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The Association of Surrogate Decision Makers' Religious and Spiritual Beliefs with End of Life Decisions

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Abstract

Context: Although religion and spirituality are important to surrogate decision makers, little is known about the role of religion in decision making regarding life sustaining treatments.

Objectives: To determine the relationships between dimensions of religion and spirituality and medical treatment decisions made by surrogates.

Methods: This prospective, observational study enrolled patient/surrogate dyads from three hospitals in one metropolitan area. Eligible patients were 65 years or older and admitted to the medicine or medical intensive care services. Baseline surveys between hospital days 2-10 assessed seven dimensions of religion and spirituality. Chart reviews of the electronic medical record and regional health information exchange 6 months after enrollment identified the use of life sustaining treatments and hospice for patients who died.

Results: There were 291 patient/surrogate dyads. When adjusting for other religious dimensions, demographic, and illness factors, only surrogates' belief in miracles was significantly associated with a lower surrogate preference for DNR status (Adjusted odds Ratio (aOR) 0.39, 95%

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confidence interval (CI) 0.19, 0.78). Among patients who died, higher surrogate intrinsic religiosity was associated with lower patient receipt of life-sustaining treatments within the last 30 days (aOR 0.66, CI 0.45, 0.97). Belief in miracles (aOR 0.30, CI 0.10, 0.96) and higher intrinsic religiosity (aOR 0.70, CI 0.53, 0.93) were associated with lower hospice utilization.

Conclusions: Few religious variables are associated with end of life preferences or treatment. Belief in miracles and intrinsic religiosity may affect treatment and should be identified and explored with surrogates by trained chaplains or other clinicians with appropriate training.

Keywords

Spirituality; Religion; Proxy; Surrogate; Decision making; End of Life

INTRODUCTION

Prior studies have shown that 40-47% of hospitalized adult patients and 71% of intensive care unit (ICU) patients are unable to make medical decisions and rely on surrogate decision makers.(1, 2) Religion has been found to be central to conflict over life sustaining treatment decisions in about 25% of cases and often involves family requests for life sustaining treatments on the basis of miracles or other religious beliefs.(3-6) Although surrogates often rely on faith to make decisions and cope (7-10) there is evidence that clinicians do not discuss religious beliefs in family meetings, even when they are an important concern of the family.(11)

Although prior research on patients making their own decisions has found that more religious patients tend to prefer and receive more life sustaining treatments at the end of life than those who are less religious,(12-14) there is very little research describing the role that religion and spirituality play in surrogate decision making. Understanding the relationship of religion, spirituality and surrogate decision making is an important part of delivering care to the many patients who are unable to make their own decisions. The goal of this study was to test the hypothesis that religion and spirituality are associated with a surrogate's preferences for medical care for hospitalized older adults.

Because religion and spirituality are multidimensional in nature, we evaluated several dimensions to determine which are more highly associated with medical decisions and treatments. Spirituality is usually defined more broadly than religion and includes meaning, purpose, connectedness to others and the sacred, relationships and relation to the transcendent.(15) Spiritual well-being is the extent to which an individual feels positively connected to these domains such that they enhance quality of life.(16) Organizational religious activity is the extent to which individuals participate in religious groups such as by attending religious services, while non-organizational religious activity involves private activities such as prayer.(17) Intrinsic religiosity measures personal religious commitment or the extent to which a person perceives their life is guided by religion.(17) Religious coping involves calling on beliefs or practices in times of distress. This may be positive, such as feeling comforted by prayer, or negative, such as feelings that a negative event is a punishment for past wrongdoing or sin.(18) Finally, because of evidence that belief in

miracles often arises in end of life decision making, (3, 5) we addressed this dimension of belief.

METHODS

This analysis was conducted using data from an observational study of surrogate decision makers for hospitalized older adults.(19, 20) Enrollment of participants for this analysis was between August 2012 and June 2015. The Indiana University Institutional Review Board approved the study.

Setting and Participants

Patient/surrogate dyads were enrolled from three hospitals in one metropolitan area. The hospitals were a university based tertiary referral hospital, an urban safety net hospital and a suburban hospital that is part of the university health system. Eligible patients were 65 years or older admitted to the medicine or medical ICU services of each hospital who were entirely unable to participate in decision making due to altered mental status. Surrogates were 18 years or older and legally authorized to make decisions according to Indiana law. Patients were identified by reviewing daily admission lists. We conducted a brief 3-5 minute screen with inpatient physicians (attending, fellow, or resident) to identify whether or not the patient relied on a surrogate and whether they faced one of three categories of major decisions (life sustaining treatment, procedures and surgeries, or discharge with services or to a facility) requiring surrogate input during the hospital stay. Eligible surrogates had participated in one or more of the decisions. Surrogates were approached for informed consent and enrollment.

Data Collection and Instruments

Baseline surveys were conducted by phone or in person by a trained research assistant (RA) between hospital days 2 and 10. The survey included social and demographic characteristics of the patient and surrogate and surveys assessing several dimensions of surrogate's religion and spirituality. Spiritual well-being was assessed with the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp) non-illness, a 12 item measure that has been validated in a religiously diverse population without life threatening illness.(16) The FACIT-Sp can be used with individuals from multiple religions as well as individuals who do not regard themselves as religious. Organizational (attending religious services) and non-organizational (private activities such as prayer) religious activity and intrinsic religiosity (the extent to which one's life is guided by religion for its own sake) were assessed with the Duke University Religion Index.(17) The item assessing organizational religious activity addresses how often participants "attend church or other religious meetings." Responses range from never, once a year or less up to more than once a week. Non-organizational religious activity addresses "private religious activities, such as prayer, meditation or Bible study." Three items assessing intrinsic religiosity were summed for this subscale. Religious coping involves the ways a patient relies on religion to cope with stress. Positive religious coping can promote healthy adjustment to stress, while negative religious coping reflects spiritual struggles, such as feeling that one is being punished by God.(18) Positive and negative religious coping were assessed with the Brief RCOPE.(18)

Belief in miracles was assessed with a single item developed by the investigators that stated, “I believe that divine intervention or a miracle might change the course of (patient’s) illness.” Responses to this item were assessed on a 5 point Likert scale but were dichotomized for analysis into “yes” responses (agree or strongly agree) and “no” responses (strongly disagree, disagree, or neither).

Income was assessed with a single item asking if the surrogate felt their income was comfortable, just enough or not enough to make ends meet. Health literacy was assessed with a the Rapid Estimate of Adult Literacy in Medicine-Short Form (REALM-SF) for surrogates interviewed in person and with a single validated item asking about trouble completing medical forms for those interviewed by phone.(21, 22) The REALM-SF has been validated in multiple patient samples that ranged in mean age from 42-70, predominantly white and African American and were majority male. Responses were dichotomized as lower or equal versus higher than 6th grade reading level. We measured anxiety using the Generalized Anxiety Disorders seven item scale, which has been validated in adults medical patients, and trust using the Healthcare System Distrust Scale, which a been validated in outpatients in a large health system.(23, 24) Patient illness severity was assessed during chart review limited to the first 24 hours of hospitalization using the Cumulative Illness Rating Scale (CIRS).(25) The surrogate was also asked whether or not the patient had discussed their preferences for future medical treatment with anyone.

Code status Preferences and End of Life Treatment

Surrogates’ preferences for the patient’s code status at baseline were assessed with the following item:

There are a number of things doctors can do to try to revive someone whose heart has stopped beating, which usually includes shocks to the heart and use of a machine to help with breathing. Some patients choose to not have these interventions and die peacefully. Thinking of (Patient’s) current situation, would you want the doctors to try to revive him/her?

“No” responses were coded as a preference for DNR status. “Yes and “don’t know” responses were coded as preferences for full code status, given that this is the default order for code status. We conducted chart reviews that included the electronic medical record at the hospital where the patient was enrolled, plus data from the Indiana Network for Patient Care (INPC), a regional health information exchange that includes 106 hospitals in central Indiana, covering over 90% of care provided in the Indianapolis area.(26, 27) Use of INPC increased the likelihood that we will capture aggressive care and/or hospice utilization that occurs in the 30 days before patient death since patients may be admitted to health systems other than the ones included in our study. Based on a review of the literature (28-32) we developed a list of interventions that may be burdensome at the end of life: surgery, other medical procedures requiring informed consent, chemotherapy, dialysis, hospitalization, stay in an ICU, an emergency department visit, intubation/ventilation, cardiopulmonary resuscitation, or artificial nutrition or transfusion.. Trained research assistants reviewed the electronic medical record and regional health information exchange and noted whether each intervention was present or absent in the 30 days before death. Hospice use was based on a

combined variable including surrogate report of hospice use during a 6 month follow-up telephone interview or by documentation of hospice enrollment in the EMR or INPC.

Data analysis

For all enrolled patients, we created a dichotomous variable for surrogate preference for DNR status during the hospitalization. We first examined the bivariate associations between each religion variable and the outcome. We then conducted multivariable logistic regression analyses that included the religion/spirituality scales, demographic variables, and other variables that we expected to be associated with DNR preferences based on prior literature, including race, health literacy, and trust.(33-35) For the subset of patients who died within 6 months of study enrollment, we created a dichotomous variable for aggressive care in the 30 days before death and a dichotomous variable for hospice enrollment. Separate logistic regression analyses were performed for each outcome using the approach described for DNR status. All analytic assumptions were verified and all analyses were performed using SAS v9.4 (SAS Institute, Care, NC).

RESULTS

Patient and Surrogate Characteristics

There were 718 eligible dyads. Of those, 331 were enrolled (46.1%). We found that 291 dyads had complete data on the measures included in this analysis (Table 1). Missing data was most common for the religion measures, with surrogates stating that the item did not apply to them or refusing to answer. Patients had an average age of 81.9 SD (8.3). They were 29.6% African American and 81.1% Protestant. Surrogates had a mean age 58.2 SD (11.1) and were most commonly the adult child of the patient (67.7 %). We found 44.7% of surrogates reported attending religious services weekly or more; 77.3% endorsed the item, “my religious beliefs are what really lie behind my whole approach to life.” There were 58.8% who agreed that divine intervention or a miracle could change the course of the patient’s illness.”

Medical Care

We found that 167/291 (57.4%) of surrogates expressed a preference for the patient to have a do not resuscitate (DNR) status at the time of study enrollment. Chart review was completed for the 123 patients who died within the 6 month observation window. We found that 92 (74.8%) received at least one life sustaining treatment within 30 days of death and 56 (45.5%) were enrolled in hospice.

Association of Religion/Spirituality and Medical Care

Of surrogates who preferred DNR status, 83 (49.7%) believed that a miracle might save the life of their family member, compared to 88 (71.0%) of those who prefer full code. When adjusting for other religious dimensions, demographic, and illness factors, belief in miracles was significantly associated with a lower surrogate preference for DNR status (Adjusted Odds Ratio (aOR) 0.39, 95% confidence interval (CI) 0.19, 0.78; Table 2). No other religious or spiritual variables were associated with preference for DNR status.

Among the 123 patients who died in the six months after hospital discharge, 92 (74.7%) received one or more aggressive intervention in the last 30 days of life. Higher intrinsic religiosity was associated with lower receipt of life-sustaining treatments within the last 30 days in adjusted analyses (aOR 0.66, CI 0.45, 0.97); Table 3). More frequent participation in organized religious activity and higher positive religious coping were bivariately associated with this outcome but not after adjustment for other predictors in Table 3. A multivariable sensitivity analysis that was performed with a list of the most aggressive interventions (admission to ICU, mechanical ventilation, surgery, or cardiopulmonary resuscitation) found different results; we found 44 (35.8% of patients had one or more aggressive interventions using this definition. Non-organizational religious activity was associated with lower receipt of very aggressive care (aOR 0.60, CI 0.37, 0.99; Table 4). Of patients who died 56 (45.5%) received hospice care. Belief in miracles (aOR 0.30, CI 0.10, 0.96) and higher intrinsic religiosity (aOR 0.70, CI 0.53, 0.91) were associated with lower hospice utilization (Table 5).

DISCUSSION

This study of surrogate decision makers for hospitalized older adults found that belief in miracles was associated with lower surrogate preferences for DNR status and with lower enrollment in hospice. Higher intrinsic religiosity was weakly associated with lower likelihood of aggressive life sustaining treatments but strongly associated with lower hospice enrollment at the end of life. In contrast to prior studies assessing patient's own decision making, (12-14, 36) most dimensions of religion and spirituality such as spiritual well-being, religious coping and religious practice were not associated with end of life preferences or care.

Belief in miracles remained significantly associated with lower preferences for DNR status and hospice use when controlling for other demographic variables that may be associated with end of life care, including patient age, ICU admission, and the surrogate's race, health literacy, education and age. Hope for a miracle suggests beliefs in divine or supernatural intervention in the world. This may lead a surrogate to focus on religious beliefs and minimize the importance of prognostic or other clinical information from the physician.(37) Enrollment in hospice requires acknowledging that the patient has a prognosis of 6 months or less and is associated with the end of life. Surrogates may perceive hospice enrollment as a form of "giving up" on hope for survival and perceive this as inherently in conflict with their hope for a miracle. However, it is important to note that among the 171 surrogates who endorsed the miracle item, nearly half preferred DNR status and one third of the patients were enrolled in hospice, suggesting that many surrogates found belief in miracles to be compatible with comfort care.

The findings regarding intrinsic religiosity were more complex. It was weakly associated with lower use of life sustaining treatments but was strongly associated with lower hospice utilization, even when controlling for belief in miracles and other factors. Intrinsic religiosity expresses the personal religious commitment or motivation that informs the person's way of being in the world. When a person lives life rooted in religious commitment for its own sake the person may be motivated by inner convictions and actions "which just seem right."

Whatever religious convictions the intrinsically religious person has internalized require actions consistent with those convictions. Such an approach may explain resisting admission to hospice because it may seem to call into question the surrogate's core convictions.

Our findings contrast with other studies that have found various dimensions of religion such as religious coping, a sense of growing closer to God, higher religious practice, and rating religion as more important in their lives to be associated with both preferences for life sustaining treatment and receipt of these treatments for patients making their own medical decisions.(12-14, 36) The difference in findings between the present study and several prior studies of patients' decision making for their own healthcare may be due to the population of the patients, as some of the prior studies included younger patients with illnesses such as cancer. There may be a greater acceptance of death when patients are older or have severe cognitive impairment as in the present study. Also, life threatening illness may be perceived as part of the normal life course. Religious individuals may frame the end of life as part of "God's plan" for older adults.(3)

The lack of associations between life sustaining treatments at end of life and any religious variables, including belief in miracles, may also suggest that other health system factors, such as prognosis, physician recommendation or local patterns of medical practice related to end of life care, may be more important in decisions about interventions delivered at the end of life than the surrogates' beliefs. Our prior research has also found that surrogate decision makers call upon religious beliefs to explain or justify both acceptance of death and hope for a cure. (10) Religious faith may be important in decision making even if it does not predict the direction of surrogate preferences for life sustaining versus comfort focused care.

Strengths of this study include the use of multiple, valid measures of potentially relevant aspects of religion and spirituality and a rigorous approach to assessing surrogate preferences and medical care at the end of life. The study also has limitations. Specific beliefs other than belief in miracles may affect decision making (38) but were not assessed in this study. Surrogates' participation in religious activities may have been adversely affected by their caregiving responsibilities to the patient. We were able to obtain detailed perceptions of the surrogates' religious beliefs and attitudes but could not obtain this information for the patients because they were unconscious or cognitively impaired at the time of decision making. Study measures had generally been validated in patient samples rather than family members. Although we found there was a very high concordance between religious affiliation between patients and surrogates, our study could not carefully account for the patients' own religious beliefs. The study may not have been adequately powered to detect some differences, especially among the lower number of patients who died. Finally, while we did not correct for multiple comparisons because we emphasized the multivariable results and the odds ratios are not independent within a logistic regression; we note when associations are stronger based on the confidence interval.

The associations between some religious variables and medical decisions raise ethical questions about the role of the surrogate's beliefs and preferences in decision making for patients. Standard frameworks for surrogate decision making advocate relying on patient preferences and best interests in decision making and do not account for the role of the

surrogate's personal beliefs.(39, 40, 41) However, this study finds that the surrogate's own belief in miracles and intrinsic religiosity play some role in decision making. Clinicians working with surrogates need to navigate challenging situations in which they believe that the surrogate's religious beliefs and the patient interests are in conflict. Prior authors have noted that belief in miracles is a cause of ethical conflict in some of these cases.(3) When these situations arise, high quality spiritual care provided by chaplains or other trained clinicians could lead to greater concordance between the surrogate's beliefs and preferences and what is in the best interest of the patient. Prior research has found that spiritual care provided to patients by chaplains or other members of the medical team may lead to greater utilization of hospice and fewer life-sustaining interventions at end of life (42). Future work could explore whether spiritual care affects decision making for surrogates as well.

The findings of this study have important clinical implications. Clinicians need to explore religion and spirituality with individual surrogates in order to determine the effect they may have on decision making. Knowledge of the surrogate's practices or beliefs cannot predict views about end of life care in most cases. All clinicians can begin the conversation with a patient or surrogate by taking a spiritual history. Expert guidelines have been published to help clinicians when conflicts arise (43). In-depth spiritual assessment can be conducted by trained chaplains, who can explore both the surrogate's understanding of a miracle and its role in decision making. Chaplains have the training to provide theological and spiritual guidance to families regarding the role of miracles in life threatening illness. They are also best situated to understand the role that religion plays in the life of the surrogate and provide support as the surrogate navigates difficult decisions.

In conclusion, the lack of association between many dimensions of religion and spirituality with end of life care in surrogate decision making stands in contrast with much of the research previously conducted with patients making decisions for themselves. Our findings suggest that it is not religion or spirituality in general that predict associations with end of life care, but rather specific dimensions of religion or spirituality. Because religion has been shown to be important to surrogates, clinicians should explore religion with each individual surrogate and avoid assumptions about the role it will play in decision making. Belief in miracles and intrinsic religiosity should be a particular focus. Chaplains can provide in-depth exploration, spiritual support and theological counseling, especially when surrogates are struggling with decisions or when disagreements arise about goals of care at the end of life (44).

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REFERENCES

1. Raymont V, Bingley W, Buchanan A, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet* 2004;9443:1421–7.
2. Torke AM, Sachs GA, Helft PR, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Intern Med* 2014;3:370–7.

3. Bandini JI, Courtwright A, Zollfrank AA, Robinson EM, and Cadge W. The role of religious beliefs in ethics committee consultations for conflict over life-sustaining treatment. *J Med Ethics* 2017;6:353–358.
4. Sulmasy DP Spirituality, religion, and clinical care. *Chest* 2009;1634–1642. [PubMed: 19497898]
5. Widera EW, Rosenfeld KE, Fromme EK, Sulmasy DP, and Arnold RM. Approaching patients and family members who hope for a miracle. *J Pain Symptom Manage* 2011;1:119–25.
6. Mendola A Case study. Faith and futility in the ICU. Commentary. *Hastings Cent Rep* 2015;1:9–10.
7. Elliott BA, Gessert CE, and Peden-McAlpine C. Decision making by families of older adults with advanced cognitive impairment: spirituality and meaning. *J Gerontol Nurs* 2007;49–55. [PubMed: 17718378]
8. Braun UK, Beyth RJ, Ford ME, and McCullough LB. Voices of African American, Caucasian, and Hispanic surrogates on the burdens of end-of-life decision making. *J Gen Intern Med* 2008;3:267–74.
9. Boyd EA, Lo B, Evans LR, et al. "It's not just what the doctor tells me:" factors that influence surrogate decision-makers' perceptions of prognosis. *Crit Care Med* 2010;5:1270–5.
10. Geros-Willfond KN, Ivy SS, Montz K, Bohan SE, and Torke AM. Religion and Spirituality in Surrogate Decision Making for Hospitalized Older Adults. *J Relig Health* 2016:765–777. [PubMed: 26337437]
11. Ernecoff NC, Curlin FA, Buddadhumaruk P, and White DB. Health Care Professionals' Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions. *JAMA Intern Med* 2015;10:1662–9.
12. Sullivan MA, Muskin PR, Feldman SJ, and Haase E. Effects of religiosity on patients' perceptions of do-not-resuscitate status. *Psychosomatics* 2004;2:119–28.
13. Balboni TA, Vanderwerker LC, Block SD, et al. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *J Clin Oncol* 2007;5:555–60.
14. Phelps AC, Maciejewski PK, Nilsson M, et al. Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA* 2009;11:1140–7.
15. Puchalski CM, Vitillo R, Hull SK, and Reller N. Improving the spiritual dimension of whole person care: reaching national and international consensus. *J Palliat Med* 2014;6:642–56.
16. Peterman AH, Fitchett G, Brady MJ, Hernandez L, and Cella D. Measuring Spiritual Well-Being in People With Cancer: The Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp). *Ann Behav Med* 2002:49–58. [PubMed: 12008794]
17. Koenig HG and Bussing A. The Duke University Religion Index (DUREL): A Five-Item Measure for Use in Epidemiological Studies. *Religions* 2010:78–85.
18. Pargament K, Feuille M, and Burdzy D. The Brief RCOPE: Current psychometric status of a short measure of religious coping. *Religions* 2011:51–76.
19. Torke AM, Monahan P, Callahan CM, et al. Validation of the Family Inpatient Communication Survey. *J Pain Symptom Manage* 2017;1:96–108 e4.
20. Torke AM, Callahan CM, Sachs GA, et al. Communication Quality Predicts Psychological Well-Being and Satisfaction in Family Surrogates of Hospitalized Older Adults: An Observational Study. *J Gen Intern Med* 2018;3:298–304.
21. Arozullah AM, Yarnold PR, Bennett CL, et al. Development and validation of a short-form, rapid estimate of adult literacy in medicine. *Med Care* 2007;11:1026–33.
22. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 2008;5:561–6.
23. Kroenke K, Spitzer RL, Williams JBW, and Löwe B. The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. *General Hospital Psychiatry* 2010:345–359. [PubMed: 20633738]
24. Shea JA, Micco E, Dean LT, et al. Development of a revised Health Care System Distrust scale. *J Gen Intern Med* 2008;6:727–32.

25. Salvi F, Miller MD, Grilli A, et al. A Manual of Guidelines to Score the Modified Cumulative Illness Rating Scale and Its Validation in Acute Hospitalized Elderly Patients. *J Amer Geriatr Soc*. 2008;1926–1931. [PubMed: 18811613]
26. Indiana Health Information Exchange. Available from: <http://www.ihie.org/> June 24, 2018.
27. McDonald CJ, Overhage JM, Barnes M, et al. The Indiana network for patient care: a working local health information infrastructure. An example of a working infrastructure collaboration that links data from five health systems and hundreds of millions of entries. *Health Aff (Millwood)* 2005;5:1214–20.
28. Levinsky NG, Yu W, Ash A, et al. Influence of age on Medicare expenditures and medical care in the last year of life. *JAMA* 2001;11:1349–55.
29. Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *NEJM* 2009;16:1529–38.
30. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;8:733–42.
31. Barnato AE, Tate JA, Rodriguez KL, Zickmund SL, and Arnold RM. Norms of decision making in the ICU: A case study of two academic medical centers at the extremes of end-of-life treatment intensity. *Intensive Care Med* 2012;1886–1896. [PubMed: 22940755]
32. Hickman SE, Nelson CA, Perrin NA, et al. A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the physician orders for life-sustaining treatment program. *J Am Geriatr Soc* 2010;7:1241–8.
33. Blackhall LJ, Frank G, Murphy ST, et al. Ethnicity and attitudes towards life sustaining technology. *Social Science & Medicine* 1999;12:1779–89.
34. Johnson KS, Elbert-Avila KI, and Tulsy JA. The influence of spiritual beliefs and practices on the treatment preferences of African Americans: a review of the literature. *J Am Geriatr Soc* 2005;4:711–9.
35. Volandes AE, Paasche-Orlow M, Gillick MR, et al. Health literacy not race predicts end-of-life care preferences. *J Palliat Med* 2008;5:754–62.
36. Balboni T, Balboni M, Paulk ME, et al. Support of cancer patients' spiritual needs and associations with medical care costs at the end of life. *Cancer* 2011;23:5383–91.
37. White DB, Ernecoff N, Buddadhumaruk P, et al. Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients. *JAMA* 2016;19:2086–94.
38. Balboni TA, Prigerson HG, Balboni MJ, et al. A scale to assess religious beliefs in end-of-life medical care. *Cancer* 2019.
39. Emanuel EJ and Emanuel LL. Proxy decision making for incompetent patients. An ethical and empirical analysis. *JAMA* 1992;15:2067–71.
40. Brock DW Deciding for others: surrogate decision making for incompetent adults. *R I Med J* 1991;3:105–11.
41. Sulmasy DP, Snyder L. Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making. *JAMA*. 2010;304(17):1946–1947. doi:10.1001/jama.2010.1595 [PubMed: 21045102]
42. Balboni TA, Balboni M, Enzinger AC, et al. Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life. *JAMA Intern Med*. 2013;173(12):1109–1117. doi:10.1001/jamainternmed.2013.903 [PubMed: 23649656]
43. Cooper RS, Ferguson A, Bodurtha JN, and Smith TJ. AMEN in challenging conversations: bridging the gaps between faith, hope, and medicine. *J Oncol Pract* 2014;4:e191–5.
44. Wirpsa JM, Johnson ER, Bieler J, et al. Interprofessional Models for Shared Decision Making: The Role of the Health Care Chaplain. *J Health Care Chaplain* 2019 1:20–44.

Table 1.

Surrogate and Patient Characteristics. Values are number (percent) unless otherwise indicated (n=291).

Surrogate characteristics	Number (percent)
Relationship to patient	
Spouse	48 (16.5)
Spouse-equivalent	1 (0.3)
Son/Daughter	197 (67.7)
Son/Daughter-in-law	8 (2.8)
Grandchild	7 (2.4)
Neighbor/Friend	1 (0.3)
Other	29 (10.0)
Age, mean (standard deviation)	58.19 (11.06)
Gender, female	203 (69.8)
Race	
White	205 (70.5)
African American	85 (29.2)
More than one race	1 (0.3)
Hispanic/Latino	1 (0.3)
Religion	
Protestant	233 (80.1)
Catholic	30 (10.3)
None	14 (4.8)
Other	14 (4.8)
Self-assessed income	
Comfortable	159 (54.6)
Just enough	100 (34.4)
Not enough	32 (11.0)
Education, mean (standard deviation)	13.96 (2.47)
Health literacy (6 th grade)	193 (66.3)
Anxiety, mean (standard deviation)	4.10 (4.82)
Was a caregiver to the patient prior to hospital admission	171 (58.8)
Distrust in healthcare system, mean (standard deviation)	3.16 (0.33)
Spiritual well-being, mean (standard deviation)	30.36 (6.06)
Organized religious activity	
Attend services, weekly or more	130 (44.7)
Non organized religious activity	
Private religious activities, weekly or more	210 (72.2)
Intrinsic religiosity ^a	
In my life, I experience the presence of the Divine (<i>i.e.</i> , God).	230 (79.3)
My religious beliefs are what really lie behind my whole approach to life.	225 (77.3)
I try hard to carry my religion over into all other dealings in life.	225 (77.3)
Belief in miracles	171 (58.8)

Surrogate characteristics	Number (percent)
Patient characteristics	
Age	81.86 (8.29)
Gender, Female	187 (64.3)
Race	
White	205 (70.5)
African American	86 (29.6)
More than one race/other	0 (0)
Hispanic/Latino	1 (0.3)
Religion	
Protestant	236 (81.1)
Catholic	32 (11.0)
None	17 (5.8)
Other	6 (2.1)
Admit location, ICU	72 (24.7)
Has the patient discussed future medical care?	128 (44.0)
Medical Preferences and Treatment	
Surrogate Prefers DNR status during hospitalization	167 (57.4%)
Died within 6 months of hospitalization	123 (42.3%)
Any life sustaining treatment within 30 days of death ^b	92 (74.8%)
Surgery	7 (5.8)
Invasive procedures	46 (38.3)
Chemotherapy	0 (0)
Dialysis	6 (5.0)
Hospitalization	87 (72.5)
Intensive Care Unit	38 (31.7)
Emergency Department visits	83 (69.2)
Intubation/mechanical ventilation	32 (26.7)
Cardiopulmonary resuscitation	12 (10.0)
Artificial nutrition	34 (28.3)
Blood transfusion	25 (20.8)
Hospice enrollment prior to death (n=123)	56 (45.5)

^aCoded as 'yes' if response was "tends to be true" or "definitely true" and 'no' if it was "unsure" or less.

^bResponses for individual interventions sum to more than 92 because a patient may have had more than one intervention.

Table 2.

Surrogate preferences for do not resuscitate (DNR) status during the hospital stay (n=291).

	Univariate OR (95% CI)	P value	Multivariable^a aOR (95% CI)	P value
Surrogate characteristics				
Spiritual well-being	0.97 (0.93, 1.01)	.1406	0.95 (0.88, 1.02)	.1741
Organized religious activity	0.94 (0.81, 1.08)	.3524	0.89 (0.70, 1.13)	.3324
Non organized religious activity	0.99 (0.87, 1.13)	.8744	1.16 (0.92, 1.45)	.2179
Intrinsic religiosity	0.97 (0.90, 1.04)	.3694	1.04 (0.90, 1.20)	.6220
Positive religious coping	0.98 (0.95, 1.01)	.2352	1.04 (0.97, 1.11)	.3069
Negative religious coping	1.06 (0.96, 1.17)	.2664	1.08 (0.95, 1.23)	.2308
Belief in miracles	0.40 (0.25, 0.66)	.0003	0.39 (0.19, 0.78)	.0080

^aThe multivariable analyses controlled for the following variables: other dimensions of religion and spirituality, patient and surrogate age, race, gender; surrogate religion, income, education, health literacy, baseline anxiety, health system distrust and relationship to patient; patient illness severity and whether the patient had discussed future medical care with anyone.

Table 3.

Receipt of any aggressive interventions within 30 days of death for patients who died within 6 months after enrollment (n=123).

	Univariate OR (95% CI)	P value	Multivariable ^a aOR (95% CI)	P value
Surrogate characteristics				
Spiritual well-being	0.99 (0.92, 1.06)	.6472	1.20 (0.98, 1.46)	.0774
Organized religious activity	0.76 (0.59, 0.99)	.0408	0.85 (0.54, 1.33)	.4759
Non organized religious activity	0.79 (0.62, 1.00)	.0531	1.03 (0.64, 1.63)	.9131
Intrinsic religiosity	0.83 (0.69, 0.98)	.0304	0.66 (0.45, 0.97)	.0323
Positive religious coping	0.93 (0.87, 0.99)	.0280	0.93 (0.81, 1.07)	.3241
Negative religious coping	0.95 (0.83, 1.08)	.4227	0.88 (0.70, 1.11)	.2794
Belief in miracles	0.75 (0.32, 1.74)	.4990	1.80 (0.52, 6.24)	.3522

^aThe multivariable analyses controlled for the following variables: other dimensions of religion and spirituality, patient and surrogate age, race, gender; surrogate religion, income, education, health literacy, baseline anxiety, health system distrust and relationship to patient; patient illness severity and whether the patient had discussed future medical care with anyone.

Table 4.

Receipt of the most aggressive interventions (ICU admission, mechanical ventilation, cardiopulmonary resuscitation, or surgery) within 30 days of death for patients who died within 6 months after enrollment (n=123).

	Univariate OR (95% CI)	P value	Multivariable aOR (95% CI)	P value
Surrogate characteristics				
Spiritual Well-being	1.05 (0.98, 1.12)	.2090	1.06 (0.85, 1.33)	.6060
Organized religious activity	1.09 (0.88, 1.36)	.4205	1.60 (0.95, 2.70)	.0781
Non organized religious activity	0.98 (0.81, 1.20)	.8521	0.60 (0.37, 0.99)	.0457
Intrinsic religiosity	1.00 (0.90, 1.12)	.9953	1.12 (0.84, 1.47)	.4432
Positive religious coping	0.99 (0.94, 1.04)	.6245	0.99 (0.84, 1.17)	.9047
Negative religious coping	0.97 (0.85, 1.12)	.6872	1.33 (0.99, 1.78)	.0615
Belief in miracles	1.79 (0.83, 3.89)	.1387	1.89 (0.44, 8.20)	.3951

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Table 5.

Receipt of hospice at end of life for patients who died within 6 months after enrollment (n=123).

	Univariate OR (95% CI)	P value	Multivariable^a aOR (95% CI)	P value
Surrogate characteristics				
Spiritual Well-being	0.99 (0.93, 1.05)	.7763	1.18 (1.00, 1.40)	.0507
Organized religious activity	0.99 (0.81, 1.22)	.9332	1.29 (0.84, 1.97)	.2494
Non organized religious activity	0.84 (0.69, 1.02)	.0725	0.99 (0.67, 1.47)	.9612
Intrinsic religiosity	0.89 (0.79, 0.99)	.0324	0.70 (0.53, 0.91)	.0070
Positive religious coping	0.97 (0.92, 1.03)	.3170	1.05 (0.93, 1.18)	.4737
Negative religious coping	0.96 (0.84, 1.09)	.5317	1.03 (0.81, 1.30)	.8373
Belief in miracles	0.32 (0.15, 0.68)	.0028	0.30 (0.10, 0.96)	.0431

^aThe multivariable analyses controlled for the following variables: other dimensions of religion and spirituality, patient and surrogate age, race, gender; surrogate religion, income, education, health literacy, baseline anxiety, health system distrust and relationship to patient; patient illness severity and whether the patient had discussed future medical care with anyone.