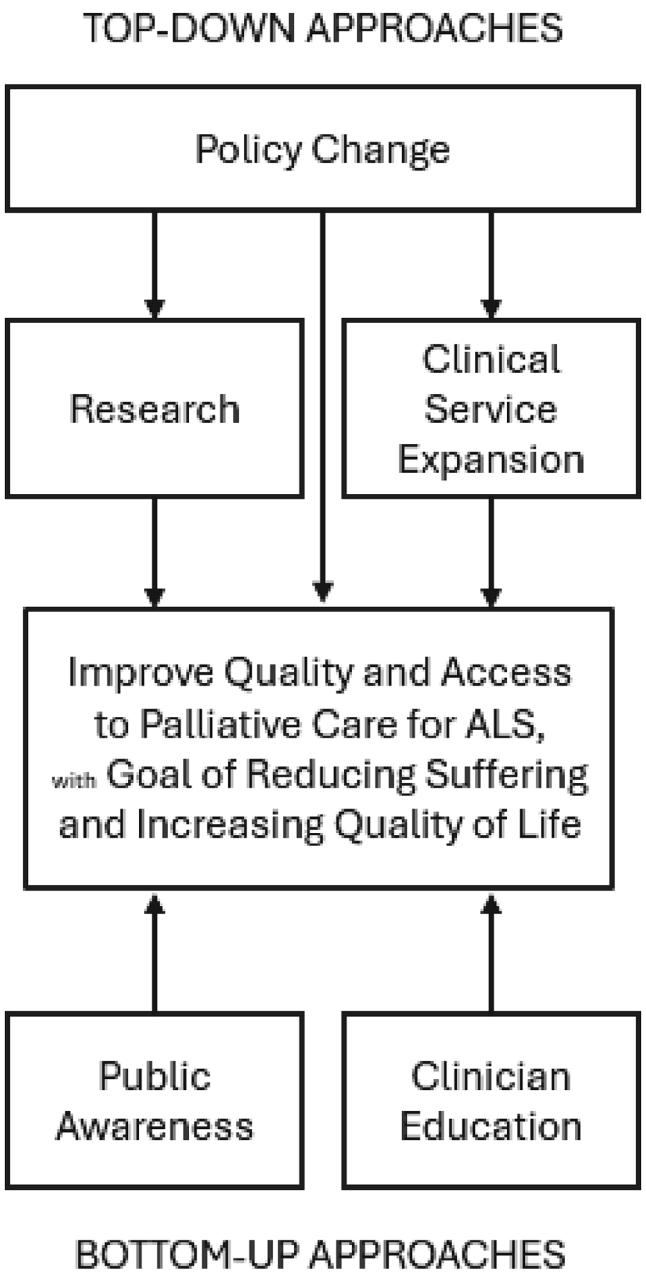

FIGURE 1 | Conceptual framework of priority areas where focus could advance palliative care for people facing ALS. ALS, amyotrophic lateral sclerosis.

Conversation Guide, the Center to Advance Palliative Care (CAPC), the INPCS Annual Meeting, the INPCS Neuropalliative Care Certificate Course, the INPCS Education Speaker Series, and the INPCS Palliative Care for ALS Working Group monthly meeting series (Table 2) [36, 39–45]. However, only the Palliative Care for ALS Working Group meeting series is specific to ALS, and ALS clinicians have expressed a desire for additional educational resources that focus on addressing the palliative care needs of people with ALS specifically. Accordingly, the Palliative Care for ALS Working Group is developing multimedia, online courses for ALS clinicians of all disciplines about addressing the palliative care needs of people with ALS, which will be freely available through the ALS Association website [46]. The group is also developing a webinar and toolkit to provide education and resources about ALS to interprofessional palliative care clinicians, which will be available on the CAPC and INPCS websites. Each of these curricula is being codesigned with close stakeholder involvement, which is becoming a medical education best practice [47]. The INPCS website will serve as a centralized platform to collate educational content for both ALS and palliative care clinicians about palliative care for people with ALS so as to facilitate the dissemination of high-quality content and reduce barriers to access [48].

Systemic changes should ideally be made to encourage clinicians to fully utilize the educational resources available to them [49, 50]. This is especially true for clinicians who have less nonclinical time for continuing education (e.g., nurses, chaplains, social workers) [51]. Systemic changes could include stipends or recognition for engaging in continuing education; continuing education credits; board certification requirements; or institutional promotion pathways for nurses, social workers, chaplains, and other clinicians who value continuing education and specialized training.

For clinicians in training, neurology residencies and neuromuscular fellowships should, and some do, incorporate clinical rotations and didactics in palliative care (including serious illness communication training; Table 1). Many nursing, social work, and rehabilitation therapy training programs are also increasing their palliative care content and experiences. Palliative care training programs, too, should incorporate—and some are incorporating—rotations and didactics focused on neurology topics such as ALS. In addition, an increasing number of neurologists are choosing to do a 1-year, full-time hospice and palliative medicine fellowship to become neuropalliative care specialists; these providers who have expertise in both ALS and palliative care can make invaluable contributions both through patient care and by educating their fellow clinicians in each field.

Another powerful way to promote bidirectional learning between ALS and palliative care clinicians is through regularly collaborating in the care of patients. This can occur through embedding palliative care clinicians in ALS clinics, which is recommended in National Institute of Health and Care Excellence guidelines from the United Kingdom, and/or by developing consistent working relationships between ALS and palliative care teams (Table 1) [52]. As evidence of the bidirectional education that can occur when clinicians collaborate closely, a 2026 study showed that ALS teams with an embedded palliative care clinician rated the skills of their ALS team as a whole, and those of palliative care clinicians, higher in several areas, including management of pain and dyspnea and end-of-life care, compared with teams that did not have an embedded palliative care clinician [53]. Another study showed that advance care planning documentation improved in neurologists who worked with an embedded palliative care clinician [54].

3.2 | Clinical Service Expansion

Although outpatient palliative care began in cancer centers, over the past decade it has been increasingly extended to people with other serious conditions, including neurologic, cardiac, pulmonary, and hepatic illnesses, motivated by emerging research and

TABLE 1 | Summary of recommendations.

Clinician education
1. Educate neurology clinicians and trainees about palliative care, through didactics, on-demand resources, and clinical experiences
2. Educate palliative care clinicians and trainees about ALS, through didactics, on-demand resources, and clinical experiences
3. Increase collaboration and communication between ALS and palliative care clinicians, providing opportunities for on-the-job training
Clinical service expansion
1. ALS teams should routinely screen for palliative care needs and develop guidelines about how to respond to identified needs, including criteria for referral to palliative care
2. ALS and palliative care teams should have robust psychosocial staffing to address the profound psychosocial and spiritual issues that arise for people with ALS
3. Care should be provided to care partners as well as patients with ALS
4. Increase the number of palliative care services that can care for people with ALS, leveraging clinician billing and telemedicine; use a directory to make it easy to find and access these programs
5. Strengthen collaboration between ALS and palliative care clinicians, through embedding palliative care clinicians on ALS teams and/or increasing palliative care referrals
Research
1. Randomized trials are needed to clarify the impact of palliative care for ALS, which people with ALS need palliative care, and the ideal care delivery model
2. Create systems to routinely screen people with ALS and their care partners for quality of life and other patient- and family-centered palliative care needs
3. Generate more high-quality evidence about how to improve symptoms (e.g., sialorrhea, muscle cramps, dyspnea, fatigue) and other needs in ALS specifically
Public awareness
1. Partner with ALS organizations to improve awareness and understanding of palliative care among people with ALS, their care partners, and ALS clinicians
Policy change
1. Make collaboration with palliative care a criterion for ALS Treatment Center of Excellence designation
2. Pass the Palliative Care and Hospice Education and Training Act
3. Revise hospice policies for ALS to cover equipment (e.g., noninvasive ventilators), services (e.g., respiratory therapy), and in-home care that contribute to comfort and quality of life

Abbreviation: ALS, amyotrophic lateral sclerosis.

clinical experiences that have demonstrated the benefits of palliative care for these populations [10, 55–58]. In a 2025 study, people with lived experience with ALS who received palliative care alongside their ALS care reported that the service helped improve their symptoms (including pain, other physical symptoms, and mood), support their care partners, increase their understanding of their care options, and provide timely responses to their questions and concerns [1, 2]. In addition to this and other studies that have shown improvements in symptoms, quality of life, and prognostic awareness with palliative care [9, 10, 59, 60], multiple studies have demonstrated substantial cost savings from palliative care, largely by helping people with serious illness avoid unwanted hospital admissions at the end of life [56, 61, 62]. These findings have captured the attention of health system leaders struggling in the face of ballooning health care costs and have helped catalyze growth of the field of palliative care.

In addition, palliative care providers (physicians and advance practice providers) in the US can bill for their services, and mental health professionals (e.g., social workers, psychologists) can bill for counseling, helping substantially to offset the cost of interdisciplinary palliative care teams [63]. Furthermore, the expansion of telemedicine, which was accelerated by the COVID-19 pandemic, has substantially extended the reach of palliative care services to many homebound patients and people in rural areas, and a large, multisite study demonstrated that this approach is not inferior to in-person care [64]. In a recent survey of people with ALS who used telehealth services, 62% of respondents said they felt it improved their quality of life, and many also reported that it saved them time and money compared with in-person care [65]. Taken together, these findings demonstrate that palliative care for ALS is feasible, impactful, and gaining steam.

TABLE 2 | Neuropalliative care educational resources.

Curriculum/ resource	Format	Intended audience	Strengths	Accessibility/ limitations	ALS specificity
Education in Palliative and End-of-Life Care for Neurology (EPEC-N) https://www.inpcs.org/i4a/pages/index.cfm?pageid=3324	Modular curriculum of presentations and presenter guides for instructor use	Neuropalliative care clinicians	Neurology-specific framing; addresses prognostic uncertainty and disease trajectories. High-quality slides, table of contents	Requires a speaker or facilitator with subject area expertise. No live or recorded instruction. All presentations are free, open source	Limited ALS-specific details; may require supplementation
VitalTalk https://vitaltalk.org	Communication skills curriculum, workshops, live role-play exercises	Clinicians of any discipline caring for patients with serious illness	Communication frameworks transferable to ALS. Training courses with role-play and feedback	Courses are expensive and many require more than a 1-day time commitment. Several toolkits and the mobile app are free	Not ALS specific; requires adaptation
Serious Illness Conversation Guide https://ariadnelabs.org/serious-illness-care/	Structured conversation guide, scripts and tools	Clinicians of any discipline caring for patients with serious illness	Clear structure for serious illness conversations. User-friendly PDF available	Must sign in to receive the guide	Not ALS specific; requires adaptation
Center to Advance Palliative Care (CAPC) https://capc.org	Online courses, toolkits, certificate programs	Clinicians of any discipline caring for patients with serious illness	Strong foundational and systems-level PC education, some is relevant to ALS	Organizational annual CAPC membership fee required to access many of the courses and toolkits	ALS-specific content is in development
International Neuropalliative Care Society (INPCS) https://inpcs.org	Educational resources, webinars, conferences	Neuropalliative care clinicians	Neuropalliative care focus. Modules, webinars, and disease-specific resources freely available	More of a community and network than a cache of educational resources	Some ALS-specific content

(Continues)

TABLE 2 | (Continued)

Curriculum/ resource	Format	Intended audience	Strengths	Accessibility/ limitations	ALS specificity
INPCS Palliative Care for ALS Working Group https://inpcs.tradewing.com/login?redirect=%2Fcommunity; https://www.youtube.com/playlist?list=PLeuJE_iCmCE5SAka4gNAXMe0-qpSl8R	Webinar series, case-based discussions	Clinicians, researchers, and others with specific interest in PC for people with ALS	ALS-specific content from people who provide PC to people with ALS; program development guidance	The Working Group can be joined through the INPCS online community; past webinars available on YouTube channel	All content is specific to palliative care for ALS

Abbreviations: ALS, amyotrophic lateral sclerosis; PC, palliative care.

Although access to palliative care for people with ALS is improving, it is still a relatively new area of practice that is not yet universally available [66]. In a 2025 survey, ALS clinicians reported that they refer an average of 58% of their patients to outpatient palliative care at some point in the illness, though the study's authors acknowledged that clinicians may have overestimated this percentage because of recall bias, and they noted that many people are referred late in the course of the illness [1]. In a different study of people with ALS who received palliative care, 33% said they felt they received the service too late in the course of their illness, and none thought they received the service too early [2]. Lack of access to palliative care programs that can care for people with ALS has been cited by ALS clinicians as a significant barrier to ideal care [1]. To address this barrier, some ALS clinics are embedding palliative care clinicians within their teams, and others are developing collaborations and consistent working relationships with separate palliative care clinics or home-based palliative care programs that can see their patients [66]. At the same time, ALS clinicians should continue to bolster their skills in symptom management, advance care planning, and psychosocial support in order to be able to address the needs of people with ALS who do not have access to palliative care or do not have a high level of distress and thus do not need a palliative care specialist.

A number of changes are needed to ensure that all people with ALS have appropriate care for their palliative care needs (Table 1). First, ALS teams should routinely and systematically screen patients for a broad range of palliative care needs, including physical and emotional symptoms, psychosocial needs, spiritual and existential distress, and care partner needs, using a tool such as the ALS-Specific Quality of Life Short Form or the Brief Needs Assessment Tool, which has been used in other neurologic populations and could be modified for ALS [67, 68]. Multidisciplinary ALS clinics should develop guidelines about those needs that can be addressed by members of the ALS team, which patients should be referred to palliative care specialists, and who on the ALS team should introduce palliative care to patients and families (generally the neurologist, though workflows may vary between clinics).

Given that people with ALS and their care partners experience substantial emotional, psychosocial, and existential distress, both ALS and palliative care teams should have robust staffing of psychosocial clinicians, such as social workers, psychologists, and/or chaplains, to the extent possible given financial realities. Care should be directed not just to patients but also explicitly to care partners, who are important in their own right and essential to patient well-being [69].

As described in the previous section, palliative care clinicians' knowledge of ALS must be increased so that more palliative care clinicians feel comfortable caring for this population and can do it with expertise. With this training, existing palliative care programs that are focused on people with cancer or otherwise exclude patients with ALS should consider expanding their eligibility criteria to include people with ALS and other serious neurologic conditions. To help ALS clinicians, patients, and families find and access these programs, an online directory of palliative care programs that have particular expertise in ALS has been created [70]. Additionally, continuing

to enable care by means of video telemedicine is essential to maximize the reach of palliative care to people with ALS, many of whom are homebound.

Although this Working Group believes each of these changes is achievable in many health settings, the authors acknowledge that they may not all be possible everywhere or in the near term. Despite strong evidence for the benefits of multidisciplinary ALS care, less than half of people with ALS receive this care, and primary care doctors and community neurologists seeing people with ALS, in particular, may not have the time to make all the changes suggested in this report [4]. However, the number of multidisciplinary ALS clinics, like palliative care programs, is growing steadily. Furthermore, an advantage of palliative care may be to offload some work from busy neurologists, including those in resource-limited settings, and help them feel more supported [71]. Clinicians should be encouraged to start with changes that feel achievable—for example, using the directory of palliative care programs with experience in ALS [70] to find appropriate programs to which to refer patients—and strive for more resource-intensive changes (e.g., adding psychosocial clinicians to their team), when possible, and potentially with support from programs like the Hoffman ALS Clinic Capacity Awards Program, which provides funds to increase access to multidisciplinary ALS care [72].

3.3 | Research

More high-quality research is needed to further characterize the benefits of palliative care for people with ALS and their care partners, clarify which palliative needs can be addressed by ALS teams and who needs palliative care specialists, and explore the best models for palliative care delivery for this population (Table 1). Several single-center trials have provided promising evidence for the benefits of palliative care for people facing ALS. For example, a single-center, randomized controlled trial of immediate versus delayed palliative care for 50 people with advanced ALS, multiple sclerosis, or Parkinson's disease in Italy found that there were significant improvements in quality of life, pain, dyspnea, bowel symptoms, and sleep at 16 weeks of follow-up in the immediate palliative care arm [15]. In the US, a case series showed that an interdisciplinary palliative care team frequently addressed physical symptoms, psychosocial and spiritual concerns, advance care planning, and care partner needs for people with ALS. Rates of advance care planning increased significantly during the time that patients were receiving palliative care, and hospice use was common [16]. A case series from another US institution similarly showed that palliative care for people with ALS was associated with higher rates of advance care planning discussions, designation of health care proxies, and hospice use [17]. Two other US groups have published about their experience integrating a palliative care specialist into an ALS team, demonstrating that palliative care physicians helped patients with physical and psychological symptoms, advance care planning, and medical decision-making [19, 20]. In addition, a prospective feasibility study conducted in Canada showed that people with ALS who received palliative care and their care partners reported that palliative care was helpful and that they would recommend it to others with ALS [18]. Furthermore, proactive, early palliative care has been shown to be impactful for a variety of conditions, including other neurodegenerative disorders [9, 10, 12, 13]. Despite this promising emerging evidence, there is still a lack of high-quality, multisite, randomized controlled trial evidence to delineate the impact of palliative care for people with ALS specifically, which is urgently needed to help ALS clinicians, patients, and care partners understand the role and value of palliative care and induce health systems to fund palliative care for this population.

Second, we do not yet know which people with ALS need palliative care delivered by palliative care specialty teams rather than having their palliative care needs addressed by the ALS team. Multidisciplinary ALS teams are large, include a wide range of disciplines, and have prolonged visits with patients and families that frequently cover each of the core components of palliative care: symptom management, advance care planning, and psychosocial support for patients and care partners [1]. Given this structure, it is possible that multidisciplinary ALS teams can sufficiently address many people's palliative care needs. However, only about 40% of people with ALS receive care at multidisciplinary ALS clinics, and these clinics typically see patients only quarterly, which may be an insufficient visit frequency for people with particularly intense needs or rapidly progressive ALS [1, 4, 22, 73]. In addition, the staffing of psychosocial clinicians on ALS teams is often inadequate to address the tremendous psychosocial needs of patients and care partners facing ALS [1, 74]. For these reasons and others, there likely are people and families facing ALS who would benefit from palliative care alongside their ALS care. High-quality research is needed to answer the questions of how ALS teams can best address people's palliative care needs, which people with ALS need additional support from palliative care specialists, and what the ideal care delivery model for palliative care for people with ALS is. These data could help motivate ALS clinicians to address palliative care needs and refer appropriate patients to specialty palliative care. In addition, given that there are many areas of the US with scarce access to multidisciplinary ALS care and palliative care, research into the most efficient ways to address the palliative care needs of patients in resource-limited settings is needed [25, 66, 73]. Furthermore, there is a need for research investigating how disparities can be minimized and how equity in access to palliative care for people facing ALS can be improved.

Third, more research is needed to determine practical methods to routinely screen for quality of life and other palliative care needs in people with ALS and their care partners (Table 1). Assessing the quality of life of people with ALS is an important component of ALS care, as this issue is of utmost importance to people with ALS, and routine, systematic assessment of quality of life can help identify the people most likely to benefit from palliative care [75, 76]. Furthermore, quality of life is an important outcome that should be used in studies about palliative care for ALS [58]. Several quality of life measures have been developed and used for people with ALS, but as yet there is no consensus about which one is best, for either clinical or research purposes [77–80]. The field would also benefit from further input from people with lived experience about what quality of life means to them and what truly reflects and affects their quality of life, in order to create more clarity and reach a consensus about how quality of life in ALS should be assessed and addressed [81]. Quality of life measures should ideally probe a wide range of

contributing factors (e.g., joy, meaning, purpose) as well as factors that detract from quality of life (e.g., demoralization, loss of control) [82]. On a related note, research is needed that focuses on how best to practically screen for other common palliative care needs beyond quality of life (e.g., symptoms, care partner well-being) in people with ALS.

Finally, substantially more research is needed that addresses how to improve symptoms in ALS (Table 1). Although impressive, coordinated research efforts have been made to study disease-modifying treatments for ALS, substantially fewer studies have investigated specific approaches to manage symptoms in ALS [22, 83–86]. There are many symptoms that are common in ALS, including fatigue, pain, spasticity, muscle cramps, sialorrhea, tenacious respiratory secretions, dyspnea, anxiety, and demoralization, which have a profound impact on people's daily experience and need to be better characterized. Even more importantly, there is a need for high-quality studies about how to best treat these symptoms in ALS specifically rather than extrapolating from research conducted in other populations. There are also other concerns related to ALS, such as the high rate at which medical aid in dying is requested and used, that warrant further investigation in this population specifically [3, 87]. This is a complex topic that will benefit from careful examination using both quantitative and qualitative methods, taking into consideration regional and cultural differences as well as ethical principles.

3.4 | Public Awareness

Advancing palliative care for those affected by ALS will also require a widespread shift in public awareness given that misunderstandings regarding palliative care remain common (Table 1) [88–91]. The Health Information National Trends Survey recently found that 88% of US adults had either never heard of palliative care (71%) or had misconceptions about it (16%) [88, 91]. Despite data from multiple clinical trials showing that people who receive palliative care live as long as—and in some cases longer than—those who do not, palliative care is still widely conflated with hospice and end-of-life care [9, 10, 14, 55, 91]. Lack of knowledge about palliative care may be especially common in the ALS community because palliative care has not been available to people with ALS for as long as it has for people with cancer, for example, and neurologists also often do not understand palliative care fully [92].

However, when people with ALS understand what palliative care is, and experience it, they have overwhelmingly positive impressions about it, highlighting that focused efforts to overcome the stigma and misconceptions that prevent initial contact with palliative care are important [2, 88]. In a recent survey, 44% of people facing ALS preferred the term "supportive care" to describe palliative care services, whereas 32% preferred the term "palliative care," and 18% preferred another term, such as "symptom management" [1, 2]. Regardless of which name is used, a widespread, coordinated effort is needed to describe the service in straightforward terms that people can understand and remember, such as "an extra layer of support to improve quality of life in the face of ALS." Its goal should be explained as "to help people live as well as possible for as long as possible." Nonprofit ALS advocacy organizations, which represent and have the ear of the ALS community, will be essential to this messaging campaign. The INPCS Palliative Care for ALS Working Group is partnering with ALS organizations to develop and publicize online resources for people with ALS, their care partners, and ALS clinicians to demystify palliative care [93].

Integrating palliative care clinicians into the multidisciplinary ALS team, so that people receive it as part of their routine ALS care, could also help reduce stigma about and barriers to initiating palliative care by reframing palliative care as longitudinal, complementary support provided throughout the illness [53]. A scoping review found that public awareness of and perceptions about palliative care are strongly influenced by the availability of such services [88].

3.5 | Policy Change

Several policy changes could substantially accelerate progress. First, practice guidelines should be updated as emerging evidence demonstrates how to best address the palliative care needs of people with ALS [21, 52]. Subsequently, ALS organizations should consider whether integration of palliative care clinicians into the ALS team and/or concerted collaboration with palliative care teams should be a criterion for Treatment Center of Excellence designation, which could be a powerful intervention to drive practice change, as it has been in other disease areas (Table 1) [94]. The International Alliance of ALS/MND Associations has made steps in this direction, asserting that care partners have the right to palliative care support [95].

Second, federal policy to support palliative care workforce growth is needed. The palliative care workforce is projected to decline over the next decade and, without policy change, not return to current levels until approximately 2045 [96]. Thus, renewed advocacy for passage and full funding of the Palliative Care and Hospice Education and Training Act is warranted, given that the bill has been stalled in congressional committees since 2023. This bill would increase palliative care curricula, palliative care training programs for clinicians of multiple disciplines, and early career research awards. Each mechanism is needed to address the projected decrease in the palliative care workforce and build both clinical and academic pipelines.

Finally, hospice policy in the US should ideally be adjusted to allow for more services for people with ALS. Although palliative care is distinct from hospice care, many people with ALS who are receiving palliative care eventually transition to hospice care, and Medicare rules about what care, treatments, and equipment can be provided in hospice are not currently aligned with the needs of people with ALS. Several changes to the Medicare hospice benefit are needed to better accommodate people with ALS. For example, many people with ALS are not able to keep their noninvasive ventilator, or receive respiratory therapy services to adjust its settings, while receiving hospice care [74, 97]. As another example, most people with advanced ALS require intensive, hands-on in-home caregiving to help them adjust their position, toilet, and eat or be fed, and yet compensation and assistance for hands-on care for people in hospice is currently limited. The Department of Veterans' Affairs offers an instructive

care model that helps to address both of these shortcomings; veterans with ALS are able to receive care from a hospice team and other medical teams concurrently and, because ALS is a service-connected disability, those with ALS can receive funds to help cover the costs of in-home care [98]. Other people with ALS also deserve these allowances.

4 | Conclusions

Collaborative work by a group of ALS and palliative care clinicians, researchers, advocates, people living with ALS, and care partners from across the US developed a set of consensus priorities for advancing palliative care for ALS with the ultimate goal of improving quality of life for people with ALS. Progress in the areas of clinician education, clinical service expansion, research, public awareness, and policy change is needed to catalyze improvements in care. Funders and people working in the fields of ALS and palliative care are encouraged to prioritize these areas. The Palliative Care for ALS Working Group will continue to serve as a convening body for this work and welcomes anyone who is interested to get involved. By working together, people with ALS can be helped to live as well as possible for as long as possible, until there is a cure.

Author Contributions

Kara E. Bischoff: conceptualization (equal), methodology (equal), project administration (lead), writing – original draft preparation (lead), writing – review and editing (lead). **Yaowaree L. Leavell:** writing – original draft preparation (supporting), writing – review and editing (supporting). **Jessica M. Besbris:** writing – original draft preparation (supporting), writing – review and editing (supporting). **Christi Lero:** writing – original draft preparation (supporting), writing – review and editing (supporting). **Kelsey Noble:** writing – original draft preparation (supporting), writing – review and editing (supporting). **Astrid Grouls:** writing – review and editing (supporting). **Jerome Kurent:** writing – review and editing (supporting). **Benzi M. Kluger:** writing – review and editing (supporting). **Steven Z. Pantilat:** writing – review and editing (supporting). **Ambereen K. Mehta:** conceptualization (equal), methodology (equal), writing – original draft preparation (supporting), writing – review and editing (supporting).

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Ethics Statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Conflicts of Interest

Dr. Pantilat has served as a consultant to InflectionIQ, has received honoraria from the Cambia Health Foundation and The Governance Institute, and has received royalties from McGraw-Hill. All relevant financial relationships have been mitigated according to American Council for Continuing Medical Education standards. The remaining authors have no conflicts of interest.

Data Availability Statement

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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