Are Preferences for Aggressive Medical Treatment Associated with Healthcare Utilization in the Very Old?

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Abstract

Objectives: To examine the relationship between end-of-life (EOL) treatment preferences and recent hospitalization or emergency department (ED) care in the very old.

Design: Quarterly telephone follow-up of participants in the EOL in the Very Old cohort.

Setting: The EOL in the Very Old Age cohort drew from 1403 participants in the Health, Aging, and Body Composition (Health ABC) study who were alive in year 15 of follow-up. 87.5% ($n = 1227$) were successfully recontacted and enrolled.

Participants: Preferences for treatment at the EOL and reported hospital and ED use were examined for 1118 participants (18% involving proxy reports) over 6 months, 1021 (16% with proxy reports) over 12 months, and 945 (23% with proxy reports) over 18 months in 6-month intervals.

Measurements: Preferences for eight EOL treatments, elicited once each year; hospitalization and ED use reported every six months.

Results: Preferences for more aggressive treatment (endorsing ≥ 5 of 8 options) were not significantly associated with inpatient or ED treatment. Inpatient and ED treatment were not associated with changes in preferences for aggressive EOL treatment over 12 months.

Conclusion: Alternative measures that tap attitudes toward routine care, rather than EOL treatment preferences, may be more highly associated with healthcare utilization.

Keywords: cohort studies; end-of-life; Health ABC; healthcare utilization; treatment preferences

Introduction

A RECENT REPORT from the Institute on Medicine stresses the need to honor individual preferences near the end of life (EOL): “All people with advanced illnesses who may be approaching the end of life are entitled to access high-quality, compassionate evidence-based care, consistent with their wishes.”¹ Unfortunately, the wishes or EOL treatment preferences of the very old are not always obvious.

First, among older adults, endorsement of limitations on treatment at the EOL has been shown to be quite variable,

even when elicited with a standardized paradigm such as the Physician Orders for Life-Sustaining Treatment (POLST). In skilled nursing facilities in Oregon, over 60% of residents rejected use of a feeding tube and over 80% rejected resuscitation.² In California, a much smaller proportion rejected these treatments, 38% and 50%, respectively.³ This variation may not only reflect the more ethnically- and age-diverse population served by facilities in California but also the effects of education. People with greater education are more likely to specify treatment plans and limit EOL treatment.⁴

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Second, EOL treatment preferences may change. Over half the patients followed by a palliative care service changed preferences for place of death (although in most cases patients achieved greater clarity in preferences).⁵ Just two-thirds of patients with advanced cancer receiving intensive care unit (ICU) care were stable in expressed preferences over follow-up.⁶ A systematic review found that most studies reported stability in preferences, with about 70% of patients consistent in preferences for EOL treatment. However, in a third of the studies assessed investigators did not find a consistent relationship between changes in health status and preferences.⁷ Inpatients and the seriously ill, people with more education, and people who engaged in advance care planning had greater stability in preferences.

Finally, the degree to which older adults share these preferences with family or healthcare professionals varies. Findings from the Canadian Study on Health and Aging suggest that cognitively impaired older adults are more likely to designate substitute decision makers than older adults without cognitive deficit, but they are also less likely to discuss preferences for EOL care with surrogate decision makers.⁸ Among hospitalized patients who had discussed EOL treatment preferences, only slightly more than half had discussed preferences with a member of the healthcare team, and documentation in the medical record was poor.⁹ Reasons for not sharing preferences with family may reflect an older person's desire not to burden family members, but also family members' own discomfort with such discussions.

It is difficult to honor EOL treatment preferences if they are hard to predict, in some cases unstable, and not always shared. To explore one source of variation in EOL treatment preferences among the very old, we examined the relationship between preferences and recent inpatient or emergency department (ED) care. In aim 1 we assessed the extent to which EOL treatment preferences were related to subsequent hospitalization or ED use in the following 6 and 12 months. In aim 2 we asked if changes in EOL treatment preferences over 12 months were related to hospitalization or ED use. Figure 1 maps research questions against the timeline of study assessments.

In aim 1 we hypothesized that older adults with a preference for less aggressive treatment would be less likely to receive inpatient or ED treatment over follow-up. The rationale for this hypothesis is suggested by recent declines in multiple hospitalizations among people aged 85+ and greater use of in-home and community hospice in the last year of life,¹⁰ both of which

may reflect greater concern by older adults to avoid aggressive care. In aim 2 we hypothesized that people who have had inpatient or emergency room treatment would be more likely to report declines in preferences for aggressive care. We reasoned that hospital care may lead very old adults and their families to seek less aggressive care in the future.

Methods

Sample

The EOL in Very Old Age study is an ancillary investigation using the Health, Aging, and Body Composition (Health ABC) cohort. Health ABC participants were recruited in 1997–1998 to investigate changes in body composition and mobility decline. Participants were recruited by mail from a random sample of white Medicare beneficiaries and all Black community residents meeting age criteria in Pittsburgh and Memphis. At baseline, the 3075 participants were aged 70–79. Beginning in year 15 of Health ABC, EOL cohort follow-up replaced Health ABC's semiannual contact with quarterly telephone interviews. EOL cohort follow-up added questions on preferences for aggressive care, daily symptom burden, health decision making, contact with healthcare professionals, and concerns about health and healthcare. For Health ABC participants unable to participate in interviews, proxies were interviewed on the same schedule and completed parallel questions, in which proxies were asked to report participant preferences.

Of 1403 Health ABC participants known to be alive at the start of year 15, 1227 (87.5%) completed proband or proxy interviews in the first quarter of EOL cohort follow-up. Proxies, family members who for the most part shared homes or had daily contact with participants, provided interviews for 15.4% (189/1227) of the sample in the initial quarter. Each quarter, 2%–4% of the sample switched to proxy interviews, so that by the end of year 16 proxies completed interviews for 18.3% of the sample. Some respondents who missed the year 15 quarter 1 interview were reached at subsequent quarterly interviews. Over eight quarters of follow-up, cumulative mortality was 16.2%.

Analyses

The EOL cohort completed telephone assessment every three months, with interviewing completed over each three-

Aim 1. Are preferences for more aggressive EOL treatment associated with greater hospital admissions or ED use?

Aim 2. Does intensity of hospitalization and ED treatment predict decline in preferences for more aggressive EOL treatment?

FIG. 1. Mapping of study questions and timeline of assessments.

month interval. EOL treatment preferences were elicited once each year in the January–March quarter. Self- or proxy-reported inpatient and ED treatments were reported for the prior six months in the April–June and October–December quarters (Fig. 1).

To determine if preferences for less aggressive EOL treatment were associated with fewer hospital admissions or less ED use (aim 1), we assessed associations between treatment preferences elicited in the first quarter of 2012 (January–March) and hospitalization or ED use over the following year in two 6-month periods (January–June, May–December). We repeated the analysis for preferences elicited early in 2013, again with six months of follow-up.

For aim 2, we examined preferences reported in 2012 and 2013 (elicited in January–March in both years) to see if people experiencing hospital or ED treatment in 2012 were more likely to report declines in the preference for more aggressive care.

Probands and proxies reporting for probands were asked to specify preferences for eight kinds of medical interventions typical of EOL treatment. These included cardiopulmonary resuscitation (CPR), ventilator use, feeding tube for more than a week, dialysis, open-heart surgery, defibrillator, biopsy, and diagnostic imaging (magnetic resonance imaging, ultrasound, or angiogram). The count of endorsed responses indicated preference for aggressive treatment. Scale reliability (standardized Cronbach's alpha) was 0.96 in probands and 0.87 in proxy respondents. For assessing the association between preferences and healthcare utilization, we dichotomized the distribution of scale scores at the proband-reported median, 4, to indicate groups with strong and less strong preferences for aggressive treatment. Separate analyses of the more intensive interventions, such as ventilation, dialysis, and CPR, did not change results, so we present results from the full set of treatment preferences. To assess change in preferences, we subtracted the 2012 summed preference score from the 2013 score. Negative values indicate a decline in preference for aggressive EOL treatment.

Hospitalization and ED use were assessed by proband or proxy report of treatment over the prior six months in either setting. Separate questions were asked for hospitalizations related to a heart problem, congestive heart failure, stroke, or any other reason. Reports of any hospitalization or ED visit were combined into a single indicator of healthcare utilization in each six-month period.

Covariates in analyses included self-reported mobility status, cognitive performance, and a count of comorbid conditions. Mobility was assessed in terms of ease walking a quarter mile, which ranged from “don't do” to “very easy,” and a 4-point measure for proxy reports. For probands, cognitive performance was assessed with the Telephone Interview for Cognitive Status,¹¹ a telephone adaptation of the Mini-Mental State Examination. Telephone Interview for Cognitive Status (TICS) performance ≥ 33 indicates no impairment, 26–32 potential impairment, 21–25 mild impairment, and ≤ 20 moderate-to-severe impairment. The median score was 28. When proxy respondents were required, interview questions addressed reported problems with memory. For comorbidities, probands and proxies reported physician diagnoses of any of seven conditions (hypertension, diabetes, heart attack or angina, congestive heart failure, stroke, cancer, and chronic obstructive pulmonary disease) in the prior six months.

Analyses were carried out separately for proband and proxy interviews. After characterizing the sample using descriptive statistics, the primary analytic approach involved use of logistic regression models. In aim 1, logistic regression models for each six-month interval were estimated to assess the odds of hospital or ED use associated with strong or less strong preferences for aggressive EOL treatment. Models were adjusted for sociodemographic factors (race, gender, education, site, and age), physical function (ease of walking), and cognitive status (TICS). For proxy respondents we used the same covariates except for replacing TICS score with reported memory impairment and adding a measure of contact with participants.

For aim 2 we estimated logistic regression models to examine the independent effect of hospital or ED use on declines in preferences for aggressive EOL treatment. Decline in aggressive care preferences was dichotomized, so that any negative value represented decline. The same set of covariates was used in separate proband and proxy models.

Missing values for some covariates reduced sample size. This was largely due to missing values in the TICS assessment, which 10% of probands did not complete. However, dropping the TICS covariate did not change model estimates. Because of the importance of cognitive status in articulating treatment preferences, we present models that include the TICS assessment.

Death over follow-up may affect the relationship between preferences for aggressive care and hospitalization or ED use. That is, people at the highest risk of dying may differ both in preferences and in likelihood of healthcare utilization. To address this effect, we estimated additional logistic regression models that excluded participants who died or were lost to follow-up between assessment intervals. Results were similar (available upon request), so we present only full models.

Results

Differences between proband and proxy participants

Table 1 compares participants able to complete the telephone interview themselves (probands) and participants with proxy respondents in the EOL in Very Old Age cohort. Probands were two years younger than participants requiring proxy interviews, with median age of 86 versus 88, $p < 0.001$. Participants with proxy respondents were also less likely to have completed high school (69.3% vs. 82.3%, $p < 0.001$). Proxies were more likely to provide interviews for probands residing in long-term care settings (14.3% vs. 2.8%, $p < 0.001$). Among probands completing the TICS, 41.1% scored 25 or lower, whereas proxies reported a high prevalence of memory problems (84%) among participants.

Probands and proxies were similar in other sociodemographic features: 66.0% of probands were white compared to 60.9% of proxy respondents. 57.8% of probands were female and 62.4% of proxy respondents. 49.6% of participants were Pittsburgh residents compared to 45% of proxies. Of the seven comorbidities, probands and proxies both reported a median of two conditions in the prior six months.

A majority of probands (61.6%) and proxies (56.0%) reported a legal power of attorney and witnessed living will.

TABLE 1. END OF LIFE IN OLD AGE COHORT, BY REPORTER STATUS (YEAR 15, QUARTER 1)

	<i>Proband self-report (n = 1038)</i>	<i>Proxy report (n = 189)</i>
Age, median (IQR)	86 (4)	88 (6)***
White, %	66.0	60.9
Female, %	57.8	62.4
Site		
Pittsburgh, %	49.6	45.0
Memphis, %	50.4	55.0
Education, 12+ year, %	82.3	69.3***
Number comorbidities, median (IQR)	2 (2)	2 (2)
Cognitive impairment, %	41.1	84.0***
Residing in skilled nursing facility or assisted living site, %	2.8	14.3***
Both legal power of attorney and witnessed living will, %	61.6	56.0

Comorbidities: report of diagnosis of congestive heart failure, cancer, myocardial infarction, stroke, chronic obstructive pulmonary disease, diabetes, or hypertension.

Cognitive impairment: TICS score <28, median, for probands; or report of memory problem by proxies.

*** $p < 0.001$; other comparisons N.S., not significant.

Wilcoxon Mann-Whitney test for comparison of medians, χ^2 for comparison of percentages.

IQR, interquartile range; TICS, Telephone Interview for Cognitive Status.

Preferences for more aggressive EOL treatment and hospital admissions or ED use

Table 2 shows the association between preferences for aggressive EOL treatment and healthcare utilization in each six-month follow-up period for the proband and proxy samples. Participants reporting preferences for more aggressive treatment (endorsing ≥ 5 of the 8 treatments) were more likely to have at least one inpatient or ED treatment in the next six months (e.g., 20.1% vs. 16.3% among probands for the first follow-up period), but differences did not achieve significance. The same was true for proxy respondents who reported participant preferences (26.1% vs. 25.5% in first six-month follow-up period). Results were similar in subsequent six-month follow-up periods.

In multivariable analyses, probands with preferences for more aggressive treatment were more likely to have in-

patient or ED treatment (e.g., in the first six months of follow-up, probands with a low preference for aggressive treatment were only 0.74 as likely to have a hospitalization or ED episode as probands with a high preference), but differences again did not achieve significance (Table 3). Only ease of walking a quarter mile and residence (Pittsburgh vs. Memphis) were consistent significant predictors of subsequent healthcare utilization. Self-reported greater ease of walking was associated with lower likelihood of inpatient or ED treatment. Memphis participants were less likely to report hospitalization and ED episodes compared to Pittsburgh participants, consistent with differences in regional hospital bed availability. Among proxy reporters, healthcare utilization was not strongly associated with any of the predictors (results available upon request).

TABLE 2. END-OF-LIFE TREATMENT PREFERENCE AND HOSPITAL EMERGENCY DEPARTMENT UTILIZATION OVER SIX MONTHS

		<i>At least one ED visit or hospitalization</i>		
	<i>Preference for aggressive EOL treatment</i>	<i>January–June 2012, %</i>	<i>July–December 2012, %</i>	<i>January–June 2013, %</i>
Probands	January–March 2012			
	Low (0–4)	16.3 (81/497)	15.4 (70/454)	
	High (5–8)	20.1 (85/422)	16.8 (68/404)	
	January–March 2013			
	Low (0–4)			18.1 (79/437)
Proxies	High (5–8)			17.6 (53/301)
	January–March 2012			
	Low (0–4)	25.5 (39/153)	27.6 (34/123)	
	High (5–8)	26.1 (12/46)	30.0 (12/40)	
	January–March 2013			
	Low (0–4)			22.8 (37/162)
	High (5–8)			26.7 (12/45)

Percentages are based on number of participants with event/number in preference group for each time interval.

ED, emergency department; EOL, end of life.

TABLE 3. END-OF-LIFE TREATMENT PREFERENCE AND HOSPITAL EMERGENCY DEPARTMENT UTILIZATION OVER SIX MONTHS: MULTIVARIABLE MODELS AND PROBANDS

<i>Predictor status in first 3 months of interval</i>	<i>ED or use, OR (95% CI)</i>		
	<i>January–June 2012 (n = 785)</i>	<i>July–December 2012 (n = 756)</i>	<i>January–June 2013 (n = 633)</i>
Preference for EOL treatment			
High	1.00	1.00	1.00
Low	0.74 (0.50–1.10)	0.83 (0.54–1.26)	0.99 (0.63–1.54)
Race			
Black	1.00	1.00	1.00
White	0.70 (0.46–1.06)	1.34 (0.84–2.13)	1.06 (0.66–1.70)
Gender			
Female	1.00	1.00	1.00
Male	1.30 (0.87–1.92)	1.03 (0.68–1.56)	1.54 (1.00–2.37)*
Education			
≥12	1.00	1.00	1.00
<12	1.36 (0.80–2.31)	1.68 (0.97–2.93)	1.73 (0.98–3.06)
Site			
Pittsburgh	1.00	1.00	1.00
Memphis	0.46 (0.31–0.69)***	0.67 (0.44–1.01)	0.65 (0.42–0.99)*
Age	1.01 (0.94, 1.08)	0.97 (0.89, 1.05)	1.04 (0.96, 1.12)
Ease of walking quarter mile	0.79 (0.73–0.87)***	0.85 (0.77–0.93)***	0.81 (0.74–0.90)***
Cognitive status (TICS)	1.01 (0.98–1.05)	1.01 (0.97–1.05)	1.00 (0.97–1.03)

Results show regression model estimates for each of three different time periods.

* $p < 0.05$, *** $p < 0.001$.

CI, confidence interval.

Effect of hospital or ED use on preferences for aggressive EOL treatment

Preferences for aggressive care over 12 months declined on the 8-point measure by a mean of 0.24 ± 1.8 among probands and 0.48 ± 2.3 among those with proxy-reported preferences. Declines in the preference for aggressive care were larger among participants with hospitalization and ED treatment. For example, in proxy reports for participants with no hospitalization or ED treatment, preferences for aggressive care declined by -0.11 ; declines were more pronounced for participants with one hospitalization or ED episode (-0.97) or two or more (-0.75). However, in multivariable models, having one or more inpatient or ED episodes was not associated with a statistically significant decline in preferences for aggressive EOL treatment in proband or proxy reports (Table 4).

Discussion

In a sample of very old adults we did not find an association between preferences for aggressive EOL treatment and hospital or ED use. This finding ran contrary to our expectation that people who prefer limited EOL treatment in very old age would be less likely to use the hospital or ED. Likewise, we did not find an association between inpatient or ED use and declines in preferences for aggressive treatment. Preferences for aggressive EOL treatment declined over 12 months, but were not significantly different among people with and without hospitalization or use of the ED. For both analyses, point estimates were in the hypothesized direction, but did not achieve statistical significance. Absence of a significant effect may be due to limitations in the use of self-reported

healthcare utilization, which would bias results toward a null finding. The reliability of proxy reports on participant EOL treatment preferences is also unclear.

Other factors may also attenuate the association between EOL treatment preferences and healthcare utilization. First, intensive medical procedures are common in very old age and near the EOL. In the United States, 20.9% of people aged 85 or older had at least one hospitalization in 2014¹⁰ (Table 81). One study found that 18% of older people had a hospitalization with an intensive procedure in the six months before death.¹² Many factors apart from EOL treatment preferences are involved in inpatient and emergency room care. In cases of a fall or syncope, for example, older people with low preferences for aggressive care may still have an ED episode. It may be that measures of elective or planned procedures would show a stronger relationship between healthcare utilization and EOL treatment preferences. A stronger relationship might also be evident in the final one to two months of life, when people may be more likely to act on preferences to limit treatment.

Second, our measure of EOL treatment preferences is heavily loaded toward ICU interventions that may not be relevant for routine hospitalization or ED treatment. Six of the eight (CPR, ventilator use, feeding tube, dialysis, open-heart surgery, and defibrillator) are intensive treatments not likely to govern decisions for routine hospitalization or ED treatment. Alternative measures that tap attitudes toward routine care, such as whether someone would “visit a doctor right away for a health problem” or “get tests even if a doctor thought unnecessary,”¹³ may be more highly associated with healthcare utilization.

A third issue involves elicitation of EOL treatment preferences. We elicited preferences without allowing people to

TABLE 4. EFFECT OF HOSPITALIZATION/EMERGENCY DEPARTMENT EXPERIENCE ON DECLINE IN PREFERENCES FOR AGGRESSIVE END-OF-LIFE TREATMENT

<i>Predictor</i>	<i>Decline in preference for aggressive EOL treatment, OR (95% CI)</i>	
	<i>Proband (n = 642)</i>	<i>Proxy (n = 106)</i>
Hospitalization/ED use		
Any	1.00	1.00
None	0.95 (0.66–1.38)	0.48 (0.20–1.17)
Race		
Black	1.00	1.00
White	1.06 (0.74–1.52)	0.51 (0.18–1.40)
Gender		
Female	1.00	1.00
Male	0.96 (0.69–1.34)	0.79 (0.30–2.07)
Education		
≥12	1.00	1.00
<12	0.73 (0.46–1.14)	0.36 (0.12–1.08)
Site		
Pittsburgh	1.00	1.00
Memphis	0.73 (0.52–1.00)	1.13 (0.48–2.69)
Comorbidity count	0.90 (0.77–1.04)	0.97 (0.67–1.39)
Age	1.01 (0.95–1.07)	1.03 (0.89–1.20)
Ease of walking quarter mile	0.96 (0.89–1.04)	1.32 (0.94–1.86)
TICS	1.00 (0.98–1.03)	
Memory problem		
Yes		1.00
No		1.32 (0.39–4.51)
Level of contact		
Less than daily		1.00
Daily		1.90 (0.56–6.44)
Share residence		2.13 (0.77–5.91)

qualify responses. For example, we asked, “If you had trouble breathing, would you want a ventilator or breathing machine?” Responses were limited to yes, not sure, no, or refused. This approach would not allow a person to specify “yes, but not in the event of serious, likely permanent brain injury.” A more nuanced elicitation would allow a finer assessment of preferences and may further clarify associations between preferences and healthcare utilization.

These explanations suggest that imprecise or inappropriate measures may be responsible for the absence of an association. However, an alternative explanation is that EOL treatment preferences and health service utilization are truly unrelated. Preferences for aggressive EOL treatment may not be driven by a desire to specify care, as we hypothesized, but rather reflect more general ideas about dignity, pain management, reluctance to burden others, religious sense, desire for longevity, and family wishes.¹⁴ If this is the case, perhaps we should not expect a strong association between stated EOL treatment preferences and healthcare utilization.

Still, patient preferences matter for treatment choices and healthcare utilization. A Dartmouth Atlas study of traditional fee-for-service Medicare spending across Health Care Hospital Referral Regions found that individual preferences matter, even if facility and health factors account for the bulk

of variation in regional Medicare expenditures. The number of physicians, specialists, and hospital beds explained 23% of variation across regions in Medicare spending and patients’ health and income another 12%.¹² Patient preferences explained 5% of regional variation. In our sample regional supply factors may also be relevant, as participants in Memphis were less likely to report inpatient or ED treatment than Pittsburgh participants. However, the Dartmouth Atlas study found a different picture in the case of EOL care. In this study patient preferences were more influential, explaining 7.6% of regional variation. The authors noted that patient preferences explained the largest share of variation in EOL spending between the highest and lowest quintiles of hospital referral regions. In the Dartmouth Atlas study, preferences involved attitudes toward routine care and the wish to take advantage of therapies. These measures were correlated with spending at the EOL and, by implication, treatment choices.

Consistent with the Dartmouth Atlas study, it is reasonable to think that preferences for more or less aggressive EOL care may affect health service use among the very old, who are at high risk of dying by virtue of their great age. Among people aged 85 or older, high utilization of hospitalization (defined as two or more hospitalizations in a year) has declined between 2010 and 2014 (from 6.6% to 6.3%). Hospice use has increased among Medicare enrollees in the same period (from 13.1% to 15.5%), while ED use among people aged 75 or older has declined (from 27.4% to 24.4%)¹⁰ (Tables 74, 81, and 107). These trends may not only indicate new opportunities to avoid hospitalization but also greater concern by older adults to avoid aggressive care. Thus, while our measures of aggressive EOL care were not associated with healthcare utilization, more sensitive assessments may find this association.

Limitations of this research include use of self-reported hospitalization and ED episodes rather than claim data. The six-month recall period for these reports may bias results toward the null, as suggested earlier. Still, we were unable to detect an association between EOL preferences and utilization over multiple observation periods, both in proband and proxy reports. We also examined the association between preferences and utilization in two ways, seeking to determine if preferences predict later utilization and if utilization is associated with a decline in preferences over time. While the research did not find a significant association between EOL treatment preferences and healthcare utilization, we suggest a need for further research using claim data to replicate these results.

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Author Disclosure Statement

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