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RESEARCH

# Embedded Palliative Care for Amyotrophic Lateral Sclerosis

## A Pilot Program and Lessons Learned

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## Abstract

### Background and Objectives

Palliative care (PC) is recommended for people with amyotrophic lateral sclerosis (ALS), but there is scant literature about how to best provide this care. We describe the structure and impact of a pilot program that integrates longitudinal, interdisciplinary PC into the care of patients with ALS.

### Methods

Observational cohort study of patients with ALS referred to outpatient PC and seen for at least 3 PC visits October 2017–July 2020.

### Results

Fifty-five patients met the inclusion criteria. Three-quarters (74.5%) were Caucasian, and 78.2% spoke English. Patients were referred for advance care planning (58.2%), support for patient/family (52.7%), and symptoms other than pain (50.9%). Patients had a mean of 5 scheduled PC visits, the majority occurred by video. A PC physician, nurse, social worker, and chaplain addressed pain (for 43.6% of patients), nonpain symptoms (94.5%), psychosocial distress (78.2%), spiritual concerns (29.1%), care planning (96.4%), and supported family caregivers (96.4%). With PC, the rate of completion of advance directives increased from 16.4% to 36.4% ($p = 0.001$) and Physician Orders for Life-Sustaining Treatment forms from 10.9% to 63.6% ($p < 0.001$). Of the 27 patients who died, 77.8% used hospice, typically for more than 30 days. Eleven patients obtained aid-in-dying prescriptions, and 8 took these medications, accounting for 29.6% of the deaths.

### Discussion

Integrating longitudinal, interdisciplinary PC into the care of patients with ALS is feasible, addresses needs in multiple domains, and is associated with increased rates of advance care planning. Controlled studies are needed to further elucidate the impact of PC on patients with ALS, their families, and clinicians.

Amyotrophic lateral sclerosis (ALS), the most common motor neuron disease, is characterized by progressive weakness and loss of function that can be severely distressing for patients and their loved ones.[1-3] Motor neurons controlling the limbs, trunk, and muscles of speech, swallowing, and respiration are involved, with death usually resulting from respiratory failure

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within 2–3 years from diagnosis, although a minority of patients can live significantly longer.[2,4] At present, only 2 Food and Drug Administration–approved disease-modifying medications are available, which slow disease progression modestly but do not reverse or cure the disease.[5-8] Although the specific symptoms experienced by each patient with ALS are variable, progressive weakness, spasticity, sialorrhea, dysarthria, dysphagia, weight loss, shortness of breath, and pseudobulbar affect are all common.[9-13] Up to 15% of patients with ALS also develop frontotemporal dementia.[14] These myriad symptoms, the relentless progression of losses, and the inevitability of death from the illness frequently strain both patients and their caregivers. Interdisciplinary care aimed at decreasing physical, psychological, social, and spiritual suffering is recommended.[15-17] Furthermore, particularly given the communication challenges that are common in ALS, early conversations about patients' values and preferences are important to prepare for decisions about life-prolonging interventions such as artificial nutrition and mechanical ventilation.[18]

Palliative care (PC) is defined by the Center to Advance Palliative Care as "specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family."[19] To date, small studies have suggested that PC can improve quality of life for patients with ALS and their caregivers and also reduce health care utilization at the end of life.[20-24] Studies have also shown that PC provided early in the ALS disease course may be associated with lower rates of prolonged or complicated grief for caregivers.[25] Early PC for patients with ALS has been recommended by multiple professional organizations, including the European Federation of Neurological Societies, the National Institute for Health and Care Excellence, and the American Academy of Neurology, to assist with symptom management, care planning, and support for family caregivers.[26-29] Despite these consensus recommendations, there is scant literature demonstrating effective models for delivering integrated PC to patients with ALS.[13,22,30] Here, we describe a collaborative care model developed to provide longitudinal, interdisciplinary PC to patients and families facing ALS to understand its role and impact as well as to share lessons learned that can inform other groups who are developing such collaborations.

# Methods

## Study Design and Setting

We conducted an observational cohort study of patients with ALS who were longitudinally comanaged by the ALS and PC clinic teams through a collaborative care pilot program at the University of California, San Francisco (UCSF). In October 2017, we embedded a specialty PC team within the ALS clinic at UCSF. Patients with ALS are referred to the PC team for comanagement by ALS physicians at their discretion, generally for assistance with symptom management when it became complex or intensive, for assistance with goals of care discussions when they became complicated, and/or for psychosocial or spiritual support for the patient or family when distress was particularly marked. When patients are referred for PC comanagement, the PC teams work in close collaboration with the interdisciplinary ALS team to provide intensive and expert support that is not possible from either team alone. For example, in patients who are comanaged, the ALS physician often focuses on tracking the patient's neurologic status, prognosticating in light of the trajectory that was observed, and counseling about disease-modifying treatments such as edaravone, whereas the PC physician focuses on management of physical and psychological symptoms such as sialorrhea, shortness of breath, pain from disability, and reactive depression. The ALS nurse often helps with care coordination relating to disease-modifying treatments, indwelling lines or percutaneous endoscopic gastrostomy (PEG) tubes, and assistive equipment, while the PC nurse follows-up between visits about symptoms to assesses patients' responses to medications and other therapeutic trials. The part-time ALS social worker counsels patients about their eligibility for Medicare based on their ALS diagnosis and services available through the ALS Association, whereas the PC social worker provides emotional support to patients and family members and assists with nonpharmacologic symptom management through mindfulness and other coping strategies. Overall, the 2 interdisciplinary teams are very collaborative but not duplicative and operate with clear division of labor.

The transdisciplinary PC team consists of physicians, a full-time nurse, a full-time social worker, and a part-time chaplain. The PC team sees patients as an transdisciplinary team, with a physician, the nurse, and either the social worker or chaplain (depending on patients' needs and clinician schedules) seeing patients together during the vast majority of scheduled visits. Individual PC clinicians follow up with patients frequently between scheduled team visits, based on needs that are identified. At the beginning of our collaboration, PC providers shadowed ALS clinicians during their visits, and vice versa, to better understand each other's practice and consider how the 2 teams could work together to deliver well-coordinated, comprehensive care. Initially, we had a model where most patients saw the PC team on the same day that they came to the medical center to see the ALS team. This approach has evolved in time, as telemedicine has been increasingly adopted, so that now patients primarily see the PC team via video on a different day than their ALS visit. We have found this model to be preferable because patients often become fatigued from sequential ALS and PC visits on the same day and because the desired frequency of PC visits is often different than for ALS visits. The frequency of PC follow-up visits is determined by the PC team based on the patient's and family's needs; generally every 1 to 3 months. Close communication and collaboration between the ALS and PC teams has continued throughout this evolution;

clinicians route notes to each other after each clinical encounter and meet periodically for case conferences about shared patients, in addition to communicating informally.

### Participants

Patients with ALS who were seen by the PC team at least 3 times between October 2017, when our embedded PC pilot program began, and June 2020 were included in the study cohort. The requirement of having had at least 3 PC visits was used as an inclusion criterion so that we could understand the impact of longitudinal PC comanagement on patients with ALS and not focus on patients who had recently established PC through this growing pilot program.

### Procedure

A study coordinator abstracted baseline demographic and clinical characteristics, including ALS Functional Rating Scale–Revised score (range 0–48, with higher scores indicating better function), number and mode of PC visits, and life-sustaining treatments received from the electronic health record (EHR). Our PC team collects standardized Palliative Care Quality Network data on all clinical encounters, which include screenings and interventions performed by the PC team, and rates of advance care planning (ACP) documentation.[31] For patients who died, the coordinator also collected information about their end-of-life course, including hospice utilization, location of death, and use of California's End of Life Options Act, which allows for medical aid in dying (MAID).

### Analysis

Descriptive statistics, including frequencies, means, and 95% confidence intervals, were used to examine the distribution of measures. McNemar tests were conducted to determine the change in rates of advance directives and Physician Orders for Life-Sustaining Treatments (POLST) forms from before to after PC consultation. An alpha of <0.05 was used to determine statistical significance. All data analysis was undertaken using the Statistical Package for the Social Sciences for Mac version 27.

### Standard Protocol Approvals, Registrations, and Patient Consents

This study was approved by the UCSF Internal Review Board (IRB number 13-10538).

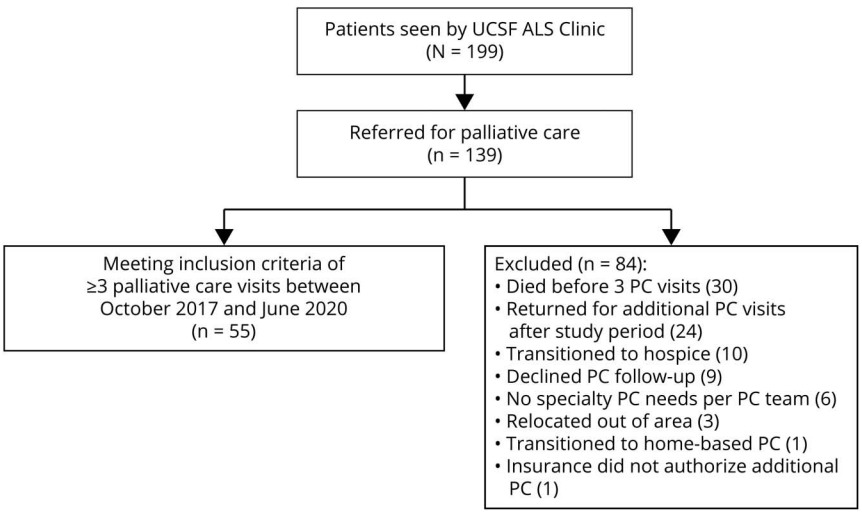
### Data Availability

All data not published within the article will be shared in an anonymized form at the request of any qualified investigator.

## Results

A total of 55 patients with ALS had at least 3 visits with the PC team over the study period and were included in our study cohort (Figure 1). Average age was 65.8 years, and 47.3% were women. Overall, 74.5% (n = 41) of patients identified as White, 11.0% (n = 6) as Asian, and 9.1% (n = 5) as mixed race/other (Table 1). Nine percent (n = 5) were Hispanic. The preferred language was English for 78.2% of patients (n = 43). Over half of patients (58.2%) had Medicare, and 7.3% had Medi-Cal as their primary insurance type. Nearly three-quarters of patients (72.7%) were married, and 96.4% had a family caregiver. The mean distance from patients' city of residence to the clinic was 72.3 miles (range 0–355 miles). Overall, the demographics of patients who were included in our study cohort were similar to the demographics of the entire population of patients seen at the UCSF ALS clinic, where average age was 66.0 years, 48.2% were women, 71.8% were White, and 64.8% were married.

**Figure 1** Flowchart of Patients With ALS




ALS = amyotrophic lateral sclerosis; PC = palliative care; UCSF = University of California, San Francisco.

**Table 1** Demographic and Clinical Characteristics at the Time of PC Referral

| Characteristic | |
|---|---|
| **Age, y, mean (range)** | 65.8 (26–87) |
| **Sex, female, % (n)** | 47.3 (26) |
| **Preferred language, % (n)** | |
| **English** | 78.2 (43) |
| **Arabic** | 3.6 (2) |
| **Cantonese** | 3.6 (2) |
| **Spanish** | 3.6 (2) |
| **Tagalog** | 3.6 (2) |
| **Other** | 7.2 (4) |
| **Race, % (n)** | |
| **White** | 74.5 (41) |
| **Asian** | 11.0 (6) |
| **Hawaiian/other Pacific Islander** | 1.8 (1) |
| **Black or African American** | 1.8 (1) |
| **American Indian** | 1.8 (1) |
| **Mixed/other** | 9.1 (5) |
| **Hispanic/Latino, % (n)** | 9.1 (5) |
| **Married, % (n)** | 72.7 (40) |
| **Family caregiver (yes), % (n)** | 96.4 (53) |
| **Distance from residence to San Francisco, miles, mean (median, range)** | 72.3 (37.0, 0–355) |
| **Primary insurance, % (n)** | |
| **Medicare** | 58.2 (32) |
| **Medi-Cal** | 7.3 (4) |
| **Private** | 32.7 (18) |
| **Veteran's administration** | 1.8 (1) |
| **Time from first ALS symptoms to first PC visit, mo, mean (median, range)** | 36.9 (25, 4–197.0) |
| **Time from first UCSF ALS clinic visit to first PC visit, mo, mean (median, range)** | 16.7 (6, 0–137.0) |
| **Palliative performance scale score (n = 54), mean (median, range)** | 50.7% (50%, 10–90%) |
| **ALSFRS-R score (n = 52), mean (median, range)** | 26.8 (28, 1–44) |
| **FVC % predicted (n = 48), mean (median, range)** | 53 (48.5, 10–117) |
| **PEG tube (n = 55), % (n)** | 49.1 (27) |
| **Tracheostomy (n = 55), % (n)** | 14.5 (8) |

Abbreviations: ALS = amyotrophic lateral sclerosis; ALSFRS-R = Amyotrophic Lateral Sclerosis Functional Rating Scale–Revised; FVC = forced vital capacity; PC = palliative care; PEG = percutaneous endoscopic gastrostomy; UCSF = University of California, San Francisco.

Patients were referred to PC a median of 6 months after establishing care with the ALS team at UCSF. Twenty-three patients (41.8%) were seen by PC within 3 months of establishing care in the UCSF ALS clinic. Patients had a moderate amount of debility from their ALS at the time of PC referral, with a median ALS Functional Rating Scale–Revised score of 26/48. Only 5.5% had stage 1 ALS, 21.8% had stage 2 ALS, 32.7% had stage 3 ALS, and 32.7% had stage 4 ALS (7.3% were not staged); this is in contrast to the overall population of patients with ALS seen at UCSF in which 27.3% had stage 1 ALS, 29.3% had stage 2 ALS, 23.2% had stage 3 ALS, and 11.1% had stage 4 ALS (6.6% were not staged).

In their referrals, ALS providers indicated 1 or more reasons for referring patients, chosen from a drop-down menu with a free text option in an electronic referral order. The most common reasons for referral to PC included goals of care/ACP (58.2% of patients, n = 32), support for patient/family (52.7%, n = 29), nonpain symptom management (50.9%, n = 28), support to make specific treatment decisions (23.6%, n = 13), pain management (9.1%, n = 5), and hospice referral/discussion (9.1%, n = 5). Overall, 19 patients were referred for reasons in the realm of care planning, 16 patients were referred for symptom management, and 17 patients were referred for both care planning and symptom management.

Patients had an average of 5.0 scheduled visits with the interdisciplinary PC team (median 4, range 3–16). Video telemedicine was the most common modality by which patients saw the PC team, with 58.2% of patients having only video visits, 32.7% having both video and in-person visits, and 9.1% having in-person visits only. Physicians were present in all scheduled PC visits. For initial visits, the nurse was present 81.8% of the time (n = 45), the social worker was present 47.3% of the time (n = 26), and the chaplain was present 30.9% of the time (n = 17). For follow-up visits, the nurse was present at least 1 scheduled visit for 89.1% of patients (n = 49), the social worker for 76.4% of patients (n = 42), and the chaplain for 56.4% of patients (n = 31) (Table 2). Throughout the course of PC, needs were identified in multiple domains, and the PC team very frequently intervened on these diverse needs when they were identified (Table 2).

Before the first PC visit, 16.4% of patients (n = 9) had an advance directive, and 10.9% of patients (n = 6) had a completed POLST form in the EHR. By the date of our chart review, the percentage of patients with an advance directive in the EHR had increased to 36.4% (n = 20, $p = 0.001$), and the percentage with a completed POLST form had increased to 63.6% (n = 35, $p < 0.001$) (Figure 2). The vast majority of patients (92.7%) had a surrogate decision maker documented in the EHR. Over half of patients (56.4%) had chosen a "do not resuscitate/do not intubate" code status, 10.9% of patients elected to be "full code," 9.1% elected to be "partial code," and 23.6% remained undecided regarding

**Table 2** Palliative Care Needs Identified and Interventions[a]

| Area of need | Need identified, % (n) | Intervention provided, % (n) |
|---|---|---|
| **Pain** | 49.1 (27) | 43.6 (24) |
| **Nonpain symptoms** | 98.2 (54) | 94.5 (52) |
| **Psychosocial needs** | 81.2 (45) | 78.2 (43) |
| **Spiritual needs** | 40.0 (22) | 29.1 (16) |
| **Advance care planning/goals of care** | 98.2 (54) | 96.4 (53) |
| **Family caregiver support** | Not measured | 96.4 (53) |

[a] Needs could be identified by palliative care clinicians at any point in the course of care. Palliative care interventions could be provided by palliative care clinicians at any point in the course of care.

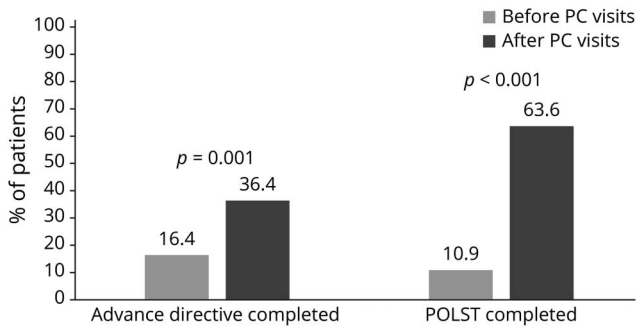
code status. Nearly half of the patients (49.1%) had a PEG tube placed (up from 29.1% at the time of PC referral), and 14.5% of patients were ventilated via tracheostomy (up from 7.3% at the time of PC referral).

Twenty-nine of the 55 patients had died by the date of chart review. Of decedents, 81% (n = 22) died at home, 5 patients died in the hospital, and 2 died in a care facility (Table 3). Of patients who died, 75.9% (n = 22) used hospice at the end of life, with 16 of these patients having a hospice length-of-stay greater than 30 days. Among the 55 patients in the entire study cohort, 17 (30.9%) inquired about MAID. Of the 29 patients who died, 11 were prescribed MAID medications, and 8 ingested MAID medications to end their lives, accounting for 29.6% of deaths in this cohort.

## Discussion

Our study demonstrates the feasibility and efficacy of PC comanagement for patients with ALS. We found that patients with moderately severe ALS were referred to PC a median of 6 months after establishing care in the ALS center for comprehensive PC including ACP, support for patient and family, and nonpain symptom management. The majority of patients received care from all members of the interdisciplinary PC team, who frequently addressed not just the physical but also the psychological, practical, and spiritual domains in their course of care. Rates of ACP substantially increased for patients cared for by the PC team. Importantly, not all patients chose to forego life-sustaining interventions, illustrating how PC can support patients with a wide range of values and goals of care. There was a high rate of hospice utilization, with over three-quarters of patients who died using hospice services at the end of life, typically for more than 30 days.

**Figure 2** Trends in Advance Care Planning With PC




PC = palliative care; POLST = Physician Orders for Life-Sustaining Treatment.

Of relevance to other teams looking to develop a similar collaboration, the structure of our care model shifted with time and as we gained experience and trust. We began with a model of embedding the PC team within the ALS clinic, which allowed for frequent face-to-face communication and extensive, bidirectional education in both formal and informal ways. Over time, we evolved to a model of seeing patients on different days, with the majority of PC visits occurring by video telemedicine, driven by the fact that most patients did not have enough energy to engage in both ALS and PC visits on the same day. This approach had the added benefit of decreasing the barrier to frequent follow-up visits for patients with rapidly evolving PC needs. Through this transition, the collaboration between the ALS and PC teams has remained strong, grounded in the trust and relationships that were built early and facilitated by routine practices such as routing clinic notes. Most patients appreciate the opportunity to meet with the PC team by video, even for sensitive conversations, particularly given how far they live from the medical center and how burdensome it is for them to travel.[32]

In our care model, patients are referred to PC at an ALS neurologists' discretion. This model has worked well for us as our ALS clinicians have been both effective and consistent at identifying PC needs, aided by our active collaboration, and it is more efficient than having the PC team meet all patients with ALS. However, at centers where ALS neurologists may not consistently identify PC needs, an ALS social worker or nurse could be engaged to help identify patients with PC

**Table 3** End-of-Life Care for Patients Who Died

| End-of-life care (n = 29) | |
|---|---|
| **Used hospice, % (n)** | 75.9 (22)[a] |
| **Hospice length of stay, d, n** | |
| **3–7** | 1 |
| **8–30** | 4 |
| **>30** | 17 |
| **Location of death, % (n)** | |
| **Home** | 75.9 (22) |
| **Hospital** | 17.2 (5) |
| **Other care facility** | 6.8 (2) |
| **Prescribed MAID medication, % (n)** | 40.7 (11) |
| **Took MAID medication, % (n)** | 29.6 (8) |
| **Time between initial PC visit and death, mo, mean (median, range)** | 7.67 (7, 1–19) |

Abbreviations: MAID = medical aid in dying; PC = palliative care.
[a] Nineteen of 22 patients who used hospice died at home.

needs or a routine screening process could be developed to ensure that patients who are likely to benefit from PC (based on severity of symptoms or rate of disease progression) get referred, assuming that there is buy-in for such a system. Of interest, we did not find much resistance to PC from patients or families. Instead, we found that ALS is an illness where people are particularly receptive to PC, likely because the incurable nature of the disease is well known and the distress caused by the illness is so immense.

Another key finding was that each member of the interdisciplinary PC team has a key role to play in the care of patients and families who are facing ALS. For example, physicians managed physical and psychological symptoms—such as sialorrhea, shortness of breath, pain from immobility and spasticity, insomnia, depression, and anxiety—in both pharmacologic and nonpharmacologic ways. They also helped estimate and communicate prognosis and facilitated goals of care conversations. The nurse worked closely with patients and families between visits to manage symptoms, to coordinate care, and to triage issues that arose. The social worker counseled patients and family caregivers about coping and helped them connect with mental health services, as well as other resources, in the community. The spiritual care provider supported patients and families who were experiencing anticipatory grief or loss of meaning and helped them access internal sources of strength. She also engaged in legacy work with patients who were interested in this activity. Our interdisciplinary PC visits were typically scheduled every 3 months, unless patients were very distressed or in a particularly active phase of their illness and needed to be seen more frequently, but between these visits individual members of the PC team reached out to patients or family members to offer support that was specific to their discipline.

Of interest, a full 30% of patients in our cohort inquired about MAID, which has been legal in California since June 2016, and nearly 30% of deaths occurred through ingestion of MAID medications. This finding is fairly consistent with a 1998 study[33] that surveyed patients with ALS in Oregon and Washington and found that 56% of patients with ALS reported that they would consider MAID if it was legal, and 44% said that they would request a prescription. The close collaboration between the ALS and PC teams allowed us to provide highly coordinated care in these cases, which was particularly important given that (1) California's MAID law requires that 2 physicians document the patients' prognosis, capacity to make a decision, and eligibility for MAID, and (2) patients with ALS frequently have a narrow window between when they desire these medications, when they qualify based on a prognosis of less than 6 months, and when they can no longer self-administer the MAID medications via an enteral route due to dysphagia or limb weakness.[34] This coordination was greatly appreciated by patients and families, who frequently reported that this made a stigmatizing and emotionally trying process more manageable and allowed them to access a type of care that they, in many cases, felt very strongly about.

This study has several important limitations. First, it is a single-center study at an academic medical center and thus may not be broadly generalizable to other care settings. However, many patients with ALS receive at least some of their care from a specialized ALS center, and most of these are affiliated with large medical centers. We only analyzed data from patients with 3 or more PC visits by the date of the chart review. This decision was made to understand the impact of longitudinal PC comanagement for patients with ALS, particularly given that—as a growing program—we have many patients who have recently initiated care with the PC team. A future study will explore the impact of 1- to 2-visit consultations and the reasons that some patients chose not to return for subsequent visits. About half of the patients in our cohort were alive after the date of the chart review and have continued to receive care from the PC team. These patients had not received a full course of PC by the time of the chart review, and it is likely that additional ACP and other care will be provided to them; therefore, the impact of longitudinal PC is likely underestimated in this study. Preconsult surrogate and code status preferences were not consistently documented, so we were not able to analyze how the rate of these metrics changed with PC. In addition and importantly, because this was an uncontrolled cohort study, we were not able to compare the rate of ACP or hospice utilization in patients who received PC to that of comparable patients who did not receive PC. Because patients with ALS who are referred to PC are likely different than patients

## TAKE-HOME POINTS

- A novel program to provide longitudinal palliative care comanagement program for patients with ALS proved feasible and addressed needs in multiple domains, including the physical, psychological, practical, and spiritual domains.
- Patients were referred a median of 6 months after establishing care with the ALS team, generally for advance care planning, symptom management, and/or support for patient and family.
- With palliative care comanagement, rates of advance care planning increased, hospice utilization was high, and requests for medical aid in dying were common.

with ALS who are not referred to PC, it was difficult to identify an appropriate control group. We hope to proceed to a randomized, controlled study with a stepped wedge design in the future to further elucidate the impact of PC on this patient population.

In conclusion, we found that close collaboration between ALS and PC teams to provide longitudinal care to patients with ALS is feasible. We demonstrated that patients with ALS have PC needs in multiple domains that can be comprehensively and consistently addressed through interdisciplinary PC comanagement and referral to hospice, when appropriate. Rates of ACP significantly increased with PC comanagement. Future work is needed to further clarify the impact of PC on health care utilization, patient and family experience, and to explore the optimal timing for PC involvement.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