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Minorities, men, and unmarried amyotrophic lateral sclerosis patients are more likely to die in an acute care facility

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Abstract

Objective—Studies suggest that dying at home is a more favorable experience. This study investigated where amyotrophic lateral sclerosis (ALS) patients die and the patient demographics associated with dying in an acute care facility or nursing home compared to home or hospice.

Methods—Centers for Disease Control and Prevention Multiple Cause Mortality Files from 2005–2010 were used to identify ALS patients and to classify place of death. Multinomial logistic regression was used to determine the association between patient demographics and place of death.

Results—Between 2005 and 2010, 40,911 patients died of ALS in the United States. Place of death was as follows: home or hospice facility 20,231 (50%), acute care facility (25%), and nursing home (20%). African Americans (adjusted multinomial odds ratio (aMOR) 2.56, CI 2.32–2.83), Hispanics (aMOR 1.44, CI 1.30–1.62), and Asians (aMOR 1.87, CI 1.57–2.22) were more likely to die in an acute care facility, whereas females (aMOR 0.76, CI 0.72–0.80) and married individuals were less likely. Hispanics (aMOR 0.68, CI 0.58–0.79) and married individuals were less likely to die in a nursing home.

Conclusions—Minorities, men, and unmarried individuals are more likely to die in an acute care facility. Further studies are needed to better understand place of death preferences.

Keywords

End of life care; Amyotrophic lateral sclerosis; Quality of life; Place of death

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Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive degenerative disease of the motor neurons. As the typical survival is 2–5 years, end-of-life planning is an important component of routine care(1) and should aid patients in achieving a “good death” by addressing factors such as pain and symptom management, quality communication with physicians, and preparation for death(2).

Location of death is proposed as a quality measure for end of life care for all diseases(3). Death at home is associated with an improved quality of life near the end of life, less caregiver strain(4), and is generally viewed as a more satisfying and favorable experience per caregiver report(4, 5). Although death at home is not always considered as important as other factors in the process of dying(2), it does appear to be the desired location of death in many studies, but this request may not be met in all circumstances(3, 6). Furthermore, patients dying in a hospital or nursing home have unmet needs compared to patients who die at home with hospice care(5), and in cases of terminal cancer, quality of end-of-life care is inferior for those who die in a hospital compared to those who die at home with hospice care(4). In contrast, patients who die in hospice care have the fewest unmet needs(7).

In ALS, place of death is an important consideration because “not dying at home” is correlated with “not dying peacefully”(8). The purpose of this study is to investigate the current proportion of ALS patients who die at home and/or in hospice versus an acute care facility (ACF) or nursing home (NH) in the United States. Furthermore, we sought to evaluate the association between patient demographics and dying in an acute care facility or nursing home compared to home and/or hospice to inform future intervention efforts aimed at improving end of life care for ALS patients.

Methods

The Centers for Disease Control and Prevention (CDC) Multiple Cause Mortality Files for the years 2005–2010 were evaluated to determine an ALS death defined as a death certificate with ALS (ICD-10 G122) as the underlying cause of death. This dataset reports details of every death with in the United States in a given year as reported on death certificates. Place of death was abstracted from the death certificate and divided into four categories: home and/or hospice, acute care facility, nursing home, or other. Acute care facility deaths were defined as deaths occurring during acute inpatient hospitalization, at an outpatient medical facility, in an emergency department, or in patients who were dead on arrival to the hospital. Patient characteristics including age, sex, race/ethnicity, educational status, and marital status, were collected from the death certificates. Multinomial logistic regression was used to determine the association between independent variables (all patient characteristics included in the model) and the dependent variable (death in an acute care facility or nursing home versus home and/or hospice). Statistical analysis was performed with STATA version 12.1 (StataCorp College Station, TX). The study was Institutional Review Board exempt.

Results

Between 2005 and 2010 40,911 patients died of ALS in the United States. Patient demographics are shown in Table 1. Mean age at time of death was 68.7 (SD 12.2) and 45.5% were female. Of the total population, 92.6% were white, 5.5% African American, 4.2% Hispanic, and 1.59% Asian. The most common location of death was home/hospice (49.7%), followed by an acute care facility (25.0%), nursing home (19.6%), and other (5.7%) (Table 2). Multinomial logistic regression revealed that females have a lower odds of dying in an acute care facility (adjusted multinomial odds ratio (aMOR) 0.76, CI 0.72–0.80) compared to males (Table 3). African Americans have an increased odds of dying in an acute care facility (aMOR 2.56, CI 2.32–2.83) but are equally likely to die in a nursing home (aMOR 1.09, CI 0.96–1.25). Hispanics have an increased odds of dying in an acute care facility (aMOR 1.44, CI 1.30–1.62) but a decreased odds of dying in a nursing home (aMOR 0.68, CI 0.58–0.79) compared to Whites. Asians have an increased odds of dying in an acute care facility (aMOR 1.87, CI 1.57–2.22) and a lower odds of dying in a nursing home, although this is not statistically significant (aMOR 0.80, CI 0.62–1.03). Single patients (ACF: aMOR 1.69, CI 1.52–1.89, NH: aMOR 4.30, CI 3.83–4.83), divorced patients (ACF: aMOR 1.51, CI 1.40–1.63, NH: aMOR 3.35, CI 3.09–3.64), and widowed patients (ACF: aMOR 1.26, CI 1.17–1.35, NH: aMOR, CI 2.16–2.50) all have an increased odds of dying in an acute care facility and in a nursing home compared to married patients. Age is significantly associated with an acute care death (aMOR 1.003, CI 1.001–1.005) and a nursing home death (aMOR 1.04, CI 1.04–1.05).

Discussion

In the United States between 2005 and 2010, over 40,000 people died of ALS, of which 25% died in an acute care facility, 50% at home or in hospice, and 20% in a nursing home. Although there has been an increasing emphasis on dying at home and/or with hospice, our data suggests that almost half of recent ALS patient deaths continue to occur in other locations. Racial/ethnic minorities, men, and unmarried individuals were more likely to die in an acute care facility. Hispanics were less likely to die in a nursing home, whereas unmarried individuals were more likely.

African Americans and Hispanics, are more likely to die in an acute care facility relative to whites. Although this may represent preferences such as the aggressiveness of care at end-of-life in these groups(3), this could be related to other factors including lack of access or affordability of home care services or availability of informal caregivers which prevent patients from staying at home at the end-of-life. Our data are consistent with other studies investigating all causes of death that highlight different preferences and practices at end-of-life in African-Americans and other minority groups(2, 3, 9). These results suggest an opportunity may exist to enhance end of life care for ALS minority patients. We also found that Hispanics are less likely to die in a nursing home, which is consistent with previous work and also highlights the importance of separately evaluating nursing home deaths(3). Similar to Hispanics, Asians are more likely to die in an acute care facility and appear less likely to die in a nursing home. The interpretation of this data is uncertain as this category does not differentiate amongst different Asian heritages. In addition, other similar studies do

not explicitly evaluate Asians as an individual racial/ethnic group, and therefore future studies are needed to understand end of life preferences in this group.

The finding that men are more likely to die in an ACF compared to women is consistent with studies that revealed similar associations when considering all causes of death(3, 5). However, our study is the first to evaluate this association in an ALS cohort. This observation could be the result of many factors including a difference in end-of-life wishes, the availability of informal caretakers to maintain the patient in a home or hospice setting, or a different disease course. Similar to minorities, this result may indicate an opportunity to improve the end of life experience for men, but further studies are needed to determine the reasons men are more likely to die in acute care facilities.

That unmarried individuals are more likely to die in an acute care facility and more likely to die in a nursing home is not surprising given the degree of disability associated with ALS, often resulting in loss of independence. The availability of a spouse to assist with activities of daily living likely allows these patients to stay in a home or hospice setting. Other studies have shown similar findings by demonstrating a relationship between marriage and home death(3, 10).

One limitation is that we do not have information on the patient's preferred place of death. In addition, by relying on death certificate data, we cannot control for other potential factors that may have influenced place of death such as disease severity, other medical comorbidities, or acute illness. More insight on these limitations is required prior to making public health decisions. Strengths of this study include the comprehensive capture of a large nationwide sample of patients with a gold-standard definition of cause of death and separate evaluation of nursing home as a place of death.

According to the 2010 US Census, the national population by race was 74.2% white, 12.6% African American, 4.8% Asian, and 16.3% Hispanic or Latino(11). The racial makeup of our study varies from the national population and possible reasons could include either a higher incidence of ALS in Whites, undiagnosed or unreported cases of ALS in the minority populations, or improper collection of medical history on death certificates. A recent review of the ethnic variation of incidence in ALS showed lower rates in Africans, Asians, and Hispanics compared to Whites(12). Moreover, in a study of the Cuban population, the overall mortality rate was similar to the United States Hispanic mortality rate and even lower in Blacks and mixed race individuals(13) and an Ecuadorian study showed a reduced incidence of ALS in this South American population compared to the United States(14). However another study of an inner city population in London showed a similar incidence of ALS in patients with a European ancestry compared to an African ancestry suggesting similar incidence rates in these groups, although the confidence intervals are large(15).

In summary, although the preferred place of death for most patients is home, racial/ethnic minorities, men, and unmarried individuals are less likely to achieve this goal. Further studies are recommended to better characterize the sentiments of these populations and to identify whether barriers exist for executing a patient's preferred end-of-life plan.

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Abbreviations

ACF	acute care facility
ALS	amyotrophic lateral sclerosis
aMOR	adjusted multinomial odds ratio
CDC	The Centers for Disease Control and Prevention
NH	nursing home

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Table 1

Patient Demographics

	Home or Hospice Facility Death	Acute Care Death	Nursing Home Death	Other	Total
	(n = 20,321)	(n = 10,244)	(n = 8,009)	(n = 2,337)	(n = 40,911)
	N(%) unless otherwise specified	N(%) unless otherwise specified	N(%) unless otherwise specified	N(%) unless otherwise specified	N(%) unless otherwise specified
Mean Age (SD) in Years	67.5 (11.9)	67.3 (12.4)	73.1 (11.5)	69.4 (12.5)	68.7 (12.2)
Female	9,131 (44.9%)	4,080 (39.8%)	4,193 (52.4%)	1,220 (52.2%)	18,624 (45.5%)
Race/Ethnicity					
White	19,174 (94.4%)	8,972 (87.6%)	7,557 (94.4%)	2,185 (93.5%)	37,888 (92.6%)
African American	791 (3.9%)	980 (9.6%)	346 (4.3%)	116 (5.0%)	2,233 (5.5%)
Hispanic Ethnicity	864 (4.3%)	598 (5.8%)	223 (2.8%)	49 (2.1%)	1,734 (4.2%)
Asian	300 (1.5%)	247 (2.4%)	82 (1.0%)	23 (1.0%)	652 (1.59%)
Other	56 (0.3%)	45 (0.4%)	24 (0.3%)	13 (0.6%)	138 (0.34%)
Marital Status					
Unknown	21 (0.1%)	28 (0.3%)	12 (0.1%)	283 (12.1%)	344 (0.8%)
Single	823 (4.0%)	674 (6.6%)	620 (7.7%)	131 (5.6%)	2,248 (5.5%)
Married	14,663 (72.2%)	6,665 (65.1%)	3,632 (45.3%)	1,092 (46.7%)	26,052 (63.7%)
Divorced	1,921 (9.5%)	1,311 (12.8%)	1,330 (16.6%)	324 (13.9%)	4,886 (11.9%)
Widowed	2,893 (14.2%)	1,566 (15.3%)	2,415 (30.2%)	507 (21.7%)	7,381 (18.0%)

Table 2

ALS Deaths per Year Per Place of Death

Location (% per year)	2005	2006	2007	2008	2009	2010	Total
Acute Care	1,739 (27%)	1,656 (25%)	1,716 (26%)	1,698 (25%)	1,709 (24%)	1,726 (24%)	10,244
Home or Hospice	3,018 (46%)	3,210 (49%)	3,350 (50%)	3,455 (50%)	3,449 (49%)	3,839 (49%)	20,321
Nursing Home	1,406 (22%)	1,401 (21%)	1,308 (19%)	1,293 (19%)	1,307 (19%)	1,294 (19%)	8,009
Other	337 (5%)	312 (5%)	344 (5%)	436 (6%)	539 (8%)	369 (8%)	2,337
Total ALS Deaths	6,500	6,579	6,718	6,882	7,004	7,228	40,911

Table 3

Logistic Regression of Death in an Acute Care Facility for ALS Patients

	Odds of dying in ACF vs Home/Hospice		Odds of dying in Nursing Home vs Home/Hospice	
Parameter	Adjusted multinomial odds ratio	95% CI	Adjusted multinomial odds ratio	95% CI
Age (year)	1.00 *	1.00–1.01	1.04 *	1.04–1.05
Female	0.76 *	0.72–0.80	0.98	0.92–1.03
Race/Ethnicity (reference: white)				
African American	2.56 *	2.32–2.83	1.09	0.96–1.25
Hispanic	1.44 *	1.30–1.62	0.68 *	0.58–0.79
Asian	1.87 *	1.57–2.22	0.80	0.62–1.03
Other	1.69 *	1.13–2.51	1.24	0.76–2.03
Marital Status (reference: married)				
Unknown	2.66 *	1.51–4.71	2.76	1.36–5.63
Single	1.69 *	1.52–1.89	4.30 *	3.83–4.83
Divorced	1.51 *	1.40–1.63	3.35 *	3.09–3.64
Widowed	1.26 *	1.17–1.35	2.32 *	2.16–2.50

*
= significant