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# A qualitative investigation of selecting surrogate decision-makers

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## ABSTRACT

**Background** Empirical studies of surrogate decision-making tend to assume that surrogates should make only a 'substituted judgement'—that is, judge what the patient would want if they were mentally competent.

**Objectives** To explore what people want in a surrogate decision-maker whom they themselves select and to test the assumption that people want their chosen surrogate to make only a substituted judgement.

**Methods** 30 undergraduate students were recruited. They were presented with a hypothetical scenario about their expected loss of mental capacity in the future and asked to answer some questions about their choice of surrogate. These data were analysed qualitatively using thematic content analysis.

**Results** Most respondents talked about choosing someone who was caring and competent in certain ways, giving interesting evidence for their judgements. Surprisingly few highlighted how well they thought their chosen surrogate knew their preferences and would be able to make a substituted judgement. Moreover, few specified that their chosen surrogate had similar attitudes and values to their own and so would make a similar decision to theirs in the circumstances presented. Some respondents also referred to the social role of their chosen surrogate or the social dynamics of their situation which influenced their choices, as well as to ideas of reciprocity and characteristics of honesty and loyalty.

**Conclusion** In the event that they lose mental capacity, many people will not select a surrogate to decide about medical treatments on their behalf solely on the basis that they expect their surrogate to make a substituted judgement.

## INTRODUCTION

The concept of substituted judgement is a difficult one to think about as it is based on a hypothetical possible world—namely, what the person who now lacks sufficient mental capacity to make decisions entirely for himself would want if he were still competent.<sup>1</sup> Its rationale, however, is to construct—albeit somewhat artificially—a person's autonomous wish. There are other ways in which a person's autonomy may be more or less hypothetically constructed. For example, some argue that advanced decision-making is better able to reflect genuine autonomy.<sup>2,3</sup> Others feel that, despite being strictly non-competent, a person's wishes are still relevant to any decision which would affect him or her and may even be decisive, perhaps in the absence of a nominated surrogate or advance decisions, and especially when it chimes with the values of professionals in charge of his care.<sup>4</sup>

Recent legislation in the UK—namely the Mental Capacity Act 2005 and Adults with Incapacity (Scotland) 2000—has increased interest in surrogate decision-making for those who lack sufficient mental capacity to make their own decisions.<sup>5,6</sup> Surrogates or, more formally, attorneys (those with 'lasting powers') now have the legal authority to make decisions about their charge's financial affairs and health matters and people can now nominate another named person or people (attorneys) to make such decisions in the event that they lose capacity. If more than one attorney is nominated, they would make decisions either jointly or separately. For clinical research involving drugs, the Clinical Trials Regulations 2004 also give a surrogate (or 'legal representative') the legal authority to make decisions on behalf of a mentally non-competent adult.<sup>7</sup>

There has been considerable research on surrogate decision-making across numerous psychology studies—mostly from the USA where non-competent adults have had legal representation for some time. Yet it is tricky to translate these results directly to the UK context as there are some differences in emphasis. In the USA surrogates are charged with making a wholly 'substituted judgement' on the basis of any advance instructions which the person may have written and, in the absence of knowing the person's wishes, the surrogate may seek to determine what is in the person's best interests. In the UK any advance decisions must be respected and, in the absence of evidence of these, a surrogate—who must be nominated by the person in advance—should determine what is in the person's 'best interests'. In the absence of a nominated surrogate, the professional with a duty of care determines what is in the person's best interests. However, the criterion for best interests includes an element of substituted judgement but, crucially, includes other factors such as the patient's actual wishes—such as they are—when not sufficiently non-competent to entirely decide for himself.<sup>8</sup> In short, substituted judgement may be sufficient in the USA but not in the UK. In determining best interests, the Mental Capacity Act says that the decision maker should:

- ▶ Protect the person's position in the event he is likely to regain capacity.
- ▶ Consider the person's past and present wishes and feelings (particularly any advance statements).
- ▶ Consider the beliefs and values that would be likely to influence his decision if he had capacity.
- ▶ Consider the other factors that he would be likely to consider if he were able to do so.

Notice the appeal to what the person would want if he had capacity—the element of substituted judgement.

Psychological experiments on the reliability of surrogate decision-making typically present a healthy and mentally competent ‘patient’ and surrogate independently with a hypothetical scenario, often asking the pair to imagine that the patient is now non-competent and is at the end of his life. The researchers then ask the ‘patient’ what he would want in these circumstances and the ‘surrogate’ what he thinks the patient would want. The overwhelming result from a meta-analysis of such studies is that surrogates typically do not make similar decisions to their patient charges at all, even when they have been selected by the patient or are known to them very well personally and are in close and loving relationships with them.<sup>9</sup>

There have been various attempts to explain why surrogates find it so difficult to judge what their patient would decide even after discussion with or advance written instruction from the patient.<sup>10</sup> First, it could be that people change their minds over time making it more difficult to predict their wishes, although those who had made explicit advance instructions are typically less likely to change their minds.<sup>11</sup>

Second, surrogates could be unsure and, as a result, they might want to err on the side of caution when opting for treatment. However, Moorman and Carr found that, when surrogates made ‘errors’, overtreatment and undertreatment were equally prevalent in scenarios of terminal illness with severe physical pain and terminal illness with severe cognitive impairment.<sup>11</sup> Uhlmann *et al* meanwhile found that spouses significantly overestimated the patient’s preferences for cardiopulmonary resuscitation and ventilation after stroke and chronic lung disease.<sup>12</sup> Another US study sought to interview surrogates about their experiences of both substituted judgement and determining best interests.<sup>13</sup> They found that determining best interests was regarded as more onerous by surrogates, but they thought that this was required only when they were not confident about reporting a substituted judgement.

Third, surrogates may be subject to personal biases.<sup>14</sup> For example, Marks *et al* sought to measure how often personal values interfered with the surrogate’s ability to predict what patients would decide and showed that surrogates often—perhaps unwittingly—project their own values onto patients.<sup>15</sup> This attribution bias can be considered to be an example of what social psychologists term the ‘false consensus effect’—overestimating the probability that others hold the same views or would act in the same way as oneself—which has been demonstrated in many contexts. Lemay *et al* show that these data correlate with marital adjustment and so projection of values may not be as problematic as it seems at first sight.<sup>16</sup> In any case, there is some, albeit weak, research data which suggests that neither patients nor surrogates view deviation from the patient’s prior instructions as a violation of the patient’s autonomy.<sup>17 18</sup> Another study showed that most inpatients who are older or have serious illnesses would not want their prior stated resuscitation preferences automatically followed if they were to lose decision-making capacity. Most patients in both groups would prefer their family and physician to make resuscitation decisions for them.<sup>19 20</sup> The responsibility for making these decisions can be hard on the surrogate, although there are no data on what patients think of this pressure.<sup>21</sup>

Whatever the explanation for the failure of substituted judgements, if indeed these data suggest a ‘failure’, the studies have methodological limitations—for example, many use hypothetical scenarios with healthy adults. They also ask the wrong question for the UK context which has a unique legal

framework. Under the Mental Capacity Act 2005, all decisions must be made in the patient’s best interests in line with the preceding common law.<sup>22</sup> However, the criterion for determining best interests now explicitly includes—though is not confined to—what the person would want if they were mentally competent (ie, substituted judgement), and presents an amalgam of criteria including what the patient actually wants in his or her current non-competent state.<sup>4</sup>

There are currently no studies (or available datasets) that seek to examine the following questions: (1) When or why patients choose particular people to act as their surrogates (or attorneys). (2) Whether people would prefer to make legally enforceable advance decisions if they thought their surrogate would not make a substituted judgement or if the role were to become too burdensome. (3) How these surrogates, once nominated, go about determining the new criteria for best interests as defined uniquely by the Mental Capacity Act 2005. In particular, it is unclear how surrogates, once nominated, weigh up the different patient preferences, both actual and hypothetical, in order to inform their judgement of best interests.

## METHOD

### Recruitment

Thirty undergraduates were recruited from University College London (UCL) through a general advertisement as part of their participation in another study of decision-making. Participation was entirely voluntary and the project as a whole was carried out according to the UCL’s research governance framework concerning surveys with healthy volunteers.

### Data collection

Once recruited, one of the authors (MT) presented the participants with a scenario and open-ended questionnaire and recorded their responses anonymously. They were asked to imagine the following scenario: ‘In the next few weeks a relatively routine set of blood tests taken by your GP bring to light a hereditary condition which means that—similar to dementia—the functioning of your critical faculties will steadily diminish over the next few years. This will mean that your memory and your ability to find the right words, think clearly and make judgements will suffer gradual increasing impairment. You are advised that eventually this would result in a level of “confusion” where you would no longer be deemed capable of making decisions on your own behalf’.

They were told that in such circumstances it would be usual to appoint a person to have Power of Attorney to take decisions on their behalf in terms of healthcare and welfare, finances and possessions. They were asked ‘to consider to which person you would want to grant your Power of Attorney, to identify this person (eg, by their initials, so that this person can be kept specifically in mind), to give reasons for this decision being clear about which qualities and/or characteristics you associate with your chosen person are important in making your decision, and to show how you know that (s)he has these qualities/characteristics’.

### Data analysis

Two of the authors (SE and PB) independently carried out a thematic analysis of the data, drawing out themes from the content of the responses. The data were first broken down and comparisons were made between responses and conceptualisations made on the basis of these comparisons. Initial themes were then discussed among the other authors to enhance the validity of this coding process. Following this ‘open’ coding,

these themes were grouped together under overarching categories.<sup>23</sup> It became apparent within the analysis (post hoc) that many of the themes which arose relate to components of trust, although the literature on trust was not initially applied. Some—but by no means all—responses spanned several themes and are reported as such only where we thought it was particularly interesting. For example, one respondent said, “My family would mean well but is not as good with practical decisions,” and so she compares the relevance of caring and competence, two of the themes we drew out.

## RESULTS

One participant had already nominated his spouse under the Mental Capacity Act 2005 and registered her with the Office of the Public Guardian, while the rest were thinking about this possibility hypothetically and for the first time.

Of the 30 participants, 12 chose a blood relation, nine chose their spouse or partner, six chose a friend, two chose a family member in-law, and one chose their son *and* sister-in-law as surrogates saying, “I like the idea of more than one person making decisions for me if I can’t do it anymore.”

Six of the 30 could not think of an alternative to the person chosen as their surrogate. The following themes concern the characteristics sought in a surrogate, alongside explanations as to how respondents knew their chosen surrogate possessed these characteristics in contrast to alternatives.

### Esteem of general qualities

#### General competence (15/30)

Half of the respondents referred to the competency of their surrogate while emphasising different forms of competency. Some focused on particular features of mental competence such as intelligence:

“Karen is clever and well organised.”

Or a meticulous nature:

“He’s good with details and complicated projects.”

One even emphasised that his chosen surrogate was more logical than he was:

“Very logical (I’m not!).”

One thought that competence at decision-making specifically was worth pointing out initially, while a further eight rejected alternative candidates because they were perceived as poor at decision-making. One respondent thought one friend was not decisive enough, another thought that one friend tended to walk away from problems rather than solve them, while another respondent thought that a relative found it difficult to listen to others and so would be a poor decision maker.

“I think he [my father] would do the best for me too, but sometimes he might get distracted by his own opinions and not really listen to experts. I think that listening to experts would be a big part of this.”

Two respondents said they would pick a professional person they knew as their surrogate, although it was not clear whether they thought that professionalism itself was important for the task or whether it served only as evidence that their chosen surrogate was generally competent at dealing with difficult jobs:

“I would ask my friend J. He is a professor at university and I trust his opinions. He’d be good at it.”

Legal expertise was sought by one respondent:

“An old school friend who is a lawyer. Not my lawyer ... I.S. knows my attitudes and preferences regarding various matters, but more importantly he is professional and would make necessary decisions carefully with my best interests in mind.”

A further six of the 30 cited evidence of their surrogate’s competence in their own lives to support their judgement, particularly at their jobs:

“He ... has done well in his career.”

Or in their home life, however distant these inferences about surrogate decision-making seemed to be:

“She is also very organised at home with children and with her five dogs.”

One respondent seemed to indicate that a person’s stability was important although did not elucidate further, simply saying:

“He doesn’t change much.”

#### Caring (5/30)

The idea that a surrogate should be caring was a strong feature in five of the responses. For example, one respondent said:

“She ... thinks of others first and goes out of her way to help.”

One of the five respondents thought that only family could be trusted to care about his interests saying:

“I wouldn’t trust someone who wasn’t family to always put my interests first.”

In citing evidence of kindness to back up these judgements, one respondent referred to his surrogate’s kindness to others while five gave evidence of helping the respondent himself make decisions in the past:

“... [the chosen surrogate] has helped me make a lot of decisions (not just the car and university).”

Another claimed that her chosen surrogate already makes many of the decisions either on his own or together with the respondent so there would not be much difference:

“He loves me and helps me already. I’m not ill but my husband takes care of most bills already. We talk about our decisions together. So I think he would make decisions for me the same way we make them now.”

One respondent pointed out that caring alone was not enough to be an effective surrogate,

“My family would mean well, but not as good with practical decisions.”

Another respondent said that caring would distinguish his choice as the most appropriate surrogate for him out of various competent people he might have chosen.

#### Veracity (3/30)

Three respondents appealed to notions of honesty or good character when explaining their choice:

“Susan is a good person, honest and hard-working.”

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One provided evidence of good character from past experience:

"There have been times when Andrew could have got things wrong or taken advantage but he didn't."

### The 'right' choice (4/30)

Four respondents simply referred to the 'right' decision without explaining what they meant by this:

"I'd trust him to do the right thing more than family or any other friends ..."

One of the four referred to her chosen surrogate having the 'right' values to inform a decision:

"She raised me well, with good values."

### Perception of specific attributes in relation to self

#### Knowledge of person (8/30)

Eight respondents alluded to how well their surrogate knew their preferences and it is therefore the first theme which comes close to the idea of a substituted judgement:

"He knows me and the things like my attitudes and plans."

Five said that they thought they were close to their surrogate, which we took to mean that they knew each other's preferences:

"We are very close and speak often. We got to know each other particularly well while my father was undergoing a long illness."

Seven indicated how long they had known their surrogate as a proxy measure for how close they are or how well they knew each other:

"We have been friends since we were 7 years old."

Three respondents referred to explicit conversations they had had with their chosen surrogate about their preferences and about the future:

"We used to talk a lot about what we wanted and things that might happen in the future."

#### Similarity in outlook (7/30)

A perception of closeness (and substituted judgement) could also rest on the person and chosen surrogate having similar attitudes and values as well as knowledge of each other's preferences. Five respondents made this explicit:

"She would make decisions very similar to those I would make."

A further two respondents had discounted a possible surrogate on the basis that they had different values:

"I wouldn't ask any family members unless I had to. They have very different values to me and probably wouldn't let Andrew [chosen surrogate and partner] be involved."

#### Reciprocity (2/30)

One respondent referred to a reciprocal understanding between the respondent and chosen surrogate:

"I trust him and would do the same for him."

Another was unsure whether the chosen surrogate would want to reciprocate despite seeing it is a relevant consideration for her:

"I don't know if she'd want me to do the same thing."

### Concern for others and social norms

#### Concern for surrogate (10/30)

One respondent thought that her chosen surrogate would not be very inconvenienced by the task:

"She ... would be able to make decisions for myself and my family without it being too much trouble."

Some discounted a possible surrogate on the grounds that they would not cope with the responsibility of it either because they are susceptible to stress:

"My son is much more even-tempered than his mother (my wife Dorothy) ... decision-making wouldn't stress him in the same way."

or because they already had a lot of responsibilities to cope with:

"R already looks out for mum a little so she might have trouble helping out with me too. If mum made decisions for me I think she would ask R what to do anyway. Friends have their own lives ..."

Another was concerned that his father was getting older and the task may be too much of a strain for him:

"His kindness would make him better to help than others, but he is already in his early 70's. If he couldn't help, my oldest brother would probably want to help and he's a lot like dad."

One respondent thought her father would not want to take the role of surrogate and so rejected him as a candidate:

"My dad is also intelligent ... He loves me but wouldn't want to take the lead if my parents had to make medical decisions for me."

Another did not think his chosen surrogate would be prepared to fulfil this role in real life without explaining why:

"He's good with details and complicated projects. He knows me and the things like my attitudes and plans. I'd trust him to do the right thing more than family or any other friends. I don't think he'd say yes in real life though."

#### Fear of offending someone or expected social role (6/30)

One respondent thought that one family member would be upset if they were not chosen as a surrogate:

"... it would be strange for Jen to not have control over the family situation. She wouldn't like that – it would cause trouble ..."

Three respondents thought that those they had rejected as a surrogate would not be upset by this. One referred to the social role their surrogate would expect to fulfil stating:

"It would be natural for her as part of looking after the family."

Two simply stated their relationship with that person, which carried implicit expectation or authority to be surrogate. One respondent rejected a possible surrogate whom they considered to be competent on the basis that she did not have sufficient social authority within the family to act on her behalf:

"My younger sister would be well equipped to act on my behalf but it wouldn't be fair to ask her before my dad and brother."

## CONCLUSION

This study presents new data on how people select a surrogate in the event that they would lose mental capacity. However, there are limitations to the methods we used which will need to be addressed in future work. The project is a small qualitative analysis of responses to a hypothetical loss of mental capacity in only one medical situation and, while one respondent had actually registered an attorney with the Office of the Public Guardian, the rest were considering the situation maybe for the very first time. The subjects were mostly undergraduates and so may find the scenario rather distant from their day-to-day concerns. The respondents also gave rather brief responses and were not prompted for more detail for fear of influencing the direction of their explanations. The data were thus spontaneous and immediate responses and were not necessarily sensitive to detailed reasoning and to logical challenge from the researcher.

Nevertheless, these data are important in showing that, unlike in most of the empirical research on the topic, we cannot simply assume that people select a surrogate on the basis that they think he or she would judge what they would want if they were still mentally competent to decide for themselves. The themes described above reflect the conceptual ideas involved in trust—namely, caring, competence, veracity, authority and reciprocity as well as altruistic concern for the well-being of their chosen surrogate. Trust involves the construction of positive expectations through inferred knowledge about the trustee's competence and motivations.<sup>24 25</sup> This enables a belief that the trustee will place the interests of the truster first, with no alternative agenda.<sup>26</sup> These criteria are accordingly much broader than mere similarity of decisions, with trust arguably a more useful concept for understanding the selection of a surrogate than parallel decision outcomes. Our data support this idea with a relatively high frequency of responses that were indicative of trust in competence or trust in motive, but with a relatively low frequency of responses indicative of substitutive judgement, only knowledge of preferences and similarity in outlook, which may also reveal aspects of trust.

However, it is not clear which characteristics the respondents felt were both necessary and sufficient, although some testimonials demonstrated that caring alone was not enough and that the surrogate must be competent with it. Furthermore, it was not clear how the respondents would weigh up different characteristics if forced to make a trade-off. For example, participants might explain that they would reject certain individuals on the grounds that they were not competent without saying what was distinguishing about their choice of surrogate among those who were competent except in one case where the chosen surrogate was also seen to be most caring of the person's interests.

Our results may spark a new programme of research into surrogate decision-making and we suggest that further research in this area is urgently needed, especially in the context of the Mental Capacity Act 2005. It is important for people to know how they can expect their nominated surrogates to determine their best interests and what role, if any, there is for substituted judgement in so doing. These data may well affect the choices people make about their surrogate and under what circumstances they might prefer to make a legally enforceable advance decision.

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