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Exploring variables related to medical surrogate decision-making accuracy during the COVID-19 pandemic

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A B S T R A C T
Objective: Surrogate medical decision making is common in the United States healthcare system. Variables that may influence surrogate decision making have been proposed. Little work has examined relations between these variables and outcomes of surrogate decision making. This study investigated whether surrogates’ characteristics, including their knowledge of treatment options, and interpersonal factors predicted surrogates’ accuracy and intervention selections. Specifically, predictor variables included: trust in the medical profession, trait-level anxiety, depression, anxiety about COVID-19, religiosity, perceived emotional support, understanding of treatment options, empathy, willingness to accept responsibility for medical decisions, reluctance to burden others, and perceived similarity between oneself and the patient.

Methods: 154 pairs of patients and their surrogates completed an online survey. Patients indicated preferred treatments in hypothetical decision scenarios. Surrogates indicated the treatment that they thought the patient would prefer.

Results: When taken all together in a predictive model, the variables significantly predicted surrogates’ accuracy, $F(6) = 3.03, R^2 = .12, p = .008$. Variables also predicted selection of intensive interventions, $F(4) = 5.95, R^2 = .14, p = .00$. Surrogates reporting greater anxiety about COVID-19 selected more intensive interventions.

Conclusions: Consistent with prior research, this study found that surrogates’ characteristics influence the interventions they choose, with anxiety about COVID-19 having considerable bearing on their chosen interventions.

Practice implications: These findings can inform development of decision-making interventions to improve surrogates’ accuracy. Providers may attend to variables highlighted by this study to support surrogates, particularly within the stressful context of COVID-19 and possible future pandemics.

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1. Introduction

Decisions about medical treatment at end-of-life are some of the most challenging that a patient can face. End-of-life care is a timely topic in the United States, with surveys revealing increased concerns for maintaining personal control over the circumstances of one’s death and greater fears of pain and dependency at end-of-life [26]. The ongoing coronavirus (COVID-19) pandemic has further brought critical care services and end-of-life care to the forefront of public consciousness [32]. Given the considerable stress that the pandemic has placed on the United States healthcare system, clinicians are being urged to facilitate patient completion of advance care planning, in order to avoid life-sustaining treatment when it is unwanted and decrease demand on the intensive resources [12]. Advance care planning often involves patients designating a surrogate decision maker who can be consulted to make treatment decisions on their behalf if they are unable to express a choice. This situation occurs among nearly half of hospitalized older adults [46] and close to 50% of all patients considered to be at end-of-life [45].

Surrogates are most often encouraged to use the substituted judgment standard, specifying that they should make decisions in accordance with what the patient would have selected [45]. This approach raises surrogate decision-making accuracy as an issue, regarding whether surrogates adequately predict patient preferences through their decisions. Copious research suggests that surrogates are often inaccurate when predicting patient preferences. In one systematic review, Shalowitz et al. [36] concluded that

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individuals serving as surrogates predict patient preferences only slightly better than chance, with 68% accuracy on average.

Despite consensus that surrogate decision-making accuracy is a pertinent topic, little research has investigated what variables predict accuracy. While several studies of surrogate decision-making accuracy and theoretical models (e.g., [30,46]) have proposed factors that may impede surrogate accuracy when identifying patient preferences, no research has yet formally investigated whether these factors predict surrogates’ accuracy.

The current study sought to replicate work by Hare et al. [22] in which they investigated surrogate medical decision-making accuracy using five hypothetical treatment decision vignettes to patient-surrogate pairs. Findings indicated that agreement between patients and their surrogates occurred, on average, 70% of the time. It is important to note that the study by Hare et al. [22] and the current study recruited patient-surrogate pairs from a healthy community sample. Therefore, individuals were assigned to the role of “patient” for the purposes of the study. The term “patients” with which they are labeled is not meant to denote the presence of any current illness or clinical features.

This study also extended prior work by investigating the extent to which specific variables can predict accuracy. Frequently proposed variables were selected for use in this study, as determined by the relative frequency with which they had appeared in empirical and theoretical discussions of surrogate decision-making accuracy to date. Variables featured intrapersonal characteristics of surrogates and interpersonal variables operating between surrogates and other individuals who may be involved in the decision-making process. Specifically, predictor variables included: trust in the medical profession, trait-level anxiety, depression, anxiety about COVID-19, religiosity, perceived emotional support, understanding of treatment options, empathy, willingness to accept responsibility for medical decisions, reluctance to burden others, and perceived similarity between oneself and patient. Since data collection occurred during the COVID-19 pandemic, COVID-19-related anxiety was examined in light of findings that anxiety about COVID-19 is strongly related to broader mental health concerns, such as anxiety and depression [1], and general engagement in health care behaviors [38]. Given the relative dearth of research in this area, the study was broad and exploratory in scope.

2. Method

2.1. Recruitment and participation procedures

All procedures occurred through an online survey hosted through Qualtrics. Recruitment and participation procedures were approved by the West Virginia University Institutional Review Board. Healthy individuals residing in the community responded to the study advertisement and were assigned the role of “patient” for the purposes of this study. Patients with a surrogate, or who could identify an individual most likely to serve in this role, were initially recruited through Amazon Mechanical Turk and a university alumni and faculty listserv. Since issues related to medical treatment decisions and end-of-life are often most salient for middle-aged and older adults, a minimum age criterion of 45 years old was used for patients. Patients were provided with a link to an online survey to share with their surrogate partner for them to complete. Participants indicated their consent to participate by reading a consent form and proceeding to the next page of the survey. Surrogates were required to be over age 18, capable of reading English, and to have access to an email account. Data collection occurred between May 1, 2020 and August 1, 2020. All participants received an Amazon gift card.

First, all participants completed a demographic questionnaire (see Appendix A). Following the demographic questionnaire, participants completed the online survey. The first portion of the survey consisted of hypothetical medical decision vignettes (see Appendix B). Two versions of the survey were created, a surrogate version and a patient version, that differed based on the language used in the decision vignettes. Next, all participants completed measures corresponding to each of the predictor variables (see Appendices C-J). The order in which participants completed these measures was randomized.

Missing values analyses verified that patterns of missingness were consistent with missingness occurring completely at random or at random. An expectation maximization procedure was used to account for problematic missingness (greater than 5% of items in a measure; [18]).

2.2. Participants

One-hundred-and-sixty-one groups, or 322 total participants, were recruited. All participants identified as residing in the United States. Seven pairs were excluded from subsequent analyses: three pairs due to the surrogate’s omission of a substantial portion of the survey, three due to the patient’s omission of a substantial portion of the survey, and one due to the surrogate responding incorrectly to more than one attention check item. Therefore, a final sample of 154 patient-surrogate pairs remained.

2.3. Materials

2.3.1. Criterion variable measure

2.3.1.1. Choice of end-of-life medical treatment. This study employed the same five medical treatment decision vignettes used by Hare et al. [22], with two additional vignettes pertaining to coronary bypass surgery and dialysis treatment for chronic kidney disease, which are commonly considered in advance directive treatment preference documentation ([52]; see Appendix B). In response to each vignette, respondents selected either to accept (scored as “1”) or decline (scored as “0”) the treatment offered in the vignette. Scores were summed across the vignettes to create a total intervention score, with higher scores indicating a greater tendency to accept presented interventions. To operationalize surrogates’ accuracy, patient-surrogate agreement scores were calculated for each pair. Vignettes on which the pair agreed were scored as 1 and summed. Agreement scores for each pair ranged from 0 to 7, with higher scores denoting greater accuracy by the surrogate. The kappa statistic also was calculated to measure agreement between patient-surrogate pairs. Kappa is a measure of agreement widely used in the surrogate decision-making accuracy literature to date [36,37], since it provides a measure of agreement that is corrected for chance agreement.

2.3.2. Predictor variable measures

In the regression analyses evaluating the prediction of surrogates’ accuracy and intervention selections, surrogates’ reports on the following variables were used as predictor variables.

2.3.2.1. Treatment understanding. In relation to the treatment decisions, participants also rated the extent to which they felt they understood the costs and benefits associated with the treatment offered in each vignette. Scores were summed across the seven vignettes to obtain a total “treatment understanding” score. Higher scores reflected greater self-assessed understanding.

2.3.2.2. Understanding of patient treatment preferences. Surrogates responded to a single item indicating the extent to which they had talked with their partner about end-of-life care preferences, using a 4-point scale.
2.3.2.3. COVID-19. To assess respondents' current experience of the pandemic, participants indicated on a 10-point scale, with ratings ranging from "1 = not at all" to "10 = very much so," their response to the following: "How worried are you about the COVID-19 pandemic?".

2.3.2.4. Trust in the medical profession. The extent to which participants trusted the medical profession was assessed by the 11-item scale developed by Hall and colleagues (TIMPS; [21]). The measure demonstrates good psychometric properties, with high internal consistency reliability ($\alpha = 0.89$; [21]).

2.3.2.5. Perceived emotional support. The Communication Based Emotion Support Scale (CBESS; Weber et al., [51]) assessed the degree to which participants perceive that they receive emotionally supportive messages from their partner in this study. The scale demonstrates strong psychometric properties, with good internal consistency reliability reported ($\alpha = 0.93$; Rittenour and Martin, 2008).

2.3.2.6. Perceived similarity between self and patient. To assess surrogates’ perceived similarity to patients regarding values related to end-of-life treatment, the Quality of Life Values Inventory (QVVI; [8]) was used. As an additional measure of values related to quality of life, the 13-item Life Values measure designed by Schonwetter and colleagues (LVI; 1996) was used. The QVVI demonstrates adequate internal consistency reliability among community-dwelling samples ($\alpha = 0.61–0.67$; [8,9]). To assess perceived similarity, participants rated each of the 18 items from both of these measures using a five-point Likert-type scale ranging from 1 (exactly the opposite of me) to 5 (exactly the same as me) to reflect the extent to which they thought their partner’s values regarding the item were similar to their own. Ratings on the items were summed to produce a total perceived similarity score.

2.3.2.7. Empathy. Participants’ levels of empathy, or concern for others, was measured by Davis’ [13] Interpersonal Reactivity Index (IRI). Higher scores indicate greater empathy. Satisfactory internal consistency reliability has been demonstrated for this measure ($\alpha = 0.71–0.77$; [13]).

2.3.2.8. Willingness to assume full responsibility for medical decisions. The extent to which participants were willing to take full personal responsibility for medical decisions was assessed using the behavioral involvement subscale of the Health Opinion Survey (HOS; [25]). Higher scores indicate favorable attitudes towards self-directed decisions about medical treatment. The behavioral involvement scale demonstrates good internal consistency reliability (KR-20 = 0.74–0.75; Chewning et al., 2012).

2.3.2.9. Anxiety. The State-Trait Anxiety Scale, Trait Subscale (STAI-T; [41]) assessed trait-level anxiety. The STAI-T measures the respondent’s tendency to experience anxiety and perceive situations as threatening. The measure has high test-retest reliability, ranging from .73–.86 [41].

2.3.2.10. Depression. The Center for Epidemiological Studies Depression Scale-Revised (CESD-R; [16]) assessed depressive symptoms consistent with DSM-V criteria for depression. Higher scores indicate greater depressive symptoms. The measure demonstrates high internal consistency reliability ($\alpha = -0.93$, [48]).

2.3.2.11. Reluctance to burden others. This exploratory variable was assessed using the three-item measure developed by Winter and Parks (RBO; [53]). Surrogates responded to these items using the substituted judgment standard and provided the response they thought the patient would choose on a Likert-type scale ranging from 1 (not at all important) to 5 (very important). Ratings were summed to produce a total RBO score. Patients completed this measure as a self-report.

2.3.2.12. Religiosity. Religiosity was assessed by the Duke University Religion Index (DUREL; [24]). Higher scores indicate greater religiosity. The measure demonstrates adequate internal consistency reliability ($\alpha = 0.78–0.91$; [24]).

3. Results

3.1. Surrogate characteristics

Surrogates ranged in age from 22 to 88 years old ($M = 47.38$ years; $SD = 9.98$) and reported an average of 15 years of education ($SD = 4.32$). Over three-quarters identified as Christian (57.8%) or Roman Catholic (18.8%). In terms of reported relation to their patient partner, most (83.8%) surrogates were spouses or romantic partners, 7.1% were parents, 3.9% were siblings, 3.9% were close friends, and 6% were adult children or another family member. Surrogates reported relative familiarity with the role of serving as a surrogate, with 77.9% indicating that they had served as a surrogate in a formal capacity. See Table 1 for further demographic information.

3.2. Patient characteristics

Patients ranged in age from 45 to 71 years old ($M = 51.24$, $SD = 5.52$) and reported 15.5 years of education ($SD = 4.66$), on average. Similar to the surrogate sample, over three-quarters of patients identified as Christian (58.4%) or Roman Catholic (14%). See Table 2 for further demographic information.

Surrogates tended to approve administration of treatment, with an average treatment intervention score of 5.63 on the 7-point intervention selection scale. Notably, 42.9% of surrogates indicated that they would provide treatment in all 7 vignettes. For patients, there was also a tendency to approve interventions, with an average

| Characteristic                  | N  | %    |
|-------------------------------|----|------|
| Sex                           |    |      |
| Female                        | 116| 75.3 |
| Male                          | 38 | 24.7 |
| Race/ethnicity                |    |      |
| White/Caucasian (not Hispanic)| 131| 85.1 |
| Black/African-American        | 9  | 5.8 |
| Asian-American                | 9  | 5.8 |
| Hispanic                      | 3  | 1.9 |
| Native American/Pacific Island| 1  | 0.6 |
| Mixed                         | 1  | 0.6 |
| Religion                      |    |      |
| Agnostic                      | 4  | 2.6 |
| Atheist                       | 9  | 5.8 |
| Buddhist                      | 89 | 57.8|
| Jewish                        | 3  | 1.9 |
| Muslim                        | 3  | 1.9 |
| Other                         | 4  | 2.6 |
| Protestant                    | 5  | 3.2 |
| Roman Catholic                | 29 | 18.8|
| Seventh-Day Adventist         | 2  | 1.3 |
| Spiritual but not religious   | 5  | 3.2 |
| Marital Status                |    |      |
| Single                        | 9  | 5.8 |
| Married/committed relationship| 139| 90.3 |
| Divorced                      | 2  | 1.3 |
| Separated                     | 1  | 0.6 |
| Widowed                       | 3  | 1.9 |

Table 1 Surrogate demographic characteristics.
score of 5.46%, and 39.2% of patients desiring treatment in all vignettes. Surrogates’ accuracy when predicting treatment selections was worse than that which would be expected by chance, kappa = 0.268, \( p < .000 \). Guidelines from Cicchetti and Sparrow [11] classify this level of agreement as “poor.” Of the 154 pairs, 46.1% agreed on all seven decision scenarios; therefore, 53.9% of the sample featured a surrogate inaccurately predicting the patient’s preferences on at least one treatment decision. When predicting preferences, surrogates could err by “overtreating,” or providing interventions that the patient would not have selected, or by “undertreating” and withholding a desired intervention. Of the 80 pairs in which the surrogate inaccurately predicted preferences for at least one scenario, 49 (61.2%) featured the surrogate undertreating, while 31 (38.8%) indicated overtreating.

Bivariate correlation analyses revealed significant relations between accuracy and several of the variables individually, see Table 4. Accuracy did not significantly differ across demographic variables including the surrogate’s gender, marital status, ethnicity, religious preference, or relationship to the patient.

None of the variables appeared as unique predictors in a multiple linear regression analysis evaluating the prediction of surrogates’ accuracy; see Table 3. However, the overall predictive model was significant, \( F(6) = 3.03, R^2 = .12, p = .008 \). The following predictor variables were used: surrogates’ ratings of trust, religiosity, empathy, perceived similarity to patients on end-of-life values, perceived degree of patients’ reluctance to burden others, and differences between patients and surrogates on end-of-life values. Collinearity

| Table 2 |
| Patient demographic characteristics. |
| Characteristic | N | % |
| Sex | | |
| Female | 44 | 28.8% |
| Male | 109 | 71.2% |
| Race/ethnicity | | |
| White/Caucasian (not Hispanic) | 132 | 86.3% |
| Black/African-American | 7 | 4.6% |
| Asian-American | 10 | 6.5% |
| Hispanic | 2 | 1.3% |
| Native American/Pacific Islander | 1 | .7% |
| Mixed | 1 | .7% |
| Religion | | |
| Agnostic | 6 | 3.9% |
| Atheist | 14 | 9.2% |
| Christian | 89 | 58.2% |
| Jewish | 1 | .7% |
| Muslim | 4 | 2.6% |
| Other | 2 | 1.3% |
| Protestant | 9 | 5.9% |
| Roman Catholic | 22 | 14.4% |
| Seventh-Day Adventist | 3 | 2.0% |
| Spiritual but not religious | 3 | 2.0% |

| Table 3 |
| Percent of patient-surrogate pairs who agreed on each decision vignette. |
| Treatment Vignette | % Agreement |
| Ventilation | 75.6% |
| CPR | 83.6% |
| Feeding Tube | 76.1% |
| Chemotherapy | 81.3% |
| Amputation | 82.8% |
| Cardiac Bypass | 88.8% |
| Dialysis | 85.1% |

| Table 4 |
| Correlations between selected surrogate intrapersonal and inter-personal variables. |
| Age | Education | COVID | Worry | Similar Values to Patient | Willingness to take Decisional Responsibility | Trust | Anxiety | Empathy | Depression | Religiosity | Reluctance to Burden Others | Emotional Support | Treatment Knowledge |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Education | 1 | -0.08 | 1 | -0.12 | -0.19 | -0.23 | 1 | -0.15 | -0.07 | 1 | 0.03 | 1 | 0.05 | 1 |
| COVID | -0.08 | 1 | -0.12 | -0.19 | -0.23 | 1 | -0.15 | -0.07 | 1 | 0.03 | 1 | 0.05 | 1 | 0.05 |
| Worry | -0.10 | -0.12 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 |
| Similar Values to Patient | -0.10 | -0.12 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 |
| Willingness to take Decisional Responsibility | -0.10 | -0.12 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 |
| Trust | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 |
| Anxiety | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 |
| Empathy | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 |
| Depression | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 |
| Religiosity | 0.11 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 |
| Reluctance to Burden Others | -0.15 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 |
| Emotional Support | 0.05 | 0.11 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 |
| Treatment Knowledge | 0.05 | 0.11 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 | 0.11 | -0.02 | 1 | -0.02 | 0.07 |

Note. \( * p < .05 \) (2-tailed).

Note. ** \( p < .01 \) (2-tailed).

Note. *** \( p < .000 \) (2-tailed).
diagnostics, variance inflation factors, and tolerance values were within normal limits. Conditioning plots and Levene’s test supported assumptions of equality of variances and normal distributions (Table 5).

The variables significantly predicted treatment selection, or surrogates’ tendencies to approve treatment in the decision vignettes; $F(4) = 5.95$, $R^2 = .14$, $p = .00$. Of the predictor variables, surrogates’ reports of COVID-19-related anxiety ($B = 0.219$, $p < .005$) appeared as a unique predictor.

4. Discussion and conclusion

4.1. Discussion

In concordance with Hare et al. [22], and evidence from the surrogate decision-making accuracy literature [40], surrogates predicted patients’ preferences with poor accuracy. This finding adds to the body of evidence suggesting that individuals who make decisions for patients in end-of-life situations may not be trusted to consistently select the patient’s desired treatment (Torke, 2008). The level of agreement found in this study is not ably lower than that reported in a systematic review of the literature by Shalowitz et al. [36,37]; 68% agreement, on average), yet it is consistent with levels reported by more recent investigations of surrogate decision-making accuracy [35]. As the first investigation to specifically examine trust in the medical profession may hinder surrogates’ decision making (e.g., [46]), as empathetic support from partner (CBESS) tends to peak in middle-adulthood (O’Brien et al., [31]).

Accuracy was also positively correlated with religiosity, such that surrogates with greater self-reported religiosity were more accurate. This is the first study to specifically examine religiosity relative to surrogate decision-making accuracy. An explanation for this relation could lie in previously demonstrated positive associations between religiosity and personality variables not assessed by this study, such as conscientiousness [23]. Surrogates who report greater religiosity may be those who are more conscientious, and who therefore completed the decision activity with greater care and attention to patient preferences.

Surrogates who were more accurate predictors of patient preferences also tended to be those who reported greater trust in the medical profession. Researchers have proposed that low trust in the medical profession may hinder surrogates’ decision making (e.g., [46]). As the first investigation to specifically examine trust in the medical profession as related to surrogate decision-making accuracy, this study provides preliminary support for these conjectures.

Perceiving the patients’ values as more similar to one’s own (as measured by ratings on the Quality of Life and Life Values Index) was also associated with accuracy. This is consistent with prior research evaluating surrogates’ execution of the substituted judgment standard and their reflections of the process. Surrogates often state that they rely on known mutual interests between themselves and the patient to guide their decisions (Vig et al., [49]). However, researchers caution that high perceived similarity can undermine decision making if surrogates mistakenly interpret their own values as identical to those of the patient [17].

The selected variables significantly predicted surrogates’ treatment selections. A unique predictor variable was COVID-19-related anxiety, such that surrogates with greater anxiety about COVID-19 selected more intensive treatments for patients. Although current understandings of COVID-19-related anxiety are nascent, this specific type of anxiety demonstrates positive relations with anxiety and depressive disorder symptoms [1], which was also evident in this study. Moreover, anxiety about COVID-19 is associated with feelings of hopelessness and the use of maladaptive coping mechanisms (e.g., drugs and alcohol; [27]). Importantly, these negative emotions and coping behaviors pertain to oneself and one’s current situation, not involving another person. In this study, surrogates were acting on behalf of the patient, a person to whom they were not emotionally attached.

4.2. Conclusion

This study underscores how surrogates’ confidence in the value of prior discussions about end-of-life care is not strongly tied to their accuracy. Surrogates may misinterpret higher-frequency discussions as being of higher-quality, producing an inflated assessment of one’s knowledge of treatment options and patient preferences. Values related to end-of-life decisions are complex, and surrogates may unintentionally adopt a myopic view of treatment decisions [35]. For instance, surrogates may fail to appreciate the number and variety of values implicated in a decision and focus too narrowly on a single identified value, such as the desire to sustain life at any cost [44].

Several interesting relations emerged to enhance understandings of potential mechanisms underpinning surrogates’ accuracy. First, the relation between accuracy and empathy is consistent with understandings of empathy as a construct that promotes perspective-taking [28]. Moreover, the observed role of empathy may have been particularly pronounced given the age of the recruited sample ($M_{age} = 47$ years for patients, 51 years for surrogates), as empathy tends to peak in middle-adulthood (O’Brien et al., [31]).

The discrepancy in treatment decisions between patients and surrogates is particularly alarming given that surrogates reported
presumably close. Evidence from the self-other decision-making literature reflects that individuals often choose different decisions for another person than they would for themselves; for instance, they are more likely to make a “safer” choice than they would for themselves in situations where risk aversion is valued [43]. Therefore, surrogates may have chosen an intensive treatment intervention to “save” the patient in these vignettes, despite feeling pessimistic about their personal circumstances in the distressing context of a global pandemic.

Participants’ approaches to the decision vignette regarding ventilation in particular must be considered in the unique context of COVID-19, a disease with symptoms primarily affecting the respiratory system, that can produce severe complications such as pneumonia that require the use of mechanical ventilation [15]. During the pandemic, estimates of the number of needed ventilators in the United States have ranged from several hundred thousand to over one million [19]. The country’s insufficient ability to meet this demand was well-broadcast and concerns for the adequate provision of critical care supplies have been raised [33]. Heightened public attention towards mechanical ventilation may have prompted participants to reexamine their views towards this treatment option in particular; such that patients’ personal desires to receive ventilation may have shifted, unbeknownst to their surrogates. Therefore, surrogates may have been less accurate on this decision because they chose decisions based on understandings of what patients may have selected before the pandemic.

As with any study, limitations exist. First, hypothetical scenarios can only model a real-world decision-making scenario, and these findings are therefore limited with respect to generalizability. Surrogates’ accuracy may be lower when working with a hypothetical situation that does not pertain to the patient’s actual condition. With regards to the hypothetical situations used in the current survey, the question concerning treatment knowledge and understanding may have been confusing to participants. Phrasing regarding “costs and benefits” of treatment options may have led participants to solely consider financial costs of treatments, rather than more comprehensive risks and burdens. However, logistical constraints of gathering data at the exact moment at which surrogate decision making takes place, particularly during a pandemic limiting access to healthcare facilities, impeded this possibility.

Regarding statistical limitations, the reported regression coefficient values for the multiple linear regression models were relatively modest in magnitude; therefore, important predictor variables may have been missed. The surrogate decision-making process is complex and involves the interplay between multiple variables. Future research will be important to identify other related variables in an effort to better account for variance in surrogates’ accuracy when predicting patient treatment preferences. The kappa statistic also has limitations with regards to its interpretation as a measure of chance-corrected agreement (e.g., the “kappa paradox,” [10]). However, this statistic was reported in order to maintain consistency with the surrogate decision-making accuracy literature to date (e.g., Shalowitz, 2006; [6,30,40]) and enable comparisons with prior studies.

With respect to demographic characteristics the recruited sample underrepresents the diverse population of patients, and their associated surrogates, who are encountered in United States intensive care units where end-of-life surrogate decision-making occurs [2]. Patient-surrogate pairs of minority backgrounds are important to prioritize in future work, as medical decision-making tendencies can vary considerably across groups (e.g., [50]). Moreover, the recruited sample was not an ideal representation of real-world surrogate decision makers, as surrogates tend to be older (e.g., mean age of 59.6 years reported by Snyder et al. [42]) and are most often adult children of the patient [42]. The current surrogate sample was younger than average and consisted mostly of spouses; therefore, they may have a different understanding of patients’ wishes and responded to scenarios differently than surrogates encountered in real medical decision-making situations. Additionally, the individuals assigned the role of “patient” for the purposes of this study were healthy, community-dwelling adults. Patients for whom surrogates most often make decisions are those with chronic conditions, severe illness, or frailty (Vig et al., [49]). Therefore, “patients” in the current study were not wholly representative of those involved in real-world surrogate medical decision-making situations.

Work conducted during the COVID-19 pandemic may prioritize the psychometrically sound assessment of COVID-19-related anxiety, a variable with demonstrated importance in this study. At the time of study design, no validated assessment measures of this construct existed, and a single-item measure was used. Since completion of data collection, researchers have begun to design and validate assessment measures to more comprehensively capture COVID-19-related anxiety (e.g., Coronavirus Anxiety Screener; [27]). Ultimately, more research is needed regarding the relation between perceptions of COVID-19 and treatment preferences, specifically with regard to self-other decision-making discrepancies.

4.2. Conclusion

This study examined decision making between patient-surrogate pairs on hypothetical treatment decision vignettes. In addition to examining the relation between accuracy and selected variables, the study evaluated the extent to which surrogates accurately predicted patients’ preferences. Findings further amplify concerns for surrogates’ accuracy, and their ability to execute the substituted judgment standard, by revealing inconsistencies in patient-surrogate agreement when selecting treatment interventions. Certain interpersonal and intrapersonal variables, as reported by surrogates, predicted accuracy across all decision vignettes. These variables include surrogates’ religiosity, trust in the medical profession, empathy, perceived similarity to patients on values related to end-of-life, and perceptions of patients as being more reluctant to burden others. Surrogates’ interpersonal and intrapersonal characteristics also influence the interventions they select for patients, with anxiety about COVID-19 having considerable bearing on surrogates’ chosen interventions.

4.3. Practice implications

The selected variables in this study significantly predicted surrogates’ intervention selections on behalf of patients. Of the predictor variables, surrogates with greater anxiety about COVID selected more intensive treatments for patients. Findings from this broad, exploratory study can be used to further the development of targeted decision-making interventions to improve surrogates’ accuracy. Providers may attend to these variables when working with surrogates in their decision-making role. For instance, during the current pandemic, providers may specifically attend to facilitating surrogates’ trust in the medical profession and ability to cope with anxiety surrounding COVID-19. These findings speak to the importance of considering decision-specific support for surrogates when making decisions on behalf of patients. For instance, ample patient decision guides and tools exist to aid with medical decisions, such as those relating to mechanical ventilation or dialysis [7], and could be similarly adapted for use with surrogates.

CRediT authorship contribution statement

Spalding Rachael: Conceptualization, Methodology, Data Analysis, Writing. Edelstein Barry: Supervision, Securing funding, Reviewing, Editing.
Declaration of Competing Interest

I have no conflicts of interest to disclose.

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Appendix A. Demographic Questionnaire

Name: ____________________.
Age: ______.
Sex: (choose one).
Male Female Transgender Female Transgender Male Gender Non-conforming.
Years of Education: _____.
Marital Status: (choose one).
Single Married/Committed Relationship Separated Divorced Widowed.
Ethnicity: (choose all that apply).
Caucasian/White.
African American/Black.
Asian American.
Hispanic/Latino.
Pacific Islander.
Native American (American Indian/Alaskan Native).
In what geographic region of the United States do you live? Northeast Southeast Midwest Southwest Northwest.
Do you have health insurance? Yes No.
How would you rate your physical health, overall? Poor Fair Good Very good Excellent.
Have you heard of COVID-19 (coronavirus)? Yes No.
To what extent are you worried about COVID-19? Not at all A little Some what Moderately Very much.
In this study, both you and another individual from your life will be participating. What is your relationship to this person? (choose one).
Spouse/partner Sibling Parent Adult child Close friend Other family member.
To what extent have you talked with this person about end-of-life decisions, including personal preferences? Not at all A little Moderately Very much.
For this study, it is important that you do not discuss the contents of this survey with this person.
By typing your full name in the space provided, you agree that you will not discuss any portion of this survey with this person: ____________________.

Appendix B. Decision Task

Surrogate Instructions: When reading the following vignettes, please imagine the person you identified on the demographic questionnaire is the patient. Also imagine that you are formally serving in a surrogate decision-making role where a healthcare provider is asking you to give instructions. When making these decisions, please make the decision that you think the patient would choose.

Note: use of the word “you” and “the patient” in the vignettes will vary based on survey version (patient or surrogate), as indicated by italics. Respondents’ choice options for each decision are indicated in bold text.

Part A: Ventilation (from [22]).
Sometimes when a patient cannot breathe on his/her own, a tube is placed down the windpipe of the patient and attached to a breathing machine, which can either totally or partially take over breathing for the patient. The following case is about a woman who cannot breathe on her own.

Mrs K. is a woman the patient/your age who has recently suffered a major stroke, leaving her in a coma and unable to breathe without a machine. After a few weeks, the doctor tells you that it is unlikely that Mrs K. will come out of the coma and that no one can be certain what her level of functioning would be if she ever did come out of the coma. What if this were the patient/you and the doctor asked you whether the breathing machine should be removed or continued? What would you say? (Remove/Continue).
To what extent do you feel you understand the costs and benefits associated with this treatment? Not at all A little Some what Moderately Very much.
To what extent do you feel that your family and friends find this treatment acceptable? Not at all A little Some what Moderately Very much.
To what extent do you feel confident in this decision? Not at all A little Some what Moderately Very much.

Part B: Resuscitation (from [22]).
If a patient’s heart or breathing stops while in the hospital, an emergency team will be called to try to get the heart and lungs started again. This is called CPR (resuscitation).
Again, think of the first case. Suppose the doctor wanted to know whether to try to resuscitate the patient/you if their/your heart stopped beating? What would you say? (Do not attempt CPR/Attempt CPR).
To what extent do you feel you understand the costs and benefits associated with this treatment? Not at all A little Somewhat Moderately Very much.
To what extent do you feel that your family and friends find this treatment acceptable? Not at all A little Somewhat Moderately Very much.
To what extent do you feel confident in this decision? Not at all A little Somewhat Moderately Very much.

Part C: Tube feeding (from [22]).
A patient who cannot eat can be fed through a nasogastric (NG) tube. This tube is placed down the nose and through the esophagus into the stomach. High-energy liquid foods are delivered down the tube. Often the patient has some diarrhea for the first week or two because of the different type of food that is being digested. Other types of artificial feeding methods that can be used are intravenous lines or a tube placed through the belly wall into the stomach.
Think of Mrs K. again. Because Mrs K. cannot eat or drink, she must be given artificial nutrition and hydration to keep her alive. A feeding tube may keep her alive perhaps for many more years. If this were the patient/you would you or would you not have the feeding tube placed? (No/Yes).
To what extent do you feel you understand the costs and benefits associated with this treatment? Not at all A little Somewhat Moderately Very much.
To what extent do you feel that your family and friends find this treatment acceptable? Not at all A little Somewhat Moderately Very much.
To what extent do you feel confident in this decision? Not at all A little Somewhat Moderately Very much.

Part D: Chemotherapy (from [22]).
Mr. L. is a man the patient's/your age who has been diagnosed as having a type of cancer that probably cannot be cured. Because of mental confusion, Mr. L. cannot make medical decisions on his own. His doctor recommends to you that chemotherapy be started. The doctor explains that the chances of curing Mr. L. are very small but that the chemotherapy may help him live longer. You are also told about the side effects of chemotherapy, which can make a patient very ill. What if this were the patient/you? What would you tell the doctor to do? (Do not begin chemotherapy/Begin chemotherapy).

To what extent do you feel you understand the costs and benefits associated with this treatment?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel that your family and friends find this treatment acceptable?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel confident in this decision?

Not at all A little Somewhat Moderately Very much.

Part E: Amputation (from [22]).

Mr. S. is a man the patient's/your age who has for many months been unable to make medical decisions for himself because he has become mentally confused. Because of diabetes, he has developed gangrene, or blood poisoning, in his leg. The doctor recommends that unless Mr. S. has his leg removed, he will almost certainly die in a very short time. If the leg is not amputated, medications can be given to control the pain, but he would almost surely die in a matter of days from the blood poisoning. What if this were the patient/you? What would you tell the doctor to do? (Do not amputate/Amputate).

To what extent do you feel you understand the costs and benefits associated with this treatment?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel that your family and friends find this treatment acceptable?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel confident in this decision?

Not at all A little Somewhat Moderately Very much.

Part F: Coronary Artery Disease—Bypass Surgery.

Bypass surgery helps improve blood flow to the heart in people with severe heart disease. Bypass surgery might improve your chances of living a longer life. Most of the time, bypass surgery is open-chest surgery. It can ease symptoms, such as chest pain and shortness of breath. For some people, this procedure can improve heart function and reduce the risk of dying of heart disease. Although complications from bypass surgery are uncommon, risk is a part of every surgical procedure. Potential risks include wound infection and bleeding, adverse reactions to anesthesia, fever, pain, stroke, heart attack, or even death. Bypass surgery is not a cure for heart disease. The surgery doesn't change the way arteries harden or narrow because of heart disease. Even after surgery, you can still get new places in your arteries that are narrowed, so you will still need to continue medicines and lifestyle changes to give you the best chance of living a longer, healthier life.

Suppose that the patient/you has started experiencing some symptoms of chest pressure and shortness of breath at times. Your doctor gives you some tests and diagnoses you/the patient with severe heart disease and says that you should consider bypass surgery as a treatment option. Would you choose for yourself/the patient to have the surgery? (Have bypass/Do not have bypass).

To what extent do you feel you understand the costs and benefits associated with this treatment?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel that your family and friends find this treatment acceptable?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel confident in this decision?

Not at all A little Somewhat Moderately Very much.

Part G: Chronic Kidney Disease—Dialysis Treatment.

Chronic kidney disease (CKD) is a long-term health problem where the kidneys slowly stop working. Over time, the damaged kidneys may stop working altogether. When the kidneys work less than about 10–15% of their normal rate, the kidney disease is described as established kidney disease (EKD). There is no cure for people with established kidney disease. Once people have established kidney disease, they have it for the rest of their life.

Dialysis is a treatment for established kidney disease that uses equipment to clean your blood and do some of the work that healthy kidneys do. Patients usually receive three dialysis treatments per week, and each treatment session usually takes at least 3 h to complete. Dialysis does about 10% of the work of healthy kidneys and improves some of the symptoms of kidney disease, but does not cure the chronic kidney disease. Failing kidneys will keep getting worse. Most people with established kidney failure who have dialysis treatments live longer than people who do not. Without treatment, the average life expectancy for a person diagnosed with established kidney failure is 6 months, whereas the average life expectancy of a person receiving dialysis treatment is about 4 years. Once a person begins dialysis treatment, they will need to have dialysis for the rest of their lives, or until they have a successful kidney transplant.

There are some common problems people may get when they have dialysis including fatigue, dizziness, and adjusting to the dialysis routine. All people having dialysis are seen by a specialist team at hospital, and in their homes, to help make the changes needed to their food, drink, and medicines.

Suppose that the patient/you has a diagnosis of established kidney disease. The doctor presents dialysis treatment as the next treatment option that you/the patient could seek at this time. Would you choose for yourself/the patient to begin dialysis treatment? (Begin dialysis/Do not begin dialysis).

To what extent do you feel you understand the costs and benefits associated with this treatment?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel that your family and friends find this treatment acceptable?

Not at all A little Somewhat Moderately Very much.

To what extent do you feel confident in this decision?

Not at all A little Somewhat Moderately Very much.

Appendix C. Trust in the Medical Profession Scale (TIMPS; [21]).

Please use the below scale to indicate how much you agree with each statement.

1. Doctors in general care about their patients' health just as much or more than their patients do.

2. Sometimes doctors care more about what is convenient for them than about their patients' medical needs.

3. Doctors are extremely thorough and careful.

4. You completely trust doctors' decisions about which medical treatments are best.

5. Doctors are totally honest in telling their patients about all of the different treatment options available for their conditions.

6. Doctors think only about what is best for their patients.

7. Sometimes doctors do not pay full attention to what patients are trying to tell them.
8. Doctors always use their very best skill and effort on behalf of their patients.
9. You have no worries about putting your life in the hands of doctors.
10. A doctor would never mislead you about anything.
11. All in all, you trust doctors completely.

**Appendix D. Communication-Based Emotional Support Scale (CBESS; Weber and Patterson, [51])**

Please use the below scale to indicate how much each statement is true of you, in general, with regard to your partner in this study.

1 2 3 4 5.
(almost never true) (rarely true) (occasionally true) (often true) (almost always true).

1. My partner helps me work through my thoughts and feelings about major life decisions (e.g., career choices).
2. My partner patiently and sensitively listens to me “let off steam” about an outside problem that I am having.
3. When I tell my partner about a problem I am having, they don’t seem to be paying attention.
4. My partner helps me cope with problems concerning other friends or family members.
5. My partner avoids me when I am depressed.
6. My partner is good listeners when I am upset.
7. When I am feeling down, my partner can say and do supportive things.
8. When I want to talk to someone about something that is bothering me, my partner seems to have something else to do.
9. My partner shows genuine concern for my problems.
10. My partner gives me good advice when I ask for it.
11. My partner makes it easy to discuss my personal feelings.
12. My partner listens to my side of the story even when they think that I am wrong.
13. My partner makes an effort to make me feel better when I am depressed.

**Appendix E. Center for Epidemiological Studies Depression Scale-Revised (CESD-R; [16])**

Please use the below scale to indicate how frequently you experienced each of the following symptoms over the past two weeks.

1 2 3 4 5.
(not at all or < 1 day) (1–2 days) (3–4 days) (5–7 days) (nearly every day).

1. My appetite was poor
2. I could not shake off the blues.
3. I had trouble keeping my mind on what I was doing.
4. I felt depressed.
5. My sleep was restless.
6. I felt sad.
7. I could not get going.
8. Nothing made me happy.
9. I felt like a bad person.
10. I lost interest in my usual activities.
11. I slept much more than usual.
12. I felt like I was moving too slowly.
13. I felt fidgety.
14. I wished I were dead.
15. I wanted to hurt myself.
16. I was tired all the time.
17. I did not like myself.
18. I lost a lot of weight without trying to.
19. I had a lot of trouble getting to sleep.
20. I could not focus on the important things.

**Appendix F. Life Values Inventory (LVI; [34])**

Below are some values that individuals may find important to them with regard to medical decision making at end-of-life. Please use the below scale to indicate the extent you think that your partner’s values are similar to your own.

1 2 3 4 5.
(exactly the opposite of me) (somewhat similar to me) (exactly the same as me).

1. To preserve good quality of life, even if one doesn’t live as long.
2. To live as long as possible, regardless of the quality of life.
3. To maintain the capacity to think clearly.
4. To feel safe and secure.
5. To be able to make one’s own decisions.
6. To avoid being a burden on one’s family.
7. To leave good memories of one’s last days to loved ones.
8. To be with loved ones before dying.
9. To avoid pain and suffering.
10. To experience a comfortable dying process.
11. To be treated with dignity when unable to speak for oneself.
12. To be treated with respect.
13. To be treated in accordance with one’s religious beliefs.

**Appendix G. Quality of Life Values Inventory (QLVI; [8])**

For each of the following values statements, please use the scale below to indicate the extent to which you think that your partner’s values are similar to your own.

1 2 3 4 5.
(exactly the opposite of me) (somewhat similar to me) (exactly the same as me).

1. I’d rather not live than be a burden on anyone else.
2. Quality of life is more important than preservation of life.
3. At the end of my life, other people will have the right to live their own lives; they will have taken care of me long enough.
4. Life must be preserved at any cost.
5. At the end of my life, I should think of myself first; if I need help, others will take care of me.

**Appendix H. Interpersonal Reactivity Index (IRI; [13])**

Please use the below scale to indicate how much you agree with each statement.

1 2 3 4 5.
(strongly disagree)(neither agree nor disagree) (strongly agree).

1. When I am reading an interesting story or novel, I imagine how I would feel if the events in the story were happening to me.
2. I really get involved with the feelings of the characters in a novel.
3. I am usually objective when I watch a movie or play, and I don’t often get completely
4. caught up in it.
5. After seeing a play or movie, I have felt as though I were one of the characters.
6. I daydream and fantasize, with some regularity, about things that might happen to me.
7. Becoming extremely involved in a good book or movie is somewhat rare for me.
Appendix J. Reluctance to Burden Others Scale (RBO; [53])

Below are some values that individuals may find important to them with regard to medical decision making at end-of-life. Please use the below scale to indicate the extent you think that your partner feels these are important.

1 2 3 4 5.

1. Avoiding burdening family and friends emotionally as a result of medical treatment decisions
2. Avoiding burdening family and friends financially as a result of medical treatment decisions
3. Avoiding being dependent on others.

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8. When I watch a good movie, I can very easily put myself in the place of a leading character.
9. Before criticizing somebody, I try to imagine how I would feel if I were in their place.
10. If I’m sure I’m right about something, I don’t waste much time listening to other people’s arguments.
11. I sometimes try to understand my friends better by imagining how things look from their perspective.
12. I believe that there are two sides to every question and try to look at them both.
13. I sometimes find it difficult to see things from the “other guy’s” point of view.
14. I try to look at everybody’s side of a disagreement before I make a decision.
15. When I’m upset at someone, I usually try to “put myself in his shoes” for a while.
16. When I see someone being taken advantage of, I feel kind of protective toward them.
17. When I see someone being treated unfairly, I sometimes don’t feel very much pity for them.
18. I often have tender, concerned feelings for people less fortunate than me.
19. I would describe myself as a pretty soft-hearted person.
20. Sometimes I don’t feel sorry for other people when they are having problems.
21. Other people’s misfortunes do not usually disturb me a great deal.
22. I am often quite touched by things that I see happen.
23. When I see someone who badly needs help in an emergency, I go to pieces.
24. I sometimes feel helpless when I am in the middle of a very emotional situation.
25. In emergency situations, I feel apprehensive and ill-at-ease.
26. I am usually pretty effective in dealing with emergencies.
27. Being in a tense emotional situation scares me.
28. When I see someone get hurt, I tend to remain calm.
29. I try to lose control during emergencies.

Appendix I. Health Opinion Survey (HOS; [25])

Please use the below scale to indicate how much you agree with each statement. 1 2 3 4 5.

1. Except for serious illness, it’s generally better to take care of your own health than to seek professional help.
2. It is better to rely on the judgements of doctors (who are the experts) than to rely on “common sense” in taking care of your own body.
3. Clinics and hospitals are good places to go for help since it’s best for medical experts to take responsibility for health care.
4. Learning how to cure some of your illnesses without contacting a physician may create more harm than good.
5. Recovery is usually quicker under the care of a doctor or nurse than when patients take care of themselves.
6. If it costs the same, I’d rather have a doctor or nurse give me treatments than to do the same treatments myself.
7. It is better to rely less on physicians and more on your own common sense when it comes to caring for your body.
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