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Decision Making for Participation in Dementia Research

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Abstract

Objectives—This study examined the decision-making process used by individuals asked to participate in dementia research and their opinions on how future proxy research decisions would or should be made, including participants' preferred ethical standards for decision-making.

Design—Cross-sectional qualitative methods.

Setting—University research institutions.

Participants—Informants were 39 of 46 cognitively impaired individuals (i.e., subjects) who were asked to join one of six dementia studies and 46 study partners or surrogate decision-makers.

Measurements—Semi-structured individual interviews were audio recorded and transcribed for content analysis.

Results—Within dyads, subjects and surrogates often differed in their perspectives on how decisions were made regarding whether to join a study, and no single method was identified as a predominant approach. While there was only fair agreement within dyads on who ultimately made the decision, subjects and surrogates most often said it was the subject. For future proxy research decisions, subjects and surrogates most often preferred the ethical standard of best interests and least often favored substituted judgment. However, many participants preferred a combination of best interests and substituted judgment or a more complex approach that also considers the interests of others.

Conclusions—Individuals with mild to moderate cognitive impairment can and do engage to some extent in the decision-making process for dementia research and can discuss their opinions on how they would want such decisions made for them in the future. These findings support the recommended approach for obtaining proxy consent and subject assent if the individual lacks consent capacity.

Keywords

Dementia; Clinical research; Decision making; Qualitative research

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Objectives

There is a clear and urgent need for research into the causes, treatments and prevention of Alzheimer disease (AD) and other types of dementia, which affect millions of Americans (1). While individuals in early stage dementia may have the capacity to give informed consent for research, as dementia progresses it leads to a loss of decisional capacity (2). If consent capacity is lacking, research participation is dependent upon a legally authorized representative (i.e., surrogate decision-maker) to provide proxy consent, with the assent (or lack of objection) of the person with dementia (PWD) (3). The ethically and legally endorsed hierarchy of standards for making proxy decisions is (a) known wishes, (b) substituted judgment (i.e., reflecting the person's values), and (c) best interests (i.e., what is perceived to be best for the person) (4,5). Most dementia studies also require the involvement of a capable person to serve as a study partner for the memory-impaired participant (6–8). Family caregivers usually serve as surrogates and/or study partners in dementia research.

We know little about how the decision to participate in dementia research is actually made. Most empirical examinations of decision-making for dementia research rely on hypothetical scenarios for individuals to consider and speculate on whether they would choose to participate in studies that vary by study characteristics (e.g., risks, benefits, burdens) (9–11) or would want a proxy to decide for them (12). Exceptions to this approach are two studies in which caregivers were interviewed about how and why decisions were made to join a dementia study (13,14), and a mailed survey of proxy decision-makers for PWDs who participated in research (15). These studies found that decision-making usually involved the PWDs to some degree; there was often a weighing of patient and caregiver preferences, but there was sometimes ambiguity about who made the decision; and reasons for joining a study often included hope for direct or indirect benefits, trust in the investigators, and altruism (13–15). However, these studies lacked the views of the PWDs who were involved in the process. The perspectives of these primary participants in dementia research warrant attention and understanding.

This study examines decision-making for participation in dementia research from the vantage points of both the primary participants and their caregivers. First, we look at how these individuals made the decision to join a dementia study. Their views on how this process actually occurs can inform investigators and study recruiters on what leads people to participate in dementia research. Second, we examine how these individuals would expect or want future research decisions to be made if the PWD could not participate in that process. Who should make such decisions, and what ethical standards do they prefer? Examining the preferred ethical standards of individuals currently involved in research can inform investigators and policy makers on the issues of primary concern to these dementia research stakeholders.

Methods

This study is based on data from the Consent for Dementia Research Study (CDRS) that examined the informed consent process for individuals recruited for dementia research (16). The CDRS involved six IRB-approved studies at two universities enrolling people with dementia or memory problems and at risk for dementia. Each enrollment encounter examined in the CDRS included the potential participant (i.e., the *subject*) and at least the study partner or proxy decision-maker (i.e., the *surrogate*). The Western Institutional Review Board approved and monitored the CDRS. Verbal permission was obtained to observe and audio record the consent sessions and obtain subjects' clinical information (e.g., diagnosis, Mini-Mental State Examination (MMSE) (17) scores). We obtained written informed

consent to interview participants. Assent of subjects and proxy consent of surrogate decision-makers were obtained for subjects who did not answer correctly four questions to assess their understanding of the interview component of the CDRS.

Dementia Studies

The CDRS included three drug and three non-drug studies. The drug studies were testing whether FDA-approved medications were effective for treating cognitive impairment (one study) or depression (two studies). Two of these studies were randomized placebo-controlled trials, and one used an open label method. The other three studies included a randomized non-drug intervention trial, a natural history study of dementia, and a study involving the use of stored blood samples for future genetic research. Three of the six studies enrolled only persons with AD, two included subjects with any type of dementia, and one enrolled individuals with the dementia of Parkinson's disease. The majority (83%) of the 46 enrollment encounters in the CDRS were from the three non-drug studies. Only one subject declined to join a non-drug study.

Participants

Following each enrollment encounter, we asked the subject and surrogate to participate in separate interviews. All 46 surrogates and 39 (84.8%) subjects agreed to be interviewed. Subjects who declined to be interviewed tended to have lower MMSE scores ($M=18.9 \pm 5.6$) than those interviewed ($M=22.9 \pm 5.0$) ($t=-1.904$, $p=.063$). Participants' characteristics are shown in Table 1.

Data Collection

We conducted semi-structured interviews to obtain participants' perspectives on the decision-making process for the dementia study and on how they thought future research decisions would or should be made for subjects if unable to participate in decision-making. We asked how the prior research decision was made, who made the decision, and what their reasons were for joining the dementia study. For future research decision-making, we asked who the subject would want to make such decisions if the individual were unable to do so. Subjects were asked how they would want the person of their choice to make future research decisions for them, and surrogates were asked how they would make a future research decision for the person. For how future research decisions should/would be made, we asked them to consider these choices: (1) based on what the person would have decided if able to do so (i.e., substituted judgment), (2) based on what would be best for the person (i.e., best interests), or (3) based on something else.

The principal investigator (PI, BSB) conducted and audio recorded all interviews. Most interviews (77%) occurred on the day of the dementia study enrollment encounter, 14% were on the following day, and 9% occurred within a few days or weeks after the encounter. Most interviews (81%) were conducted in person, with the remainder by telephone. Since many interviews were conducted on the day of the enrollment encounter, some occurred at the end of a long study visit. As a result, four interviews were shortened by selectively including questions of greatest importance to the CDRS to minimize participant burden. In addition, some subject interviews ($n=7$) were abbreviated when it was evident that the person could not respond meaningfully to questions that required recall of events or had difficulty communicating.

Data Analysis

The audio-recorded interviews were transcribed verbatim; transcripts were verified and coded to facilitate analysis (18). We developed a set of codes to reflect the interviews' major

content areas. The PI and a research assistant coded all transcripts independently and added new codes to categorize emerging issues. Coded transcripts were compared to ensure inter-coder agreement, discrepancies were resolved by consensus, and all transcripts were reviewed to incorporate newly added codes. The data were organized by cases, consisting of data from the subject (if available) and/or the surrogate, and content analyzed (19) using an iterative process. Matrices (20) were created to organize the data from each case around issues relevant to the prior research decision and future research decision-making. We compared data in the matrices within and across cases to identify patterns and themes revealed in the interviews and made comparisons based on surrogate's relationship (spouse versus non-spouse) to the subject and based on the subject's level of cognitive impairment (MMSE 18 versus 19). We used counts and percentages to summarize the results and identified representative quotes. Findings were verified by re-immersion in the data to confirm the results.

Results

Our findings focus on decision-making from two vantage points, prior research decisions and future proxy research decision-making. For each question, we report the number of individuals who responded and their most common responses.

PRIOR RESEARCH DECISIONS

How were decisions on whether to join a dementia study made?—Surrogates (n=46) described five general approaches to how decisions were made after learning of the study (see Table 2). In 39% of cases, the surrogate and/or the subject consulted with others (e.g., the subject's children, physician, minister, attorney) to help them reach a decision. Two other common decision-making approaches were that the researcher described the study and the subject decided to join it (28%) or, when the researcher suggested the study, the surrogate decided that the subject should participate and encouraged the person to agree (17%). In some cases (9%), surrogates said the subject sought out the study, made the decision, and then asked the surrogate to participate. Finally, some surrogates (7%) sought out the study, discussed it with the subject to the extent the person could understand it and asked if she/he were willing to participate.

Subjects' (n=35) descriptions of the decision-making process often differed from that of their surrogate (see Table 2). The most common approach reported by subjects (26%) was that the surrogate told them about the study and encouraged or told the person to join the study. Some subjects (23%) said that the researcher talked to them about the study, the subject and surrogate discussed it, and either they or the subject made the decision. Other subjects (20%) gave simple responses (e.g., "the doctor suggested it"), were non-specific about the process, or did not know how the decision was made. Some subjects (14%) sought out the study and made the decision, and a few (11%) reported that other people were involved in the decision-making process. In two cases (6%), the subject said the surrogate brought her to the site and the subject agreed to join the study.

Who made the decision to join the dementia study?—Both surrogates (n=46) and subjects (n=32) were most likely to say that the subject ultimately made the decision (44% and 50%, respectively); although this was less common for cases in which the subject had a lower (18) MMSE score. The next most common responses from surrogates and subjects were that they made the decision together (22%, 28%) or the surrogate made the decision (22%, 16%). In some cases, surrogates (13%) (particularly non-spouses) reported that they and another family member or friend made the decision, and subjects (6%) said that others (e.g., a relative) made or helped to make the decision. In 50% of cases, subjects' opinions on

who made the decision agreed with the surrogate's response. Disagreements were more common when the subject had a lower MMSE score.

What were the reasons for joining a dementia study?—The majority of subjects (85%) and surrogates (82%) mentioned more than one reason for joining the study. Table 3 shows that the most common reasons reported by subjects and surrogates were the desire, or at least hope, that the study would help the subject in some way. For those in the natural history study, the desire to obtain a diagnosis, information on treatments, or to track the subject's illness progression were most common. Those in the intervention studies also frequently hoped that it would benefit the subject, while most recognized there was no guarantee that it would. The second most common reasons mentioned by both subjects and surrogates were altruistic (e.g., "to contribute," "to help others in the future," "to help find a cure"). Subjects were more likely than surrogates to mention trust in either the clinician who suggested the study or the university where the study was located. Unique to subjects were their reports of joining the study because of encouragement from the surrogate, a family member or friend. While no surrogates reported being encouraged by others, several (27%) believed that the subject joined the study primarily because of the surrogate's or a clinician's encouragement. Surrogates more than subjects were motivated by hopes that the study would help the subject's family (e.g., children, grandchildren) or help the surrogate (e.g., understand the subject's illness, help the surrogate help the subject, receive emotional support).

FUTURE RESEARCH DECISIONS

Whom would subjects want to make future research decisions for them?—

Among surrogates (n=40), the majority (55%) (most of whom were spouses) mentioned only themselves as the person the subject would want to make future research decisions. One-third of surrogates thought the subject would want the surrogate and/or other individuals (usually family members) to make future research decisions. Two surrogates said they currently make decisions for the subject, and three believed that the subject either would not want to or should not participate in research if unable to make a future decision. Among subjects (n=39), 51% mentioned only the surrogate (most of whom were spouses) as their preferred decision-maker, 39% would want the surrogate and/or other family members as decision-makers, and 10% mentioned only other family members. In the 33 cases with both subject and surrogate responses, the majority (73%) agreed with each other.

How would or should surrogates make future research decisions?—When

surrogates (n=45) responded to how they would make a future research decision for the subject (see Table 4), 42% chose only the best interests standard, 20% said they would use a combination of best interests and substituted judgment, and 9% would use only substituted judgment. However, 29% chose the third option, "something else," which often incorporated multiple concerns including best interests and/or substituted judgment as well as other issues. For example, some would also consider how much time or energy would be required of the surrogate or whether it would be feasible for the subject (e.g., to cooperate with study procedures) or for the subject and surrogate to manage (e.g., travel to study visits).

Among subjects (n=34), 35% chose only best interests, 18% reported a combination of best interests and substituted judgment, and 15% preferred only substituted judgment. As with surrogates, 29% of subjects chose the "something else" option, which often included best interests and/or substituted judgment along with other issues. For example, some also wanted surrogates to consider their own best interests or those of other family members. Others would want the decision based simply on the surrogate's best judgment or the surrogate's judgment after consulting with others. Only one subject said, "I don't know."

However, he clearly knew whom he wanted to make such decisions, saying, “Oh, I trust my wife.” In six cases, subjects and surrogates agreed, with four dyads choosing only best interests, one couple preferring only substituted judgment, and another preferring a combination of best interests and substituted judgment. For cases in which the subject had a lower MMSE score, a slight majority of both subjects (54%) and surrogates (53%) chose only the best interests standard.

Conclusions

In this study, a substantial portion of individuals with mild to moderate cognitive impairment engaged, to some extent, in the decision-making process for dementia research, as others have found (13, 21), and were able to discuss their opinions on how and by whom they would want such decisions made for them in the future. In most cases, deciding whether to join a study was a collaborative process between the subject and surrogate, often with advice from others. Surrogates tended to play a greater role in decision-making when subjects were more cognitively impaired. These findings support the recommended approach for enrolling cognitively impaired participants in dementia research using proxy informed consent with subject assent if the individual lacks consent capacity (3). These results also serve as encouragement for investigators and study recruiters to engage potential subjects, to the extent possible, in the consenting process and explicitly seek their opinions. This supports the ethical principle of respect for persons and may positively influence retention of study participants.

Our second major finding is that both subjects and surrogates were most likely to choose only best interests as the ethical standard for future proxy research decision-making and least likely to choose only substituted judgment. Karlawish et al. (21) also found that proxies making dementia research decisions were more likely to use best interests than substituted judgment. This order of preference differs from the normative ethical perspective that favors substituted judgment over best interests. However, many of our participants preferred either an approach that weighs best interests *and* substituted judgment or a more complex approach that also considers the interests of others, particularly family members or specifically the surrogate, who usually serves as a study partner. Berger et al. (5) note that a continuum exists between substituted judgment and best interests and suggest that surrogate decision-making is a complex, dynamic and personal process, as our data reflect.

In this study, subjects and surrogates within dyads often differed in their perceptions of how research decisions were made, and no single method was found to be a predominant approach. While differences in their perceptions are likely due in part to subjects' memory impairments, some surrogates also had difficulty reporting details of the decision-making process, if they learned of the study several months before enrollment or if the subject sought out the study. Differences in the process prior to the informed consent session, in addition to differences in subjects' cognitive abilities, highlight the importance of an enrollment encounter in which study information is presented in a manner that maximizes subjects' and surrogates' understanding.

Both subjects and surrogates were most likely to identify the subject as being the person who ultimately made the enrollment decision. This finding differs from that of Sugarman and colleagues (14) who found that proxies most often said that it was a shared decision between the patient and proxy; although they reported considerable vacillation in proxies on who actually made the decision. In our study, agreement within dyads on this issue was fair. In the complex process of research decision-making that involves one cognitively impaired individual whose willingness is required for enrollment, it is not surprising that those involved would often differ in their perceptions of who ultimately made the decision.

However, this suggests that investigators should inform surrogates explicitly of their responsibilities as the proxy decision-maker if the potential subject lacks consent capacity.

The most common reasons expressed by subjects and surrogates for choosing to join a study were the desires or hopes that participation would benefit the subject in some way, while at the same time being beneficial to others in the future. Our findings on what motivates dementia research participants are generally consistent with those of other investigators (13–15) and demonstrate that decisions are influenced by multiple factors related to study characteristics, need for dementia-related help, and desires to make a contribution to medical science advancement. The strong hope that many individuals hold for direct benefits from research poses a challenge for recruiters to guard against therapeutic misconceptions.

In this study, the majority of subject-surrogate dyads agreed on whom the subject would want to make future research decisions, with the surrogate being the most likely person of choice (particularly in cases with a spouse as surrogate), but few agreed on their preferred ethical standard. We believe that disagreement on the preferred ethical basis for proxy decision-making is of greater concern than disagreement on how and who made the prior research decision since the subject's ability to participate in making future decisions will decline. Since many individuals who lack consent capacity still retain the capacity to appoint a proxy decision-maker (22), individuals with early stage dementia should be encouraged to appoint a surrogate decision-maker and to express their preferences for the standards on which they would want future proxy research decisions made.

This study has a number of limitations. First, while most interviews occurred in close proximity to participants' enrollment encounter, our data are primarily retrospective since decision-making often occurred over weeks or months before enrollment. Second, with the exception of one case, participants agreed to join the dementia study. Individuals who decline to participate in studies may have different attitudes toward research and decision-making. Third, this study's purpose was not to assess subjects' consent capacity for the dementia study that they joined. We have reported previously that consent capacity assessment occurred only for the three drug studies, and that in the majority of cases both the subject and surrogate signed the subject's consent form (16). Fourth, characteristics of the sample, consisting predominately of Caucasians and individuals asked to participate in minimal risk non-intervention studies, limits extrapolation of our findings. Finally, because this study was conducted at only two research institutions and involved a small heterogeneous sample of dementia studies, the generalizability of the findings may be limited.

This is one of few studies that have examined the process of how actual decisions about participating in dementia research were made and the first to include the perspectives of the primary participants. Similar studies that include samples with greater ethnic/cultural diversity and a more balanced mix of minimal versus more-than-minimal risk studies are needed. Further empirical research is also needed to determine whether the desires and expectations that participants hold at enrollment are fulfilled and to document their experiences over the course of dementia research participation.

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Table 1

Characteristics of Subjects and Surrogate Decision Makers

Characteristics	Subjects (n=39)		Surrogates (n=46)	
	%	Mean (SD)	%	Mean (SD)
Sex				
Females	51.3		73.9	
Male	48.7		26.1	
Race				
White	87.2		87.0	
African American	12.8		13.0	
Age (years)		74.2 (8.8)		63.1 (12.6)
Education (years)		14.6 (3.3)		14.4 (2.4)
Marital Status				
Married	74.4		76.1	
Widowed	12.8		4.3	
Other ^a	12.8		19.6	
MMSE Score ^b		22.9 (5.0)		
24	53.9			
19 – 23	30.8			
18	15.4			
Diagnosis				
Alzheimer disease	66.7			
Other dementias ^c	12.8			
MCI ^d	10.3			
Depression	7.7			
Relationship to Subject				
Spouse			60.9	
Daughter/son			21.7	
Other relative			10.9	
Non-relative			6.5	

^aOther marital status – divorced, separated, never married

^bMMSE – Mini-Mental State Examination

^cOther causes of dementia – Frontotemporal dementia (1), Parkinson's disease dementia (3), Lewy body dementia (1)

^dMCI – Mild cognitive impairment

Table 2

Illustrative Quotes on How the Decision Was Made to Join a Dementia Study

Subjects' Perspectives (n=35)	Surrogates' Perspective (n=46)
<p>Surrogate told subject about the study, encouraged/told subject to join & subject agreed – (26%)</p> <p>"Well I can very clearly tell you. I joined this because my wife told me to. Because she appropriately wonders what's going on with my brain, what should we be doing about it, and my worry is the exact reverse. I only worry about what it will do to her. Where on the other hand she wonders what we should be doing about it. So, she is responsible for my being here."</p>	<p>Consulted with others before deciding – (39%)</p> <p>"...so she [<i>study coordinator</i>] asked me to again speak with my family, my dad and my brother and four sisters and see if that was something that we were interested in, and we did that and we all agreed that that was something that we wanted to move forward with...."</p>
<p>Clinician/study coordinator suggested it, subject & surrogate discussed it, & they or the subject decided – (23%)</p> <p>"I talked with [<i>Doctor</i>], and then he mentioned it and there was some literature on it in his office and he said it might be a good idea. That's all, nothing else. My wife and I discussed it briefly but that was it."</p>	<p>Clinician/study coordinator suggested it & subject decided – (28%)</p> <p>"Well, I think we understood. My husband said he wasn't going to do it, and I said 'Fine, so we won't do it.' I said 'Why?' We discussed this and he said he just didn't want to, and then I said, 'Well read it again,' and he did and he still didn't want to. I said, 'Fine.' About two days later, he got up and he said, 'I'm gonna do the study.' Don't ask me why, so that's how we're doing it."</p>
<p>Simple response / not specific / didn't know – (20%)</p> <p>"I don't really know. I couldn't tell you."</p> <p>"Some people suggested it, but I said, 'You know, if I didn't want to do it, I wouldn't do it.'"</p>	<p>Clinician/study coordinator suggested it, surrogated decided & encouraged subject to agree – (17%)</p> <p>"I probably made the decision, but I asked her of course if she wanted to do it, but if I hadn't have asked her or initiated it, then she probably wouldn't have done it on her own. She probably certainly would have gone to the clinic, but the study piece, she probably wouldn't have on her own. She wasn't gung-ho and say yeah I want to go and do that, but I was the one gung-ho about that."</p>
<p>Subject sought out the study & made the decision – (14%)</p> <p>"Actually, I heard it on TV one night, and they said they was wanting people in this study that had it in their family already. And I just said, 'You know, I'd like to get into that,' and I have never done anything like this before. Never went into any type of study or research. But, I said, 'I would like to do that' and he [<i>surrogate</i>] said OK."</p>	<p>Subject sought out study, made the decision & asked surrogate to participate – (9%)</p> <p>"Well she [<i>subject</i>] just called me and told me that she was having this appointment in October, and she gave me a warning about a month ago. And she said, 'Make sure you have that day free because I'm going to [<i>Study site</i>] for the study.' So, she didn't give me any details. She just gave me the title of it and that was it. So, you know the information that you associate with that title, so I just said oh well maybe she is experiencing these things. And I said, 'All right I will do it.'"</p>
<p>Other people involved in decision-making – (11%)</p> <p>"Well, I did decide on my own. And then, I spread the news so I could get their approval, with my son and daughter-in-law and so on. I talked to them a little bit. And my daughter also."</p>	<p>Surrogate sought out the study, discussed it with subject & asked if subject was willing – (7%)</p> <p>"When I got the information, we sat down one night and turned off the television. I said, 'You know I'd like to go over this with you.' I did go over all of that with her. I read it aloud. I asked her if she wanted to read it or if she wanted me to read it aloud to her and she wanted me to read it aloud, partly because her vision isn't all that great. But, I needed to know did she feel she wanted to know any more or would she just as soon not go through any of this, and she was very, 'No, I do want to.'"</p>
<p>Surrogate brought subject to study site & subject agreed – (6%)</p> <p>"My sister-in-law was coming here, and I joined her. And, that's how I got involved."</p> <p>"It was more his [<i>surrogate's</i>] idea. I didn't know anything about it until he said, 'We're going.' And, he wouldn't do a thing in the world to bother me or hurt me or anything like that if he didn't think we had a shot at something, we wouldn't be here."</p>	
<p>Did not know – (3%)</p> <p>"I don't know."</p>	

Table 3**Reasons for Agreeing to Participate in a Dementia Study**

Any Reasons Mentioned for Agreeing ^{a,b}	Subjects (n=34)	Surrogates (n=45)
Hopes for or wants help for the subject	73.5	80.0
To help people in the future (i.e., altruism)	61.8	53.3
Trust in the clinician or university	35.3	15.6
Encouraged to join by surrogate/family/friend	32.4	0.0
To help subject's surrogate or family members	17.7	40.0
To be informed of new treatments or other studies	5.9	11.1
Study required little of the subject	5.9	6.7
Study risks were acceptable	5.9	4.4
Financial reasons	5.9	4.4

^aOne subject declined to join the dementia study.

^bMost subjects (85%) and surrogates (82%) mentioned more than one reason.

Table 4**Illustrative Quotes on How Future Proxy Research Decisions Should/Would Be Made**

Subjects' Perspectives (n=34)	Surrogates' Perspective (n=45)
<p>Best interests – (35%)</p> <p>“What's best for me. If I am not able to make a decision I think she is the person who would know me best to do it.”</p> <p>“What he thinks is best for me I would say. In that situation, I can't want or not want.”</p> <p>Best interests & substituted judgment – (18%)</p> <p>“Well the two may not be different. What's best for me and what I would do might be the same thing and I think that's what she would make the decision on. She would consider both.”</p> <p>“Both of those together. Well, I would, I think it should be a matter of what [<i>Surrogate</i>] thinks is best and what I think is best.”</p> <p>Substituted judgment – (15%)</p> <p>“I would want her hopefully to make that decision on what she thought I would think. OK. Not what she thinks, not what somebody else thinks, but what I think...what she thinks I would have done.”</p> <p>“Based on her knowledge. On her knowledge of me and what my desires would be.”</p> <p>“Something else” – (29%)</p> <p>“I think all of the above. I mean, I don't think you make a decision in a narrow framework. You consider family, you consider loved ones, you consider a lot of things about yourself, your age, your health. There's just a lot that goes into such a decision...”</p> <p>“Based on something else. It's for her to consult whatever counselors she wants to consult, reserving the final decision for herself, based on your own feelings. You have to mull it over.”</p>	<p>Best interests – (42%)</p> <p>“Based on what would be best for him, not on what he would decide. I've made most of my decisions in life as to what would be best for him. What would be best for my family. There is no other way to decide. Depending upon what the study was of course. If it was a study that was giving a placebo and a real drug I would say no. Because chances are he would get the placebo and he wouldn't get any better. If they were giving a real drug to everybody to see how it worked and the results, I would say yes, because there could be an outcome, there could be betterment. That's how I would make that decision.”</p> <p>Best interests & substituted judgment – (20%)</p> <p>“I would hope that I could make the decision based on what she would have wanted to do and I would also hope that in the vast majority of cases I could do that and feel like I was doing what was best for her at the same time.”</p> <p>Substituted judgment – (9%)</p> <p>“For research, I would make it based on what I thought she would want. If it was treatment, I probably would make it based on what I thought was best for her, but for research, I'd probably go with what I thought she would want.”</p> <p>“Something else” – (29%)</p> <p>I think it would be not on the basis of one of your points or the other. It would be a combination of those things. It would also be a combination of whether I thought I had the time to support it myself, or if one of my sisters was interested in it. And whether I thought there was any benefit to her in doing it, bringing her down here. Because we take her to her doctor's appointments and do grocery shopping for her and we all have our own families and so it has to be important enough for us to want to invest the time.”</p>