Surrogate End-Of-Life Decisions: Projection or Simulation

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Abstract

Background: Substituted judgment at the end-of-life is often needed to extend autonomy of decisionally-incompetent patients who don’t have advance directive. Its moral appeal centers on surrogates’ ability to simulate patients’ choices as opposed to projecting their personal choices. The accuracy of the standard substituted judgement model has been questioned, and an integrative patient’s life-story narrative version has been suggested. The accuracy of the latter cannot be evaluated using the common methodology of life-saving intervention and binary-decision scenarios. We explored the accuracy of the life-story narrative version of substituted judgment using forced-ranking and Q-methodology.

Methods: A volunteer sample of seven family pairs (3 husband-wife, 1 parent-child, 3 sib-sib) participated in a pilot study. All 14 respondents rank-ordered 47 opinion statements on end-of-life issues using a 9-category symmetrical distribution according to their personal preferences (personal sort), and 11 of the 14 according to predicted preferences of individuals in their pair (surrogate sort). Accuracy of within-pair prediction was explored by comparing: 1) correlation of individual statements’ ranking scores between surrogate sorts and their paired-personal sorts (simulation) to correlation between surrogate sorts and their self-personal sorts (projection), and 2) percentage of surrogate sorts that co-loaded with their paired-personal sorts to percentage of surrogate sorts that co-loaded with their self-personal sorts, using factor Q-methodology.

Results: Mean (SD) age was 31.9 (8.9) years; 50% were females; 43% reported average religiosity, 65% ≥ very good health, 64% ≥ very good life quality, and 100% ≥ high school education. Mean (95% confidence interval) simulation and projection correlations were 0.222 (0.136 to 0.305) and 0.976 (0.971 to 0.980), respectively, with a mean difference of 0.754 (0.628 to 0.880, p < 0.001). With 5-factor extraction, 45% of the 11 surrogate sorts co-loaded with their paired-personal sorts and 82% with their self-personal sorts. With 3-factor extraction, the corresponding percentages were 45% and 91%.

Conclusions: Q-methodology may be useful in exploring the accuracy of substituted judgment that is based on patients’ life-story narratives. Surrogate end-of-life decisions by family members are more likely to project personal choices and life-story narrative than to simulate patient’s choices and life-story narrative.

Keywords: End-of-life choices; Q-methodology; Surrogate decision-making; Substituted judgment; Life-story narrative

Background

The principle of respect for patient autonomy and the right of self-determination dominate medical decision-making in developed countries. The concept of prospective autonomy proposes that personal choices ought to inform healthcare decisions for decisionally-incapacitated patients. Such extension of patient’s autonomy is accomplished through advance directive and surrogate decision-making; patients are encouraged to document their wishes with respect to life-saving interventions in a living will and their choice of a surrogate decision-maker in a durable power of attorney for healthcare.

Although the use of advance directives has markedly increased, about 30% of ≥ 60 year-old US adults who died between 2000 and 2006 required decision-making at the end-of-life but lacked decision-making capacity [1]. People may not execute written directives due to their reluctance to contemplate the prospect of death, their belief that their family knows their wishes or that what to be done is standard, or their belief that end-of-life decisions are not their (sole) responsibility or right, are not important to them, or could not be made in advance. Further, individuals may be unsure about their own values and healthcare goals at the end-of-life, and no advance directive is expected to provide clear instructions for all possible scenarios. Moreover, people may want their healthcare agents to take their instructions as suggestions to consider rather than as final decisions to execute, giving them leeway to respond as they see appropriate.

A surrogate decision-maker can be patient-designated or the next-of-kin according to a standardized legally-determined hierarchy. He/she is expected to make decisions in accordance with patient's instructions, and if unknown, to predict the decisions that the patient would have made (substituted judgment). According to the substituted judgment standard, decisions should not be based on what surrogates prefer for themselves, what they think is in the best interest of the patient, or what they think most people in that condition would want [2].

Advantages of substituted judgment

There are several theoretical advantages of substituted judgment, including, promoting and extending patient autonomy, respecting patients’ preferences regarding who makes decisions for them, respecting the status of family members as vital individuals in the patient’s life, [3] and providing comfort to family members by framing the decision as the patient’s own choice [4]. Qualitative exploration of family members’
perspectives showed a desire to be involved and an acceptance of moral responsibility [5]. On the other hand, substituted judgement results in usually-uninformed and nonprofessional individuals making the most delicate and irreversible decisions [4] with the associated moral, emotional, and cognitive demands [6].

**Accuracy of substituted judgment**

Because there is no way to determine patients' choices when they are incapacitated, empirical studies had to assess the accuracy of substituted judgement in hypothetical scenarios. Although some studies showed reasonable accuracy, [7,8] a systematic review of 51 studies found low to moderate accuracy, which was increased with more extreme scenarios, under conditions of forced choice, and when family members were specifically directed to use substituted judgement [5]. Another systematic review of 16 studies involving 151 life-saving hypothetical scenarios and 19526 patient-surrogate paired responses found 68% accuracy, that there was no significant difference between patient-designated and legally assigned next-of-kin surrogates, and that prior discussion of patient's treatment preferences did not significantly improve accuracy. Nevertheless, surrogates were more accurate than physicians at predicting patients' preferences [9]. A more recent study on 38 dyads of African-American dialysis patients and their surrogates showed that 60% of surrogates were unsure how their loved ones would feel about continuing life sustaining treatment, that there was only 35% congruence between patients and their surrogates in end-of-life treatment preferences, and that surrogates' confidence had little association with their actual understanding of patients' values and goals [10]. Other pieces of evidence suggest that the moral basis for substituted judgment is not sound; individuals' own preferences regarding life-sustaining treatment change over time, surrogates' judgments may be more related to their own preferences than to patients' preferences, [11] and stress, sorrow, and uncertainty that accompany end-of-life may further reduce surrogates' predictive accuracy [9]. However, it was argued that the moral authority of a family proxy need not be contingent on his/her accuracy in predicting patient's choice; it may be justified by the trust that lies behind their selection, and that fact that even though individual persons have the diseases, whole families experience illnesses [6].

In addition to the concerns about surrogates' accuracy in predicting patient-preferred decisions, there are concerns about surrogates' accuracy in predicting patient-preferred way of decision-making. Healthcare decision can be made solely by the patient based on the informed choice model (self-decision-making), deferred to the treating physician ("reliant" decision-making), or together with the treating physician (shared decision-making). For the incapacitated patient, the corresponding choices are substituted judgement standard (patient alone), the best interest standard (family alone), or a mixture thereof (patient and family), respectively. People may value the exercise of free choice more than the precise content of the choice, [12] and it is not clear whether patients care more about who makes decisions for them or what decisions are made [3]. A study of 52 dyads of seriously-ill patients and their family members that evaluated surrogates' prediction of how patients want them to make decisions on their behalf found agreement in 56% and 46% for conscious and unconscious scenarios, respectively; surrogates were more likely to err by attributing to the patient a preference for substituted judgment when the patient preferred patient-family shared decision-making or family-only decision-making based on the best interest standard [13].

Finally, although patients and families may have the same end-of-life priorities they may hold them at different hierarchies. Which is more important, being awake or being free of pain, prolonging life or dying at home, supportive care aimed at comfort and dignity or maximal care aimed at maintaining life? It has been observed that for patients, ability to self-care was the most important and burden on family was the third most important end-of-life issues, whereas for surrogates, amount of pain was the most important issue and burden on family was not an important issue [6]. An integrative view of priorities in their hierarchy cannot be assessed by the commonly-used methodology that involves life-saving intervention and binary-decision scenarios.

**Alternatives to substituted judgment**

A population-based treatment indicator was proposed as a supplement to or replacement of surrogate decision-making and/or as an advanced directive option; [3] it is based on the observation that preferences for receiving a given intervention correlate with the acceptability of the predicted post-intervention health status [14,15]. A preliminary US population-based treatment indicator that was based on previous data showing that most patients want life-saving interventions when there is at least a 1% chance that they will lead to an acceptable status, that most patients would not want to be kept alive if they were in coma with no chance of recovery, and that most patients considering permanently in coma or otherwise permanently unable to reason, remember, or communicate as no better than death, was found to be as accurate as surrogates in predicting patients' choices (accuracy 78.5% vs 78.4% for surrogates) [3]. It is of note that the proposed indicator did not address non-life-saving intervention, post-intervention health status beyond ability to reason, remember, and communicate, or the degree of intervention's invasiveness [3]. Further, such indicators do not address the patient as an individual or as a member of a unique set of relationships. Furthermore, their development requires data on culture-specific and other characteristics that may influence end-of-life preferences.

A patient's life story narrative model of surrogate decision-making focuses on respect for persons (rather than narrowly on respect for autonomy); in addition to taking into consideration each patient's prior wishes, it embraces individuality, religious affiliation, and equal human dignity, respects privacy and confidentiality, values relationship, and considers the patient's risk-taking attitude and utility estimation of possible outcomes. It balances rather than rigidly prioritizes among patient instructions, wishes, values, and interests; rather than trying to predict the actual choices that the incapacitated patient would have made, it makes, in the current context, decisions that are consistent with the patient's life-long choices and experiences [4].

Several studies have explored general public's end-of-life priorities in Western [16-20] and other countries [21-25]. Most studies used independent rating of choices and analysed results by averaging across individuals, which tend to attribute maximum importance to a large number of choices [26] and to obscure individual priority structures [24,25]. Exploratory factor analysis revealed that four latent domains underlie the Quality of Dying and Death (QODD) instrument [27]. Q-methodology, a special type of by-person exploratory factor analysis, is a process whereby respondents model their point of view by ranking-ordered opinion statements into piles (Q-sort) along a continuum defined by certain instructions [28]. Using the Q-sorts as variables, it produces grouping of respondents who rank-ordered the statements into similar arrangements [29]. We have recently studied the usefulness of the Q-methodology in exploring end-of-life choices; we found that averaging analysis masked important priorities and dis-priorities that were revealed by Q-methodology analysis [24,25].
Almost all the studies that evaluated substituted judgment’s accuracy used life-saving intervention and binary-decision scenarios. They did not address non-life-saving interventions, other end-of-life choices, such as having family members around at the last moments and place of death, or issues related to transcendence, information disclosure, and coping. Further, there is often a continuum of decisions anchored by two distinct goals rather than a decision with a binary answer. A deeper and more integrated approach, such as the Q-methodology, is needed to assess surrogates’ accuracy in predicting how patients would balance priorities and their accuracy in decision-making that is based on the patient’s life story narrative model.

The aim of this pilot study was to explore the utility of forced-ranking and Q-methodology in evaluating the accuracy of the patient life-story narrative version of substituted judgment.

Methods

This study was part of an exploratory cross-sectional study [24] that was conducted in accordance with the Declaration of Helsinki after approval of the Research Ethics Committee of the King Faisal Specialist Hospital and Research Center (KFSH&RC). All respondents provided verbal informed consent.

Study Instrument

The development and validation of the study instrument (Q-set) were reported previously [24]. Q-sorting requires respondents to arrange statements according to their subjective relative importance into graded priority and dis-priority, using a symmetric forced distribution (sorting sheet). The sorting sheet for this study had 9 categories (1=extreme dis-priority, 5=non-priority, 9=extreme priority) with symmetrically distributed number of slots under each category: categories 1 and 9, 3 slots each; categories 2 and 8, 4 slots each; categories 3 and 7, 6 slots each; and categories 4, 5, and 6, 7 slots each. The Q-set (Additional File 1) has 47 end-of-life opinion statements distributed in 8 thematic domains: symptoms and personal control (n=7), treatment preferences (n=5), whole-person concerns (n=8), moment of death (n=5), family/friends (n=6), achieving sense of completion/spirituality/religiosity (n=5), preparation for death (n=5), and relationship with healthcare professionals (n=6). Time spent and Q-sort completeness (i.e., each statement is sorted only once) were checked, and respondents were asked to correct identified mistakes. Respondents were asked to identify a family member (spouse, sibling, parent, or child) that would accept to participate in the study. Paired family members separately sorted the statement is sorted only once) were checked, and respondents were asked to control their Q-set twice, according to their own point of view and according to their paired family member point of view.

The following data were also collected: age, gender, sorting time, self-declared religiosity, general health, life quality, employment status, living arrangement, death experience in family/close friends, type of intra-pair relationship, and degree of intra-pair familiarity.

Volunteer sample

KFSH&RC Saudi employees, patients, and patients’ companions attending outpatient clinics were invited to participate through direct contact and within-institution advertisement. Eligibility criteria were Saudi nationality, age ≥18 years, education ≥high school, and ability to understand study purpose and procedures.

Analysis

Data were verified by double entry and validity checks. Correlations of individual statements’ ranking scores between surrogate sorts and their paired-personal sorts (which reflects simulation) and between surrogate sorts and their self-personal sorts (which reflect projection) were calculated using Pearson’s correlation coefficient. To estimate mean correlation coefficient, correlation coefficients were z transformed, z values were averaged, and the results were back transformed [30]. To compare mean correlation coefficients, combined standard error was calculated as the square root of the sum of squares of the separate standard errors, and the z test and 95% confidence interval were determined [31].

Q-sorts were analyzed using PCQ for Windows (PCQ Software, Portland, OR, USA). Centroids were extracted and Varimax rotated. Q-sorts with loading in excess of 0.38 (p < 0.01) were considered significant. The percentage of surrogate sorts that significantly co-loaded with their paired-personal sorts or with their self-personal sorts were determined for 3-factor and 5-factor solutions.

Results

All 25 Q-sorts were evaluable. Mean (SD) sorting time was 39.4 (12.6) minutes. Respondents’ demographics are presented in (Table 1).

Averaging analysis

Mean of differences in ranking scores of the 47 statements between personal sorts and their corresponding surrogate sorts ranged from -1.2 to 1.1 on a scale of 1 to 9 (Figure 1). We arbitrary considered an absolute mean of differences of ≥1 as important and of <0.1 as unimportant.

Statements, “I want to die maintaining my dignity,” “I want to be referred to as a person not as a disease or a number,” and “I want to die being able to control my bowels” received higher scores in personal sorts than in surrogate sorts (mean of differences 1.1, 1.0, and 1.0, respectively), indicating surrogates’ prediction error due to value underestimation. Statements, “I want to die at home,” and “I want to receive medical information regularly from medical staff” received higher scores in surrogate sorts than in personal sorts (mean of differences -1.2 and -1.0, respectively), indicating surrogates’ prediction error due to value overestimation. Mean of differences in ranking scores for the following statements was <0.1: “I want to die at peace with God,” “I want to die free of depression,” “I want to avoid being a financial burden to my family/friends,” “I want to discuss my fears about dying with my physician,” indicating quantitative concordance.

Factor analysis

Individual statement’s ranking score indicates preference for a specific action but does not provide an overall assessment of priorities and dis-priorities of the person or reflect his life-story narrative. Using the Q-sorts as variables, Q-methodology produced grouping of respondents (factors or opinion types) who rank-ordered the statements into similar arrangements. Such grouping provides a deeper, wholesome, and more integrated picture of the respondent. We examined within-pair concordance in loading, i.e., co-loading of surrogate sorts and their paired-personal sorts on the same factor. As a control, we evaluated co-loading of surrogate sorts with their self-personal sorts and between surrogate sorts and their self-personal sorts (which reflect projection). Using 5-factor extraction, the five factors accounted for 54% of the total variance (8%, 17%, 13%, 7, and 9% for factors 1 to 5, respectively) and 72% of the 25 Q-sorts (2, 7, 5, 3 and 1 loaded on factors 1 to 5, respectively). Of the remaining Q-sorts, one did not have significant
loading on any of the 5 factors, and 6 were confounded (loaded significantly on more than one factor). There were no consensus statements among the five factors. Statement, “I want to have my family/friends with me at my last moments.” distinguished factor 2 from other factors (rounded scores 8 vs. 3 to 4), statement “If I go into coma, I do not want to be placed in an intensive care unit.” distinguished factor 4 from other factors (rounded scores 9 vs. 1 to 4), and statement, “I want to die at the peak of my life;” distinguished factor 5 from other factors (rounded scores 9 vs. 2 to 5). Only 5 out of the 11 (45%) surrogate sorts co-loaded with their paired-personal sorts. In contrast, 9 (82%) co-loaded with their self-personal sorts. The results are summarized in (Table 2).

Discussion
The aim of this pilot study was to explore the utility of forced-ranking and Q-methodology in evaluating the accuracy of the patient life-story narrative version of substituted judgment. In contrast to previous studies that addressed substituted judgment’s accuracy using life-saving intervention and binary-decision scenarios, we presented our respondents with 47 opinion statements that covered a multitude of end-of-life issues, including, life quantity and quality (symptoms and personal control, treatment preferences, whole person concerns), connectedness (moment of death, issues related to family/friends), transcendence, coping, information-disclosure, and decision-making.

We repeated our analysis using 3-factor extraction in term of sensitivity analysis. The three factors accounted for 42% of the total variance (11%, 17%, and 14% for factors 1 to 3, respectively) and 88% of the 25 Q-sorts (4, 8, and 10 loaded on factors 1 to 3, respectively). Of the remaining Q-sorts one did not have significant loading on any of the 5 factors, and 2 were confounded (loaded significantly on more than one factor). Only 5 out of the 11 (45%) surrogate sorts co-loaded with their paired-personal sorts. In contrast, 10 (91%) co-loaded with their self-personal sorts. The results are summarized in (Table 2).
Co-loading of surrogate, paired-personal, and self-personal Q-sorts using 3-factor and 5-factor Q-methodology analysis.

Table 2: Co-loading of surrogate, paired-personal, and self-personal Q-sorts using 3-factor and 5-factor Q-methodology analysis.

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Data represent Q-sorts that co-loaded on the same factor. The first letter of each dyad represents the conservator (surrogate) and the second letter represents the conservatee. The 14 respondents (A to N) sorted the Q-sort for themselves (personal sorts, represented by two identical letters) and 11 of the 14 sorted the Q-sort for their relatives (surrogate sorts, represented by two different letters). Surrogate sorts that co-loaded with their paired-personal sorts are underlined. *Sorts that simultaneously co-loaded on more than one factor.

Very little difference in prioritizing for the self-compared to prioritizing for the family member. This could be due to familiarity with the family member or to shared estimates of values among family members. The latter appears more likely because, some issues, such as maintaining dignity, being referred to as a person, and being able to control bowels were assigned higher scores when ranked for the self, whereas other issues, such as dying at home and receiving medical information regularly, were assigned higher scores when ranked for the family member. Further, the correlation in individual statements' ranking scores between surrogate sorts and their self-personal sorts was much stronger.

We found a large and highly significant difference between mean coefficient of correlation of individual statements' ranking scores between surrogate sorts and their self-personal sorts and that between surrogate sorts and their paired-personal sorts. Moreover, surrogate sorts were about twice as likely to co-load with their self-personal sorts than with their paired-personal sorts, indicating that even at a more global level, substituted judgment is inaccurate and would more likely project family members' personal preferences than simulate the decisionally-incompetent patients' preferences. These results are in agreement with previous studies that used life-saving intervention and binary-decision scenarios and showed inaccuracy of the standard version of substituted judgment, [5,9,10] and predict inaccuracy of the substituted judgment version that is based on patient's life-long narrative.

The psychological considerations and mechanisms that may contribute to inaccuracy of surrogate decision-making have not been well studied. In addition to family member's perceived attitude to risk, subjective utility of possible outcomes, wishes, and values, surrogates may invoke their own preferences, financial considerations, religion and spirituality, social values and norms (the most socially desirable outcome could be selected genuinely expecting that it is consistent with the family member's wishes, or as part of own reputation management), or the family member's best interest. Other possible reasons for inaccuracy include choosing the "safer error", which results in surrogates being more likely to choose interventions that the patients refuse than to withhold wanted care. In decision-making, surrogates may start with their own preference as a reference point (anchor) and then adjust their value estimation to reflect their perceived differences between the family and the patient member, or they may compare the preferred outcomes from a number of different perspectives, what they would do if they were the beneficiary of the decision (projected), what they believe is the best outcome for the beneficiary (benevolent), and what they believe the family member would choose (simulated) [32]. The latter is expected to be affected by familiarity with the family member and the ability to empathize or take another person's perspective. A study on surrogate utility estimation of healthcare and commodity items showed significant partial-correlations between what surrogates predicted for their partners and what the partners actually stated while controlling for their own utility judgment, suggesting that people engage in perspective-taking rather than simple anchoring and adjustment, and that utility estimation is not the cause of inaccuracy in surrogate decision-making [32].

The moral and legal appeal of substituted judgment centers on surrogates' ability to simulate patient's preferences as opposed to projecting their personal ones. If both the standard version of substituted judgment (trying to predict the actual choices that the incapacitated patient would have made) and the version based on the patient life-long narrative (making, in the current context, decisions that are consistent with the patient's life-long choices and experiences) are inaccurate and thus don't fulfill the moral and legal requirements, more attention would be given to population-based treatment indicators [3]. However, several questions remain. Should respect for autonomy eclipse respect for person and the importance of family and community? Are there family or community rights that should be considered in addition to the right of self-determination? Does surrogate decisions-making benefit or burden families? And how does one balance respect for family, impact on family, respect for patient's treatment preferences, and respect for patient's preferences regarding who makes decisions and how decisions are made [3].

Study Limitations

The following limitations should be taken into account when...
interpreting the results of this pilot study. Our sample size was small, larger studies are required to corroborate our results. The study was based on a volunteer sample recruited from a single urban, academic center, and the sample had relatively high education level and lacked ethnic diversity, therefore the generalizability of our findings to other settings is limited.

Conclusions

The results of this pilot study support the following conclusions: 1) Surrogate end-of-life decisions by family members are more likely to project personal choices and life-story narrative than to simulate patients’ choices and life-story narrative, in violation of the substituted judgement principle. 2) Q-methodology appears to be useful in exploring the accuracy of the version of substituted judgment that is based on patients’ life-story narrative. If our findings are supported by findings of larger studies and of studies in other settings, then one may conclude that both the standard model and the life-story narrative model of substituted judgment are not accurate; and that more attention should be given to an expanded, culture-specific version of the population-based treatment indicator model.

Authors’ Contributions

SH performed data analysis and literature review and co-wrote the manuscript. FAF participated in data acquisition. MMH designed the study, supervised the collection, analysis, and interpretation of data; in the writing of the manuscript; approved the final version, and agree to be accountable for all aspects of the work.

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