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Participation of Very Old Adults in Healthcare Decisions

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Abstract

Background—Some elderly people receive tests or interventions from which they have low likelihood of benefit or for which the goal is not aligned with their values. Engaging these patients in the decision process is one potential approach to improve the individualization of care. Yet some clinicians perceive and some survey data suggest that older adults prefer not to participate in the decision-making process. Those preferences, however, may be formed based on an experience in which factors, such as communication issues, were barriers to participation. Our goal was to shed light on the experience of very old adults in healthcare decision-making from their own point of view to deepen our understanding of their potentially modifiable barriers to participation.

Design and Methods—Semi-structured interviews of participants aged 80 and older (n=29, 59% women and 21% black) were analyzed using the constant comparative method in a grounded theory approach to describe decision-making in clinic visits from the patient's perspective.

Results—Average age of participants was 84 (range 80–93) and each described an average of 6.4 decision episodes. Active participation was highly variable among subjects. Marked differences in participation across participants and by type of decision -- surgery, medications, diagnostic procedures, and routine testing for preventive care -- highlighted barriers to greater participation. The most common potentially modifiable barriers were the perception that there were no options to consider, low patient activation, and communication issues.

Conclusions—The experience of very old adults highlights potentially modifiable barriers to greater participation in decision-making. To bring very old patients into the decision process, clinicians will need to modify interviewing skills and spend additional time eliciting their values, goals, and preferences.

Keywords

decision making; attitudes and perceptions; physician-patient communication; oldest old; qualitative study

INTRODUCTION

There is growing concern that the U.S. healthcare system fails to deliver care that is aligned with the needs and preferences of a rapidly growing segment of the population-- the oldest old (1, 2). The concern comes from studies which show provision of aggressive care at the end of life and for chronic diseases when it is not preferred, screening for occult cancer

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when life expectancy is short, and the low rate at which pain and geriatric syndromes are identified (3–8). Such gaps between the services provided and what really matters to the patient suggest that the process by which we make healthcare decisions with elderly adults is not centered on their individualized needs and preferences, a central part of what determines decision quality.

Decision quality is measured by assessing the degree to which the patient is well-informed and his preferences are reflected in the choice (9). One approach to improving decision quality is to adopt a shared decision-making process (9–12) which involves the clinician “communicating personalized information on options, outcomes, probabilities, and scientific uncertainties, and patients communicating the personal value or importance they place on benefits and harms so that agreement on the best strategy can be reached” (13, p64). Many studies have been conducted to advance shared decision making using decision aids in diverse clinical contexts that show the value of such an approach in terms of improved decision process and quality (14).

Both elderly patients and clinicians, however, perceive many barriers to elder participation in a shared decision process (15, 16). A critical barrier is physicians’ impression that elders wish to defer decision-making to their providers (16) -- a perception that conflicts with findings in survey studies that show the preference for participation in healthcare decisions is variable at all ages, although a higher proportion of older adults prefer less participation (15, 17–21). The surveys, however, do not reveal the reasons behind the preference; it may be driven by not feeling knowledgeable enough about health or medicine to make a meaningful contribution to the discussion, rather than a wish to be uninvolved in the decision process (19). Yet little other existing research directly addresses the dynamics of participation by the elderly adult, as opposed to asking about their preference for participation. Studies to date have mostly employed hypothetical situations or a single specialized healthcare decision that may not reveal what is actually happening in general practice (15, 22, 23). A fundamental question remains unanswered: “How do older patients participate in healthcare decision-making?”

We addressed this question by conducting a qualitative study using in-depth interviews of people over age 80, listening to them describe their experiences of making healthcare decisions in the clinic setting with their doctors. The qualitative method, as opposed to a method based on surveys, allows for description of experience without making assumptions about preferences for participation or about how the decision process occurs. Our goal was to understand the level of participation of very old adults, understand the process by which participants experience medical decision making, and identify barriers to greater participation in their healthcare decision-making, in particular those that may be modifiable.

METHODS

Participants and Recruitment

All participants were required to be at least 80 years old. Recruitment was based on purposive sampling to obtain breadth of experience (24) with respect to income, education level, and ethnicity. We recruited subjects from regions with high and low healthcare utilization (Memphis, TN and Lebanon, NH respectively) because we were concerned that patients having many healthcare interventions might experience decisions differently than those having fewer interventions. A region’s intensity of end-of-life care was used as a proxy for general utilization in Medicare populations (25). In Tennessee, we recruited in four senior centers each located in a different neighborhood and serving economically and racially diverse populations. In New Hampshire, we recruited in an affluent continuing care community, subsidized housing, senior centers and subsidized elder day care. Employees at each site facilitated recruitment of volunteers and were instructed not to refer anyone with known cognitive impairment. We also required that participants be able to give their name, address, and phone number independently. One volunteer was not enrolled because she did not have the recall to participate without family assistance.

Data Collection

Participants met individually with an interviewer either in their home or in a senior center. Written informed consent was obtained in accordance with the IRB-approved protocol. The in-depth, semi-structured interviews lasted 45 to 75 minutes and were audio-taped and transcribed. We used physician interviewers (L.B, J.B.) because conducting effective open-ended interviews required fundamental understanding of medical conditions, medications, and procedures to identify areas for further probing questions. However, they had no clinical relationship with participants and did not identify themselves to the participants as physicians.

The interview guide (Appendix) was informed by Yates' ten cardinal issues in human decision making (26). The questions followed the recommended funnel structure (24, 27), beginning with open-ended questions that allow the interviewee to tell her story from her own perspective and then proceeding toward more detailed questions. The interview proceeded from questions about overall health and current healthcare, to opportunities for making choices, the decision-making process itself, healthcare values and goals, and perceptions of alignment between goals and current care. The central feature of the protocol was asking participants to describe -- in long narratives -- any decisions that were made during their most recent clinic visit. If none were recalled, then the interviewer prompted with questions about any changes that occurred from the visit pertaining to different types of care (surgery, medications, diagnostic procedures, and routine testing for preventive care). We did not explicitly ask their preference for participation out of concern that the question may create bias in their described account of how the decision process occurred. While asked about the most recent clinic visit, participants were free to discuss any decisions in recent memory. We explored patient experience by decision type to elicit a spectrum of expected participation from high, such as surgery which requires signed consent, to low, such as lab tests. The guide was refined after each of the first few interviews as we learned how best to stimulate storytelling by the participants.

Data Analysis

After interviewing was complete, the units of analysis, termed decision episodes, were demarcated in each transcript. A decision episode was defined as an interview segment that included a judgment about taking or not taking an action. A decision episode began when a participant described a health issue that arose during an interaction with a clinician. It included the participant's spontaneous description and responses to interviewer probes. To qualify as a decision episode, the health issue had to be an actual (not hypothetical) past experience of the participant, described in sufficient detail to understand the 'who, what, when, where, why, and how' about the decision.

Two researchers (J.B., C.R.) coded the transcripts using the constant comparative method in applying a grounded theory approach (28), supported by qualitative data analysis software (Atlas.ti). A sequence of actions (and non-actions) in the participants' decision processes uncovered themes by comparing and contrasting decision episodes across participant characteristics and across types of care. The coders reached "saturation," the point at which no new themes were being identified, by the end of the 13th interview. The decision episodes in the remaining 16 interviews were reviewed for confirming and refuting evidence related to the identified decision process and to identify any relationships between themes and demographic groups represented in the sample. Funding agencies had no influence on the design, conduct, or interpretation of the study.

RESULTS

Description of Sample

Our 29 participants ranged in age from 80–93 (mean 84). More than half were women (n=17, 59%) and one-fifth black (n=6, 21%) with the remaining non-Hispanic white. Most participants were widowed (n=17, 59%), followed by married (n=10, 34%), one divorced and one single individual. Half of the participants had at most a high school education (n=14, 48%), five (17%) had some college, and ten (34%) were college graduates. Twelve (41%) interviews were conducted in New Hampshire and 17 (59%) in Tennessee. Among the 29 participants 186 decision episodes were identified (2–13 episodes per participant).

Variation in the Decision-Making Process by Type of Care

By examining the decisions episodes, we were able to determine the steps that made up the decision process which included: recognizing a decision is being made, identifying options, obtaining medical information about options, identifying and making patient values and preferences known, weighing the options according to patient values, making the decision, and finally re-evaluating the decision. Variations in how each step was experienced are shown in Table 1. Once we understood the potential steps in the process, we examined how decisions proceeded by different types of decisions (such as surgery, medications, diagnostic procedures, and routine testing for preventive care). Not all steps occurred for every decision, nor did they necessarily occur in the order listed previously. Through these differences across decision type, we were able to assess the general level of participation of older adults in each type of decision.

Decisions for surgery (59 decision episodes) had the greatest level of participation. Participants described understanding that there was a choice. They frequently talked with other people who had experienced the procedure, discussed the decision with family, and sometimes their primary care provider. Even though they were aware that their consent was required prior to surgery, they often perceived their role in the decision as limited to accepting or rejecting the offered procedure as opposed to actively participating by voicing their values and preferences. “He [the doctor] didn’t say you can or you can’t. He said this is what we offer. And I had the choice.”

We found that the process for changing medications (49 decision episodes) also demonstrated high participation, but unlike surgical decisions in which discussion occurred *during* the visit with the physician, active participation occurred *after* the visit when filling the prescription. The participants often described re-evaluating the medication decision after getting printed information from the pharmacy or learning the cost of the medication. One participant was asked to increase a dose and said “Well, reading up on what comes with my prescription, it says ‘do not double’. So I said no. So I don’t take two.” When participants felt the medication was not right for them, some responded by continuing to comply passively but many actively non-adhered, usually without communicating the change in regimen to the physician. “At one point I was taking about 17 pills, … so I just dropped everything and I do pretty much on my own.”

Decisions about whether to have diagnostic procedures, such as gastrointestinal endoscopies or advanced imaging, (23 decision episodes) were generally perceived as “needed” without a sense there may be more than one way to approach their problem or any options to consider. Yet participants did re-evaluate these decisions and in several cases expressed regret about the original decision, questioning whether it was the right test or stating to the interviewers that they would not do it again. In contrast, tests commonly performed for preventive care (37 decision episodes) such as blood tests, EKGs, annual chest x-rays, and cancer screening were usually described as “routine”. Patients did not recognize these as involving a decision or any risk, and did not reevaluate or express any discord. (“She [the doctor] just decided to give me a test and I didn’t even ask her why you [sic] requested me to take a blood test. I didn’t even ask.”) Five participants stood out as striking exceptions by actively declining screening for occult cancer when it was recommended because they said they would not accept cancer treatment.

The differences in decision processes across the types of care from surgery to “routine testing” highlight the importance of whether the participants felt there were any options for them to consider or even any decision to be made. While participants did not discuss signing consent forms, it is likely the requirement for active consent for surgery made the decision explicit, as did the action of filling a prescription. But to participants, testing for preventive care often appeared to be a necessary action in which there was no choice. We found many instances in which the participant did not perceive a choice or even that a decision was being made. (“Anyways, she [the doctor] is very good at explaining things. As far as choices, I am trying to think if there ever was a case.”)

Level of Participation in the Decision Process

We further assessed the general level of participation for each individual by coming to consensus regarding each person’s participation across all decision types. Many participants described low overall participation. Some explicitly stated that they did not participate: “I don’t really make decisions…I always believe in letting the expert do it unless I see that it is not going right;” while a few (n=6) demonstrated exceptionally high participation: “I made a very informed decision [regarding back surgery]. It was great. I don’t think there was anything I didn’t consider.” Whether their overall participation was low or high, the majority of participants made robust efforts to get information about the pros and cons of the available options, whether they made the decision or not, suggesting at least interest in being informed about the decision at hand. Many different types of sources were used, including peer experiences, written materials, other clinicians, and the internet. However, information seeking did not necessarily indicate being well informed because of the inconsistent quality of data sources. (“My book is 20 years old.”)

Factors Related to Level of Participation

Through the comparison of decision episodes and patients that demonstrated high and low participation, factors related to level of participation were further highlighted. As described in the previous section, the perception that there were no options was a major barrier to participation in a decision. And in its most exaggerated form, the patient did not realize a different action or even non-action could be considered, highlighted by the examples of “routine” testing and screening. Other factors were also barriers (illustrated in Table 2 and described below), including low patient activation, obstructed communication with the clinician, patients seeking information from very few sources, patient beliefs that clinicians know his/her values, and patients not addressing discord with their doctor directly.

The participants’ belief that they had an important role to play in their own health, a concept called patient activation (29), was related to how much they participated in decisions. Those who felt they knew too little about their health were more likely to report that the physician made the decisions. (“I figure the doctor knows more about my body than I do so I go by what they, he, whoever says.”) Highly activated patients described asking questions and asserting their own preferences or values. (“You know a lot of the time doctors don’t ask you and you can’t really ask them. But I feel confident, anything I want to know I’ll ask her.”)

Several barriers in communication between the patient and physician could interfere with patients engaging in the decision process. As shown in Table 2, participants described interactions in which they felt unable to make their needs heard and interactions in which communication that felt rushed or closed them down. (“It’s so hard to get them to pay any attention to you. They don’t listen to what you’re saying. ‘You’re an old lady and, tada, tada, tada’ -- you know?”) Communication barriers precluded the possibility of information sharing and dissuaded participants from asking questions. Not only did some participants report being unheard, three felt that their input would not matter. They ascribed financial motives to physicians’ recommendations, leading them to feel their preferences would not be respected even if they were communicated.

Seeking information was a central activity of people who had the highest participation in decisions, while those who relied solely on their physician simply deferred to the clinician’s judgment. (“Well, I knew if they [the doctors] said that I needed to have it, I figured they wouldn’t tell me a lie.”) Such deference contrasts with the process of those with high participation who sought information from multiple sources (“from everybody, every pamphlet, every place I pass”) or multiple people (“I wanted lumpectomy and radiation and I found people who had done that. It was hard, I had to find people, search them out.”)

Another barrier was the belief that the physician already knows all relevant information about patient values. As shown in Table 1, many elderly patients said that the physician through training or longevity of their relationship was aware of his/her values. One respondent was striking because during the interview she appeared to change her view about whether her physician knew that her goal was to maintain quality of life: “Oh I am sure she knows that … (whispers) yeah, yeah….” *and how would she know that?* “By looking at me…laugh…you know what, maybe I’d ought to tell her that.”

Nearly all participants were able to recall instances when they disagreed with their doctor’s recommendation and the most common patient approach was not to address the discord. They avoided conflict in one of three ways. Most often participants simply complied without comment or choose not to adhere, usually without informing the physician. A few (n=3) avoided the conflict altogether by changing physicians, which is remarkable considering the likely challenges of establishing with a new physician at advanced age. A few did address the discord directly either by asking more questions or outright telling the provider that they disagreed. This very common response of avoiding conflict suggests that conflict avoidance may be a particularly salient barrier for older adults. In addition, when elderly patients disagree but do not voice their concerns, the physician anecdotal belief that they do not wish to be involved in decisions may be reinforced.

DISCUSSION

Main Findings

The experience of very old adults when making healthcare decisions with their clinicians demonstrates that they do participate to some degree and have the *potential* to be active participants in decision-making. However, modifiable barriers would need to be addressed to achieve greater participation. As a foundation for engaging very elderly patients in decision processes, physicians need to explain explicitly the options because very elderly patients may not perceive any options, typically because they believe that doctors recommend only clearly indicated actions or have already taken patient values into account. Open communication with clinicians about options to consider, patient values, and potential patient discord could also facilitate greater participation of very old adults in healthcare decisions.

Level of Participation Clarified as a Behavioral Concept

Our findings about participation of the very old in decision-making must be put in the context of what is already known about preferences for involvement in decision-making. There are many studies that focus on how to measure the level of involvement and on the preference for involvement in the decision-making process, yet these studies have not focused on very old adults (30–34). Work by Degner highlighted that the potential roles for patient participation are complex and preferences for those roles are diverse within demographic groups (17). Based on surveys, others have confirmed the variability but suggest a lower preference for involvement with advancing age; however, they do not further explain reasons for the expressed preference (15, 18, 23, 35). We did not seek to assess *preference* for involvement as in these other studies, but rather whether the self-described behaviors of very old adults demonstrate taking actions that exhibit participation or potential for participation in the decision process. The distinction between exhibited participation and preference is important because some people may not have the appropriate information, skills or support to feel they can participate in a knowledgeable way (21, 36–41). The self-perception of inadequate skills may lead to a stated preference for lower participation in decision-making (19). Another study has taken a similar approach to distinguish preference from behavior in elderly adults. While very old participants had negative attitudes toward consumerism (which is when the patient is not a passive recipient but rather listens to options and comes to his own decision), Beiseker found the directly observed communication style with clinicians was equally likely to employ consumerist communication behaviors as younger adults (21).

Understanding the Experienced Decision Process through Models of Decision Making

Any efforts to provide decision support to very old adults also need to be informed by how the decision process proceeds for this population. The Ottawa Decision Support Framework is a commonly used model to design shared decision-making interventions (42, 43). The first step in this model is to clarify the options available for consideration. Yet for the very old, we suggest that, even before clarifying the aspects of a decision, the patient and clinician need to state explicitly that there is a decision at hand. This notion is what is called “deciding to decide” in the decision psychology literature (44). In its absence an older patient may assume there is only one way to proceed. For example, screening for occult cancer has been “routine” across the elders’ lives and they may not recognize that anyone might consider stopping.

Another helpful framework is to understand how the “information exchange” between a clinician and patient occurs, which has been used to identify paternalistic, informed, or shared decision-making (34, 45). In both paternalistic and informed models, information flows from the physician to the patient, the difference being who weighs the options and makes the decision. In the shared model information exchange is bidirectional; medical information flows from the doctor to the patient and value information flows from the patient to the doctor. Many participants described trusting that their physician already knows their values, which may influence whether they perceive any need to be involved in the decision process. Yet we know from other studies that the agreement between patient-stated preferences and what their clinicians say is fair at best (8). Like other studies, we found that there can be either positive or negative effects of a patient’s trust that the clinician knows what is best – positive when the trust fosters open communication and negative when the patient assumes no communication is necessary (15, 19, 46).

Overcoming Barriers Among Elderly Adults

The barriers to greater participation among the very old adults interviewed for this study were similar to those in other populations – low patient activation and communication issues. While the type of barriers may be similar in very old and younger populations, their prevalence and poignancy may be more prominent in older people. We found that every participant who was engaged in healthcare decisions believed they had an important role in their health, but not every participant who believed they had an important role in their health was engaged in the decision-making process. Hibbard has commented that basing the assessment of decision quality on the participation of the patient incorporates implicitly the concept of patient activation (47). Others have reported that a similar concept, self-efficacy, was a predictor of the belief that it was possible to be engaged in decisions and of level of involvement (15, 46). And another related concept of health literacy regarding the ability to understand health information, is needed to participate in decision-making (48). While interventions that target patient activation, self-efficacy and health literacy have been developed (49, 50), their application to decision-making is less robust. And accepting an active role in decision-making may require entirely new skills for an older population who has grown up through the paternalistic era of medicine and who may be less savvy about information technology.

Another prerequisite for participation in decisions is effective communication with the clinician. Communication barriers have been reported to impede patient’s involvement in decisions. (15, 35, 51). The mere frequency of hearing loss, speech impairments, and slowed speed of cognitive processing at advanced age make communication barriers more frequent if not more severe in older populations (52). Additionally, the prevalence of cognitive impairment further creates barriers, which we did not address in this study.

Potential Approach to Improve Participation of Older Adults in Decision Making

While incorporating patient values into healthcare decisions is important for all ages, it is critical for older adults as goals may change when life expectancy shortens. For younger, healthier populations who are decades from death, the clinicians’ assumption that life extension is the overriding goal of care will be accurate in the vast majority of people. But in the last decade of life, preferences for quality of life may become dominant over adding years to life -- but not always -- making it risky for clinicians to assume they know what is most important for an older adult without asking (55, 56). The critical nature of assessing goals of care is most poignant when considering stopping an ongoing testing or treatment strategy or opting out of a treatment that may be considered standard in other populations. In our study, the starkly different response of participants regarding screening for occult cancer between those who felt the tests were “routine” and those who considered the downstream consequences of screening demonstrated the potential impact of explicitly re-evaluating these decisions with very old adults in the context of their goals.

Similarly, the discord and post-visit stoppage of medication by patients shows that elderly patients perform their own balancing of burden and cost without the benefit of a full review of how the medication may address other health goals. It represents a missed opportunity for clinicians to tailor medications (or other treatments) to goals and possibly improve adherence by directly addressing the discord between personal values and goals and medical indications during the visit. Instead, due to the patients’ non-confrontational style (indicated by stopping the medication after the visit or changing doctors) the discord goes unnoticed by clinicians. Whether this behavior is a unique generational characteristic or a general pattern in other age groups is worth further consideration.

Limitations

When interpreting the results of this study, there are four limitations to keep in mind. While recruitment of participants was designed to capture the greatest breadth of potential viewpoints and include race, gender, region, and educational differences, the qualitative method and small sample does not allow us to make generalizations about differences across these sociodemographic groups. Also, omitted from the sample were those whose decisions were made by a surrogate and those who did not speak English. The second limitation was use of a semi-structured as opposed to unstructured interview. The strength of our approach was to assure consistency of the data collected across all interviewees and limit interjection of interviewer bias, but it is possible that certain salient issues may have been overlooked. Third, we did not ask preference for role in decision-making to prevent biasing participants but as a result we cannot assess how the behaviors we describe align with preferences for participation. Fourth, we studied solely the patient’s perspective. There are other barriers and facilitating factors from the clinicians’ and family members’ perspective (12, 53, 54).

Conclusion

Overcoming the barriers to greater participation will likely need to The approach of providing decision aids may not be adequate among elderly patients who may need coaching on the equal importance of information about their personal values.

The onus of increasing participation of very old patients will likely fall heavily on clinicians because the dynamic of the visit needs to change. To begin, the way clinicians communicate can deter these patients from sharing their concerns and questions (57, 58), and clinicians cannot assume a patient’s preference for involvement from appearances (59). This means the physician may need to spend more time helping the elder to understand the options, make clear when reasonable alternatives of action exist, and probe more often about the patient’s preferences. For Epstein and Peters, “respecting and responding to patient preferences – the hallmark of patient-centered care – means eliciting, exploring and questioning preferences *and helping patients construct them*.” (60). Clinicians will likely need additional skills, time and effort to achieve this standard (16, 61).

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Appendix: Interview Guide

Opportunity for Choice

1. Could you tell me about the last time you went to see a doctor or healthcare provider?
2. Think of a recent doctor visit when a decision was made about your healthcare.

   a. Did you feel like you had a choice? How did you know?
   b. What were the choices?
   c. Did you get all the information you needed about the choices?
3. Probing question if needed to initiate discussion:
   a. Can you tell me about the last time you had a change in medication?
   b. Is there a time in the last few years when you decided to have or not have surgery?
   c. Can you tell me about a time when you decided to have or not have testing (or work-up) done for a problem you were having?
   d. Do you do preventative healthcare? What about vaccinations? What about screening tests?

Decision-making *(want more than one example, want variations in intensity of decisions)*

1. How was the decision made?
2. Did you get the information needed to make the decision?
   a. Where do you get your information?
   b. Are there times when you leave the doctor's office and wish you had more information?
      i. Why do think this happens?
      ii. What do you do?
3. Did you talk with anyone about the choices/decision?
4. Who made the final decision? How involved were you?
5. How did you feel about the decision, at the time?
6. How do you feel about the decision now?
7. Do you think the doctor knew everything about you that he/she needed to when the decision was made?
8. Did your age and/or health status change the options you had or decision that was made?
9. Did the cost of the care change the decision that you made?
   a. Has cost been a factor in other healthcare decisions for you?

Patient Values and Goals, alignment, implementation

1. What do you value in terms of your health and healthcare?
2. “To help in thinking about your individual goals and values for your health and healthcare I have created some scales…..” Place self on scale, repeat putting doctor on scale. (Visual analog scale anchored by “quality of life” and “prolongation of life”)
   a. How do you define quality of life for yourself?
   b. Have you always defined it this way?

    c. Have you always felt this way (quality of life vs. prolongation of life)? When do you think it changed?

3. Do you feel that your doctor knows that this is what you want for your healthcare?
    a. Why or why not? How do they know?
    b. How do you help them understand?
4. Do you think that the healthcare you receive now matches with these?
5. Thinking back to the decision to ______that we discussed earlier, did the values and goals we have just talked about play a role in your decision?
6. What is most important to you about your health (what matters most)?
    a. How do you achieve this?
    b. Does your healthcare help you achieve this?
7. Do you think that your doctor knows what concerns or worries you most about your health?
8. Are there times you feel the doctor doesn’t understand you of what you want?
    a. Can you think of a time when you felt like the doctor’s advice wasn’t right for you?
    b. Have you ever avoided a doctor’s appointment? Why?
    c. Are there things that you don’t talk to your doctor about?
        i. Why?
    d. How would you describe your relationship with your doctor?

Table 1

Steps in the decision process experienced in the clinic setting by people older than 80 and the variation in how each step was experienced.

Step in Process	**Property**	**Example Quote**
Recognize a decision needs to be made	No recognition	*How about mammography, is that something you do?* “Oh yeah, I have that every year” *And do you ever talk to him about having it not having it or is it something you do every year?* “Well, he insists that I have it and I just keep up with it.”
	Recognized	*Can you tell me, at that visit, were there any sort of decisions that had to be made during that visit?* “I’d gone to that stomach doctor and he told me to go back and he would send the reports that he had to my family doctor and then I’d go back over there and talk to him. So last week I went over there and he changed the medicine that the other doctor put me on.”
Identify Options	None	*When you go to the doctor …, do you think you get all the information that you need, or do you feel like you have questions that are not answered?* “No…I go to the doctor and do whatever they say. I feel like I have to go along with it. I don’t know…I don’t even know what any other plan or nothing I could do.”
	Yes, but only to accept or decline	*Were there any other choices, than to have the surgery for you?* “No, the doctor said that it was a routine operation, so if you want to get better, we ought to do it, so I agreed to it.”
	Yes with options	*Were there choices about that other than surgery?* “Well yeah. They told me they have two things that can happen to you. We can give you radiation treatment. Give you regular treatment. Give you the knife. Oh that’s three.”
Obtain Medical Information about Options	Use only the doctor	“I think I know the why of everything we discuss, what it is and why it is. Sometimes I question what he’s doing…He says, ‘We can’t do this because of that.’ I am not a doctor. I do not know why we are doing this. I have to take his word on this, but I can question him.”
	Based on personal experience	*And where do you get information when you need information about medical things?* “Just from experiences, I suppose.”
	Use other people’s experience	“Of course everybody there is old [senior center], and many of the women there had had cataract operations, and they said ‘It was just wonderful’ … I got such great reports, and I said to myself ‘I don’t think it is that bad’ but I will go ahead and get it over with.”
	From written materials	“I read every piece of paper I can see. Any time I go into a place, I pick up the pamphlets that they got on diseases and just read them. I come home with a dozen… If you don’t read you don’t know nothing.”
	From the Internet	“I have more time to spend on the Internet than with them - busy medical people - and I spend a lot of time looking up a variety of things. Every medicine, before I take something new I always check it out and I’m alert to possible side effects.
Identify and make patient values & preferences known	Belief professional training provided knowledge	*Do you feel like your doctor understands the things that you need and that you want for your health?* “Definitely.” *And how does he know those things?* “I don’t know how he knows, ‘cause he’s a doctor I guess. They had to go to school quite a while to be a doctor… (laughs)….they should know something… (laughs).”
	Assumed based on the length of relationship	“Anything he says is good because I have been going to him for 19 years…I just do what the doctor tells me. He will not have operations unless they are necessary.”
	Unspecified trust that the doctor knows	*Do you feel like your doctor knows that, that what you’re looking for in your healthcare is to maintain quality of life?* “Oh I am sure she knows that (whispers)…yeah, yeah….” *And how would she know that?* “By looking at me (laugh and pause)…you know what, maybe I ought to tell her that.”
	Direct communication	*You have the conversation with him?* “I sure do.” *You tell him? What do you tell him?* “Well, I want to live as long as I can, but I want to have quality of life with it.”

Step in Process	Property	Example Quote
		You have actually had that conversation? “Yes.”
Weigh options according to patient values	Physician alone	“He told me, he said, ‘You need surgery and you’re in bad shape.’ He said, ‘You have two arteries that are 90% blocked.’ He said, ‘Now, we can put stents in. They might help you, might not. Bypass surgery will help.’ I said, ‘Yes let’s get her going.’”
	Joint	“I wanted to have surgery, and he supported me in this. He said, ‘Okay this is your decision, that’s all right.’ We went over the pros and cons a number of times. Now I remember this very clearly. ‘Now you call me in the week….I’ll do the surgery for you, but if you don’t want it that’s ok and we’ll keep working on your back.’”
	Patient alone	“I would tell him, ‘Now doctor, you had me on so much of this (medication) and I’ve cut it in half and I’ve gone a year and you tell me everything is great.’” *And how does that go when you tell him that information?* “Well he kind of grins and says, ‘Well, we’ll adjust it a little bit,’ but I’m usually experimenting with it.”
Make the decision	Physician	“She just decided to give me a test and I didn’t even ask her why you requested me to take a blood test. I didn’t even ask.” *Do you know what she tested for?* “No, I guess she just decided.”
	Joint	“I usually talk with her, or I go back and forth with her and we come to a conclusion.”
	Patient	“He pushed me, pushed me to that decision. I had made the decision, but he was very helpful in supporting me in what I clearly wanted: surgery…But then he made me decide.”
Re-evaluation	Reflect on decision	“I had a cataract operation two years ago…I am glad that I did it; it was a plus for me. I like my eye doctor. I was convinced that he did the right thing.”
	Described regret	“They took out the small bone so it would heal correctly and I still regret that. I don’t think that was necessary.”
	Discord with physician regarding decision	“Well I argued about doing the sigmoid but (sic) I disagreed but they both insisted. So I thought, ‘Well, I suppose it cannot hurt. It was only a sigmoidoscopy.’ There was no anesthesia… They seemed to go further than needed. It was excruciating. It was like being hung, drawn and quartered.”

Note: Interviewer comments in italics, Participant comments in quotation marks.

Table 2

Factors Related to Lesser or Greater Participation in Healthcare Decisions by Very Old Adults Demonstrated by Contrasting Quotations from Low Participation and High Participation Respondents

Factor	**Low Participation Respondents**	**High Participation Respondents**
Awareness that a decision or choice is possible	No Awareness	High Awareness
	We talked about changing your medication. Tell me, when you go see your cardiologist does he ever order any tests for you? “Yes he does I sort of ask him about doing a diabetes test and he ordered that and then he had me to have a bone scan and that’s been within the last year. And of course I’ve had my mammogram.” – age 82	“He [doctor] told me and you better go get a mammogram” *Oh the mammogram, he told you to go get one and then what happen?* “I am not going to and he said why and I said frankly doctor at my age I could not take the chemo. I know it. *And what did he say?* “He stood there looked down his nose at me. He knows that sometimes I win and he gets mad and leaves.”-age 83
Patient Activation	Low Patient Activation	High Patient Activation
	“They know more about the subject and they know more about me and my health conditions than I do. I am fairly knowledgeable about things, but I figure the doctor knows more about my body than I do so I go by what they, he, whoever says.”	“People tell me I’m really healthy and I feel healthy. I’m vigilant about it…I try to be a partner.”
Communication	Perceived as obstructed	Perceived as open
	Are you able to tell him everything that you think you need to about your blood pressure? “No, I tried but I think that is one of my problems. I don’t get everything across, or either he doesn’t hear at all, or something.”	“There’s been a huge change in how doctors are willing to receive whatever the thoughts are from their patients…Younger doctors are more open to receiving (whereas) 60 years ago when I was 20, physicians were pretty much God in their field.”
Perceived Clinician Motives	Reported as Financially influenced	Reported as Patient-centered
	“Now every time I have gone to the specialist, that has led to surgery…Whether I have a real problem or not, it seems they all want their money and want the surgery, but I’ve learned at my age I’m not going to play that kind of game.”	“(I want her) to be honest, no hiding of anything, to be open, and I am open with her. And she is pretty good with being what I want of her. She doesn’t push anything on me, she is so good.”
Information Sources	Rely solely on clinician	Access to multiple sources
	“I don’t know why he did it (bone densitometry) but he said I needed it and I just did it.”	“I have a lot of conversations with myself and I talk with the physician, I talk with my husband, everyone has had back pain so there were lots of people to talk to about back pain. I talked with the medical staff here. I talked with people who had had the operation.”
Knowledge of Patient Values	Assumed by Patient	Directly Communicated
	Do you feel like your doctor understands the things that you need and that you want for your health? “Definitely.” *And how does he know those things?* “I don’t know how he knows, cause he’s a doctor I guess. They had to go to school quite a while to be a doctor….laughs….they should know something…laughs”	*Have you been able to communicate that with them?”* “oh you bet…it’s plastered all over my charts, DNR all over the place”
Addressing Discord	Avoid Addressing Discord	Actively Address Discord
	“I was complaining about dry mouth, and he said Avapro won’t ruin your mouth and my daughter, he went to see her and he walked out and that was the end of my talk, didn’t tell me a thing.” *How did you feel about that?* “Then I went and looked for another doctor.”	“(The) surgeon who I went and talked with, he was strongly in favor of operating. But when I said, ‘What are the chances of this really getting better,’ about the best that he could promise me was that it would probably stop any further deterioration. …he was less than happy with my decision [not to have surgery] and it was pretty strong.” *How did he express that?*

Factor	**Low Participation Respondents**	**High Participation Respondents**
		"He was aggressive. He could combat my exchange…*interesting…*yeah but I am sure he succeeded with some people."

Note: Interviewer comments in italics, Participant comments in quotation marks.