

UCSF

UC San Francisco Previously Published Works

Title

Older Adult and Surrogate Perspectives on Serious, Difficult, and Important Medical Decisions

Permalink

<https://escholarship.org/uc/item/96s4g7wd>

Journal

Journal of the American Geriatrics Society, 66(8)

ISSN

0002-8614

Authors

Petrillo, Laura A
McMahan, Ryan D
Tang, Victoria
[et al.](#)

Publication Date


2018-08-01

DOI

10.1111/jgs.15426

Peer reviewed

Older Adult and Surrogate Perspectives on Serious, Difficult, and Important Medical Decisions

Laura A. Petrillo, MD,* Ryan D. McMahan, BS, BA,[†] Victoria Tang, MD,^{‡§}
Daniel Dohan, PhD,^{§¶} and Rebecca L. Sudore, MD,^{‡§} 

OBJECTIVES: To elicit decisions that diverse older adults and surrogates perceive as serious, difficult, or important and explore what helped them make those decisions.

DESIGN: Focus groups (N=13) in which participants were asked to recall serious, difficult, or important medical decisions and what helped them make those decisions.

SETTING: Clinics, support groups and senior centers.

PARTICIPANTS: Diverse English- and Spanish-speaking older adults (age: mean 78, range 64–89) and surrogates (age: mean 57, range 33–76) (29% African American, 26% white, 26% Asian or Pacific Islander, 19% Hispanic) (N=69).

MEASUREMENTS: We used thematic analysis to analyze transcripts.

RESULTS: We identified 168 decisions. Older adults from all racial and ethnic groups frequently recalled cancer treatment decisions and decisions about chronic illness management. Surrogates described decisions about transitions in care and medical crises. Older adults valued self-sufficiency and maximizing survival and relied on personal experiences as often as medical advice. In all racial and ethnic groups, surrogates valued avoiding suffering for loved ones.

CONCLUSION: Diverse older adults and surrogates perceive life-threatening illness and day-to-day decisions about chronic disease to be serious, difficult, and important. The surrogates' goal of avoiding suffering of older adults may differ from older adults' priorities of self-sufficiency and maximizing survival. Clinicians should support older adults and surrogates in identifying important and difficult decisions and learn about the values and

information sources they bring to decision-making. With this knowledge, clinicians can customize decision support and achieve person-centered care. *J Am Geriatr Soc* 2018.

Key words: medical decision-making; advance care planning; serious illness; person-centered care

The Institute of Medicine identifies patient (or person)-centeredness (aligning care to the values and preferences of individuals) as an aim of high-quality healthcare.¹ Clinicians can promote person-centeredness by supporting older adults and surrogate decision-makers in the process of shared decision-making,² but for clinicians to support shared decision-making, all parties (clinicians, older adults, surrogates) must first identify that they face a decision with options and choose to make the decision together.³

Although many older adults and surrogates would like to engage in shared decision-making,^{4–6} limited health literacy and English proficiency, mistrust among diverse populations, poor communication with clinicians, and disempowerment often impede engagement.^{7–10} Clinicians may choose not to involve older adults in certain decisions¹¹ or may not appreciate all the decisions with which older adults and surrogates struggle. Greater awareness of the kinds of decisions older adults and surrogates perceive to be serious may help clinicians decide when to engage in shared decision-making, and by learning the values and information sources on which older adults and surrogates rely, clinicians can better customize their decision-making guidance, leading to more person-centered care.

Prior studies have examined how characteristics of individuals^{12–14} and clinical situations^{15–17} affect how large a role individuals desire in decision-making. Other studies have explored health-related values for individuals with cancer, such as self-sufficiency and spirituality, that they apply to decision-making^{18,19} and described how surrogates approach advance care planning and end-of-life

From the *Division of Palliative Care and Geriatrics, Massachusetts General Hospital, Boston, Massachusetts; [†]School of Medicine, University of California, San Francisco; [‡]Division of Geriatrics, Department of Medicine, School of Medicine, University of California, San Francisco; [§]San Francisco Veterans Affairs Medical Center; and the [¶]Institute for Health Policy Studies, University of California, San Francisco, San Francisco, California.

Address correspondence to Laura Petrillo, MD, 55 Fruit St., Founders House, Suite 600, Boston, MA 02114. E-mail: lpetrillo2@mgh.harvard.edu

DOI: 10.1111/jgs.15426

decisions, such as by applying their own values,^{20,21} but no prior study has explored the kinds of decisions that older adults and surrogate decision-makers perceive to be serious, difficult, or important and what helps them make these decisions.

We undertook this qualitative study to learn more about serious decisions that older English- and Spanish-speaking adults from diverse racial and ethnic backgrounds and their surrogates made and what helped them make those decisions. We aimed to describe themes that older adults and surrogates had in common and where they diverged and to describe difference between racial and ethnic groups.

METHODS

Study Design and Participants

Thirteen focus groups were conducted at 3 urban hospitals between 2010 and 2011, as previously described.^{22,23} A convenience sample was recruited from clinics, support groups, and senior centers affiliated with safety-net and veterans hospitals. Participants were contacted as part of a larger research participation recruitment effort, first through mailed opt-out cards and then over the telephone.

Participants provided demographic information in a telephone eligibility screen. English- and Spanish-speaking participants were eligible if they were aged 65 and older and had made a serious medical decision for themselves or were aged 18 and older and had made a serious medical decision for another person. We excluded individuals with dementia or hearing or vision impairment and those who demonstrated moderate to severe cognitive impairment (<19/50 on the Telephone Interview Cognitive Status Questionnaire²⁴). Participants were asked to self-report their health status and their health literacy, defined using a well-validated question regarding their confidence in filling out medical forms.^{25,26} Participants who answered that they were not at all, a little, or somewhat confident were categorized as having limited health literacy. The institutional review boards of participating institutions approved this study, and participants provided written informed consent.

When we designed this study, we conceived the older adult and surrogate roles as separate, and our recruitment strategy and data collection reflect that separation, but more than 80% of participants discussed experiences as both older adult and surrogate. Therefore, we combined both groups in the analysis and report participant contributions according to the perspective from which they spoke. When participants described decisions for themselves, they were referred to as older adults, and when they described decisions for others they were referred to as surrogates. We have also included ID numbers, with ID S1-S31 assigned to surrogates and ID P1-P38 assigned to older adults. Participants could report more than one decision, so the number of decisions identified could exceed the number of participants.

Focus Groups

We created a focus group guide with input from experts in the fields of geriatrics, decision-making, health literacy, and

advance care planning. Participants in groups focused on the older adult and surrogate experience were asked to describe serious medical decisions they had made and that they perceived as significant, important, or difficult, hereafter called “serious decisions.” Examples of serious decisions included decisions about emergency surgery, chemotherapy, and life-prolonging procedures such as mechanical ventilation. They were further probed to describe what helped them make serious decisions and who was involved in the decision-making process. (See Supplemental Table S1 for focus group guide.) The moderators frequently summarized participant comments and asked for confirmation of the moderators’ understanding. Groups lasted 90 minutes and were moderated by an advance care planning specialist (RS) and a native Spanish speaker for Spanish language groups and co-moderated by a co-author (RM), none of whom had a physician-patient relationship with any of the participants. We continued to conduct focus groups until we reached thematic saturation.

Data Analysis

All focus groups were audio-recorded and professionally transcribed. We used thematic analysis, including transcript data familiarization, codebook development, transcript indexing and coding (NVivo, QSR International Pty Ltd, authors RS, RM) and manual coding (author LP), and synthesis of overarching themes. All quotations that described decision-making experiences and how participants made decisions were excerpted and coded.^{3,27} The constant comparative method was used to refine the coding scheme.²⁸ We determined that thematic saturation was reached when a stable set of themes emerged and subsequent focus groups did not yield new themes.²⁹ Trustworthiness of methods was achieved using clear inclusion and exclusion criteria, a standardized focus group outline and coding manual, and an audit trail for coding. Coders achieved 84% agreement and resolved disagreements by consensus. Themes were analyzed and presented as specific to the older adult perspective, specific to the surrogate perspective, common to the older adult and surrogate perspective, and trends according to race and ethnicity.

RESULTS

Three hundred one adults were contacted by mail for participation in a series of research studies, 31 of whom refused using opt-out cards. We then contacted a consecutive sample of 114 participants by telephone, of whom 32 refused to participate and 13 were ineligible, leaving a study sample of 69 adults. We conducted 7 focus groups (4 mixed race or ethnicity, 3 Hispanic-only groups, group size range 3–6 participants) in which participants were recruited as older adults ($n = 38$) and 6 focus groups (2 mixed race or ethnicity, 2 African American, 2 Asian American, group size range 3–8 participants) in which participants were recruited as surrogates ($n = 31$). The mean age of older adult enrollees was 78 (range 64–89) and of surrogates was 57 (range 33–76); 74% of the cohort was non-white (Table 1).

Participants recalled 168 serious decisions (99 (59%) as older adults, 69 (41%) as surrogates). Five overarching

Table 1. Participant Characteristics (N = 69)

Characteristic	Value
Age, mean \pm standard deviation (range)	
Older adult	78 \pm 8 (64–89)
Surrogate	57 \pm 10 (33–76)
Race and ethnicity, n (%)	
African American	20 (29)
Asian or Pacific Islander	18 (26)
Hispanic	13 (19)
White	18 (26)
Female, n (%)	18 (48)
Spanish-speaking, n (%)	13 (19)
Self-reported health status, n (%)	
Excellent to good	44 (64)
Fair to poor	25 (36)
Limited health literacy, n (%)	15 (22)

decision themes were identified: decisions about cancer treatment, chronic illness, advance care planning, acute medical crises, and transitions (e.g., from acute care to hospice) (Table 2). Two themes of what helped participants make decisions were values and information sources (Table 3).

Types of Serious Decisions

Older adults

Older adults frequently perceived cancer decisions, particularly about surgical management of breast or prostate cancer, to be serious. A Hispanic man (ID P25) recalled, “Two weeks ago, the doctors have detected that I have prostate cancer. Right now it is stable, and they told me that I had three options: Chemotherapy, to get checked every three months, . . . [or] radiation. So, I decided to get checked every three months, and well, so far I have no problem.”

Many participants also identified decisions about chronic illness, such as osteoporosis and diabetes, as serious. A Hispanic man (ID P23) said, “I am not taking any diabetes medicines because . . . I don’t know how right they are. I don’t feel that I have diabetes.” An African-American man (ID P37) recognized the gravity of his decision to skip medications in retrospect: “I think I outsmarted myself in thinking that I was taking too many pills and I could outsmart my evaluation and my medication. So I started slipping a little. I wouldn’t take it every day.” Decisions about chronic illness management were described almost exclusively by older adults.

Surrogates

Surrogates often described decisions about transitions in care, such as changes in healthcare goals (e.g., from acute care to comfort focused) and transitions in care settings (e.g., from home to nursing home). Only surrogates reported this kind of decision. One African-American woman (ID S3) recalled, “In the end, when his body could no longer take food or fluids artificially, that was the time

to stop it and disconnect. . . . It’s time to let him go and that was a hard decision, too.”

Older Adults and Surrogates

Older adults and surrogates alike recalled decisions about advance care planning, including preferences about future care and naming surrogate decision-makers. One white female older adult (ID P8) said, “I make my own decisions, and I already have on record here what I want done at end of life. I don’t want any unusual resuscitation or anything.” Decisions about acute medical crises were also common to older adults and surrogates. Older adults described decisions about emergency surgery, such as cholecystectomy. A Hispanic woman (ID P18) said, “I’ve had gallbladder surgery a while ago, but nobody helped me in making that decision because the doctor told me that it was necessary to do it, and I couldn’t live without doing that surgery.” Other older adults described seeking medical attention for acute symptoms. A Hispanic man (ID P33) said, “I started feeling a sharp pain here. The pain was so strong that I had trouble walking. So I thought, ‘I must consult this to my doctor because I can’t be with this pain the entire time.’ I went to the emergency [room].” Surrogates typically described emergency decisions about life-sustaining treatment. An African-American man (ID S30) recalled, “My mom’s had an aneurysm, but they say she was brain-dead, they wanted to pull the plug. I said, ‘No.’”

Themes by Race and Ethnicity

Older adults and surrogates from all racial and ethnic groups consistently reported the same decision types, although white older adults more commonly described decisions about advance care planning than older adults of other races and ethnicities. African-American surrogates often reported decisions for loved ones in acute medical crises. An African-American woman (ID S31) recalled, “My son got hit with a hit-and-run and we had to make a decision within 24 hours. . . [to] take him off the life support.” African-American and Asian surrogates frequently described decisions about transitions in care for loved ones, a topic that was less common for Hispanic and white surrogates.

Factors That Helped Participants Make Serious Decisions: Values

Older Adults

Older adults frequently cited the value of self-sufficiency, the ability to make independent decisions or care for themselves, as important in decision-making. For example, an Asian man (ID P27) said, “I think if I’m going to be the one who’s dying, I want my decision to stay. I mean I don’t want my family tell me, ‘No, you can’t do it that. You have to do it our way.’” Older adults also valued maximizing survival, spiritual or religious beliefs, and avoiding suffering. One African-American woman (ID S13) said, “The goal was to do whatever it takes to stay alive, and so I made that decision.” A white man (ID P11)

Table 2. Categories and Sample Quotations Regarding Types of Decisions Participants Considered Serious, Difficult, or Important

Decision Type	Respondent	Quotation
Cancer treatment	Surrogate	The doctor examined her and took some blood tests and was telling me that she had a hidden cancer of some sort, that her life expectancy was pretty short. . . . So the real question was whether or not to do something about it and to talk it over with my brother. . . . Do you want to put your mother through a lot of tests for—that are very inpatient and she's had a great life and all that. It's kind of like getting me to think maybe about just not doing anything which I finally decide not to do anything.—ID P28, Man, White, aged 80–89
Cancer surgery	Older adult	The one that was most difficult for me was when I got a blood test showed that I had prostate cancer and so the physician I went to wanted to wait and watch. . . . I decided to have surgery.—ID P29, Man, White, aged 80–89
Chronic illness management		
Chronic medical treatment	Older adult	Regarding my pills, I have made a decision to take a medicine that comes from vegetables. The doctor doesn't know this. He always finds my blood fine and so, I believe that I am doing fine.—ID P33, Man, Latino, aged 60–69
Elective surgery	Surrogate	Well, I had to make a decision for my wife. I decided that she should have a hernia surgery and surgery on both of her knees. And I am the one who makes all the decisions for her.—ID P25, Man, Latino, aged 70–79
Transitions at the end of life	Surrogate	We made a decision all of us, as a family, because she was hospitalized due to her stroke. . . . whether to leave her in the hospital or take her home. We decided to take her home and made the commitment to take care of her in shifts.—ID P18, Woman, Hispanic, aged 80–89
Advance care planning		
Treatment preferences	Older adult	So my directive basically says, "I don't want to be kept alive artificially. If the doctors say there's not going to be any quality of life going forward, you know, just end it."—ID S7, Man, White, aged 70–79
Choice of surrogate	Older adult	I knew that I had to have somebody and it happens to be my nephew and he agrees with me that I could take care of myself as long as I could, of course.—ID P14, Man, White, aged 80–89
Acute medical crisis		
Life-sustaining treatment	Surrogate	So I have to make a decision then. She was on the life support too. . . . So the doctor explained. . . . there's no way; she's not going to make it, right. Don't let her suffer. . . . So I had to sign papers to pull the plug out.—ID S11, Woman, African-American, aged 40–49
Acute surgery	Older adult	I've had gallbladder surgery a while ago, but nobody helped me in making that decision because the doctor told me that it was necessary to do it and I couldn't live without doing that surgery.—ID P18, Woman, Hispanic, aged 80–89
Acute medical treatment	Surrogate	18 years ago, my first grandson was born. And I had to make a decision on the spot because my daughter couldn't give birth to her child. So, I told the doctor- He needed to give her a shot in her hip and yes, I made that decision.—ID P20, Woman, Hispanic, aged 60–69

Table 3. Categories and Representative Quotations About How Participants Made Serious or Difficult Decisions

Category	Respondent	Quotation
Values		
Self sufficiency	Older adult	When it's time for me to decline, Lord, just let me go and just go, but I don't want to wake up—somebody saying, "Keep her." Keep me for what? If I can't get up and do for myself, I don't want to be here.—ID S22, Woman, African-American, aged 50–59
	Surrogate	His independence is very important to him. So I would say you need to know as much as you can about that person.—ID S8, Woman, African-American, aged 60–69
Survival	Older adult	But the biggest thing that I had was a spirit of survival. I wasn't afraid; if I was born to die why would I be afraid? So, I said, "I want this one [treatment]," since it was the only one that guaranteed me a bit more life.—ID P24, Man, Latino, aged 70–79
	Surrogate	You know, eventually a few months later, he died but I didn't like that doctor said, "He's old. We should just let him go." It's—to me then, it was like murder. If you can save it, you should save it, rather than just say, "Oh, he's 90 years old. Let him go."—ID S14, Woman, Asian, aged 60–69
Avoiding suffering	Older adult	I don't believe in unnecessary prolongation of life just if it hasn't any quality and the end is going to be the same.—ID P8, Woman, White, aged 80–89
Information	Surrogate	Concerning my mother, she was suffering a lot... I asked God to take her, because I didn't want to see her suffering. If it would have been that they were giving her life artificially, I would have said to remove everything and to let her go in peace.—ID P24, Man, Latino, aged 70–79
Medical advice	Older adult	Yes, the doctor's opinion. I always like it because... they have to give me options, that is why they have studied to be doctors.—ID P26, Man, Latino, aged 70–79
Family opinion	Older adult	Yes, my children gave me advice. But I had already decided to do it.—ID P17, Woman, Hispanic, aged 70–79
	Surrogate	So she made me the executrix and then the advance directive had to be put in place... I tried to take into consideration that my mother—that was my mother's mother—and then also my siblings as well, so I did allow them to help to make the decision.—ID S13, Woman, African-American, aged 50–59
Independent research	Older adult	I go to every publication I could and I just did reading and that helped me make up my mind.—ID P29, Man, White, aged 80–89
Experience	Older adult	But anyway, my mother passed in 2000 and she had cancer for like three years, lung cancer, and she didn't know she had cancer... the little clinic and staff was treating her for asthma... they never did an x-ray on her chest. So that's how I know to get x-rays... and when I found out that I had cancer.—ID S11, Woman, African-American, aged 40–49
	Surrogate	These things are related to old age. We have seen them in our parents, our grandparents and the thing is that now it's our turn, it is logic. That is how the human body works; everything that is born must die.—ID P26, Man, Latino, aged 70–79

said, “In my case, there was my faith and my trust in the scriptures at the time of my decision, and I was nudged in the direction I went.”

Surrogates

The dominant value that surrogates reported was avoiding suffering for the older adult. A white man (ID P28) explained, “Her quality of life was very good to the end. She died in her sleep... Putting her through the severity of the tests and the invasion of whatever surgery that might be following from all that would have made her a miserable person, and she would have died in a lot of agony.”

Some surrogates felt that religion played a role in their decisions. Many surrogates described feeling like decisions were out of their hands because God had decided their fate. A Hispanic man (ID P26) said, “The Lord is the Lord of my life, at least mine and my wife’s, and He is the One who decides the day He takes us.” Similarly, an Asian woman (ID S29) said, “If I’m the wife, and my husband is suffering, you know, I think my God will not let him suffer that much, you know, as I believe that He loves everyone by taking off the tube or stop the pain or the suffering that’s killing him.”

Factors That Helped Participants Make Serious Decisions: Information Sources

Older Adults

Older adults frequently described relying on personal experience, medical advice, family opinion, and research. An African-American woman (ID S3) recalled, “The experience I had with my husband, my brother... made me get my paperwork in order.” A Hispanic man (ID P33) stated, “It is very positive to talk to your doctor because the doctor encourages us,” and a white man (ID P9) said, “My daughter is the one that pushed me on this.” An African-American woman (ID S16) commented, “I was looking up everything as it relates to cancer.”

Surrogates

Surrogates’ information sources were similar to those of older adults except they did not describe researching decisions. Surrogates relied on personal experience, especially knowledge of the older adult. An African-American woman (ID S25) said, “I kind of got to know my grandmother in a way that I hadn’t known her before for spending so much more time with her.” Family opinion was also important to surrogates. “I have four siblings, and so we’re all strong willed, and so we definitely had a difference of opinion,” recalled an African-American woman (ID S16). Surrogates also relied on medical advice. An Asian woman (ID S27) recalled, “Of course, I want to try my best to keep him alive, but the doctors say, ‘Oh, at that age, if you put the tube in and something will even hurt him more.’ So then, you know, when the doctor explained to me more details about that and that kind of changed—and I changed my mind and I say, ‘O.K., so don’t revive him.’” Some surrogates sought multiple

information sources. An African-American woman (ID S5) said, “My husband left the final decisions to me, and I prayed on it; I spoke with people in the medical profession, my mom, nurse friends, to explain what the DNR meant.”

Themes According to Race and Ethnicity

Participants from all racial and ethnic groups described similar values and information sources. Self-sufficiency in decision-making was the most commonly cited value for all older adults except Hispanic older adults, whose main goals were maximizing survival and honoring religion in decision-making. African-American and Hispanic older adults discussed how personal experiences guided them more often than medical advice, whereas Asian older adults frequently mentioned relying on medical advice.

All surrogate groups emphasized the importance of avoiding suffering for loved ones, incorporating medical advice, and relying on religion. African-American and Asian surrogates also described respecting their loved ones’ autonomy, such as an African-American woman (ID S5) who said, “And, of course, the advance directive helps because everything’s in black and white, and when the person made a decision prior, they, you know, had a clear mind.”

DISCUSSION

Diverse English- and Spanish-speaking older adults and surrogate decision-makers reported making a range of decisions they perceived as serious, difficult, or important and a range of values and information sources that helped them make these decisions. Many clinicians may be aware of the need to support older adults and surrogates in making decisions on such things as cancer treatment and life-threatening illness. They may not be aware that diverse older adults and their surrogates perceive as serious, and need support for, other decisions such as day-to-day chronic illness management and transitions to nursing home care, as our novel results demonstrate. Awareness of the decisions that older adults and surrogates perceive as serious is essential to trigger clinicians to engage in shared decision-making (Figure 1). Using the framework of the “collaborative care” model, clinicians can help older adults and surrogates identify the problems for which they need support.⁴² Then, based on older adults’ and surrogates’ desired role in decision-making, clinicians may individualize a plan to help with problem-solving skills while ensuring that older adult and surrogate values and personal and social context, as described in this study, are incorporated into the shared decision-making process to achieve person-centered care.⁴³

Surrogate decision-makers for older adults commonly recalled decisions about transitions in care, such as nursing home placement, as well as making substitute decisions during medical crises. These findings are consistent with the reality that most individuals lose decision-making capacity at the end of life. Decisions about care transitions were particularly common for African-American and Asian surrogates. The less-frequent discussion about

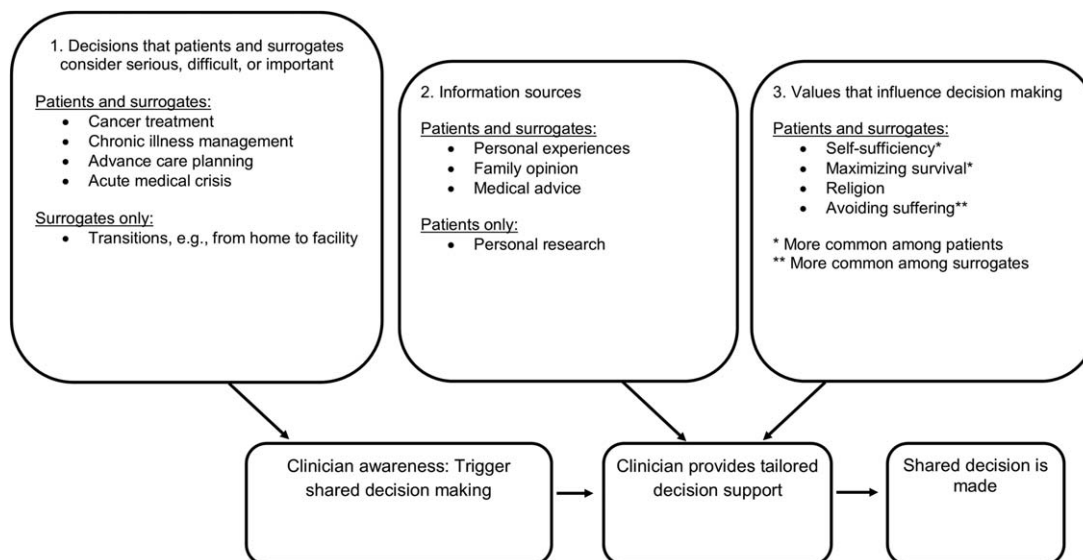


Figure 1. How knowledge of the kinds of decisions that older adults and surrogates find to be serious, difficult, or important (Box 1) triggers clinicians to engage older adults in shared decision-making. Appreciation of the information sources (Box 2) and values (Box 3) on which older adults and surrogates rely also allows clinicians to provide customized decision-making support.

advance care planning in nonwhite than white participants in this cohort is consistent with the literature on advance directive completion.³⁰ Less advance care planning in nonwhite groups may explain the greater difficulty with decisions about transitions and acute medical crises of surrogates. This and other studies demonstrate the importance of preparing surrogates for substitute decision-making, which may reduce surrogates' decisional conflict with end-of-life decisions.³¹ It also underscores the need for shared decision-making models of support for older adults and surrogates.^{27,32} Future studies to better characterize how decisions about transitions in care are made and how to best honor older adult preferences in these circumstances are warranted.

Participant perceptions of clinician involvement in decision-making were generally positive, although advice from clinicians was only one thread in the tapestry of values, experiences, and trusted sources that informed diverse older adults' and surrogates' serious decisions. Many of the values and information sources participants named were consistent with findings of prior research in specific settings. For example, the importance to older adults of maintaining control over decisions echoed those from prior studies of veterans with cancer.^{18,19,33} Furthermore, expression by older adults and surrogates that God decided their fate has previously been observed in older adults from a range of ethnic groups.^{19,34} In addition, the observation that lived experiences are fundamental to how individuals approach decisions is consistent with a prior study in women deciding about participation in a breast cancer prevention trial³⁵ and surrogates making end-of-life decisions.²⁰ That African-American and Hispanic older adults in this cohort discussed how personal experiences guided them more often than medical advice may reflect the well-documented mistrust of the medical system of historically marginalized populations.^{36,37} Despite the presence of these similar themes in specific populations in prior studies, our study contributes the novel finding that

these values are consistent in a diverse group of older adults and surrogate decision-makers and for a wide range of decision types.

This study also highlighted an important mismatch between the goals of decision-making of older adult, who emphasized self-sufficiency and control, and those of surrogates, who emphasized minimizing suffering. The use of surrogates' own values and goals may hinder substituted judgment when making decisions for older adults.^{20,21,38} Advance discussion of values with older adults and surrogates may help to reconcile these differences through mutual understanding and allow older adults and surrogates to discuss possible flexibility in surrogate decision-making in advance of a medical crisis.³⁹

Strengths of this study include the diversity of race, ethnicity, and health status of participants, the inclusion of older adult and surrogate perspectives, and the inclusion of decisions across the illness trajectory, not just at the end of life. The open-ended focus group format may have also allowed participants to recall more experiences than they might have in questionnaires. Nevertheless, several considerations are important in the interpretation of our findings. Participants were recruited from one geographic area, limiting the generalizability of our results. In addition, given the qualitative nature of this study, we did not survey participants about every important decision or everything that informed their decision-making. Our results were limited to the decisions that participants felt comfortable sharing.

In conclusion, diverse older adults and surrogates perceive a range of decisions as serious, difficult, or important, including decisions about day-to-day chronic illness management and transitions in care. With awareness of diverse older adults' and surrogates' perceptions of serious decisions, clinicians may provide support in the decision-making process that is customized to individual needs. Clinicians should also explore the range of values, experiences, sources of advice, and cultural beliefs that older

adults and surrogates use to make serious decisions, and be mindful of possible differences in values between older adults and surrogates in serious decision-making.⁴⁰ Appreciation of the values and information sources on which diverse older adults and surrogates rely should also guide the development of decision support tools for serious medical decisions.

ACKNOWLEDGMENTS

This work was presented at the American Academy of Hospice and Palliative Medicine Annual Assembly in Chicago, IL, March 2016.

Financial Disclosure: Dr. Petrillo was supported by a Veterans Affairs Quality Scholar fellowship. Dr. Sudore was supported by Veterans Affairs Investigator-Initiated Research Grant (11–110–2), National Institute on Aging Grant (R01 AG045043), Patient-Centered Outcomes Research Institute Career Development Award CDR-1306–01500, and grants from the University of California, San Francisco Tideswell Foundation, American Cancer Society, and John and Wauna Harman Foundation.

Conflict of Interest: All authors report no personal or financial conflicts of interest.

Author Contributions: Dr. Sudore designed and conducted the focus groups. Dr. Petrillo designed and conducted the qualitative analysis. Mr. McMahan assisted with the focus groups and qualitative analysis. All authors were involved in the writing of the manuscript.

Sponsor's Role: The funding sources that supported the authors had no role in the design or analysis of the study, nor in the preparation of the manuscript.

REFERENCES

- Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
- Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *N Engl J Med* 2012;366:780–781.
- Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Couns* 2006;60:301–312.
- Gravel K, Légaré F, Graham ID. Barriers and facilitators to implementing shared decision-making in clinical practice: A systematic review of health professionals' perceptions. *Implement Sci* 2006;1:1–12.
- Tariman JD, Berry DL, Cochrane B, Doorenbos A, Schepp K. Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Ann Oncol* 2010;21:1145–1151.
- Bruera E, Sweeney C, Calder K, Palmer L, Benisch-Tolley S. Patient preferences versus physician perceptions of treatment decisions in cancer care. *J Clin Oncol* 2001;19:2883–2885.
- Sudore RL, Landefeld CS, Pérez-Stable EJ, Bibbins-Domingo K, Williams BA, Schillinger D. Unraveling the relationship between literacy, language proficiency, and patient–physician communication. *Patient Educ Couns* 2009;75:398–402.
- Bauer AM, Parker MM, Schillinger D, et al. Associations between antidepressant adherence and shared decision-making, patient–provider trust, and communication among adults with diabetes: Diabetes Study of Northern California (DISTANCE). *J Gen Intern Med* 2014;29:1139–1147.
- Li DJ, Park Y, Vachharajani N, Aung WY, Garonzik-Wang J, Chapman WC. Physician-patient communication is associated with hepatocellular carcinoma screening in chronic liver disease patients. *J Clin Gastroenterol* 2017;51(5).
- Williams BA, Lindquist K, Sudore RL, Covinsky KE, Walter LC. Screening mammography in older women: Effect of wealth and prognosis. *Arch Intern Med* 2008;168:514–520.
- Whitney SN, McCullough LB. Physicians' silent decisions: Because patient autonomy does not always come first. *Am J Bioeth* 2007;7:33–38.
- Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: A systematic review. *Patient Educ Couns* 2012;86:9–18.
- Brom L, Pasman HRW, Widdershoven GAM, et al. Patients' preferences for participation in treatment decision-making at the end of life: Qualitative interviews with advanced cancer patients. *PLoS One* 2014;9:e100435.
- Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. *Patient Educ Couns* 2006;60:102–114.
- Thompson SC, Pitts JS, Schwankovsky L. Preferences for involvement in medical decision-making: Situational and demographic influences. *Patient Educ Couns* 1993;22:133–140.
- Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: Decision making and information-seeking preferences among medical patients. *J Gen Intern Med* 1989;4:23–30.
- Butow PN, Maclean M, Dunn SM, Tattersall MHN, Boyer MJ. The dynamics of change: Cancer patients' preferences for information, involvement and support. *Ann Oncol* 1997;8:857–863.
- Naik AD, Martin LA, Moye J, Karel MJ. Health values and treatment goals of older, multimorbid adults facing life-threatening illness. *J Am Geriatr Soc* 2016;64:625–631.
- Karel MJ, Mulligan EA, Walder A, Martin LA, Moye J, Naik AD. Valued life abilities among veteran cancer survivors. *Health Expect* 2016;19:679–690.
- Vig EK, Taylor JS, Starks H, Hopley EK, Fryer-Edwards K. Beyond substituted judgment: How surrogates navigate end-of-life decision-making. *J Am Geriatr Soc* 2006;54:1688–1693.
- Vig EK, Starks H, Taylor JS, Hopley EK, Fryer-Edwards K. Surviving surrogate decision-making: What helps and hampers the experience of making medical decisions for others. *J Gen Intern Med* 2007;22:1274–1279.
- Su CT, McMahan RD, Williams BA, Sharma RK, Sudore RL. Family matters: Effects of birth order, culture, and family dynamics on surrogate decision making. *J Am Geriatr Soc* 2014;62:175–182.
- McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: Perspectives from patients and surrogates. *J Pain Symptom Manage* 2013;46:355–365.
- Cook SE, Marsiske M, McCoy KJM. The use of the Modified Telephone Interview for Cognitive Status (TICS-M) in the detection of amnesic mild cognitive impairment. *J Geriatr Psychiatry Neurol* 2009;22:103–109.
- Shadbolt B, Barresi J, Craft P. Self-rated health as a predictor of survival among patients with advanced cancer. *J Clin Oncol* 2002;20:2514–2519.
- Sarkar U, Schillinger D, López A, Sudore R. Validation of self-reported health literacy questions among diverse English and Spanish-speaking populations. *J Gen Intern Med* 2011;26:265–271.
- Elwyn G, Frosch D, Thomson R, et al. Shared decision making: A model for clinical practice. *J Gen Intern Med* 2012;27:1361–1367.
- Glaser B, Strauss A. *Discovery of Grounded Theory: Strategies for Qualitative Research*. Mill Valley, CA: Sociology Press; 1967.
- Greg Guest, Arwen Bunce, Laura Johnson. How many interviews are enough? An experiment with data saturation and variability. *Field Methods* 2006;18:59–82.
- Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low completion and disparities in advance care planning activities among older Medicare beneficiaries. *JAMA Intern Med* 2016;176:1872–1875.
- Chiarichiaro J, Buddadhumaruk P, Arnold RM, White DB. Prior advance care planning is associated with less decisional conflict among surrogates for critically ill patients. *Ann Am Thorac Soc* 2015;12:1528–1533.
- Torke AM, Petronio S, Sachs GA, Helft PR, Purnell C. A conceptual model of the role of communication in surrogate decision making for hospitalized adults. *Patient Educ Couns* 2012;87:54–61.
- Braun UK, Beyth RJ, Ford ME, Espadas D, McCullough LB. Decision-making styles of seriously ill male veterans for end-of-life care: Autonomists, altruists, authorizers, absolute trusters, and avoiders. *Patient Educ Couns* 2014;94:334–341.
- Perkins HS, Cortez JD, Hazuda HP. Cultural beliefs about a patient's right time to die: An exploratory study. *J Gen Intern Med* 2009;24:1240–1247.
- Holmberg C, Waters EA, Whitehouse K, Daly M, McCaskill-Stevens W. My lived experiences are more important than your probabilities: The role of individualized risk estimates for decision making about participation in the Study of Tamoxifen and Raloxifene (STAR). *Med Decis Making* 2015;35:1010–1022.
- Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. *Public Health Rep* 2003;118:358–365.
- Corbie-Smith G, Thomas SB, St. George DM. Distrust, race, and research. *Arch Intern Med* 2002;162:2458–2463.
- Smith AK, Lo B, Sudore R. When previously expressed wishes conflict with best interests. *JAMA Intern Med* 2013;173:1241–1245.

39. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: preparing for end-of-life decision making. *Ann Intern Med* 2010;153:256–261.
40. Crawley LM, Marshall PA, Lo B, Koenig BA. Strategies for culturally effective end-of-life care. *Ann Intern Med* 2002;136:673–679.

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher’s web-site

Table S1. The focus group guide, including specific directions to older adult and surrogate groups. For additional findings from these groups, see Su et al. and McMahan et al.^{22,23}

Please note: Wiley-Blackwell is not responsible for the content, accuracy, errors, or functionality of any supporting materials supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author for the article.