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## Sense of Control in End-of-Life Decision-Making

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### Abstract

**OBJECTIVES**—Supporting older adults' decision-making regarding care at the end of life is challenging because of the fluid nature of the process; however, limited research looks at decision-making specifically among community-dwelling older adults near the end of life. This study brings forth the voice of older adults in the community with a limited prognosis, explores how they make healthcare decisions and the processes used when not in an acute crisis.

**DESIGN**—Grounded theory.

**SETTING**—Medical programs and geriatrics clinics at the University of California San Francisco and the San Francisco Veterans Affairs Medical Center.

**PARTICIPANTS**—20 community-dwelling older adults (ages 67–98) with a prognosis < 1 year.

**MEASUREMENTS**—In-depth, semi-structured interviews in participants' homes. Constant comparative analysis was used to develop codes and identify themes.

**RESULTS**—Participants generally delegated decisions to others, expressing their wishes by describing desired end-of-life outcomes and highlighting meaningful aspects of their lives. They did this in the belief that the delegate would make appropriate decisions on their behalf. In this way, participants were able to achieve a sense of control without being in control of decisions. Four themes emerged from the analysis that reflect the various approaches participants used to articulate their goals and maintain a sense of control: *direct communication*, *third-party analogies*, *adaptive denial*, and *engaged avoidance*.

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#### Related paper presentations:

Preliminary results of this study were presented in abstract form at the 48<sup>th</sup> Annual Communicating Nursing Research Conference of the Western Institute of Nursing, April 2015, Albuquerque, New Mexico.

**Conflict of Interest:** The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Author's Contributions:** Romo, Smith, Wallhagen: study concept and design. Romo: data acquisition and drafting manuscript. Romo, Allison, Smith, Wallhagen: data analysis and interpretation, critical revision of the manuscript, and approval of final version.

**CONCLUSION**—Our findings challenge the prevailing view of personal autonomy. These older adults suggest a path to decision-making that focuses on priorities and goals, allowing older adults to take a more passive approach to decision-making while still maintaining a sense of control decision-making.

### Keywords

decision-making; end-of-life care; qualitative research; sense of control

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## INTRODUCTION

Understanding patient preferences for end-of-life care is integral to caring for older adults, especially when death is a likely outcome. The Institute of Medicine report, *Dying in America*, summarizes the significant research in this area, identifying techniques to facilitate the articulation of patients' goals and support patient decision-making.<sup>1</sup> Though older adults consistently state preferences for care emphasizing symptom management and quality of life,<sup>2–6</sup> they often receive care inconsistent with these goals.<sup>1</sup>

Supporting patient decision-making is a central aspect of patient-centered care and respecting patient autonomy, and it is through autonomy that patients exert control over decision-making.<sup>7</sup> Despite the value placed on autonomy in the U.S, not all older adults necessarily want to actively participate in decision-making.<sup>8–10</sup> The diversity of patients' decision-making preferences is challenging for clinicians. Existing research provides vital information and has increased our understanding of older adults' end-of-life needs and priorities; however, most studies focused on participants who were either healthy<sup>4,5,11</sup> or were selected based on a single life-limiting disease, such as cancer.<sup>3,12</sup> Other studies used hypothetical scenarios rather than actual decisions.<sup>2,11,13</sup> The few studies that specifically engaged older adults near death explored decisions of hospitalized patients during an acute, emergent situation.<sup>14,15</sup>

Missing from the discourse are the voices of community-dwelling older adults with multiple comorbidities and a limited prognosis, but who are not in a moment of medical crisis. Understanding these voices would enable providers to better understand patients' concerns and to ensure that care is consistent with their goals and desires. Our purpose was to bring forth the voice of these older adults, explore how they made healthcare decisions, and explicate their decision-making processes in non-crisis situations.

## METHODS

### Design

Grounded theory<sup>16,17</sup> was used because it provides a systematic analytic approach intended to make transparent the underlying processes within a social phenomenon.

### Setting

Data were collected through medical care programs and outpatient geriatric clinics at the University of California, San Francisco (UCSF) and the San Francisco Veterans Affairs

Medical Center (SFVAMC). Researchers met with clinicians, described the study, answered questions, and requested referrals. Interviews were conducted in participants' homes. The UCSF Committee on Human Research and the SFVAMC Research and Development Committee provided human subject oversight.

## Participants

Eligibility criteria were: age 65 or older, a limited prognosis ( < 1 year), decision-making capacity, residing in the community, and speaking English. Because older adults frequently live with comorbidity, diagnosis was neither an inclusion nor exclusion criterion. Providers determined prognosis by answering the "surprise" question: "Would I be surprised if this patient died within the next 12 months?"<sup>18</sup> A "no" response indicated eligibility. Exclusion criteria were: residing in a skilled nursing facility, having significant cognitive impairment, and being too emotionally or physically fragile to participate in the interview. Providers determined if patients met the exclusion criteria.

Initially, participants were identified based on the inclusion criteria and providers' expectation that they would be good informants. As analysis ensued, we selected participants specifically to develop and expand emerging themes and concepts. We mailed an introductory letter to potential participants, who were invited to return a response card. We contacted respondents by telephone, explained the study, and set up a face-to-face meeting. A teach-to-consent method<sup>19</sup> was used to ensure participants understood the study; this resulted in the exclusion of three people.

Twenty participants were enrolled (ages 67 to 98). Most participants were male, white, unmarried and had education beyond high school (Table 1).

## Data Collection

Written informed consent was received using a teach-to-consent approach. No one was excluded at this stage. Interviews were audio recorded, professionally transcribed verbatim, and lasted 25 to 75 minutes (average: 45 minutes). Participants were interviewed only once, as we anticipated physical decline would preclude multiple interviews. Subsequent chart reviews confirmed that all participants experienced significant decline and 9 died during the study period. Data collection occurred June–October 2013. The interview guide was developed to elicit participants' experience with decision-making and explore the underlying processes used. Questions focused on four domains: (a) current health and healthcare; (b) recent decisions and communications with providers; (c) end-of-life decisions; and (d) anticipation for future care. At the conclusion of the meeting, participants filled out a demographic survey and a symptom assessment.<sup>20</sup> Following interviews, we reviewed charts to ascertain medical history and review providers' notes.

## Analysis

Analysis was done through the iterative process of constant-comparative analysis<sup>16,17</sup> and began with the first interview. Field notes and analytic memos were written throughout the study to capture the analytic process. Open coding was undertaken to label distinct concepts in the data, while focused and axial coding related concepts across the data and grouped

them into meaningful categories. As new codes were generated, earlier transcripts were reviewed and recoded. Initially, coding was done primarily by one researcher (RDR), with the research team meeting weekly to discuss interviews, coding, emerging concepts/themes, and to explore the appropriateness of different framings. Interpretive disagreements were resolved by consensus. The research team represented expertise in geriatric medicine, gerontological nursing, palliative and end-of-life care, ethics, decision-making, and qualitative methods. To assess face validity of the emerging themes, interim findings were presented to independent professionals with expertise in aging, medicine, nursing, social work, and sociology. Data collection and analysis continued until data revealed no new concepts or themes that furthered the analysis or understanding of the phenomenon (i.e. theoretical saturation achieved).<sup>16,17</sup> Analysis was managed using NVivo software.<sup>21</sup>

## RESULTS

In general, participants did not discuss choices directly. Instead, they used a variety of approaches to express priorities and goals, often through circumlocution. Rather than focus on specific treatment options, participants described desired outcomes at the end of life, highlighting meaningful aspects of their lives. Preferences were expressed in broad terms, such as avoiding “aggressive measures,” forgoing “heroic efforts,” not being “artificially maintained,” and not wanting to be “a vegetable.” They were, however, sometimes willing to undergo burdensome treatments if they could return to meaningful activities. One 76 year-old female did not want to be kept alive “artificially” but would undergo treatments that would allow her to continue quilting and communicating via email, activities she defined as “my life.” Through such indirect statements, participants anticipated that others would make appropriate choices on their behalf.

### Maintaining a Sense of Control

Participants acknowledged they were delegating decisions to others while also noting that they did not discuss their preferences with others. Still, they expressed the belief that their decisions were under control, giving rise to an overarching theme of *maintaining a sense of control*. One 72 year-old male participant said, “You know, with the decisions that my providers make for me, you know, it feels like everything is in control.” His perception of control arose out of an appraisal of his unique set of circumstances and the belief that his decision-making was manageable because it was delegated to a trusted person. Thus, without actively making decisions for himself, he still had the experience, or sense, of control.

We present a model of our findings in Figure 1 and provide exemplar quotes in Table 2. Participants discussed their contextual environment in terms of demands and resources that inhibited or enabled a sense of control. For these participants, making decisions themselves was perceived as a burdensome demand, particularly in light of their health status. Acute episodes of illness described specific instances during which the demands of decision-making threatened their sense of control. Trust in family and providers functioned as a resource, but lack of trust posed burdens during acute illness. Lack of trust diminished participants’ sense of control and placed social/emotional burdens upon the participants. In

contrast, strong trust sustained a sense of control and served as a resource for participants during acute illness. The nature of trust arose from the relationship participants had with family and providers. Together, they form resources and demands that either facilitate or inhibit the sense of control.

Four themes emerged that represent different approaches used by participants to achieve this balance: *direct communication*, *third-party analogies*, *adaptive denial*, and *engaged avoidance*. These are not mutually exclusive approaches. Although participants expressed views reflective of more than one approach, their overall viewpoints tended to align with one predominant approach.

*Direct communication* occurred when the participant clearly indicated what care was or was not desirable. Given their broader goals, some participants eliminated complete categories of care, such as surgeries, focusing on being “painless and comfortable” and able to “stay at home.” In this context, outcomes affected choices: “I did say no heroics, but if there’s a shot at living, give it to me.” After expressing his wishes directly, this 89 year-old male was adamant that he was not “going to think about it anymore” and anticipated his providers and family would act according to his wishes. In this way, he felt his decisions were under control.

*Third-party analogies* involved expressing one’s values and preferences by describing the experiences of others as exemplars for what participants would or would not want for themselves. Participants referred to hypothetical people in distant terms, like “one lady” or “other people.” This allowed them to distance themselves from the situation, allude to someone’s care as futile, and then reject the imagined situation for themselves. Such stories enabled participants to express priorities and values they hoped would guide providers or surrogates, without having to make decisions themselves.

*Adaptive denial* was reflected by an unspoken acknowledgement that one’s health would decline, taking steps to ensure priorities and values are met, and then putting further thoughts in the background. This allowed participants to deflect end-of-life decisions while simultaneously taking proactive measures to prepare for future needs. By displacing the burden of directly making these decisions, they avoided the distressful aspects of contemplating mortality and continued to live in a manner that reflected their values, thereby maintaining a sense of control.

*Engaged avoidance* was apparent when a participant actively avoided discussing end-of-life issues and choices entirely, firmly refusing to engage in end-of-life decision making. Consequently, they left the decisions completely in the hands of others. They sometimes intimated that they had priorities and goals regarding care, but insisted they had not and would not discuss their preferences with others. By adamantly refusing to address end-of-life concerns and focusing on only the positive, they could maintain their sense of control.

## DISCUSSION

Our participants typically avoided focusing on specific decisions. Rather, they reflected their personal priorities and values related to living at the end of life and responded to the context

in which choices would arise and the outcomes they anticipated might result. This is similar to existing research that suggests, when considering end-of-life choices, older adults often focus on outcomes rather than treatments.<sup>5,6,22</sup> Instead of making independent choices, participants preferred to delegate decisions to someone else, but often did not discuss their priorities with the person. Our study adds to the literature in an important way – despite delegating healthcare decisions, participants still expressed a sense of control over those decisions.

Older adults usually want to maintain control over their decisions;<sup>12,23</sup> but our findings suggest that, among older adults, the idea of control is nuanced and variable. Participants did not need to be actively “in” control of their decisions in order to feel their decisions were “under” control. One could argue that they were yielding control, but participants did not feel this way. Rather than giving up control, participants achieved the experience, or *sense*, of control. This sense of control arose from the various approaches used to communicate preferences and engendered a belief that their decisions were managed and under control – even without their active participation. Actively controlling decisions is presumed to be the most adaptive approach to maintain autonomy,<sup>24</sup> but delegating decisions can be, in and of itself, an exercise of autonomy. This paradigm shift for clinicians demands an understanding and appreciation of patients’ perspectives of control.

By speaking to their priorities indirectly and delegating difficult decisions, participants were able to balance the demands of decision-making with personal and social resources. This behavior is consistent with alternative constructions of control.<sup>25</sup> Our finding – the desire to avoid and/or delegate difficult decisions – may have a universal nature to it. Other researchers found that women with breast cancer were able to maintain a sense of control by yielding decision-making to a trusted person.<sup>26,27</sup>

The challenge for providers is how to support patient decision-making in this nuanced and contextual reality. Shared and surrogate decision-making have been suggested as ways to support and maintain patient autonomy.<sup>28,29</sup> In many situations, shared decision-making works well. It requires good patient-provider communication that was key to establishing a sense of control among our participants. But, shared decision-making still requires patients to be active participants. And surrogates only become involved when patients lack the capacity to make decisions for themselves. Providers may be reticent to take a proactive role in making choices for patients; however, by using an understanding of the different ways older adults express their priorities, they can adapt their discussions. Patients who avoid discussing end-of-life issues (*engaged avoidance* and *adaptive denial*) may be the most challenging, but providers will be more successful if they are attuned to key actions and statements. For example, a reference point for recommending interventions could be the observation that a room built for a future in-home caregiver suggests that staying in the home is a priority. Providers can explore *third-party analogies* and use this information to frame different outcomes from patients’ own perspectives. Patients who use *direct communication* give the best guidance to providers. Hearing strong statements like “there will be no more surgeries in my life”, providers can present treatment options consistent with patient preferences and not present options that are incongruent.

## Limitations

This study involved only those who are reflecting on past, though recent, decisions and did not include the perspectives of healthcare providers and families. Only one participant was younger than 70, so we may have missed generational differences. Likewise, the homogeneous nature of the sample does not allow us to identify differences based on race, gender, or educational level. Half of the sample was recruited through the SFVAMC and may reflect the unique nature of this healthcare setting. Still, our data rich themes and concepts were noted across all the interviews and reflect a common experience among these participants. Further, through the analytic process, we took steps to ensure the trustworthiness of the analysis.

## Conclusion

By providing a deep description of the decision-making processes among a group of community-dwelling, non-hospitalized, older adults with limited prognosis – a largely overlooked group – this study adds important insights to this body of knowledge. Our findings challenge conventional notions of autonomy that rely on independence in decision-making. Allowing patients to make choices is important; however, a focus on patient-choice alone ignores the context in which decisions are made and the fact that patients do not always want to make explicit decisions. The voices of these older adults suggest a different path to decision-making that requires the good provider-patient communication of shared decision-making and focuses on priorities and goals but allows older adults the option of taking a more passive approach while still maintaining a sense of control and personal autonomy.

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## Appendix

### Conflict of Interest Checklist:

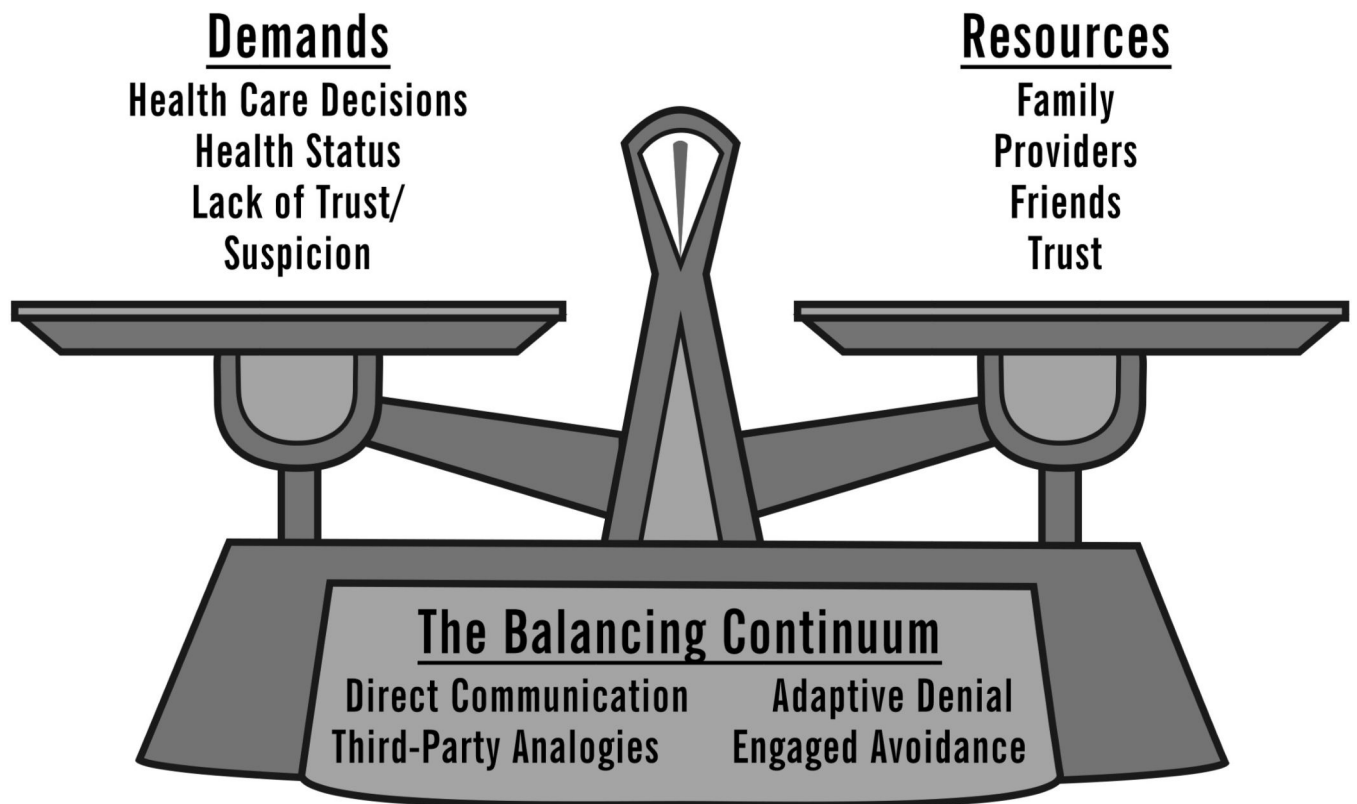


Elements of Financial/Personal Conflicts	*Author 1 (RDR)		Author 2 (TAA)		Author 3 (AKS)		Author 4 (MIW).	
	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		X		X		X		X
Grants/Funds		X		X		X		X
Honoraria		X		X		X		X
Speaker Forum		X		X		X		X
Consultant		X		X		X		X
Stocks		X		X		X		X
Royalties		X		X		X		X
Expert Testimony		X		X		X		X
Board Member		X		X		X		X
Patents		X		X		X		X
Personal Relationship		X		X		X		X

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**Figure 1. Maintaining a Sense of Control in End-of-Life Decision-Making**

Participants sought to maintain a sense of control over their decisions by delegating to others. They did this by using different approaches to articulating their goals and priorities without having to specify one choice or the other. Some approaches gave more clear direction (direct communication and third-party analogies) than others (adaptive denial and active avoidance), but all sought to balance between participants' personal and social resources and the demands of decision-making. Resources included family, providers, friends, and the trust participants had in these relationships. Demands included the healthcare decisions to be made, participants' health status, and the lack of trust or suspicion they may have had in their relationships.

**Table 1**

## Participant Characteristics

Characteristic (N=20)	Value
Age Range (median)	67 – 98 (89)
<u>Gender</u>	
Female	7
Male	13
<u>Race, n</u>	
White	17
Non-white	3
<u>Marital Status</u>	
Married/Partnered	4
Widowed	8
Divorced	6
Never married	2
<u>Education</u>	
Less than High School	1
High School	8
More than High School	11
<u>Perceived Quality of Life<sup>a</sup></u>	
Excellent	3
Very Good	9
Good	2
Average	6
Poor	0
<u>Perceived Health<sup>b</sup></u>	
Excellent	2
Very Good	4
Good	4
Average	6
Poor	4

<sup>a</sup>Response to the question: how would you rate your quality of life?

<sup>b</sup>Response to the question: how would you rate your overall health?

**Table 2**

**Exemplar Quotes<sup>a</sup>**

<b>Maintaining a Sense of Control</b>	
<b>Sub-Theme</b>	<b>Exemplars</b>
<p><b>Direct Communication</b> Involved making clear statements about priorities and goals to guide delegates. These are not discussed with the delegates.</p>	<p>“Keep me comfortable. That’s all, painless and comfortable. ... I’m not interested in surgery and stuff like that.” (male over 90)                      “I don’t want to go to the hospital anymore. And there will be no more surgeries in my life. I will not do it. [But] I’m not going to think about anymore. I’m just going to – I’ve done what I’ve done and I’m going to go about my business and one day I’m awake and one day I won’t.” (89 year-old male)</p>
<p><b>Third-Party Analogies</b> Used the experience of others as an exemplar for personal preferences.</p>	<p>“I wouldn’t [want to be put on a breathing machine] – I’ve seen one lady that was on support. Her granddaughter had her put on life support, but I would not want to do that. It’s sort of terrible to me.” (88 year-old female)                      “I saw other people for months would be on a breathing machine and I don’t know what the prospects were for recovery. [But] it doesn’t appeal to me, the fact I would be maybe months on a breathing machine.” (female over 90)</p>
<p><b>Adaptive Denial</b> Involved avoiding thoughts of ones’ declining health and the need for making end-of-life decisions but taking action to ensure priorities will be met.</p>	<p>“You know, I’ve denied death my whole life. I was always positive that things weren’t going to change, and I just didn’t think you were going to die. I built a room downstairs. I don’t want to go to assisted-living. I want to stay here. But eventually, I will need somebody, if I live long enough.” (89 year-old female)                      “These boxes. I have many boxes here. Little by little – I am the one doing it – I pack them up. Every time, every week I ship out these things.” (female over 90)</p>
<p><b>Engaged Avoidance</b> Meant actively avoiding thoughts of declining health and end-of-life decisions.</p>	<p>“I can’t even think about anything I wouldn’t want [at the end of life] because if I didn’t want it, I would avoid it, and I’d try very hard to keep from making an objective decision, you know, and things that would be contrary to my thinking in what I want to do in my life. ... I just take for granted that my daughter would know [what to do].” (72 year-old male)</p>
<b>Contextual Factors to Managing Demands and Resources</b>	
<b>Demands</b>	<b>Exemplar</b>
<p><b>Healthcare Decisions</b> Healthcare decision created ambiguity that needed to be resolved.</p>	<p>“I don’t think it’s going to get – or it has gotten a little worse in the last couple of years. [But] I don’t think – well, it probably will get a little worse” (female over 90)                      “Well, I’m now to the point where something like that would help, but I certainly wouldn’t want people not to resuscitate me for some reason.” (86 year-old male)</p>
<p><b>Health Status</b> Health status increased the complexity of decisions, particularly during acute episodes where providers where unknown to them.</p>	<p>“And he said, ‘Oh, we’re going upstairs to put in some stents,’ and [my daughter’s] going, ‘What? What? Wait, I have to research this on the internet,’ and wham, I’m upstairs and I’m getting stents. ... But you succumb to the medical powers.” (76 year-old female)                      “[They said] the pacemaker would be the most practical way to do it. They didn’t really give me a set of options because it pretty much sounded to me like the whole thing was etched in stone.” (77 year-old male)</p>
<p><b>Lack of Trust/Suspicion</b> Sense of control was threatened when trust was low or participants were not being heard.</p>	<p>“She’s very blunt sometimes and not necessarily the right way. I mean, it’s like, ‘Okay, fine. You want to kill yourself, kill yourself. I don’t have time for that.’” (67 year-old male)                      “My children try and reverse the role. And I am the one that they are taking care of which is sometimes very aggravating to me. I’m fully aware of what I can and cannot do and I don’t need my children to tell me what not to do. “ (male over 90)</p>
<b>Resources</b>	<b>Exemplar</b>
<p><b>Family/Friends</b> Participants relied on</p>	<p>“I’m more comfortable with my daughter [making decisions]. I mean, I know she wouldn’t steer me wrong.”</p>

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**Maintaining a Sense of Control**

family because they believed family would make appropriate choices. It also alleviated the burden of deciding. (88 year-old female)  
 “My poor daughter has to do all the heavy grunt work, and it’s just a burden. I’m sorry, but God, I’m glad she’s there. I can’t cope, and it’s so complex now.” (76 year-old female)

**Providers**  
 Trusting in the training and expertise of providers enabled participants to rely on them for decisions.  
 “Well, I know who he is. He’s a medical doctor, and he’s had about seven years of training; he must know something.”(male over 90)  
 “I actually had had another doctor of the “do what I tell you, little girl,” school. So we found another heart doctor who was just a dream.” (76 year-old female)

**Trust**  
 When high, trust enabled a sense of control by assure participants that decisions were in the right hands.  
 “Yes. [I feel I have control because] I have confidence in their decision over mine regarding health. I have confidence in his decision and skill, and his experience, that I can trust him.” (female over 90)  
 “I do what I am told. ... Let’s put it this way. You want to know something about cabinet making? Carpentry I do great with it. But medically, no. I can’t even pronounce the dang words.” (male over 90)

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<sup>a</sup>To protect privacy, participants aged 90 and older are identified as being “over 90.”