Factors Associated with Family Caregivers' Confidence in Future Surrogate Decision Making for Persons with Cancer

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Abstract

Background: Improving family caregiver preparation for surrogate decision making is a critical priority.

Objective: Determine a parsimonious set of intrapersonal factors associated with family caregivers' confidence in making future medical decisions for their relatives with cancer.

Methods: Cross-sectional mail survey. Family caregivers of Medicare beneficiaries with pancreatic, lung, brain, ovarian, head and neck, hematologic, and stage IV cancers from communities of eight U.S. cancer centers. Participants completed validated measures of their social and mental health, self-care behaviors, coping styles, and surrogate decision-making confidence. Using linear modeling, the Bayesian information criterion was used to identify factors associated with decision-making confidence. A bootstrap approach was used to conduct penalized inference on the selected model coefficients. Model fit validation was assessed with a random forest ensemble.

Results: Caregivers ($n=294$) were on average 65.5 years old, mostly female (72.8%), and care recipients' spouse/partner (60.2%). The parsimonious set of factors associated with low caregiver decision-making confidence included less engagement in spiritual growth self-care, more use of avoidant coping, low emotional social support, and younger care recipient age (in-sample $R^2=0.22$). These factors were also identified by a random forest approach. After overfitting adjustment (shrunk $R^2=0.09$), the strongest associations with low surrogate decision-making confidence were low spiritual growth self-care (adjusted standardized $B=0.17$, $p=0.005$) and high use of avoidant coping (adjusted standardized $B=-0.12$, $p=0.049$).

Discussion: Identifying strategies to enhance spiritual growth and reduce avoidant coping may be promising targets for interventions to improve family caregivers' confidence in future surrogate decision making.

Keywords: cancer; family caregiver; palliative care; spirituality; surrogate decision making

Introduction

THE NATIONAL COMPREHENSIVE CANCER NETWORK,¹ the National Academy of Medicine,² and the National Consensus Guidelines for Palliative Care have identified improv-

ing the preparation of the 2.8 million U.S. family caregivers of persons with cancer³ for the surrogate decision making as a priority for frontline clinicians.⁴ The role of surrogate decision making can be extraordinarily stressful and can lead to negative grief and post-traumatic aftereffects for months to years

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after an individual's death.⁵ While there are no precise population-based estimates of how many individuals require decisions by family surrogates at end of life, studies focusing on family surrogates struggling to make the "right" decision have found that patients can receive aggressive treatments that unduly prolong suffering and are contrary to their end-of-life preferences.^{5,6}

Most efforts to improve surrogate decision making have focused on the very end of life, usually in the setting of the intensive care unit.^{5,7-9} Research concerning the upstream or *early* preparation of family caregivers for a surrogate role has received less attention and has been mostly tangential to studies and trials of advance care planning and patient's designation of a healthcare proxy and completion of written advance directives.¹⁰⁻¹⁴ Little research has focused on upstream factors long before end of life and characteristics of family members themselves that might predict difficulties in the role of surrogate decision maker for their care recipient with cancer.

To better understand the upstream characteristics of cancer family caregivers who might find themselves in a surrogate role, the aim of this study was to identify a parsimonious set of modifiable intrapersonal and social factors associated with confidence to make future surrogate decisions. The primary research question was as follows: Which potentially modifiable family caregiver social and intrapersonal characteristics are associated with the confidence in future surrogate decision making for relatives? We hypothesized that poorer social and mental health, less engagement in self-care, and maladaptive coping styles would be associated with lower confidence in future surrogate decision making.

Methods

This analysis was conducted using data from the Caring for Yourself While Caring for Someone with Cancer Study conducted from March 2015 to July 2015. This study assessed well-being and self-care practices of family caregivers of persons with cancer.¹⁵ A cross-sectional mail survey was conducted in the communities of eight cancer centers in Alabama, Tennessee, and Florida who were participating in a Centers for Medicaid and Medicare Innovation (CMMI) demonstration project to implement a comprehensive lay navigation program.¹⁶ Institutional Review Board approval was gained from the University of Alabama at Birmingham and all participating medical centers.

Participants and procedures

"Family caregivers" were defined as unpaid family members or friends who assisted patients the most with their medical care. Patients were diagnosed with "poor-prognosis" cancers that were considered by the CMMI demonstration project to have high morbidity, mortality, distress, and healthcare utilization rates. Cancer types included pancreatic, lung, brain, ovarian, head and neck, hematologic, and any stage IV cancers. Details of the survey administration have been previously reported^{15,17}; in brief, survey data were collected using a modified Dillman survey technique consisting of a series of personalized mailings and postcard reminders that were repeated at regular intervals to encourage participation.¹⁸

Measures

Dependent variable: confidence in making future medical and life-sustaining treatment decisions. Caregiver confidence in surrogate decision making was measured using the 13-item Family Decision-Making Self-Efficacy Scale (FDMSE) (Cronbach's $\alpha=0.91$).¹⁹ Items ask respondents to rate their confidence in being able to help the person they care for make medical decisions on a five-point scale ranging from "Cannot do at all=1" to "Certain I can do=5"; higher scores indicate higher decision-making confidence. Items include decisions about comfort, where the person is cared for at end of life, food and fluid, pain, resuscitation, continuing to fight the disease, avoiding suffering, and respecting dignity.

Independent variables: modifiable intrapersonal and social factors potentially affecting decision-making confidence. *Social health.* Social factors included the caregivers' informational and emotional social support and their interpersonal relationship health. Informational social support was assessed using the eight-item PROMIS Informational Social Support Short Form v2.0.²⁰ Items ask about having someone to give advice and information about problems and crises. Emotional social support was assessed using the eight-item PROMIS Emotional Support Short Form v2.0 (Cronbach's $\alpha=0.95$).²¹ Items ask respondents about having someone who cares for them and values them as a person with five response options ranging from "Never=1" to "Always=5"; higher scores indicate higher emotional social support. Interpersonal relationship health was assessed using the nine-item interpersonal relationship subscale of the Health Promoting Lifestyle Profile II (HPLP-II) (Cronbach's $\alpha=0.80$).²² Items ask about getting support from caring people and showing concern, love, and warmth to others with four response options ranging from "Never" to "Routinely"; higher scores indicate more frequent positive interpersonal interactions.

Mental health. Mental health factors included measures of anxiety and depressive symptoms using the 14-item Hospital Anxiety and Depression Scale (HADS) (Cronbach's $\alpha=0.82$).²³ Anxiety and depressive symptoms subscale scores each range from 0 to 21 with higher scores indicating higher anxiety and depressive symptoms and scores ≥ 8 indicating clinically significant symptoms.

Self-care behaviors. Self-care behaviors, including stress management (e.g., taking time to relax, using stress control methods, pacing myself), spiritual growth (e.g., working toward long-term goals, believing that life has purpose, connecting with a force greater than myself), and health responsibility (e.g., reporting symptoms and health concerns to healthcare professionals), as measured by subscales of the Health Promoting Lifestyle Profile II (HPLP-II). Response categories are "Never=1," "Sometimes=2," "Often=3," or "Routinely=4"; higher scores indicate more frequent engagement in the self-care practice.²²

Coping styles. The 28-item Brief COPE was used to assess 14 types of coping thoughts and behaviors, including self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning,

humor, acceptance, religion, and self-blame.²⁴ Subscale scores range from 1 (“I haven’t been doing this at all”) to 4 (“I’ve been doing this a lot”); higher scores indicate more frequent use of the coping behavior.

Demographic and illness factor covariates. Self-reported demographics and illness variables included caregiver age, gender, race, relationship status, total household income, religious affiliation, employment status, relationship to patient, and patient age, gender, and cancer type. To control for the patient’s illness status, caregivers were prompted to assess the patient’s health with the single item, “In general, would you say your Care Recipient’s health is ...” with five response options ranging from “Excellent” to “Poor.”

Statistical analysis

Descriptive statistics for all variables were computed. Bivariate associations between caregiver characteristics and FDMSE scores were estimated and used to compute the proportion of FDMSE variance explained (R^2). To help assess clinically significant importance, the magnitude of these associations (as indicated by the proportion of variance explained) was interpreted using Cohen’s guidelines (i.e., R^2 : 2% = “small”; 13% = “medium”; 26% = “large”).²⁵ To obtain a small, or parsimonious, set of characteristics most relevant in explaining FDMSE scores while eliminating insignificant and redundant factors, we fitted a multivariable linear model using a set of factors selected automatically from all independent variables and demographic and illness covariates in a stepwise manner via the Bayesian information criterion.²⁶

To provide an assessment of the generalizability of the selected combination of factors in the absence of another sample of data for comparison, the model R^2 was corrected for overfitting (i.e., shrunk) by using a Bootstrap approach (1000 resamples²⁷) and then compared with a random forest ensemble²⁶ (Supplementary Table S1; Supplementary Data are available online at www.liebertpub.com/jpm). A correction to the coefficients and standard errors of the selected factors in the multivariable model (shown in Table 3) was conducted using the shrunk R^2 estimate to decrease the magnitude of the initial postselection model coefficients (i.e., shrink them toward the null value of zero to correct for selection bias),²⁸ and inflate the initial postselection standard errors (Supplementary Appendix SA1). Before analysis, the missing data (<3% of the analytical dataset) were imputed using a nonparametric approach,²⁹ with a single imputation considered sufficient due to the small fraction of missing data. The analyses were conducted using IBM SPSS Statistics 23 and R 3.3.2 (R Foundation for Statistical Computing, Vienna, Austria) packages.

Results

A total of 911 surveys were mailed to patients. After accounting for surveys that would not have had a potential family caregiver response (e.g., patient reports no caregiver, invalid address), there were 695 possible survey responses. Of 695 possible surveys, 294 were completed (response rate = 42.3%). Comparisons of responders and nonresponders revealed that fewer caregivers of minority ($p < 0.01$) and unmarried care recipients ($p < 0.01$) re-

sponded to the survey. There were no differences by age, gender, and cancer type.

Demographic and illness characteristics

Demographic characteristics are shown in Table 1. Caregivers ($n = 294$) were on average 65.5 years old and were mostly white (72.8%), married or living with a partner (82.6%), Protestant (76.2%), and retired (54.4%). More than half (60.2%) were the spouse/partner of the patient and had been providing care for an average of 33.5 months. Patients were on average 75.3 years old and just more than half were male (54.4%). Nearly 40% had lung cancer and 21% had head and neck cancer. Most caregivers reported their care recipient’s health as “Poor” or “Fair” (43%) followed closely by those indicating their relative’s health as “Good” (40%).

Bivariate associations

Bivariate associations between the FDMSE measure of surrogate decision-making confidence and demographic characteristics are shown in Table 1. Most of these associations were trivial (i.e., explained less than 1% of the variance). The proportion of FDMSE variance explained by both caregiver age (1%) and care recipient age (3%) had small and small-to-medium effects, respectively, such that older caregiver and care recipient age was associated with lower surrogate confidence.

Bivariate associations between FDMSE scores and caregiver social and intrapersonal factors are shown in Table 2. Small-to-medium effects (i.e., 2%–13% of variance explained) on FDMSE scores were noted for informational and emotional social support, anxiety and depressive symptoms, stress management and health responsibility self-care behaviors, and planning, seeking instrumental support, denial, reframing, venting, distraction, self-blame, substance abuse, acceptance, and religion coping styles. Medium effects (i.e., ~9% of variance explained) were found for spiritual growth and interpersonal relationship self-care behaviors and avoidant coping such that higher spiritual growth and interpersonal relationship and lower use of avoidant coping were associated with higher surrogate confidence.

Modeling results

Four factors were automatically selected among all independent variables and demographic and illness covariates in the multivariable linear modeling approach that best explained the variance in FDMSE scores: care recipient age (a demographic covariate), avoidant coping, emotional social support, and spiritual growth self-care behaviors. The effect sizes for each selected factor were small to moderate (Table 3), with spiritual growth self-care behaviors (standardized $B = 0.17$) and avoidant coping (standardized $B = -0.12$) having the largest, statistically significant associations after an overfitting adjustment and controlling for other factors in the model.

The generalizable estimate of R^2 for this model was 0.09 (down from the initial estimate of 0.22), indicating a moderate explanatory ability for FDMSE scores to the general population. The random forest approach that included all factors and covariates resulted in a generalizable estimate of R^2 of 0.15, indicating that, given the data, the complete set of

TABLE 1. CHARACTERISTICS OF FAMILY CAREGIVER RESPONDENTS (N=294) AND DECISION-MAKING SELF-EFFICACY (FAMILY DECISION-MAKING SELF-EFFICACY SCALE) SCORES BY CHARACTERISTIC

<i>Variable</i>	<i>Proportion of respondents, n (%)</i>	<i>FDMSE mean (SD) (higher scores = higher self-efficacy; range: 13–65)</i>	<i>Correlation with FDMSE</i>	<i>Proportion of FDMSE variance explained</i>
Age, mean (SD)	65.5 (12.7)	n/a	−0.10	0.01
Gender				
Female	214 (72.8)	58.7	Ref.	<0.01
Male	80 (27.2)	57.8	−0.04	
Race				
White	268 (91.2)	58.5	Ref.	<0.01
African American	23 (7.8)	58.4	−0.003	
Other	3 (1.0)			
Relationship status				
Married/partnered	243 (82.7)	58.4	Ref.	<0.01
Unmarried/unpartnered	51 (17.3)	58.9	0.02	
Total household income				
<\$50,000	158 (53.7)	57.7	Ref.	<0.01
≥\$50,000	136 (46.3)	59.4	0.09	
Religious affiliation				
Protestant	224 (76.2)	58.0	Ref.	<0.01
Nonprotestant	70 (23.8)	59.9	0.08	
Employment status				
Retired or unemployed	227 (77.2)	58.3	Ref.	<0.01
Full or part-time	67 (22.8)	59.1	0.04	
Relationship to patient				
Spouse	181 (61.6)	57.8	Ref.	<0.01
Nonspouse	113 (38.4)	59.5	0.09	
Months as a caregiver, mean (SD)	33.5 (40.3)	n/a	−0.06	<0.01
Care recipient age, mean (SD)	75.3 (6.6)	n/a	−0.18	0.03
Care recipient gender				
Female	134 (45.6)	58.5	Ref.	<0.01
Male	160 (54.4)	58.5	<0.001	
Care recipient cancer type				
Lung	114 (38.8)	60.1	Ref.	
Head and neck	62 (21.1)	56.7	−0.19	0.04
Leukemia/non-Hodgkin lymphoma	30 (10.2)	58.6	−0.08	<0.01
Ovarian	28 (9.5)	57.1	−0.15	0.02
Other	60 (20.4)	57.8	−0.12	0.01
My care recipient's health is...				
Poor or fair	127 (43.2)	58.8	Ref.	
Good	116 (39.5)	57.7	−0.06	<0.01
Very good or excellent	51 (17.3)	59.5	0.04	<0.01

FDMSE, Family Decision-Making Self-Efficacy Scale; SD, standard deviation.

factors had moderate predictive ability on FDMSE scores. The top variables in the importance ranking of the random forest (Supplementary Table S1) included the variables selected by the linear multivariable modeling approach, suggesting robustness of the four selected factors in predicting FDMSE scores.

Discussion

We identified a parsimonious set of social and intrapersonal factors associated with family caregivers' confidence in being able to perform in the future as a surrogate decision maker for patients with cancer. After overfitting and covariate adjustment, we found that low confidence in future sur-

rogate decision making was associated with fewer spiritual growth self-care activities and more avoidant coping behaviors. Given the concerted efforts over the past several decades to promote early preparation for individuals with serious illness and their families, these findings highlight understudied aspects of upstream preparation that go beyond traditional advance care planning activities (e.g., promoting the completion of advance directives).

Practicing fewer day-to-day activities to foster one's spiritual growth was associated with lower confidence in potentially having to make future surrogate decisions. Predictors of low surrogate confidence in other studies have included a lack of prior advanced care planning discussions with patients about their treatment preferences and

TABLE 2. FAMILY CAREGIVER DECISION-MAKING SELF-EFFICACY (FAMILY DECISION-MAKING SELF-EFFICACY SCALE) SCORES BY DOMAIN, *N*=294

<i>Variable</i>	<i>Instrument score range</i>	<i>Mean (SD)</i>	<i>Median</i>	<i>Correlation with FDMSE</i>	<i>Proportion of FDMSE variance explained</i>
Social health					
Informational social support	0–100	53.2 (10.5)	53.6	0.251	0.06
Emotional social support	0–100	51.2 (9.4)	50.1	0.268	0.07
Mental health					
Anxiety symptoms	0–21	6.3 (4.0)	6.0	–0.269	0.07
Depressive symptoms	0–21	6.6 (4.4)	6.0	–0.257	0.07
Self-care behaviors					
Stress management	1–4	2.5 (0.56)	2.4	0.231	0.05
Spiritual growth	1–4	2.8 (0.57)	2.8	0.377	0.12
Health responsibility	1–4	2.4 (0.57)	2.3	0.216	0.05
Interpersonal relationships	1–4	2.8 (0.50)	2.9	0.320	0.10
Coping styles					
Active coping	1–4	2.1 (0.84)	2.0	0.012	<0.01
Planning	1–4	2.2 (0.88)	2.0	0.079	0.01
Seeking emotional support	1–4	2.1 (0.83)	2.0	–0.013	<0.01
Seeking instrumental support	1–4	1.9 (0.81)	2.0	0.069	0.01
Avoidance	1–4	1.1 (0.37)	1.0	–0.292	0.09
Denial	1–4	1.4 (0.63)	1.0	–0.156	0.02
Reframing	1–4	2.2 (0.94)	2.0	0.116	0.01
Venting	1–4	1.5 (0.66)	1.0	–0.153	0.02
Distraction	1–4	1.9 (0.80)	2.0	–0.080	0.01
Self-blame	1–4	1.3 (0.54)	1.0	–0.202	0.04
Humor	1–4	1.2 (0.51)	1.0	0.039	<0.01
Substance abuse	1–4	1.1 (0.37)	1.0	–0.153	0.02
Acceptance	1–4	2.9 (3.0)	3.0	0.138	0.02
Religion	1–4	3.0 (1.1)	3.5	0.172	0.03

lack of prior experience as a surrogate decision maker.^{9,30,31} While our study is the first to add spirituality to this list of correlates of a family member's confidence in prospective decision making before care recipients become decisionally incapacitated, the impact of spirituality on family members who are actively engaged in the surrogate decision-making role has been repeatedly documented.^{32,33} For example, in a sample of 457 ICU surrogate decision makers, Ernecoff et al. found that nearly 8 in 10 endorsed "religion and/or spirituality" as fairly or very important in their lives.³² Other studies in an end-of-life setting report that these religious and spiritual beliefs can filter how surrogates process information about a patient's condition and consequentially their proxy decisions.^{34,35} Future work

should examine the longitudinal impact of a family member's spiritual health over the patient's cancer trajectory on downstream surrogate decision making when patients inevitably become too ill to make decisions for themselves. Providing spiritual and faith-based support to surrogates of cancer patients at the very end of life has been shown to reduce aggressive medical interventions in dying patients,³⁶ and thus, a clinical implication of our findings is the potential need for chaplaincy support for families much earlier in the cancer illness trajectory. Providing family caregivers spiritual support or counseling earlier in the cancer trajectory may enhance their willingness and confidence to participate in serious illness conversations and advance care planning.

TABLE 3. LINEAR MODEL PARAMETER ESTIMATES FOR CAREGIVER SURROGATE DECISION-MAKING CONFIDENCE WITH PREDICTORS SELECTED VIA THE BAYESIAN INFORMATION CRITERION AND POSTSELECTION SHRINKAGE

<i>Coefficients</i>	<i>Estimate</i>	<i>Standard error</i>	<i>p</i>	<i>Standardized B</i>
Intercept	59.9	7.5	<0.001	—
Care recipient age	–1.01	0.54	0.0637	–0.10
Avoidant coping	–3.07	1.56	0.0493	–0.12
Emotional social support	0.1	0.06	0.0905	0.10
Spiritual growth self-care behaviors	2.9	1.04	0.0053	0.17

Regression coefficients are shrunken and standard errors inflated with shrinkage/inflation factors based on a bootstrap overfitting adjustment for the data-driven predictor selection process (1000 resamples). Naive R^2 is 0.22. Overfitting-adjusted R^2 is 0.09. Shrinkage factor is 0.64. Inflation factor is 1.08. Intercept is recalibrated after shrinkage of the coefficients.

The mechanism by which spiritual growth self-care activities may affect confidence in surrogate decision making is an area in need of further investigation. Spirituality, as defined within the HPLP-II tool, is one's sense of personal development, growth, and goal attainment, feeling connected to something greater than oneself, and having a sense of purpose and meaning in life.²² The authors of the instrument note that it refers to universal aspects of human experience. This has some similarities and yet some differences with religiousness or religiosity, defined as an institutionalized system of beliefs and rituals related to the transcendent or sacred.³⁷ Differences in spirituality and religiosity are important for surrogate decision making because religiosity has been shown in prior studies of family caregiving to be related to intensive treatments near death, which is then associated with poor quality of death and dying.^{36,38} As others have similarly noted,³⁹ this suggests that spiritual versus religious beliefs likely have some similarities and yet some key differences. While both involve a search for meaning, there may be distinct aspects of each that lead to divergent ways of framing and performing in the role of surrogate decision maker, warranting further research.

The frequent use of avoidant coping, or behavioral disengagement, to deal with stressful situations was also associated with having lower surrogate decision-making confidence. Avoidant coping is the active avoidance of or escape from thoughts, feelings, or actions that directly confront the causes or effects of a stressful situation.⁴⁰ Thinking about having to make medical decisions for incapacitated relatives can be stressful as well as having discussions with care recipients about their wishes for life-sustaining treatments and care at end of life.¹¹ As mentioned previously, having these advance care planning conversations has been linked in numerous studies to surrogates feeling more confident and less burdened in this role.^{9,30,31} Furthermore, studies of patients with advanced cancer have found that avoidant coping is associated with aggressive end-of-life care⁴¹ and so it may be reasonable to suspect that a similar relationship exists for surrogates. Efforts to enhance family caregivers' adaptive coping skills may be a promising avenue of optimizing their decision-making skills. Interventions to reduce avoidant coping might be aimed at the acknowledgment and expression of emotions, such as acceptance and commitment therapy,⁴² which might thereby increase the caregiver's confidence to participate in discussions with the care recipient about future medical care.

This study has several limitations. First, the response rate for this survey of 42.3% was below Dillman's gold standard of 60%¹⁸ and there is a risk of selection bias as suggested by the differences in response rates by black/African Americans and unmarried patients. Thus, generalizability to these populations is limited. Second, it is unknown whether "confidence" in future surrogate decision making equates to actual knowledge and ability to perform in the role downstream at end of life. Longitudinal studies are needed that examine relationships between upstream "confidence" in surrogate decision making and downstream end-of-life outcomes. We also did not collect information on completion of advance directives and education, hence future work will benefit from collecting and including this information in analyses. Third, this sample was almost entirely com-

posed of Christian faiths and hence future studies will need to expand to other religious traditions and the nonreligious. Fourth, sample size limitations precluded internal validation of the selected factors in hold-out data, given the relatively large number of factors considered. Although a resampling approach (with a correction for selection bias) and a comparison with a random forest ensemble were used to provide and assessment of generalizability of the results, future studies should replicate and validate the results presented here.

In conclusion, a three-state survey of 294 family caregivers of community-dwelling persons with cancer identified two robust correlates of having high confidence in potentially having to make surrogate decisions about future medical treatments: frequent self-care behaviors that promote spiritual growth and less use of avoidant coping behaviors. In combination with efforts to increase advance care planning conversations between families and their relatives with cancer, encouraging caregivers' spiritual growth and enhancing their coping skills to lessen avoidance of stressful situations may be promising targets for interventions to improve family caregivers' future role as surrogate decision makers.

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Author Disclosure Statement

No competing financial interests exist.

References

1. Dans M, Smith T, Back A, et al.: NCCN guidelines insights: Palliative Care, Version 2.2017. *J Natl Compr Canc Netw* 2017;15:989-997.

2. National Academy of Medicine: *Families Caring for an Aging America*. Washington, DC: The National Academies Press, 2016.
3. National Alliance for Caregiving: *Cancer Caregiving in the U.S.: An Intense, Episodic, and Challenging Care Experience*. Bethesda, MD: National Alliance for Caregiving, 2016.
4. National Consensus Project: *Clinical Practice Guidelines for Quality Palliative Care*. The National Consensus Project for Quality Palliative Care, Pittsburgh, PA, 2013.
5. Wendler D, Rid A: Systematic review: The effect on surrogates of making treatment decisions for others. *Ann Intern Med* 2011;154:336–346.
6. Shalowitz DI, Garrett-Mayer E, Wendler D: The accuracy of surrogate decision makers: A systematic review. *Arch Intern Med* 2006;166:493–497.
7. White DB, Cua SM, Walk R, et al.: Nurse-led intervention to improve surrogate decision making for patients with advanced critical illness. *Am J Crit Care* 2012;21:396–409.
8. Torke AM, Wocial LD, Johns SA, et al.: The family navigator: A pilot intervention to support intensive care unit family surrogates. *Am J Crit Care* 2016;25:498–507.
9. Majesko A, Hong SY, Weissfeld L, White DB: Identifying family members who may struggle in the role of surrogate decision maker. *Crit Care Med* 2012;40:2281–2286.
10. Sudore RL, Boscardin J, Feuz MA, et al.: Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among Veterans: A randomized clinical trial. *JAMA Intern Med* 2017;177:1102–1109.
11. Fried T, Zenoni M, Iannone L: A dyadic perspective on engagement in advance care planning. *J Am Geriatr Soc* 2017;65:172–178.
12. Fried TR, Zenoni M, Iannone L, et al.: Engagement in advance care planning and surrogates' knowledge of patients' treatment goals. *J Am Geriatr Soc* 2017;65:1712–1718.
13. Song MK, Ward SE, Fine JP, et al.: Advance care planning and end-of-life decision making in dialysis: A randomized controlled trial targeting patients and their surrogates. *Am J Kidney Dis* 2015;66:813–822.
14. Green MJ, Van Scoy LJ, Foy AJ, et al.: A randomized controlled trial of strategies to improve family members' preparedness for surrogate decision-making. *Am J Hosp Palliat Care* 2018;35:866–874.
15. Dionne-Odom JN, Demark-Wahnefried W, Taylor RA, et al.: The self-care practices of family caregivers of persons with poor prognosis cancer: differences by varying levels of caregiver well-being and preparedness. *Support Care Cancer* 2017;25:2437–2444.
16. Rocque GB, Partridge EE, Pisu M, et al.: The Patient Care Connect Program: Transforming health care through lay navigation. *J Oncol Pract* 2016;12:e6333–e6342.
17. Dionne-Odom JN, Applebaum AJ, Ornstein KA, et al.: Participation and interest in support services among family caregivers of older adults with cancer. *Psychooncology* 2018;27:969–976.
18. Dillman D, Smyth J, Christian L: *Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method*, 3rd ed. Hoboken, NJ: John Wiley & Sons, Inc., 2009.
19. Nolan MT, Hughes MT, Kub J, et al.: Development and validation of the Family Decision-Making Self-Efficacy Scale. *Palliat Support Care* 2009;7:315–321.
20. PROMIS Network: *Informational Support: A Brief Guide to the PROMIS Informational Support Instruments*. Silver Spring, MD: PROMIS Network Center, 2014.
21. PROMIS Network: *Emotional Support: A Brief Guide to the PROMIS Emotional Support Instruments*. Silver Spring, MD: PROMIS Network Center, 2014.
22. Walker SN, Sechrist KR, Pender NJ: The Health-Promoting Lifestyle Profile: development and psychometric characteristics. *Nurs Res* 1987;36:76–81.
23. Bjelland I, Dahl AA, Haug TT, Neckelmann D: The validity of the Hospital Anxiety and Depression Scale: An updated literature review. *J Psychosom Res* 2002;52:69–77.
24. Carver CS: You want to measure coping but your protocol's too long: Consider the brief COPE. *Int J Behav Med* 1997;4:92–100.
25. Cohen J: *Statistical Power Analysis for the Behavioral Sciences*. Hillsdale, NJ: Lawrence Erlbaum, 1988.
26. Efron B, Hastie T: *Computer Age Statistical Inference: Algorithms, Evidence and Data Science*. New York, NY: Cambridge University Press, 2016.
27. Harrell F: *Regression Modeling Strategies with Applications to Linear Models, Logistic and Ordinal Regression, and Survival Analysis*, 2nd ed. New York, NY: Springer, 2015.
28. Royston P, Sauerbrei W: *Multivariable Model-Building: A Pragmatic Approach to Regression Analysis Based on Fractional Polynomials for Modelling Continuous Variables*. West Sussex, England: John Wiley & Sons Ltd., 2008.
29. Stekhoven DJ, Bühlmann P: MissForest—Non-parametric missing value imputation for mixed-type data. *Bioinformatics* 2012;28:112–118.
30. Hickman RL, Pinto MD: Advance directives lessen the decisional burden of surrogate decision-making for the chronically critically ill. *J Clin Nurs* 2014;23:756–765.
31. Chiarchiaro J, Buddadhumaruk P, Arnold RM, White DB: Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. *Ann Am Thorac Soc* 2015;12:1528–1533.
32. Ernecoff NC, Curlin FA, Buddadhumaruk P, White DB: Health care professionals' responses to religious or spiritual statements by surrogate decision makers during goals-of-care discussions. *JAMA Intern Med* 2015;175:1662–1669.
33. Schenker Y, Crowley-Matoka M, Dohan D, et al.: I don't want to be the one saying 'we should just let him die': intrapersonal tensions experienced by surrogate decision makers in the ICU. *J Gen Intern Med* 2012;27:1657–1665.
34. 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;315:2086–2094.
35. Dionne-Odom JN, Willis DG, Bakitas M, et al.: Conceptualizing surrogate decision making at end of life in the intensive care unit using cognitive task analysis. *Nurs Outlook* 2015;63:331–340.
36. 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;173:1109–1117.
37. Koenig H: *Spirituality and Health Research*. West Conshohocken, PA: Templeton Press, 2011.

38. Bülow HH, Sprung CL, Baras M, et al.: Are religion and religiosity important to end-of-life decisions and patient autonomy in the ICU? The Ethicatt Study. *Intensive Care Med* 2012;38:1126–1133.
39. Johnstone B, Yoon DP, Franklin KL, et al.: Reconceptualizing the factor structure of the brief multidimensional measure of religiousness/spirituality. *J Relig Health* 2009;48:146–163.
40. Vohs K, Baumeister R: *Handbook of Self-Regulation: Research, Theory, and Applications*, 3rd ed. New York, NY: The Guilford Press, 2017.
41. Maciejewski PK, Phelps AC, Kacel EL, et al.: Religious coping and behavioral disengagement: opposing influences on advance care planning and receipt of intensive care near death. *Psychooncology* 2012;21:714–723.
42. Davis EL, Deane FP, Lyons GC, et al.: Feasibility randomised controlled trial of a self-help acceptance and commitment therapy intervention for grief and psychological distress in carers of palliative care patients. *J Health Psychol* 2017;1359105317715091.

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