Documentation of Advance Care Planning Forms in Patients with Amyotrophic Lateral Sclerosis

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Abstract

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Introduction/Aims: Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disorder characterized by progressive weakness. Survival is typically only a few years from symptom onset. The often-predictable disease course creates opportunities to complete advance care planning (ACP) forms. The Physician Orders for Life-Sustaining Treatment (POLST) is a broadly used ACP paradigm to communicate end-of-life wishes but has not been well-studied in the ALS population.

Methods: In this retrospective chart review study, patients diagnosed with ALS seen between 2014 and 2018 at an academic ALS Center were identified. Demographic information, clinical characteristics, and ACP information were collected.

Results: Of 513 patients identified, 30% had an ACP document. POLST forms were competed in 16.6% of patients with 73.8% of forms signed by a neurologist. Only 5.1% of patients saw a palliative care physician. Palliative care consultation was associated with having an POLST on file ($p < 0.001$). Patients with completed POLST forms were significantly more likely to have been seen in clinic more frequently ($p < 0.001$) and have a lower Revised ALS Functional Rating Scale score on last visit ($p = 0.005$).

Discussion: Less than one-third of patients with ALS completed an ACP document, and only a small percentage completed POLST forms. The data suggest a need for greater documentation of goals of care in the ALS population.

Keywords: amyotrophic lateral sclerosis; advance care planning; POLST; motor neuron disease; ALSFRS-R

Introduction

Given the often-predictable disease course, patients with amyotrophic lateral sclerosis (ALS) have an opportunity to make informed decisions and indicate preferences for end-of-life medical care in advance. Studies have shown that patients and their families are interested in discussing what to expect regarding disease progression and advance care planning (ACP) early in the disease course.[1] Verbal communication is often difficult in later stages of disease due to dysarthria or cognitive changes. When patients do not indicate their end-of-life treatment goals, surrogate medical decision makers, often family members, are asked to make treatment decisions for the patient.[2] Although the use of surrogate medical decision makers is common, studies have shown that patients' family members and physicians do not accurately predict patient wishes, resulting in patients receiving discordant medical care.[3,4,5]

Fewer than 30% of Americans have advance directives,[6] and previous studies have reported highly variable use of advance directives in patients with ALS with rates ranging from 30-88%.[7,8] Although the majority of patients with ALS want to participate in decisions about their medical care, and earlier ACP discussions improve end-of-life decision making,[9,10,11] one study found that only 55% of physicians discussed ACP regularly with patients with ALS.[7] Many patients with ALS receive care in multidisciplinary clinics which have been shown to improve quality of life and prolong survival.[12,13] Some multidisciplinary clinics include a palliative care specialist while in others the neurologist provides primary palliative care. Several methods to improve rates of ACP document completion in the ALS population have been proposed including an ALS-specific ACP document and ACP discussion aids to help transform patient goals and preferences into actionable advance directives.[14,4]

One way that patients with advanced ALS can document their end-of-life wishes is through a Physician Orders for Life-Sustaining Treatment (POLST) form. The POLST paradigm exists in state-by-state programs which may go by alternate names.[15] POLST is an ACP document filled out by a patient's physician to ensure patient treatment preferences are communicated throughout the healthcare system.[16] It includes preferences on resuscitation, mechanical ventilation, non-oral nutrition, and antibiotics. Having a document that addresses medical treatments beyond resuscitation status is important because studies have shown that preferences regarding resuscitation are not predictive of a patient's preference for other kinds of medical treatment such as respiratory support and non-oral nutrition.[17] Few studies have been conducted to identify the prevalence of

patients with ALS who have advance directives. One study found that at first visit with a palliative care physician POLST completion rates were lower than other ACP documents.[18] The current study sought to determine the prevalence of documented ACP forms, including POLST forms in medical records of patients with ALS, as well as to identify patient and clinical characteristics associated with the presence of ACP forms.

Methods

Study Design

A single-center retrospective medical record review was conducted at Indiana University Health Neuroscience Center. The protocol was approved by the university institutional review board. Patients seen in the multidisciplinary ALS clinic were identified using clinic scheduling records. The disciplines represented at the ALS clinic in this study include neurology, physiatry, respiratory therapy, physical therapy, occupational therapy, speech-language pathology, dietary services, and social work. An orthotist, chaplain, and genetic counselor are also often present. A palliative care physician is not integrated in clinic and while available as an outpatient, accessibility is limited by a small number of outpatient palliative care providers. All patients seen in the clinic January 1, 2014 through December 31, 2018 with a reported diagnosis of amyotrophic lateral sclerosis (ICD-10-CM code G12.21) were included. All patients were over the age of 18. Patients seen in the clinic with a diagnosis of primary lateral sclerosis, progressive muscular atrophy, other motor neuron disease, or other diagnosis were excluded from this study.

Data Collection

A standardized chart review tool was created after review of the relevant literature. Demographic variables included age at first visit, gender, and race. Additionally, the number of visits in multidisciplinary ALS clinic and whether the patient was ever seen by a palliative care provider on either an inpatient or outpatient basis were collected. Clinical information including percent predicted erect forced vital capacity (FVC), maximal inspiratory pressure (MIP), and Revised ALS Functional Rating Scale (ALSFRS-R) score on first visit in clinic and last or most recent visit in clinic were collected if available. Presence of any ACP form and type of form as well as the

specialty of the physician who signed the form were recorded. Data available in the medical record through March 1, 2020 were collected and managed using REDCap electronic data capture tool.

Statistical Analysis

Variables that may be associated with presence of ACP forms based on clinical experience and the literature were determined *a priori* and included: patient age, gender, race, number of visits in the multidisciplinary clinic, consultation with palliative care provider, respiratory function parameters, and ALSFRS-R.

Bivariate analyses were conducted to determine which variables were significantly associated with presence of ACP documents using 2-sample 2-tailed t-tests for continuous variables and Pearson $\chi 2$ tests for categorical variables. Two-sided Fisher exact test was used instead of the Pearson $\chi 2$ test when more than 20% of cells had expected counts of less than 5. Mann-Whitney U test was used instead of the t-test when data did not fit a normal distribution. A secondary analysis to assess association between number of visits and ACP documents was performed excluding patients only seen once in clinic. All analyses were performed using SPSS Version 26.0 (IBM, Armonk, NY).

Results

This study included 513 patients. The median number of visits toALS clinic was 4 (IQR = 2, 7). One in five patients, n=106 (20.7%), was seen in multidisciplinary ALS clinic only once. On the last visit in clinic, 230 patients (44.8%) had an FVC <50% predicted and approximately 15% were unable to perform pulmonary function testing due to severe neuromuscular weakness, cognitive impairment, or already being tracheostomy dependent (Table 1). On the last visit, 382 patients (75.8%) had an ALSFRS-R less than 30, indicating moderate to severe functional impairment. The last ALSFRS-R score (n = 9), FVC (n = 12), and MIP (n = 14) were missing from the records of some patients.

Table 2 provides a summary of ACP documentation. Documented ACP forms were found in the medical records of 30 percent of patients with the most common ACP form being a POLST form. The majority of POLST forms were signed by a neurologist or neurology physician assistant. For five patients it was unclear whether the form was completed by a physician because the second page of the form was either left unsigned or not scanned

into the chart. A small number of patients were seen by palliative care, with only four patients evaluated on an outpatient basis. Of the 26 patients seen by palliative care, 14 had a POLST form in the medical record. Half of these forms had been completed prior to initial consult with palliative care by a provider of another specialty, and half were completed at the time of initial palliative care consultation or shortly thereafter. Patient preferences for medical interventions appear in Table 3. More than 90% chose comfort measures or limited additional interventions. The majority of patients who completed a POLST form indicated that they did not want cardiopulmonary resuscitation.

In the bivariate analysis, several factors were associated with presence of any advance healthcare directive and more specifically with presence of a POLST form. Female patients were significantly more likely to have a POLST form in the medical record as were those patients who were seen on more occasions in multidisciplinary clinic (Table 4). A secondary analysis excluding patients only seen once in the clinic also found that patients seen on more occasions were significantly more likely to have a POLST form documented. Patients with lower FVC and MIP were significantly more likely to have any ACP document. Patients with a lower ALSFRS-R score were significantly more likely to have a POLST form. However, out of 382 patients with ALSFRS-R <30 at last clinic visit, two thirds did not have an ACP form documented. Patients who had been evaluated by palliative care were significantly more likely to have a POLST form.

Discussion

In this study, less than one third of patients had any type of ACP form, and only 16.6% of patients had a POLST form present in their medical record despite a large proportion of these patients having markers of moderate or severe disease. There are many reasons why ACP forms are not being documented in this population. Providers may be reluctant to discuss these emotionally challenging topics, and when they do these conversations may not translate into completion of an ACP document housed in the electronic medical record. Additionally, providers may be unfamiliar with ACP documents and when and how they should be completed. One barrier to POLST form use is difficulty understanding and explaining the form.[17] Incorrectly completed POLST forms may result in discordant care.[19] Unlike other studies of POLST form use,[20] age and race were not associated with the presence of a POLST form in this study. However, women were significantly more likely than men to have

completed a POLST form. While some studies have found women more likely to complete ACP forms,[21] others have not,[20] and with such few papers on this topic it is an area that needs further research.

This study found that documented ACP forms were significantly more likely to be present in patients with worse respiratory function and functional status. Additionally, patients seen in clinic on more occasions were significantly more likely to have ACP documents, including POLST forms. It is unclear whether this simply represents a delay in formal documentation until markers of severe disease are present or a delay in conversations about ACP. This may reflect more time for patient and provider to develop rapport. Some physicians avoid discussing advance directives with their patients until late in the course of disease out of fear that the patient's wishes will change.[22] POLST forms can be updated as needed to reflect a change in goals of care,[23] although doing so requires a visit with a medical care provider which may be a barrier to updating this type of ACP form. It is also possible that physicians may choose not to complete a POLST form if patients indicate they want all possible medical interventions. Some argue that changing a POLST form from all interventions to limited interventions may be emotionally or cognitively challenging. Although aggressive medical treatments are the default when no ACP form is present, having a POLST form that states a patient wants aggressive interventions, particularly in patients with more advanced disease, is important to uphold the patient's autonomy and ensure concordant care is provided by the surrogate decision maker.[5] Unfortunately, with disease progression, some patients with ALS develop cognitive dysfunction and many have impaired verbal communication, which can make ACP discussions challenging, despite use of augmentative and alternative communication devices and techniques. Therefore, waiting until later in the disease course to discuss ACP may result in a missed opportunity for patients to make their end-of-life wishes fully known.

The signer for the majority of POLST forms in this study was a neurologist or neurology physician assistant, indicating that the neurology team in this clinic is providing primary palliative care to patients with ALS and that its members are familiar with POLST forms. However, patients that were seen by a palliative care specialist were significantly more likely to have an ACP form in their medical record. Most of the palliative care encounters for this study's patient population occurred inpatient, and these admissions may have triggered discussion of ACP documentation. The most common reason for palliative care consultation in inpatient neurologic conditions is to establish goals of care not previously discussed with patients' outpatient neurologist.[24] While

communication skill modules have been developed for oncologists, geriatricians, and intensivists to learn communication skills for discussing goals of care,[25,26,27] neurologists receive very little formal palliative care training.[28] Twenty percent of adult neurology residency programs have reported offering no palliative care training to residents.[29] Some patients and their families may have complex psychosocial or existential/spiritual needs that may be better served by someone with specialized palliative care training. Integration of a palliative care specialist into multidisciplinary ALS clinics has been explored,[30,31,18] but the optimal method of providing neuropalliative care remains to be seen particularly when access to palliative care providers is limited.[32] Several factors may influence whether a primary palliative approach or integration of palliative care specialist into multidisciplinary ALS clinic is appropriate including the primary clinician's experience and skill with goals of care discussions, patient acceptance of seeing a palliative care specialist, and access to a palliative care provider. ACP conversations can be very time intensive in an already long day, so separate visits with either the neurologist or a palliative care specialist may be needed to best respect the patients' time.[33]

Limitations

This study has several limitations. It is possible that ACP forms were completed by patients but not included in the medical record. However, having a medical directive that is not housed in the medical record or with the patients themselves is of little practical use. As the clinic in the present study is located at a tertiary referral center it is also possible that patients' ACP documents were located with their primary care provider or referring neurologist if they choose not to follow with the multidisciplinary ALS clinic longitudinally. A large study found median survival from first multidisciplinary clinic visit to be 14.3 months.[34] With a median of four clinic visits, patients seen on fewer occasions in this study may have been less likely to complete ACP forms. Due to the large percentage of patients who were only seen once in multidisciplinary clinic, this study adjusted for such patients , and found similar results among patients seen on multiple occasions. Up to half of patients with ALS develop some degree of cognitive impairment,[35] predominantly frontal lobe dysfunction, which may impact decision-making.[36] This study did not evaluate whether patients had evidence of cognitive dysfunction.

Patients with very advanced disease may have less regular contact with the clinic and therefore this retrospective chart review study may have missed ACP forms created at the very end of life, such as those created

when a patient entered hospice care. This study did not assess whether patients' POLST forms reflected conversations documented in the medical record nor clinical care received which should be investigated further.

Due to the structure of the clinic assessed in this study, the results may not be generalizable to other centers where differing levels of comfort with and expertise in palliative care are present or a standard approach to initiating ACP discussions exists. Additionally, as POLST familiarity and use varies from state to state, this may limit the applicability of this study to other ALS Centers.

Conclusion

This study found a low prevalence of ACP forms including POLST forms in patients with ALS seen in a multidisciplinary clinic despite many patients having markers of moderate to severe functional and respiratory impairment. Physicians may be waiting until they have established a relationship with the patient and their loved ones to allow for more open communication as ACP discussions are a difficult and personal topic. The optimal time to introduce this conversation is unclear but several authors suggest event-triggered discussions for ACP and palliative care introduction.[30,37] Despite limitations the POLST form remains a useful tool to communicate wishes of patients with advanced progressive illness throughout the healthcare system. Future studies could investigate whether preferences indicated on POLST forms translate to concordant medical care in patients with ALS specifically. In cases where ACP forms are completed but not placed in the medical record, further research into what barriers prevent this may be useful to help improve ACP delivery. In centers where access to palliative care providers is limited, neurologists need to provide primary palliative care which may require additional education and understanding of instances in which to refer to a palliative care specialist.

Abbreviations

ALS, amyotrophic lateral sclerosis

ALSFRS-R, Revised Amyotrophic Lateral Sclerosis Functional Rating Scale

ACP, advance care planning

FVC, forced vital capacity

MIP, maximal inspiratory pressure

POLST, Physician Orders for Life-Sustaining Treatment

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Table 1. Patient Characteristics

Characteristic	n (%)
Age, mean (SD), y	62.4 (11.7)
Female	228 (44.4)
Race	
Asian	6 (1.2)
Black	23 (4.5)
White	472 (92)
More than one race	1 (0.2)
Not reported	11 (2.1)
FVC on last visit (N = 501)*	
≥ 80% predicted	69 (13.8)
51-79% predicted	130 (25.9)
30-50% predicted	143 (28.5)
< 30% predicted	87 (17.4)
Unable to perform	72 (14.4)
ALSFRS-R score on last visit (N = 504)†	
≥ 40	23 (4.6)
30-39	99 (19.6)
20-29	204 (40.5)
< 20	178 (35.3)

Abbreviations: SD, standard deviation; FVC, forced vital capacity; ALSFRS-R, Revised ALS Functional Rating Scale

*Values for FVC and ALSFRS-R do not sum to 513 due to missing data

†Scores range from 0 to 48 with higher scores indicating increased independence in activities of daily living and global function

Table 2. Advance Care Planning Documentation

ACP variable	n (%)
ACP document in EMR*	154 (30)
POLST	85 (16.6)
HCR	74 (14.4)
Living will	51 (10.0)
Healthcare power of attorney	40 (7.8)
Out-of-hospital DNR	16 (3.1)
Other	13 (2.5)
POLST signer specialty†	
Neurology	59 (73.8)
Palliative care	8 (10.0)
PCP	7 (8.8)
Hospital-based physician‡	2 (2.5)
Other	4 (5.0)
Palliative care consultation	26 (5.1)
Inpatient	22 (84.6)
Outpatient	3 (11.5)
Both	1 (4.0)

Abbreviations: ACP, advance care planning; EMR, electronic medical record; POLST, Physician Orders for Life-Sustaining Treatment; HCR, healthcare representative; DNR, do not resuscitate; PCP, primary care provider

*Some patients had multiple advance healthcare directives in EMR so all ACP form types do not sum to 154

†Values do not sum to 85 due to missing data

‡This includes medical intensivists, hospitalists, and emergency room physicians

Table 3. Designation of Medical Preferences on POLST Forms

Order type	n (%)
Section A: Cardiopulmonary resuscitation (N = 85)	
Attempt resuscitation/CPR	13 (15.3)
Do no attempt resuscitation/DNR	72 (84.7)
Section B: Medical interventions (N = 83)*	
Comfort measures (Allow Natural Death)	43 (51.8)
Limited Additional Interventions	33 (39.8)
Full Intervention	7 (8.4)
Section C: Antibiotics (N = 83)*	
Use antibiotics for infection only if comfort cannot be achieved fully through other means	26 (31.3)
Use antibiotics consistent with treatment goals	57 (68.7)
Section D: Artificially administered nutrition (N = 74)*	
No artificial nutrition	34 (46.0)
Defined trial period of artificial nutrition by tube	21 (28.4)
Long-term artificial nutrition	19 (25.7)

Abbreviations: CPR, cardiopulmonary resuscitation; DNR, do not resuscitate

*Values do not sum to 85 due to missing data

Table 4. Patient Characteristics Associated with Advance Care Planning Documentation

Variable	ACP form present n = 154	ACP form absent n = 359	*P* Value	POLST present n = 85	POLST absent n = 428	*P* Value
Age, mean (SD), y	63.0 (11.9)	62.1 (11.6)	.565	62.6 (11.7)	62.3 (11.7)	.881
Female (vs. male)	83 (53.9)	145 (40.4)	**.005**	47 (55.3)	181 (42.3)	**.028**
Race			.871			.956
Asian	1 (0.6)	5 (1.4)		1 (1.2)	5 (1.2)	
Black	7 (4.5)	16 (4.5)		4 (4.7)	19 (4.4)	
White	144 (93.5)	328 (91.4)		79 (92.9)	393 (91.8)	
More than one	0 (0)	1 (0.3)		0 (0)	1 (0.2)	
Not reported	2 (1.3)	9 (2.5)		1 (1.2)	10 (2.3)	
Number of visits, all patients, median (IQR)	5 (3, 8.25)	3 (1, 6)	**<.001**	5 (3, 9)	3 (2, 6)	**<.001**
Number of visits, patients seen > 1 time, median (IQR)	5 (3, 9)	4 (3, 7)	**.011**	6 (4, 9)	4 (3, 7)	**.003**
FVC on last visit (% predicted)	43 (28, 61.5)	50 (34, 73.75)	**.005**	43 (29, 63.25)	50 (33, 72)	.075
MIP on last visit (cmH_2O)	-30 (-19.5, -44.5)	-36 (-23, -55.5)	**.001**	-31 (-22, -44)	-34 (-22, -55)	.104
ALSFRS-R score on last visit	21 (16, 25)	24 (18, 31)	**<.001**	21 (16, 24)	23 (17, 30)	**.005**
Palliative care consultation	23 (14.9)	3 (0.8)	**<.001**	14 (16.5)	12 (2.8)	**<.001**

Abbreviations: ACP, advance care planning; POLST, Physician Orders for Life-Sustaining Treatment; SD, standard deviation; FVC, forced vital capacity; MIP, maximal inspiratory pressure; IQR, interquartile range; ALSFRS-R, Revised ALS Functional Rating Scale

Abbreviations

ALS, amyotrophic lateral sclerosis

ALSFRS-R, Revised Amyotrophic Lateral Sclerosis Functional Rating Scale

ACP, advance care planning

CPR, cardiopulmonary resuscitation

DNR, do-not-resuscitate

EMR, electronic medical record

FVC, forced vital capacity

HCR, healthcare representative

MIP, maximal inspiratory pressure

PCP, primary care provider

POLST, Physician Orders for Life-Sustaining Treatment