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Factors associated with the Decision to Withhold Life-Sustaining Treatments among Middle-Aged and Older Adults Who Die in Hospital



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Purpose: As advanced medical care has resulted in the unintended consequence of prolonging deaths, there is a growing interest in the decision to withhold life-sustaining treatments. The purpose of this study was to determine factors associated with the decision to withhold life-sustaining treatments in middle-aged and older adults who die in hospital in the United States. **Methods:** This cross-sectional correlational study conducted secondary analysis of 2000-2012 exit interview data from the Health and Retirement Study. Adults aged 50 and older who died in hospital and who had made a decision regarding life-sustaining treatments were included. Multivariable logistic regression was used to identify factors related to the decision to withhold life-sustaining treatments. **Results:** Among 1,412 adults, the prevalence of the decision to withhold life-sustaining treatments was 61.1%. Significant factors associated with the decision to withhold life-sustaining treatments were being African American (Adjusted Odds Ratio [AOR]=0.50, 95% Confidential Interval [CI]=0.30~0.86), Catholic (AOR=0.5, 95% CI=0.32~0.93), having at least one private insurance policy (AOR=1.40, 95% CI=1.02~1.92), having a living will (AOR=1.71, 95% CI=1.04~2.83), and having discussed end-of-life care with someone (AOR=1.810, 95% CI=1.25~2.62). **Conclusion:** Differences in race and religious affiliation should be considered when older adults, family members, and health care providers make decisions regarding life-sustaining treatments at the end-of-life. Also, health insurance coverage for advance care planning makes it easier for people to discuss life-sustaining treatments with health care providers.

Key Words: Life support care, Terminal care, Decision making, Advance care planning

INTRODUCTION

Tremendous improvements in medical technology have helped save lives from disease and accidents and enabled people with chronic and complex conditions to live longer. However, advanced medical care has also resulted in the unintended consequence of prolonging deaths. This means people receive “futile care” to keep them alive for days, weeks, or even months beyond what was expected [1,2]. Morbidity and mortality are high in old age, but End-Of-Life (EOL) care has become increasingly complicated owing to advances in medical technology. Therefore, many adults and their family caregivers face more difficult medical decisions over the course of serious and chronic illness

at the EOL [1,2].

The definition of withholding Life-Sustaining Treatments (LSTs) is “a decision not to start or increase a life-sustaining intervention (p. 1164)” [3]. LSTs should generally be withheld or withdrawn after obtaining the consent of patients, their loved ones (i.e., spouses, children, and relatives/friends), and health care proxies if there is no hope of recovery or if terminally ill patients do not want to prolong their lives [4]. In a study, prior to hospitalization, only 11.9% of patients preferred to receive LSTs [5]. In a study by Winter and colleagues, the majority of residents (88%) wanted their physician to withhold or withdraw LSTs, while 9% wanted to receive them [6].

Many factors can be related to the decision regarding

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LSTs at the EOL. Those factors include patients' or families' preferences; the religious and cultural beliefs of health care providers, patients, and families; race/ethnicity; and socioeconomic factors [7-10]. Patient factors demonstrated to be associated with withholding LSTs are old age, female gender, being Caucasian, poor functional status, and comorbidities [10,11].

In the United States, the percentage of hospital deaths decreased from 32.6% in 2000 to 19.8% in 2015, whereas the percentage of admissions to the Intensive Care Unit (ICU) in the last month of life increased from 24.3% in 2000 to 29% in 2015 [12]. Bereaved family members reported that receiving LSTs and dying in hospital were not consistent with the decedent's preferences and did not contribute to the quality of dying in older adults [13-15]. Therefore, there has been an increase in public attention toward advance care planning, which includes a living will, Durable Power Of Attorney (DPOA), and EOL discussion as key determinants of EOL decision making, especially in the case of people for whom a decision regarding LSTs needs to be made [5,14]. However, there is limited information on advance care planning and other factors related to the decision regarding LSTs in adults who die in hospital in the United States.

1. Purpose

This study aimed to determine the factors associated with the decision to withhold LSTs based on a nationally representative study in adults over 50 years old and provide the basic data regarding adults and their family caregivers who make the decision to withhold LSTs at the EOL.

METHODS

1. Study Design and Data Source

This was a cross-sectional and correlational study that performed secondary analysis of data from the Health and Retirement Study (HRS), which is an ongoing longitudinal study designed to be representative of the United States population over age 50 [16]. The HRS core interviews began in 1992 and followed up with Americans over 50 every two years, with approximately 23,000 participants. The HRS data cover physical and mental health, insurance coverage, financial situation, work and retirement, and the use of health care services among American older adults, and are linked to Social Security, Medicare, and National Death Index records [16].

2. Sample

Adults who had died in hospital and who had made a decision regarding LSTs formed the study population. This is an aspect that has not been examined by previous studies. The 2000-2012 exit dataset of the HRS (the 2012 exit dataset released in March 2015), Tracker file, and RAND HRS data were merged to obtain demographics, socioeconomic status, clinical factors, and EOL-related factors. The HRS exit data provides information regarding four possible places of death, including hospital, nursing home, home, and hospice. The prevalence of in-hospital death in the HRS exit data between 2000 and 2012 was 36.8%. In this study, the inclusion criteria were 1) adults who died between 2000 and 2012, 2) adults aged 50 and older, 3) adults who died in hospital, and 4) adults who had made a decision involving LSTs. Of the 7,851 adults over 50 who died between 2000 and 2012, 2,893 adults died in hospital. Data were available for 1,412 middle-aged and older adults who had made a decision involving LSTs before death in hospital.

3. Measurements

The HRS exit interview questionnaires and codebook were found on the HRS website (<https://hrs.isr.umich.edu/documentation/questionnaires>). In this study, the independent variables were as follows: 1) demographic characteristics: age at death, gender, race, marital status, religion; 2) socioeconomic status: education, net worth [the net value of total wealthy, which was divided into low net worth (0~33.3 percentile), middle net worth (33.4~66.6 percentile), and high net worth (66.7~100.0 percentile); a higher net worth indicates good financial status], Medicaid, having at least one private insurance policy; 3) clinical factors: expected death, major illness that led to death (cancer, cardiovascular disease, and others), pain during the last year of life, admission in the ICU before death, use of LSTs; and 4) decision making-related factors: having a living will, having a DPOA, having discussed EOL care, participation of adults in decision making at the EOL. The dependent variable was the decision to withhold any treatment ("Did last decisions involve withholding any treatment? [Yes/No]").

4. Data Collection

Within two years of the death of an HRS core interview participant, the HRS conducts exit interviews with the proxy who had the most knowledge about the deceased at

the EOL. This is done after confirming that they are comfortable completing the interviews. Proxies are typically spouses, children, other relatives, friends, or formal caregivers. Details of the HRS exit dataset are described on the website (<http://hrsonline.isr.umich.edu>). Previously published papers examining the EOL situation of decedents are also shown on the website [2,13,17].

5. Ethical Considerations

The HRS was conducted with the approval of the University of Michigan Institutional Review Board (IRB) and involved the distribution of de-identified data to the general public. Researchers can access the HRS database after online registration. The investigator obtained separate approval from the IRB to conduct secondary data analysis. An exempt status was obtained through the Sungshin Women's University IRB based on the use of de-identified data (SSWUIRB 2018-015).

6. Statistical Analysis

Descriptive statistics were used to characterize the sample. Independent *t*-tests and χ^2 tests were used to identify important factors. The factors that were significant at a *p*-value of .05 were chosen to be entered into the multivariable logistic regression. When the factors were highly correlated with each other, the investigator selected the most significant factors among them to avoid the potential consequences of collinearity. Multivariable logistic regression was used to assess the independent effects of demographics, socioeconomic status, clinical factors, and decision making-related factors on the decision to withhold LSTs. The HRS has a complex sample design based on the Survey Research Center's 84-strata National Sample frame in the United States and includes three oversamples of African Americans, Hispanics, and Floridians. Therefore, three sample weights (strata, clusters, and person-level weights) are provided in all HRS datasets to correct for differential probability of sample selection. All analyses except descriptive statistics (Table 1) were weighted. A two-sided *p* value of .05 was considered statistically significant. All statistical analyses were conducted using the SPSS program, version 22.0.

RESULTS

1. Characteristics of the Sample

The demographic characteristics of the sample at base-

line are summarized in Table 1. The average age at death was 78.53 ± 10.45 . Approximately 52% of the subjects were women. The majority of the subjects were Caucasian (81.7%). Two-thirds of the subjects were Protestant and a quarter were Catholic. Approximately 42.5% of the subjects had graduated from high school. A quarter of the subjects were covered by Medicaid at the time of death (24.4%) and more than half (54.1%) had at least one private insurance policy. Half of the deaths had been expected (51.6%) and were caused by cancer (17.9%), cardiovascular disease (23.6%), and others (58.5%). Approximately six in 10 subjects (61.3%) suffered from pain during the last year of life. The majority of the subjects (70.1%) had experienced ICU admission before death and more than half (53.9%) had used LSTs. Approximately 44% of the subjects had a living will, more than half (55.1%) had their DPOA, and two-thirds (64.4%) had discussed EOL treatments with someone. Three in 10 subjects (29.6%) were able to participate in decision making about their medical care at the EOL.

2. Decision to Withhold Life-Sustaining Treatments according to Sample Characteristics

As shown in Table 2, the percentage of those who made the decision to withhold LSTs was 61.1%. The mean age at death was 78.32 (Standard Error [SE]=.53) in the group that made the decision to withhold LSTs and 77.24 (SE=.50) in the group that did not make the decision to withhold LSTs, and there was a significant difference ($t=210.43$, $p<.001$). There were significant differences in race ($\chi^2=42.55$, $p<.001$), religion ($\chi^2=9.62$, $p=.025$), education ($\chi^2=21.51$, $p=.005$), and net worth ($\chi^2=6.88$, $p=.002$). Also, among those who made the decision to withhold LSTs, the proportions of those covered by Medicaid and who had at least one private insurance policy were significantly higher than those who were not covered by Medicaid and did not have at least one private insurance policy ($\chi^2=13.89$, $p<.001$; $\chi^2=30.68$, $p<.001$, respectively). There were significant differences in living will, DPOA, and having discussed EOL care with someone between the two groups ($\chi^2=54.55$, $p<.001$; $\chi^2=15.02$, $p=.006$; $\chi^2=45.66$, $p<.001$, respectively).

3. Factors associated with the Decision to Withhold Life-Sustaining Treatments

The results of multivariable logistic regression are shown in Table 3. Significant factors associated with the decision to withhold LSTs were race, religion, having at least one private insurance policy, having a living will, and having

Table 1. Socio-demographic and End-of-life related Characteristics of Sample

(N=1,412; unweighted)

Characteristics	Categories	n (%) or M±SD
Age (year)		78.53±10.45
Gender	Men	676 (47.9)
	Women	736 (52.1)
Race	Caucasian	1,124 (81.7)
	African American	252 (18.3)
Marital status	Married	486 (42.3)
	Widowed	482 (41.9)
	Separated, divorced, never married	182 (15.8)
Religion	Protestant	895 (63.5)
	Catholic	362 (25.7)
	Other religion or no religion	152 (10.8)
Education	Less than high school graduate (< 12 years)	575 (40.8)
	High school graduate (12 years)	599 (42.5)
	At least some college (> 12 years)	235 (16.7)
Net worth (percentile)	Low (0~33.3)	418 (33.3)
	Middle (33.4~66.6)	417 (33.3)
	High (66.7~100.0)	419 (33.4)
Medicaid	Yes	327 (24.4)
	No	1,011 (75.6)
Having at least one private insurance policy	Yes	744 (54.1)
	No	630 (45.9)
Expected death	Yes	701 (51.6)
	No	658 (48.4)
Major illness that led to older adult's death	Cancer	249 (17.9)
	Cardiovascular disease	328 (23.6)
	Others	813 (58.5)
Pain during the last year of life	Yes	851 (61.3)
	No	538 (38.7)
Admission in the intensive care unit before death	Yes	887 (70.1)
	No	378 (29.9)
Use of life support	Yes	678 (53.9)
	No	581 (46.1)
Having a living will	Yes	613 (43.8)
	No	786 (56.2)
Having durable power of attorney	Yes	765 (55.1)
	No	623 (44.9)
Having discussed EOL care with someone	Yes	904 (64.4)
	No	500 (35.6)
Participation of older adults in the decision making at the EOL	Yes	390 (29.6)
	No	926 (70.4)

EOL=end-of-life.

discussed EOL care with someone. African Americans were less likely to make the decision to withhold LSTs as compared to Caucasians (Adjusted Odds Ratio [AOR]=0.50, 95% Confidence Interval [CI]=0.30~0.86). Catholics were asso-

ciated with lower odds of the decision to withhold LSTs as compared to those with no religion and others (AOR=0.54, 95% CI=0.32~0.93). Having at least one private insurance policy was significantly associated with in-

Table 2. Decision to Withhold Life-Sustaining Treatments according to Sample Characteristics (N=1,412; weighted)

Characteristics	Categories	Decision to withhold LSTs		χ^2 or t	p
		Yes (Weighted %=61.1)	No (Weighted %=38.9)		
Age		78.32 (0.53) [†]	77.24 (0.50) [†]	210.43	< .001
Gender	Men	60.2	39.8	0.52	.621
	Women	62.1	37.9		
Race	Caucasian	64.4	35.6	42.55	< .001
	African American	36.3	63.7		
Marital status	Married	59.9	40.1	0.63	.815
	Widowed	61.7	38.3		
	Separated, divorced, never married	62.9	37.1		
Religion	Protestant	60.2	39.8	9.62	.025
	Catholic	58.4	41.6		
	Other religion or no religion	72.4	27.6		
Education	Less than high school graduate (< 12 years)	52.6	47.4	21.51	.005
		65.2	34.8		
	High school graduate (12 years)	66.7	33.3		
	At least some college (> 12 years)				
Net worth (percentile)	Low (0~33.3)	49.8	50.2	6.88	.002
	Middle (33.4~66.6)	62.2	37.8		
	High (66.7~100.0)	68.1	31.9		
Medicaid	Yes	48.3	51.7	13.89	< .001
	No	64.7	35.3		
Having at least one private insurance policy	Yes	68.0	32.0	30.68	< .001
	No	52.8	47.2		
Major illness that led to older adult's death	Cancer and tumors	57.5	42.5	2.07	.468
	Cardiovascular disease	60.6	39.4		
	Others	62.7	37.3		
Pain during the last year of life	Yes	59.0	41.0	3.30	.145
	No	64.1	35.9		
Spend time in the intensive care unit before death	Yes	62.9	37.1	1.73	.336
	No	58.8	41.2		
Used life support	Yes	60.8	39.2	0.62	.506
	No	63.1	36.9		
Having a living will	Yes	71.3	28.7	54.55	< .001
	No	51.4	48.6		
Having durable power of attorney	Yes	65.5	34.6	15.02	.006
	No	54.7	45.3		
Having discussed EOL care with someone	Yes	67.3	32.7	45.66	< .001
	No	47.8	52.2		
Participation of older adults in the decision making at the EOL	Yes	63.4	36.6	1.01	.509
	No	60.4	39.6		

EOL=end-of-life; LSTs=life-sustaining treatments; [†] Mean (Standard error) value: put in a footnote based on author guideline.

creased odds of the decision to withhold LSTs (AOR=1.40, 95% CI=1.02~1.92). Also, a living will (AOR=1.71,

95% CI=1.04~2.83) and having discussed EOL care (AOR=1.81, 95% CI=1.25~2.62) were associated with higher odds

Table 3. Factors associated with the Decision to Withhold Life-Sustaining Treatments

Predictors	AOR	95% CI	F (p)
Age (year)	1.01	0.99~1.03	1.25 (.269)
Gender (reference: men)	1.10	0.79~1.54	0.34 (.566)
Race (reference: Caucasian)	0.50	0.30~0.86	6.66 (.013)
Religion (reference: other religion or no religion)			
Protestant	0.62	0.38~1.00	3.94 (.052)
Catholic	0.54	0.32~0.93	5.10 (.028)
Less than high school graduate (< 12 years)			
High school graduate (12 years)	1.35	0.93~1.98	2.55 (.117)
At least some college (> 12 years)	1.21	0.69~2.15	0.46 (.500)
Having at least one private insurance policy (reference: no)	1.40	1.02~1.92	4.61 (.037)
Having a living will (reference: no)	1.71	1.04~2.83	4.63 (.036)
Having durable power of attorney (reference: no)	0.85	0.50~1.43	0.39 (.534)
Having discussed end-of-life care with someone (reference: no)	1.81	1.25~2.62	10.44 (.002)
Model F=9.83, $p < .001$, $R^2 = .09$ (Cox & Snell), .12 (Nagelkerke)			

CI=confidential interval; AOR=adjusted odds ratio.

of the decision to withhold LSTs. The model explained between 9% (Cox and Snell R^2) and 12.2% (Nagelkerke R^2) of the variance in the odds of the decision to withhold LSTs. The model fit was good and it was significant ($F=9.83$, $p < .001$).

DISCUSSION

Even though there is a growing interest in the decision regarding LSTs to prevent futile care in hospitals, little is known about the factors associated with the decision to withhold LSTs in adults who die in hospital. In this study, the prevalence of the decision to withhold LSTs was approximately 61%, which was higher than in previous studies. Quill and colleagues reported that 11.7% of patients in the United States made the decision to forgo LSTs prior to ICU discharge or death [10]. Another study, which was conducted in Norway, found that a quarter of patients had a decision to limit their LSTs during their ICU stays [11]. Such differences in prevalence between previous studies and the current study may result from differences in the characteristics of the study populations. The present study population was composed of deceased middle-aged and older adults (average age: 78.5), whereas previous studies collected data at the time of ICU admission in patients who were alive [10,11], and had younger study populations (average age: 58.8) [11].

A study examining the prevalence of withholding LSTs in 177 patients who died in an emergency department in

Morocco reported that LSTs were withheld by 24.2% of patients [18], which was still lower than that of the present study. This may be because the patients who died in emergency department were in life-or-death situations and younger than the patients who generally die in hospital. In a study examining the Physician Orders for Life-Sustaining Treatment (POLST), a type of advance care planning, in nursing facilities [19], among residents who completed the POLST form, 85.7% signed the Do-Not-Resuscitate (DNR) order and 98% of residents who had a DNR form received the care they wanted before their deaths. Further studies comparing different medical settings with regard to the decision related to specific types of LSTs among middle-aged and older adults are needed.

The findings of the present study showed that race, religion, having a private insurance policy, having a living will, and having discussed EOL care were significant factors associated with the decision to withhold LSTs. African Americans had 49.7% lower odds of making the decision to withhold LSTs as compared to Caucasians, which was consistent with the findings that ethnic-minority groups had 27~35% lower odds of making the decision to withhold LSTs in the ICU [10]. Racial differences in decision making at the EOL may be affected by socioeconomic status, religious and cultural background, and health care utilization [20]. A study that interviewed Caucasians and African Americans aged 55 or older in the United States found that African Americans expressed feelings of mistrust toward physicians, whereas Caucasians preferred to have EOL dis-

cussions with physicians. Also, African Americans believed that the completion of a living will may result in withholding of LSTs even if they wanted to receive them [21]. Further studies are needed to better understand the culture regarding EOL decision making based on racial differences. For example, in East Asian countries, such as South Korea, Japan, and Taiwan, the traditional cultural perspective toward death and dying is influenced by Confucianism and Buddhism. Asians in these countries tend to show reluctance to take part in EOL discussions with others and are more focused on the role of the main decision-maker, such as the oldest son and daughter [7,22]. Therefore, to promote discussions about advance care planning and LSTs, racial differences must be taken into consideration.

Being Catholic was negatively associated with the decision to withhold LSTs, which was consistent with a previous finding that in the United States, fundamentalist Catholics were significantly more likely than non-Catholics to desire LSTs [23]. Catholic patients may believe that only God knows when it is the right time to die and may consider making the decision to withhold LSTs at their EOL inconsistent with their religious beliefs [20]. However, a study in the European Union reported that physicians who were Catholic were more likely to withhold LSTs compared to those who belonged to other religions [24], which indicated that health care providers' religious affiliation is also important in the decision to withhold LSTs. Therefore, the religious affiliations of everyone involved, including patients, family members, and health care providers, should be simultaneously considered in future investigations regarding decision making about LSTs at the EOL.

Having a private insurance policy was positively associated with the decision to withhold LSTs. In this study, net worth, Medicaid, and having a private insurance policy were highly correlated ($r > .70$); therefore, the investigator considered having a private insurance policy a factor representing participants' socioeconomic status. In the United States, having private health insurance means that people can afford to meet their physicians and nurse practitioners, enabling them to have the necessary discussions about their EOL care and complete a living will about their preferences for LSTs [13,25,26]. Most Americans make the decision to withhold/withdraw LSTs at the EOL only after discussing the issue with health care providers [18,25,26].

Having a living will was a significant factor associated with the decision to withhold LSTs. This living will described the patient's preferences about the decision regarding LSTs and helped family members and health care

providers make a decision if the patient lacked the capacity to do so [2,14,19]. Having discussed EOL care was also a very important factor in decision making regarding LSTs in this study. EOL discussions between patients, family members, and health care providers can prevent confusion, conflicts, delayed decision making, and futile care at the EOL [14,27] and help patients receive EOL care consistent with their preferences [13,18,28].

In the United States, the Patient Self-Determination Act (PSDA) passed in 1990 required health care providers in hospitals, nursing homes, and health care facilities to ask about the presence of advance directives and to include patients' preferences in medical records. The PSDA promoted the use of advance directives in health care facilities, which led to an increase in the completion of advance directives [29], but there was still a lack of awareness and support from health care providers [30]. Therefore, since 2016, the Centers for Medicare and Medicaid Services have begun providing reimbursements for EOL discussions regarding advance care planning with physicians [31]. Health care providers and policymakers expect that this health insurance coverage will make it easier for older Americans to have discussions about their EOL care with health care providers and to complete advance directives, which will ultimately lead to a decrease in receiving unwanted LSTs before death.

Various programs and community groups, such as "Five Wishes," "Respecting Choices Various programs and community groups, such as "Five Wishes," "Respecting Choices Program," and "The End-of-Life Nursing Education Consortium" in the United States seek to involve people in EOL discussions and encourage them to document their wishes in advance directives, such as the living will and POLST. Also, the use of structured communication tools regarding EOL decision making could promote the discussion about advance care planning and the completion of a living will and help people receive the care they desire, as documented in their advance directives [32]. Mass media (e.g., television programs and radio) and EOL-related websites could shed light on various cases involving EOL decisions, helping increase public interest in decisions regarding LSTs in patients' last days, months, and years [33].

This study had several limitations. First, this study could not control for other factors that may be related to EOL decision making, such as family-related factors, severity of illness, types of LSTs, and health care system (e.g., staffing, type of hospital, and hospital policies regarding EOL care), and which might influence the decision to withhold LSTs [7,10,11]. Second, this study relied

on proxy reports after middle-aged and older adults' death, which may be biased owing to memory limitations ("recall bias") and the tendency of proxies to answer in ways they deem to be socially acceptable ("social desirability bias"). Third, there was the measurement issue because most variables related to EOL care were dichotomized to yes or no answers. Especially, advance care planning includes various forms, such as living wills and POLST, and LSTs include various treatments, such as cardiopulmonary resuscitation, ventilator care, endotracheal intubation, chemotherapy, dialysis, feeding tube, and use of antibiotics [4,14,19]. Therefore, the findings of this study cannot be generalized to all aspects of EOL decision making. Last, the findings of this study cannot be generalized to middle-aged and older adults who die in nursing homes, hospice, or their own homes.

CONCLUSION

Using data from a nationally representative sample in the United States, this study examined the factors associated with the decision to withhold LSTs in Americans aged 50 or above who died in hospital. The findings of the present study suggest that differences in race and religious affiliation should be considered when middle-aged and older adults, family members, and health care providers make decisions regarding LSTs at the EOL. Also, health insurance coverage for discussions about advance care planning makes it easier for people to discuss LSTs with health care providers.

CONFLICTS OF INTEREST

The author declared no conflict of interest.

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