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## “Thinking about it for somebody else”: Alzheimer’s disease research and proxy decisionmakers’ translation of ethical principles into practice

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### Abstract

**Objectives**—Ethical guidelines suggest that, when enrolling dementia patients in research, alternative decisionmakers (proxies) should base their decision on a “substituted judgment” of how the patient would have decided. If unable to make a substituted judgment, proxies are asked to decide based on the patient’s best interests. This mixed-methods study is the first to examine explicitly whether and to what degree proxies differentiate between these two approaches, and what considerations influence their mode of decisionmaking.

**Design**—Interview study regarding enrollment of relative in hypothetical clinical trial of an investigational drug for Alzheimer’s disease (AD). Participants were randomized to respond to questions about one of four hypothetical clinical trials that differed by levels of described risk and potential benefit.

**Participants**—Proxy decisionmakers (n=40).

**Measurements**—Open-ended and rating-scaled items.

**Results**—Half of the proxies agreed with both of two rating-scaled items asking about different approaches to decisionmaking—i.e., agreeing that they would decide based on how their relative would have decided, *and* agreeing that they would decide based on what they believed was in their relative’s best interests. Narrative responses elaborated on themes within the following three major domains: *Substituted Judgment*, *Best Interests*, and *Weighing Substituted Judgment and Best Interests*. *Substituted Judgment* was framed as honoring the patient’s wishes and values. *Best Interests* was described as a perceived duty to maintain quality of life and avoid burdens or risks. Weighing the two standards emerged as a challenging, yet important, way of honoring wishes while maintaining quality of life. An unexpected theme was the attempt by alternative decisionmakers to discern their loved one’s current, vs. premorbid, research preferences.

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**Conclusions**—Tensions exist between abstract ethical principles regarding decisionmaking “standards” and their translation into research decisions.

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## INTRODUCTION

Without advances in therapies to prevent or delay Alzheimer’s disease (AD), the number of people with AD in the United States is expected to rise to 13.2 million by the year 2050.<sup>1</sup> Addressing this growing population of patients demands major investments in clinical research,<sup>2–5</sup> in turn requiring recruitment of adequate numbers of participants at various stages of disease. Recruitment, however, remains a major challenge. Moreover, informed consent for AD research raises special concerns, as patients inevitably lose the decisional capacity necessary to make research consent decisions.<sup>6–8</sup>

To meet the ethical obligation of informed consent, investigators most frequently rely on surrogate consent, alongside assent from the subject,<sup>9</sup> although in many states the legal status of this approach is unclear.<sup>10, 11</sup> Ethics guidelines and existing laws<sup>11, 12</sup> generally call on surrogates to use substituted judgment (i.e., to decide as the patient would, had he or she been competent), or, if the patient’s wishes are unknown, to decide based on the patient’s best interests.<sup>13, 14</sup> However, few studies address how proxies translate these ethical principles into practice when making research participation decisions.<sup>15, 16</sup>

Clarifying this question is important for several reasons. First, laws, policies, and institutional practices (e.g., institutional review boards’ approaches to reviewing research protocols) related to proxy consent for research in vulnerable populations may rest on assumptions about proxy decisionmaking, such as the notion that proxies are able to decide based on substituted judgment. Empirical inquiry can therefore help policymakers and other stakeholders appreciate the decision-making concerns and processes of alternative decisionmakers for vulnerable patients such as those with dementia.

Second, research aims to develop new knowledge and, while oriented toward providing societal value, research, by definition, does not guarantee benefit to individual participants. In the context of AD, ill elders are being asked to become involved in research, and alternative decisionmakers are asked to decide for another person whose research preferences are often unknown. Enrolling one’s relative in research places the challenge of balancing respect for persons and beneficence on the shoulders of the proxy decisionmaker.

Third, research participation by the patient may add to or diminish logistic and other burdens for caregivers. In addition, the views of other family members regarding the patient’s wishes or best interests may influence the primary decisionmaker. Factors beyond substituted judgment may therefore affect such decisions, yet these factors have been minimally studied.

Given the relative lack of research on how proxies for AD research operationalize and balance substituted judgment and best interests approaches, we used structured interviews to examine these issues. Based on prior literature,<sup>15–17</sup> we hypothesized that proxies would more strongly endorse the use of a best interests standard, that proxies would describe a desire to protect the patient’s quality of life, and that “best interests” would trump “substituted judgment” when research was viewed as potentially risky.

## METHODS

### Participants

Proxy decisionmakers (adult children/step-children/grandchildren, spouses, siblings) for AD patients were eligible to participate in the larger study of proxy consent, whose goal is to

examine the influences on proxy decisionmaking for AD research and the perspectives of proxies on AD research risks and benefits. Participants were recruited through community programs and events for dementia caregivers and families, as well as through online postings. Under California law,<sup>12</sup> participants were all primary decisionmakers, eligible to make research decisions for the patient. Information regarding the AD patient (age, living situation, illness severity as assessed by the Global Deterioration Scale<sup>18</sup>) was obtained from proxies. Proxies consented to participate in this study, which was approved by the UCSF Committee on Human Research.

## Procedures

Proxies were randomly assigned to a mock informed consent process for one of four hypothetical protocols, which varied in levels of described risk and potential benefit. All protocols described a randomized clinical trial of a novel pharmacologic agent designed to slow the progression of AD. Protocols were written to resemble actual AD protocols. The higher risk protocol versions included more serious, though unlikely, risks (e.g., stroke, seizures, meningoencephalitis); the lower risk versions included the risks of side effects from the study drug (e.g., insomnia, diarrhea, and more rarely, bradycardia or peptic ulcers). The proxy's understanding of the protocol was assessed with the MacArthur Competence Assessment Tool – Clinical Research,<sup>19</sup> a structured capacity interview (data to be reported separately; no cutpoint was set for adequate performance on the MacCAT-CR in order to enter the present study, as one of the aims of the larger study was to examine the performance of the decisionmakers). At the end of the MacCAT-CR interview, proxies were asked whether they would be willing to enroll their relative in the study that was described. Proxies were then interviewed in depth about their attitudes toward a variety of ethically salient aspects of consent for AD research. This structured interview consisted of scaled (quantitative) items, followed by open-ended prompts encouraging elaboration on the basis for the ratings. Ratings of study risk were obtained by asking for agreement (from 1=Strongly disagree to 5=Strongly agree) with the statement, “This study would be very risky to my relative.”

Numerous open-ended questions were also incorporated throughout the interview. Examples include “What was the risk (or risks) that most concerned you?”; “Besides risks, are there other disadvantages or worries you might have about your relative being in the study versus not being in the study?”; and “In what ways is thinking about enrolling yourself in a research study different from thinking about enrolling your relative?” (Full interview available upon request). The goal was to develop a rich, contextual understanding of proxies' decisionmaking regarding AD research. The entire interview was pre-piloted with 6 subjects, then piloted with an additional 12 subjects. Revisions were made to items and administration procedures at both stages to ensure that questions were clear, non-leading, and provided useful information. Interviews were audiorecorded and transcribed verbatim.

## Domains for analysis

Two quantitative items, presented non-consecutively during the interview, asked for level of agreement on a 5-point Likert scale with statements about the use of each of the two decisionmaking approaches, “substituted judgment” and “best interests” (Figure 1). A third, forced-choice item asked proxies to choose between the two approaches. Following each rating, open-ended probes asked participants to explain the basis for the rating, with additional probes as needed. Responses to these open-ended queries served as the primary material for the qualitative thematic analysis. Responses to other items that elicited discussion about decisionmaking approaches were also coded when appropriate (i.e., the entire interview was searched for references to these approaches).

## Data analysis

Descriptive statistics were used to characterize responses to the structured items. A paired t-test was used to evaluate for differences in endorsement of each standard. Pearson's correlations were used to examine correlations between perceived risk ratings and endorsement of each decisionmaking standard. Analysis of variance was used to examine whether there were differences across the four protocols in degree of endorsement of the two standards.

Nvivo software (Version 8.0) was used to facilitate coding and analysis of the in-depth responses using a modified grounded theory approach.<sup>20</sup> One member of the team (SRF) identified emergent themes in 15 interviews related to substituted judgment or best interests, and developed a preliminary coding scheme. Two team members (LBD and JPY) then reviewed these 15 interviews and the team revised the coding scheme. Subsequent interviews were coded using the revised coding scheme as they were transcribed. The team continually assessed whether new interviews were providing additional insights and which themes were turning up repeatedly in the data. Memos were used to document the team's procedures and decisions (process memos) and preliminary results (analytical memos).<sup>21–23</sup> Emergent codes were reviewed and revised in several consensus meetings of four team members (SRF, LBD, MH, and LR) in an iterative process to develop the final coding scheme, with several codes revised or collapsed into others. Finally, the team reviewed all coded segments, identified discrepancies in coding interpretation, and resolved disagreements by consensus. After 40 interviews, the team recognized that theoretical saturation had been achieved and developed the results presented here based on analytical memos.<sup>24</sup>

## RESULTS

### Participant characteristics

Table 1 provides demographic characteristics of the 40 participating proxies. AD patients' characteristics are shown in Table 2. Most of the AD patients (n=37; 97.5%) had not previously participated in AD-related research.

### Endorsement of decisionmaking standards

A majority of proxies (n=27, 67.5%; Figure 1) agreed or strongly agreed that they would base their decision on what their loved one would choose, were he or she able to make the decision—i.e., “substituted judgment.” But a majority (n=31, 77.5%) *also* agreed or strongly agreed that they would decide based on what would be in the best interests of their loved one—i.e., in accordance with a “best interests” standard. Nearly half of the participants (n=19, 49%) agreed or strongly agreed with *both* of these statements. There was no significant difference in the distribution of responses for these two statements ( $t=-1.53$ ,  $df=38$ ,  $p=.133$ ). In response to the forced-choice item, “Would you say you are making the decision about whether to enroll your relative in the protocol that was described based *mainly* on...,” approximately half (n=23, 57.5%) endorsed using primarily *best interests*, whereas 17 (42.5%) stated they would decide primarily based on *substituted judgment*.

### Perceptions of risk and endorsement of decisionmaking standards

There were no significant correlations between perceived risk of the research protocols and endorsement of using substituted judgment ( $r=.041$ ,  $p=.802$ ) or best interests ( $r=.034$ ,  $p=0.837$ ) standards. There were also no significant differences across the four hypothetical protocols in the degree to which either standard was endorsed, nor was the patient's stage of illness associated with the degree of endorsement of either standard.

## Narrative responses: themes related to decisionmaking standards

Examination of narrative responses to the open-ended items revealed three broad, overlapping themes regarding these decision-making approaches, with several factors framing each theme.

### Substituted judgment

**Knowing the loved one's values**—Proxies described their decisionmaking as representing their belief in what the AD patient would decide—based primarily on their overall “knowledge” of their loved one's values, wishes, past behaviors and decisions, or some combination of these:

*“I know how she was, I know how her mind worked, and she would love to make a contribution to help other people.”*

–Daughter, age 66

*“Because I know my father... We might have had a conversation before, maybe sometime when I was young... I know him, as my father, so I know his wish. I might not do it exactly the way he wanted but I will do the best I think [how] he would want it.”*

–Daughter, age 56

Proxy decisionmakers also described using “substituted judgment” more generally in decisions related to their loved one:

*“Because I always try to think of... what would she do if she was right here, and she would make the decision herself. For anything, including this. So yeah, I would put it thinking, ‘What would she do?’ Based on how long I've known her and what I think that she would say.”*

–Daughter, age 45

**Honoring their wishes**—The need to honor their loved one's life, values, and wishes—even if they personally disagreed with the decision—was mentioned by some decisionmakers:

*“Well I'd want to do what he would have want(ed). Whether I agree with it and he wouldn't agree with it is not an issue. He's the one that would be going through the study, so it has to be based on his feelings... I would want to do what he wanted, more than if it was something I thought I wanted and he didn't. You have to honor his wishes and... it's his life.”*

–Daughter, age 51

*“If she didn't have Alzheimer's I would want her to agree with what I was doing... I would want to support her belief system and her decisions.”*

–Daughter, age 64

**Prioritizing current preferences**—Some proxies contrasted the personality and decisionmaking preferences of their loved one *prior* to developing AD vs. their view of that individual's *current* preferences. Current preferences were frequently described as taking precedence—a theme that related to proxies' desire to promote their loved one's best interests (described further in the next section):

*“The situation is that there was a person there that kind of went away and can't judge for themselves anymore, so you could either judge from their past self, before*

they had Alzheimer's, or you could judge from their present selves, or you could judge from their future selves. And, mostly I kind of center around their present self. And so I think that whatever is making that person happy right now is what I should be centering my decisions on..."

-Grandson, age 46

Some proxies stated that the current preferences of the patient would be to decline participation, whereas the patient might have agreed to participate earlier, when he or she had full capacity.

*"But thinking about it in terms of how my mom would think about it, I know that she would be like, 'Yeah, no way.' Again, that's my mother with the mild dementia, not the mother that didn't have dementia. If she wasn't already compromised she might think like, 'Oh, this is, you know, I would like to help.' But she just doesn't have that tolerance anymore."*

-Daughter, age 41

The patient's current preferences and tolerance also influenced proxies' willingness to enroll their relative in another way. Regardless of premorbid preferences, if the proxy believed that the patient currently would prefer not to participate, they acknowledged a certain point beyond which they would not be willing to force the patient to participate. One proxy, when asked about his willingness to override his mother's preferences about participating, stated:

"Trying to coax her, yes. I would make the best pitch. I would do everything that I could. But, if she's staunchly against it, there's no way to move her."

-Daughter, age 61

### Best interests

**Using a "best interests" standard in daily life**—Proxies, many of whom were (or had previously been) their loved one's caregiver, expressed being accustomed to making everyday decisions using a "best interests" approach. These experiences were used, often by means of analogy to daily activities or tasks, to illustrate the use of best interests in the research context:

"...I'm in a much better position to know what is best for her. I mean she doesn't want to put her clothes on in the morning because she just doesn't want to. So, just a small example of what she wants versus what she needs."

-Son, age 47

One decisionmaker pointed out that, as caregiver, she was:

"...basically in charge of making all the decisions of how to care and what to do with them, for them. Keep them comfortable, clothed, fed, healthy enough, whatever - whatever has to be done."

-Daughter, age 54

Other decisionmakers noted that their loved one had already ceded much decisionmaking to his/her caregivers, depending on them to decide based on the ill relative's best interests:

"Even though we try to let her decide things for herself, she relies actually on us to kind of think for her."

-Daughter, age 60



“It’s so automatic for me to just make the decisions. You know, I- it’s my life!...So I always think of myself in terms of doing what I feel is best for Mom. And trying to do the best I can to make her comfortable, to make sure she’s safe, and so...I would always make sure that if I felt she was going to be in a study that I would feel that if I’m comfortable with it, then she’ll be okay.”

-Daughter, age 68

**Maximizing quality of life**—Proxy decisionmakers expressed feeling obligated to maximize their loved one’s quality of life—e.g., one stated, “*my goal in life was... to try to make it as pleasant for him as possible.*” This goal facilitated the use of a “best interests” approach to research decisions—even, in some cases, where this standard might override what the relative’s own decision might have been:

*“I think that... she was the type of person who would, all her life, would put other peoples’ needs in front of hers ... So whereas if she had the cognizant ability to say yes, she would put herself through it. She wouldn’t even be really considering what was best for herself. I, on the other hand, am responsible for what’s best for her now, and I have a more well-rounded view of how things are affecting her and her quality of life.”*

-Daughter, age 48

### **Weighing “substituted judgment” and “best interests”**

**Honoring preferences, while weighing burdens and benefits**—Some proxies spoke explicitly about the desire to incorporate both standards in considering the enrollment decision.

*“My hope would be that it would be a combination of the two. I mean I certainly wouldn’t make the decision if I knew she would not.”*

-Daughter, age 52

Some proxies said they would be less willing to enroll their relative if the risks seemed too great to them, even if their loved one were in favor of enrolling:

*“Well, maybe she could be very much for it and maybe I would feel one of the risks might not be worth it. And conversely, she may think ‘oh, maybe I don’t need to do this.’ What she thinks now sometimes is not always in her best interest. She thinks she can walk... That’s not in her best interest, to get up and walk. She can’t walk. So we have to make decisions based on what’s best for her.”*

-Step-daughter, age 69

Others stated that their decision would depend on factors such as level of risk to the patient, or psychological or logistical burdens for the caregivers:

*“Part of that [decision] would be how she would feel about things...and also how she would react now to it. Also how much risks we would want her to take on, if she were to get the Minplax. We being the caregivers. And just...being able to do the logistics of getting her here. And the time frame, you know, it’s a long interview process too.”*

-Daughter, age 48

Others explicitly described the need to weigh numerous factors concurrently—including their relative’s preferences and personality before becoming ill, possible benefits to society,



possible discomfort to their loved one, and current quality of life, particularly given the patient's age or stage of illness:

“Now with her, you have to take into consideration what kind of person she is to begin with. Then you have to think about, at this age, do you subject somebody to any unnecessary risk? And you have to evaluate... well, the trade off. Is the likelihood of benefiting science large enough to offset the likelihood of her inconvenience and her discomfort? It's very different when you're thinking about it for somebody else than for yourself.”

-Daughter, age 70

“With my mother I would be thinking more about what I think she would've wanted...before she had dementia. I would think about how it might affect her in whatever risks there were and psychologically how it might affect her....And I would also...think about my responsibility towards her as far as making the best decision. No matter what I thought that she would have thought. I would have to assess her now and think what would be... in her current lifestyle...I would have to see how much she's enjoying her life right now. If she's miserable, I'm not going to add more discomfort, possible discomfort to her.”

-Daughter, age 53

## DISCUSSION

Using both scaled questionnaire items and open-ended items, this study examined how proxy decisionmakers for people with AD described and framed their use of best interests and substituted judgment in the research context. Contrary to our hypothesis that proxies would more strongly endorse the use of best interests compared to substituted judgment, this “either/or” hypothesis appeared too simplistic to capture the complex situation confronting alternative decisionmakers, as described below. We did, however, confirm our hypothesis that proxies would describe a desire to protect the patient's quality of life when considering research. Furthermore, the mixed methods approach used here led to somewhat conflicting findings regarding whether the “best interests” standard trumped “substituted judgment” when research was viewed as potentially risky—although qualitative data supported this notion, quantitative findings did not.

These findings suggest that decisionmakers are navigating the landscape of research enrollment using several important signposts. First, decisionmakers endorsed the logic underlying substituted judgment, framing this approach as honoring the wishes and respecting the values of their loved ones. They described trying to “walk in their relatives shoes” in envisioning what they would have wanted. Unexpectedly, we found that honoring their relatives' *current* wishes was explicitly emphasized by many of the proxies interviewed, who often distinguished these from premorbid preferences. This notion does not clearly map onto the substituted judgment standard, which presumes that premorbid preferences are the “gold standard.”<sup>25</sup> Making the process still more complex, proxies often described trying to honor *both* past and present preferences. It is possible that the considerable weight given to patients' current preferences may represent a type of best interests consideration—i.e., through their everyday experiences with patients, proxies learn how their tolerance for certain activities may have changed. Thus, it may be impractical to suggest that proxies attempt to make a decision based solely on either premorbid or current preferences, given that this may not accurately match how proxies view their role and obligation.

Second, these decisionmakers articulated a deep concern for their relative's best interests. In some cases, this concern might tip the balance for or against research participation, depending on the decisionmaker's weighing of risks, burdens, and benefits. These views, in turn, incorporated numerous considerations, such as the patient's stage of illness, tolerance for research procedures, and daily routine. The time, inconvenience, and potential positive or negative effects of even relatively benign research procedures were all mentioned as factors that decisionmakers would consider.

Third, the qualitative analyses of the open-ended items, in combination with the rating-scaled items, with half of the proxies endorsing the desire to use *both* substituted judgment and best interests approaches, underscore the ways in which proxy decisionmakers strive to combine honoring their relative's wishes with maintaining quality of life. These data illustrate the real-time complexity of the task facing decisionmakers in trying to arrive at an optimal decision. The interview responses suggest that at least in some instances, the proxy's desire to respect the patients' wishes could be "trumped" by the wish to promote the patient's best interests. This observation corroborates the work of Sugarman and colleagues, who reported that some proxies vetoed their relative's research decision when they believed the research was too risky.<sup>17</sup> It remains unclear how frequently this occurs, whether vetoes are more common when declining or agreeing to research participation,<sup>26</sup> and whether this affects other aspects of the overall research endeavor—e.g., ethnic composition of research samples, difficulty of recruitment for certain types of research, or study attrition. Our quantitative data did not support a clear differentiation in the use of best interests vs. substituted judgment depending on the perceived risk of the protocol, although the sample size may have reduced the likelihood of finding significant associations.

Fourth, taken together, the findings described above suggest that substituted judgment cannot be presumed to be the most common or dominant standard being used by proxies in the research context. The law seems to have arrived at an artificial separation between "substituted judgment" and "best interests." Although few states have specifically authorized alternative decisionmakers to provide consent for dementia research, several state laws have incorporated the principle of substituted judgment as the optimal standard for surrogate decisionmaking, with "best interests" as an alternative standard in some circumstances. Yet, assumptions by policymakers that alternative decisionmakers have a clear basis for substituted judgment appear to rest on thin evidence.

Our findings have implications for various stakeholders in Alzheimer's research. For investigators, these results highlight the importance of working closely with proxy decisionmakers as partners, as these individuals carry a great responsibility for both the initial decision, as well as for ongoing research engagement—particularly in studies where the patient's illness changes over time. For policymakers, the findings argue for humility when crafting laws or regulations. Research decisions are complex human tasks; they are not made in a strictly rational manner and are influenced by numerous valid psychological and logistical issues. As a society wishing to advance research, we should recognize the immense responsibility that proxy decisionmakers must shoulder—not only ethically, but also physically, emotionally, and logistically. Services to help make research participation more convenient and rewarding—e.g., respite care, transportation, education, and other services and activities valued by research participants and families—should be incorporated into research protocols.<sup>27</sup>

This study is limited by the use of hypothetical rather than actual decisions. Nevertheless, these proxies were experienced decisionmakers for their relatives. This sample included only proxies willing to participate in our study, perhaps introducing a positive bias toward research. However, most had not taken part in previous AD-related research. The sample

was composed almost entirely of women, limiting our ability to generalize about decisionmaking by male proxies. This sample represented diverse ethnic backgrounds and relationship roles, a relative strength. We also did not inquire whether surrogates were aware of California's law regarding surrogate consent—though no respondent mentioned it spontaneously. As in any interview study, social desirability may have biased some responses. However, in-depth interviewing facilitated rapport and allowed time to explore complicated perspectives.

Reducing the burden of Alzheimer's disease on individuals, families, and society depends greatly on research efforts involving individuals who may be vulnerable in the research context. Research is grounded in principles of beneficence, respect for persons, and justice.<sup>28</sup> The principles of "substituted judgment" and "best interests" have emerged as ways of trying to fulfill the imperative to conduct ethically sound research with vulnerable people by respecting their wishes when known, and protecting their best interests if those wishes are unknown or unclear. Our in-depth examination of the perspectives of AD proxy decisionmakers provides novel data regarding how these individuals—entrusted with making research decisions for their ill relatives—translate abstract principles within the context of research decisionmaking. The present analysis should be viewed as an invitation to revisit critical issues related to protecting those with diminished autonomy while promoting urgent research involving vulnerable patients.

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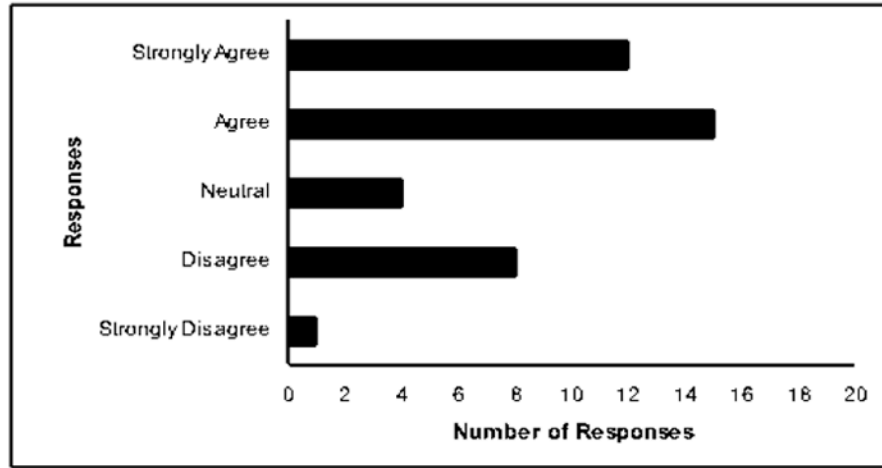
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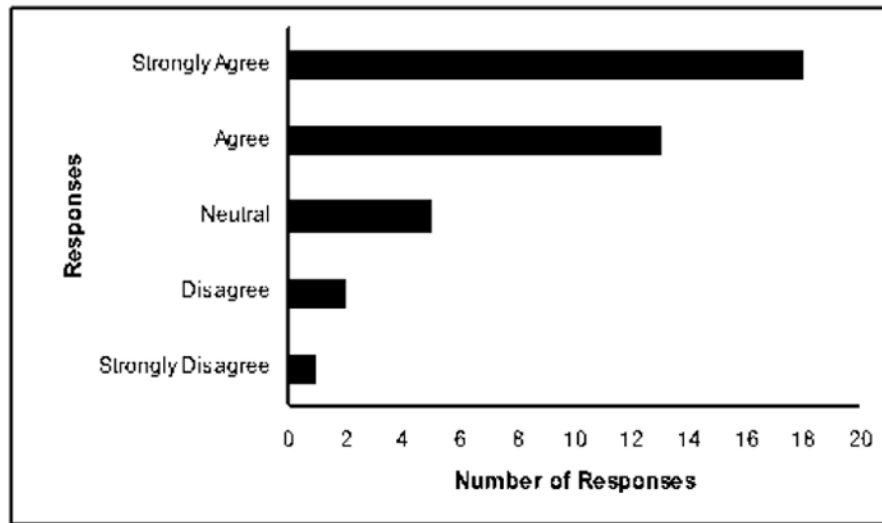
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1a.



1b.



**Figure 1. Responses to items regarding proxy decisionmaking standards (each item rated on a 5-point scale from 1 = “Strongly disagree” to 5 = “Strongly agree”)**

1a. Substituted judgment item: “I would make the decision about whether to enroll my (relative) in the study based on how I think my (relative) would decide for himself/herself”

1b. Best interests item: “I would make the decision about whether to enroll my relative in the study based on what I think would be in my relative’s best interests.”

**Table 1**

## Characteristics of proxies

| <u>Characteristic</u>              | <b>Proxies (n=40)</b> |            |
|------------------------------------|-----------------------|------------|
|                                    | <u>Mean</u>           | <u>SD</u>  |
| Age (years)                        | 56.02                 | 11.2       |
|                                    | (Range: 36 – 86)      |            |
|                                    | <u>n</u>              | <u>(%)</u> |
| Sex                                |                       |            |
| Female                             | 37                    | (92.5)     |
| Male                               | 3                     | (7.5)      |
| Relationship to AD patient         |                       |            |
| Spouse                             | 4                     | (10.0)     |
| Adult child                        | 30                    | (75.0)     |
| Other <sup>1</sup>                 | 6                     | (15.0)     |
| Race                               |                       |            |
| Caucasian                          | 22                    | (55.0)     |
| African American                   | 2                     | (5.0)      |
| Hispanic/Latino                    | 6                     | (15.0)     |
| Asian                              | 7                     | (17.5)     |
| American Indian/Native American    | 1                     | (2.5)      |
| More than one                      | 2                     | (5.0)      |
| Education (highest level attended) |                       |            |
| Elementary                         | 1                     | (2.5)      |
| High school                        | 7                     | (17.5)     |
| Undergraduate                      | 19                    | (47.5)     |
| Graduate                           | 13                    | (32.5)     |

<sup>1</sup>Other relationships: ex-spouse (n=1), daughter-in-law (n=3), adult grandchild (n=2)

**Table 2**

## Characteristics of AD patients

| <b>AD Patients (n=40)</b>  |                  |            |
|--|------------------|------------|
| <b>Characteristic</b>  | <b>Mean</b>      | <b>SD</b>  |
| Age (years)  | 82.9             | 6.5        |
|  | (Range: 65 – 97) |            |
|  | <b>n</b>         | <b>(%)</b> |
| Sex  |                  |            |
| Female   | 26               | (65.0)     |
| Male   | 14               | (35.0)     |
| Living situation   |                  |            |
| Alone in apartment/house   | 6                | (15.0)     |
| With others in apartment/house                                   | 18               | (45.0)     |
| Assisted living  | 7                | (17.5)     |
| Board and care   | 1                | (2.5)      |
| Nursing facility   | 7                | (17.5)     |
| Other <sup>1</sup>   | 1                | (2.5)      |
| Past research participation:                                     |                  |            |
| Yes  | 3                | (7.5)      |
| No   | 37               | (92.5)     |
| Global Deterioration Scale score (severity of cognitive decline) |                  |            |
| Very mild  | 1                | (2.5)      |
| Mild   | 12               | (30.0)     |
| Moderate   | 2                | (5.0)      |
| Moderately severe  | 19               | (47.5)     |
| Severe   | 4                | (10.0)     |
| Very severe  | 2                | (5.0)      |

<sup>1</sup>Other living situation: physical rehabilitation facility