Surrogate Perspectives on a Patient Preference Predictor: Good Idea, But I Should Decide How It Is Used

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Abstract

Objective: Current practice frequently fails to provide care consistent with the preferences and values of decisionally-incapacitated, critically ill patients. It also imposes significant emotional burden on their surrogates. Algorithmic-based patient preference predictors (PPPs) have been proposed as a way to address these two concerns. While previous research found that patients strongly support the use of PPPs, the views of surrogates are unknown. This study assesses the views of experienced surrogates regarding the use of PPPs as a means to improve treatment decision making for incapacitated patients.

Setting: Two academic medical centers and two community hospitals.

Subjects: Experienced Surrogates [n=26].

Interventions: An initial quantitative survey followed by an in-depth interview and a final quantitative survey.

Measurements: Overall level of support for PPPs and views on how a PPP should be used, if at all, in practice.

Main Results: Overall, 21 participants supported the use of PPPs. The remaining five indicated that they would not use a PPP because they made decisions based on the patient's best interests, not based on which treatments the patient would choose for themselves. Some respondents expressed concern that PPPs might be used to deny expensive care or be biased against minority groups. Finally, 24 respondents indicated that surrogates, not patients, should decide how treatment decisions are made, including whether and how to use PPPs.

Conclusions: Surrogates, like patients, strongly support the use of PPPs as a means to improving decision-making for incapacitated patients. These findings provide support for developing a PPP and assessing its use in practice. At the same time, patients and surrogates disagree over whose preferences should determine how treatment decisions are made, including whether to use a PPP, are made. These findings reveal a fundamental disagreement regarding the guiding principles for surrogate decision-making that need to be addressed by attempts to improve current critical care practice.

Introduction

Many critically ill patients are unable to make treatment decisions for themselves [1, 2]. One study found that up to 69% of nursing home residents have decisional impairment and that 48 hours after hospitalization, 47.4% of adults 65 and older required the involvement of surrogate decision-makers [3].

Surrogate decision-makers are charged with making treatment decisions based on the patient’s preferences. When the patient’s preferences are unknown, surrogates are instructed to make decisions based on what they think the patient would have chosen (i.e. the substituted judgement standard). When this is unclear, surrogates are expected to try to promote the patient’s best interests.
Reliance on surrogates to implement the substituted judgement standard keeps the patient’s family and loved ones involved in their care. And it is assumed that this approach also offers the best way to provide medical care consistent with the patient’s preferences and values. Unfortunately, this practice raises two significant concerns.

First, surrogates are frequently unable to predict which treatment patients would choose for themselves. In studies using hypothetical scenarios, surrogates accurately predict whether their loved one would accept or refuse a given course of treatment 54%- 68% of the time, where random guessing would have yielded 50% accuracy [4, 5].

Second, surrogates regularly experience significant distress as a result of making decisions. One study found that a third of surrogates charged with making decisions for loved ones in intensive care units developed symptoms associated with posttraumatic stress disorder; this number increased to nearly 82% for surrogates who made end-of-life decisions [6, 7, 8]. One of the sources of this distress is surrogates’ difficulty predicting patients’ preferences.

One proposal to address these two concerns is to supplement current practice with a Patient Preference Predictor (PPP) [9, 10, 11]. A PPP is an algorithmic model that predicts which treatment the patient would want based on the preferences of similar patients, possibly supplemented with information about the patient from their electronic health records and online profile [12].

A preliminary PPP was found to be as accurate as surrogates [11]. Because the tested PPP did not include factors known to be associated with patients’ treatment preferences, such as their age, a more comprehensive PPP, which incorporates a broader range of predictive factors, might be even more accurate than surrogates alone. If this turned out to be the case, PPPs could also decrease the emotional burden on surrogates, a good deal of which traces to their having to make decisions without knowing the patient’s treatment preferences [10].

Development and testing of a comprehensive PPP to determine its relative accuracy would be resource intensive. Before development, it is important to assess its feasibility in practice.

A prior study found, that if PPPs do increase surrogates’ predictive accuracy, a majority of patients support their use [13]. However, surrogates are the ones who would be involved in implementing PPPs in practice. Hence, whether use of PPPs would be feasible and welcome depends on surrogate perceptions [14]. The present manuscript thus provides the first assessment of the views of surrogates regarding two questions: Do surrogates support PPPs? How, if at all, do surrogates think PPPs should be incorporated into practice?

**Materials And Methods**

*Study Development*
To ensure participants were familiar with surrogate decision-making, we surveyed ‘experienced’ surrogates, defined as surrogates who had made at least one medical decision for an incapacitated adult within the past three years. To get more in-depth information about surrogates’ attitudes and experiences, we conducted semi-structured qualitative interviews. The qualitative data collected during the interviews were supplemented with pre- and post-interview surveys.

The interview guide (Supplemental Digital Content 1) and quantitative surveys (Supplemental Digital Content 2 and 3) were designed after an extensive literature review. Draft versions were reviewed by three content experts on surrogate decision making and revised accordingly. They then underwent cognitive and behavioral testing with five experienced surrogates.

**Interview Process**

To engage a diverse group of respondents, participants were recruited from two university-affiliated hospitals, Emory University Hospital, Atlanta, GA, and the Hospital of the University of Pennsylvania, Philadelphia, PA, and two community hospitals, Saint Elizabeths Hospital, Washington, DC, a government-run facility for individuals with persistent mental illness, and Medstar Washington Hospital Center, Washington, DC. We used convenience sampling, with clinicians who knew eligible surrogates briefly explaining the study and connecting those interested with the moderator to schedule interviews.

Interviews were conducted in person or by phone. All sessions were conducted by the same moderator (AR) with expertise in qualitative methods and were recorded and transcribed.

The moderator first asked participants to describe their experience making treatment decisions for an incapacitated patient and, for interview purposes, to focus on one decision, either the most recent or most memorable. The moderator then detailed the idea behind the PPP, explained that researchers were considering developing a comprehensive PPP, and answered any questions. The moderator then solicited participants’ overall view of PPPs using a 10-point scale. Scores of 1-4 were regarded as a lack of support, 5-7 as moderate support and 8-10 as strong support. Participants were also asked to articulate the advantages and disadvantages of PPP implementation for that decision. Handouts (Supplemental Digital Content 4, 5, 6, and 7) were used at several points to facilitate participant understanding.

In three cases, there were differences between participants’ views in the written surveys versus the interviews, or differences earlier versus later in the interviews. In these cases, the last-expressed opinion is reported as respondents’ views, on the assumption that they reflect the most considered opinion.

**Coding**

The aim of the interviews was to achieve “meaning saturation,” the point at which coding subsequent interviews revealed no new thematic categories nor yielded any “further dimensions, nuances, or insights” about the thematic categories [15, 16, 17]. Two coders independently coded each interview and discussed discrepancies, with remaining disagreements settled by a third author.
The two coders initially reviewed five randomly selected transcripts, identifying key themes. They then coded three randomly selected interviews at a time, iteratively refining the preliminary themes until reaching meaning saturation. This occurred at 22 interviews, at which time an additional 4 interviews were in process. The final analysis thus includes 26 interviews. All interviews were coded with the finalized codebook. Finally, to assess how often themes were articulated, we determined which themes were mentioned by each participant (Table 3).

**Participant Protections**

To minimize distress, surrogates were excluded if the patient had died within the previous two months. In addition, participants were reminded they could choose not to answer any questions, they could end their participation at any time. The patient for whom one of the participants was making decisions passed away after the interview had been scheduled. Because the surrogate still wanted to participate, she was included.

To protect privacy, no identifying information was collected and each respondent chose a pseudonym. The initials in the present manuscript are the initials of the chosen pseudonyms. Secondary research is limited to what the consent form describes. The protocol, consents, surveys, and handouts were approved by the Special Studies IRB, the NIH IRB with the most experience reviewing survey research.

**Results**

**Participants**

We enrolled 26 participants: 17 were interviewed by telephone and nine in-person. All the telephone interviews were conducted individually. Of the in-person interviews, eight participants were interviewed in groups of 2-3 persons and one was interviewed individually. The interviews lasted 90 -120 minutes, with the exception of one phone interview which lasted 55 minutes. For the purposes of analysis, we assessed participants’ responses individually, whether they participated in an individual or a group interview.

Nineteen participants self-identified as female, seven as male. Fourteen self-identified as African American, 11 as Caucasian, and one as Asian American (Table 1). The majority were the spouse of the patient, 20 had known the patient for at least 20 years, and 18 had made medical decisions for the patient within the past month (Table 2).

**Support**

Overall, if use of a PPP increases surrogates’ predictive accuracy, 21 participants moderately or strongly supported its use, many regarding such a tool as very valuable. A major benefit articulated in the interviews that has been cited previously was that a PPP could improve surrogate decision-making by offering evidence of the patient’s preferences. One participant stated “Two heads are better than one, my grandma always told me. So, you listen, you learn... I think PPP is extremely helpful. [JJ 381].
Besides new evidence, respondents stated that PPP’s could also help orient surrogates to considerations that should guide their decision. For example, “A plus is it gives you a road map to start off with instead of giving you a scratch piece of paper...It’s a starting point. It’s not saying it’s going to make a decision for you.” [RW 310].

Additionally, participants described a benefit not previously reported. Multiple respondents stated that surrogates often make difficult decisions on their own. By offering a tool that is based on input from others, the PPP could signal that surrogates are not alone. For example, one participant stated, "Maybe just the fact that other people have added and put into [the PPP], it may be a little reassuring that you’re not alone in this mess and you’ll come out the other side" [IB341].

A number of respondents supported the PPP for others, but not for themselves, because they felt confident they knew the patient’s preferences. One stated, “If a surrogate had no previous real discussions with the patient as to what they wanted, that might be a good crutch for them to lean on...In my case I had a good understanding of what she would want in various situations” [TH 315].

**Lack of Support**

Five participants did not support use of a PPP, even if it increases surrogates’ predictive accuracy. Two felt that surrogates should choose what is medically best for the patient, not what the patient would have chosen for themselves. Another participant expressed concern that implementation of a PPP would require knowing many things about the patient: “I recognize the intent behind it, and my first thought was, well maybe if there wasn’t somebody who was really close to the patient there, they might need some help with this. But if there wasn’t someone close to the patient then how accurate is the information that you’re going to put in to find out what they might want to know?” [VD287].

Finally, one participant worried that the PPP might be biased against underrepresented groups: “My initial reaction was an algorithm, yikes! I think algorithms can be discriminatory and in other ways flawed” [OS 250].

**Decisional Authority**

The consensus among supporters and critics alike was that, if a PPP is developed and its use increases predictive accuracy, it should be offered to surrogates. At the same time, the overwhelming majority of respondents stated that the surrogate, and not the patient, should decide whether and how the PPP would be used. For instance, one participant who was ambivalent about a PPP due to discomfort with using technology stated: “the PPP should probably still be offered to surrogates if they want it. It’s their choice” [LN 369]. Another participant, who was very enthusiastic, worried that mandating use of a PPP “could take the power out of the surrogate [and] the patient’s hands— and computerize the decision” [AH 413]. Finally, a number of respondents expressed concern that if surrogates did not have the authority to decide how to use a PPP, it might be used to deny expensive care to patients who need it.
Discussion

If a PPP increases predictive accuracy, the majority of experienced surrogates interviewed supported its use. This finding, paired with previous findings of patient support, suggests that a PPP could offer a valuable way to improve decision-making for decisionally-incapacitated patients.

Previous research has found that patients endorse three primary goals with respect to surrogate decision-making: receive the treatments they want, minimize the burden on loved ones, and keep loved ones involved in the decision-making process [14]. The present finding of experienced surrogate enthusiasm suggests a PPP could offer a way to promote all three goals. This possibility provides strong support for developing and testing a PPP to see whether it is feasible, and whether its use increases surrogates’ predictive accuracy.

One possibility would be to use the prediction of the PPP as a "soft" default [18, 19]. Specifically, clinicians could provide the surrogate with the treatment prediction of the PPP and suggest treating the patient accordingly, unless the surrogate objects. Providing the PPP prediction could help structure discussions regarding the treatment plan around an evidence-based starting point. This approach may reduce the decision-making burden on surrogates who are uncertain about the patient’s preferences. Alternatively, a soft default would allow surrogates who are confident of the patient’s treatment preferences to select that option whenever it conflicts with the PPP.

At the same time, the present findings highlight several important challenges. First, they reveal a fundamental disagreement between patients and surrogates. Respondents pointed out that surrogates have the responsibility of making treatment decisions for decisionally incapacitated patients. As a result, they overwhelmingly felt that surrogates should have the authority to decide how to make treatment decisions, including whether to use PPPs. Consistent with this view, several respondents indicated that they would not use a PPP, even if it increases predictive accuracy, because they made decisions based on what they thought was best for the patient, not based on what they thought the patient would choose themselves.

A majority of patients, in contrast, prioritize making treatment decisions during periods of decisional incapacity in ways that are most likely to result in their being treated consistent with their own preferences. In particular, most patients prefer decision-making procedures that more accurately predict their treatment preferences to methods that minimize the stress on their family [14]. These findings suggest that, if a PPP increases predictive accuracy, most patients would want it to be used, even when doing so conflicts with their surrogates’ preferences.

Taken together, these findings reveal a critical need for future research to determine whose preferences, the patient’s or the surrogate’s, should govern surrogate decision-making. If patient preferences should have authority, we might design advance directives to permit patients to indicate their preferences regarding the decision-making process, including use of PPPs. Conversely, if surrogates should have the
final say, procedures should allow them to make decisions that contradict the patient’s preferences, including the patient’s preference regarding use of PPPs.

In the meantime, clinicians should be aware of and take prospective steps to try to address this potential conflict. Specifically, clinicians should encourage surrogates and patients to discuss not only the patient’s treatment preferences, but also how treatment decisions will be made on their behalf [20]. Does the patient want the surrogate to decide based on substituted judgement or best interests or the preferences of the surrogate? Is the surrogate willing to use that approach? If a tool such as a PPP were to become available, clinicians should discuss with their patients, and encourage their patients to discuss with their surrogates, how they would want it implemented. If the patient and surrogate cannot agree, the patient should be encouraged to consider whether to assign a different surrogate.

Second, a number of respondents indicated that they would not use PPPs personally because they felt confident they knew which treatments the patient wanted. This confidence is likely protective: uncertainty regarding which treatments the patient would want is a significant source of stress for surrogates. At the same time, data suggests that even surrogates who have known the patient for decades often are mistaken about their charge’s treatment preferences [21, 22, 23]. Moreover, prior discussions between surrogates and patients do not seem to increase surrogates’ predictive accuracy [24].

This raises an ethical dilemma that should be addressed prior to implementing PPPs. In cases where surrogates are confident of the patients’ treatment preferences, use of a PPP has the potential to increase the chances that patients are treated consistent with their preferences. But, its use may also undermine surrogates’ confidence and thereby increase their decision-making burden. More work is needed to assess whether we can prime surrogates for the possibility that an accurate PPP may undermine their confidence they are making the right choice.

Third, a PPP should be developed and implemented to address the concern that it might be used to deny expensive care to patients who need it. In addition, while only one participant raised this concern, it will be important to address the potential for algorithmic bias, especially with respect to minority populations [25]. To this end, development of the PPP should include input from all groups to ensure it is not skewed in favor of majority populations. It will be critical for implementation purposes to secure the trust of all groups. One possibility in this regard would be to establish an independent board to oversee the development and implementation of a PPP.

Limitations

Our study has several important limitations that should be addressed by future research. First, we interviewed only English speaking surrogates. Second, our participants were all recruited from urban settings and may not reflect the views of others. Third, most of our respondents were female, although this may mirror the surrogate population at large given gendered differences in life expectancies, caretaking responsibilities, and state laws assigning spouses as the default surrogates when the patient did not designate a surrogate [26].
Conclusions

Current practice frequently fails to provide care consistent with the preferences of decisionally-incapacitated patients and imposes significant emotional burden on many surrogates. The present findings that experienced surrogates support the use of a PPP suggests that it might offer a means to address these challenges. This finding provides strong support for developing a comprehensive PPP and testing its predictive accuracy and impact in practice. In addition, we identified a fundamental disagreement between patients and surrogates regarding whose preferences should guide the decision-making process that must be addressed in order to improve decision-making for critically ill patients.

Declarations

Ethics Approval and Consent to Participate: The protocol, consents, surveys, and handouts were approved by the Special Studies IRB, the NIH IRB with the most experience reviewing survey research

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Consent for publication: All data has been de-identified and does not require further consent from participants.

Availability of Data and Material: The datasets during and/or analysed during the current study available from the corresponding author on reasonable request.

Competing interests: None of the authors have any competing interests to declare.

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## Tables

**Table 1:** Participant Demographics (N=26)

| Characteristic | N  |
|----------------|----|
| **Sex**        |    |
| Female         | 19 |
| Male           |  7 |
| **Age**        |    |
| 30-50          |  9 |
| 51-70          | 13 |
| 71-90          |  3 |
| Missing        |  1 |
| **Race**       |    |
| African-American | 14 |
| White          | 11 |
| Asian          |  1 |
| **Ethnicity**  |    |
| Hispanic       |  0 |
| non-Hispanic   | 26 |
| **Education level** |    |
| High school    |  6 |
| College        |  8 |
| Graduate School| 10 |
| Missing        |  2 |

**Table 2:** Surrogate Characteristics (N=26)
| Relationship to the patient |   |
|----------------------------|---|
| Spouse                     | 11|
| Parent                     |  5|
| Sibling                    |  4|
| Other                      |  6|

| Years knew patient         |   |
|----------------------------|---|
| 0-19                       |  6|
| 20+                        | 20|

| Treatment decisions made as surrogate |   |
|----------------------------------------|---|
| 1-3                                    |  4|
| 4-10                                   |  9|
| 11+                                    | 12|
| Missing                                |  1|

| Made decision(s) in past month?        |   |
|-----------------------------------------|---|
| Yes                                     | 18|
| No                                      |  7|
| Missing                                 |  1|

Table 3: Themes Expressed by Individual Participants (N=26)
| Level of Support | PPP should be offered | Surrogate should decide if use PPP | No need for PPP: I know what patient wants | No need for PPP: I use best interests | PPP might be biased | PPP might be used to deny care |
|------------------|-----------------------|-----------------------------------|---------------------------------------------|---------------------------------------|--------------------|--------------------------------|
| Strong (8-10)    |                       |                                   |                                             |                                       |                    |                                |
| PC               |                       |                                   |                                             |                                       |                    |                                |
| WS               |                       |                                   |                                             |                                       |                    |                                |
| RK               |                       |                                   |                                             |                                       |                    |                                |
| MS               |                       |                                   |                                             |                                       |                    |                                |
| MJB              |                       |                                   |                                             |                                       |                    |                                |
| DG               |                       |                                   |                                             |                                       |                    |                                |
| JL               |                       |                                   |                                             |                                       |                    |                                |
| JEJ              |                       |                                   |                                             |                                       |                    |                                |
| TH               |                       |                                   |                                             |                                       |                    |                                |
| IB               |                       |                                   |                                             |                                       |                    |                                |
| Moderate (5-7)   |                       |                                   |                                             |                                       |                    |                                |
| VD               |                       |                                   |                                             |                                       |                    |                                |
| QL               |                       |                                   |                                             |                                       |                    |                                |
| RM               |                       |                                   |                                             |                                       |                    |                                |
| JN               |                       |                                   |                                             |                                       |                    |                                |
| BD               |                       |                                   |                                             |                                       |                    |                                |
| RW               |                       |                                   |                                             |                                       |                    |                                |
| JD               |                       |                                   |                                             |                                       |                    |                                |
| JG               |                       |                                   |                                             |                                       |                    |                                |
| LN               |                       |                                   |                                             |                                       |                    |                                |
| MM               |                       |                                   |                                             |                                       |                    |                                |
| HB               |                       |                                   |                                             |                                       |                    |                                |
| Lack of Support (1-4) |               |                                   |                                             |                                       |                    |                                |
| WG               |                       |                                   |                                             |                                       |                    |                                |
| AH               |                       |                                   |                                             |                                       |                    |                                |
| MN               |                       |                                   |                                             |                                       |                    |                                |
| OW               |                       |                                   |                                             |                                       |                    |                                |
| OS               |                       |                                   |                                             |                                       |                    |                                |
Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

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