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New elements for informed decision making: a qualitative study of older adults' views

Erika Leemann Price, MD, MPH[1], **Sylvia Bereknyei, MS**[2], **Alma Kuby, MBA**[3], **Wendy Levinson, MD**[4], and **Clarence H. Braddock III, MD, MPH**[5]

[1]Veterans Affairs Medical Center, San Francisco and Department of Medicine, University of California, San Francisco

[2]School of Medicine, Stanford University

[3]National Opinion Research Center and University of Chicago

[4]Department of Medicine, University of Toronto

[5]School of Medicine, Stanford University

Abstract

Objective—To explore older adults' views of existing Informed Decision Making (IDM) elements and investigate the need for additional elements.

Methods—We recruited persons 65 and older to participate in six focus groups. Participants completed questionnaires about IDM preferences, and discussed videotapes of idealized patient-physician interactions in light of seven IDM elements: 1) discussion of the patient's role in decision-making; 2) discussion of the clinical issue; 3) discussion of alternatives; 4) discussion of benefits/risks; 5) discussion of uncertainties; 6) assessment of patient understanding; and 7) exploration of patient preference. We used a modified grounded theory approach to assess agreement with existing IDM elements and identify new elements.

Results—In questionnaires, 97–100% of 59 participants rated each IDM element as "somewhat" or "very" important. Qualitative analysis supported existing elements and suggested two more: opportunity for input from trusted others, and discussion of decisions' impacts on patients' daily lives. Elements overlapped with global communication themes.

Conclusion—Focus groups affirmed existing IDM elements and suggested two more with particular relevance for older patients.

Practice implications—Incorporation of additional IDM elements into clinical practice can enhance informed participation of older adults in decision-making.

1. Introduction

Shared decision making (SDM), the fostering of patient involvement in medical decisions, has become an accepted approach [1–3], and momentum around SDM is increasing. In 2001

Corresponding author contact information: Erika Leemann Price, M.D., M.P.H., San Francisco Veterans Affairs Medical Center, San Francisco, California 94121. Tel (415) 221-4810. erika.price@ucsf.edu.

the Institute of Medicine endorsed SDM as a component of high-quality care [4]; the principles of the Patient-Centered Medical Home include the idea that “patients actively participate in decision making” [5]; and some U.S. states are considering legislation to mandate SDM approaches.[6] Several SDM models exist [3, 7–15]; grounded in ethical theory or other conceptual models of effective communication or the psychology of decision making. SDM has been associated with positive outcomes in patient satisfaction, health behaviors, and disease management [16–21]. Yet much remains unknown about how to optimize patient involvement in decisions in clinical practice.

While numerous studies have shown that most patients prefer to hear information about choices and have the opportunity to share in decision making [3, 9, 22–26], not all patients wish to be fully involved [3, 9, 24, 27]. Older patients are of particular interest because they face more complex decisions and may face greater risks from treatments, and studies have suggested age-based differences in patients’ perceptions and desired level of involvement in decision making [28–32]. However, to our knowledge no studies systematically explore older patients' views about specific shared decision making elements.

Here we focus on our previously developed and widely used Informed Decision Making (IDM) model, which is conceptually related to shared decision making and further emphasizes provision of sufficient information for patients to participate effectively in clinical decisions. Based on integration of the bioethics literature and professional consensus, our model has been validated and applied to analysis of decision making in clinical encounters. Our model includes seven elements, incorporating the key concepts of providing information and fostering patient involvement; these elements have been used to assess the quality of shared decision making in clinical practice. [7, 8, 33]

The purposes of this focus group study were to explore older patients’ assessment of these IDM criteria and elicit additional themes informing older patients’ perceptions of shared decision-making.

2. Methods

We conducted focus groups as part of a larger study exploring communication and decision making between older patients and surgeons, described elsewhere [33], building on our previously validated IDM framework [7,8]. The framework includes seven IDM elements: 1) discussion of the patient's role in decision-making; 2) discussion of the clinical issue or nature of the decision; 3) discussion of the alternatives; 4) discussion of the pros (potential benefits) and cons (risks) of the alternatives; 5) discussion of uncertainties associated with the decision; 6) assessment of the patient's understanding; and 7) exploration of patient preference [7].

Six focus groups were conducted by National Opinion Research Center (NORC) in the Chicago metropolitan area. NORC contacted a convenience sample of senior centers and nursing homes in diverse communities. Each center coordinator or program director recruited English-speaking participants age 65 or older who were physically and mentally able to participate in a focus group. Participants received $50 for attending.

At the beginning of each session, participants gave consent and completed a questionnaire including demographic and health status information, then rated their agreement on a six-point scale from “strongly agree” to “strongly disagree” with the following statements: “I prefer that my doctor offer me choices and ask my opinion”; “I prefer to leave decisions about my medical care up to my doctor”; and “I prefer to rely on my doctor’s knowledge and not try to find out about my condition on my own.” Finally, participants rated their agreement (on the same scale) with relying on additional input from other individuals: “the experience or opinion of family members"; "the experience or opinion of my friends"; "the information and opinion my doctor provides"; "my own opinion". Comments on other sources of information or support were solicited.

The moderator from NORC then initiated a discussion of doctor-patient communication, likes and dislikes about communication with physicians, and the roles of family and friends in medical decisions. Participants watched two professionally produced videos of an older patient and an orthopedic surgeon discussing treatment for osteoarthritis: one video focused on medical treatment, and the other on surgery. The moderator asked the participants to discuss the decision making process in the videotapes. Due to similarity in discussions about the two videos, after the first three focus groups only the surgical treatment discussion was shown.

The moderator reviewed major points from the discussions, and introduced the seven IDM elements with a handout. Participants commented on the elements, including whether any should be eliminated and whether additional elements were needed. Participants then completed a second questionnaire rating the importance of each IDM element as "very important", "somewhat important", "not very important", or "not important at all".

Focus groups were audiotaped and later transcribed. Transcriptions were reviewed and coded by the authors (CB, SB, EL) using Atlas.ti software (Atlas.ti GMBH, Berlin, Germany) using a modification of the grounded theory analytic approach, described in detail elsewhere [34]. In summary, our process used thematic analysis to guide coders in exploring the salience of existing IDM criteria, while using more traditional grounded theory approaches to identify new themes. Additional themes around communication and decision making were coded as they emerged. Authors discussed discordantly coded items until consensus was achieved.

The study was approved by the institutional review boards at Stanford University and the University of Chicago.

3. RESULTS

Six focus groups comprising 59 participants were conducted in 2002. Most participants were ages 65 to 84 (90%); most were white (64%), and 66% were women (Table 1). Most (72%) had at least a high school diploma. Almost all (93%) described their health as "good or fair" or better (Table 2).

Due to poor audio quality, one session could not be transcribed; data from all groups are included in the demographics and questionnaire results, but only five are included in the qualitative analysis.

3.1 Questionnaire data

In describing their preferred roles in medical decision making, almost all participants (98%) agreed with the statement "I prefer that my doctor offer me choices and ask my opinion." By contrast, 24% *disagreed* with the statement "I prefer to rely on my doctor's knowledge and not try to find out about my condition on my own (Table 3). When asked whom they would rely on when making a decision about a medical procedure, almost all (97%) agreed with relying on a doctor; 86% agreed with relying on "my own opinion", 83% would rely on family, and 61% on friends (Table 4). Many wrote in additional sources of support including physicians, specific family members, or both.

3.2 Focus group results: existing IDM elements

Thematic analysis revealed the following representative comments about individual IDM elements:

1) Discussion of the patient's role in decision-making—This criterion refers to clear discussion about how the patient would like to be involved in decision making. Participants did not report such discussions, but often described situations where they would have been helpful. Some described discomfort with doctors' taking control of decisions:

> "I personally don't like the idea of the doctor taking the lead all the time, even though he or she is the doctor…" (Group 1)

> "I'm not going to let myself just be cut because he's the doctor…" (Group 2)

Others described situations in which patients wanted *more* direction from physicians but did not realize they could ask for it:

> "I've seen people walk out of a room where I felt that the doctor wanted to give them advice but if they didn't ask he wasn't going to." (Group 6)

Still others appreciated physicians' control of medical decisions:

> "He listens, and he examines you, and he comes to his decision. He's an excellent doctor." (Group 3)

While many participants described the desire for more control, others appreciated more direction from physicians. The range of roles participants preferred, and the reports of discordance between participants' desired roles and their physicians' assumptions, support the need for open discussion about patients' desired roles as an element in medical decision making.

2) Discussion of the clinical issue or nature of the decision—Participants endorsed discussion of clinical information during medical appointments. Some wanted more details in the videotaped discussion:

> "I think they should have showed a picture of exactly what a hip replacement is… what they're going to pull out, what they're going to put in." (Group 4)

Many participants emphasized delivery as well as content, focusing on the need for understandable language:

> "[If] they would just explain to you in ordinary layman's language…when it comes to medical terms it's way over our heads." (Group 4)

> "There has been many times when I've had to ask him, 'Doc, bring it down into layman's terms. I didn't have eight years of medical school!'" (Group 5)

These and other comments demonstrate strong support for thorough and understandable discussion of clinical issues. Participants also connected this element with trust in the patient-physician relationship: "It helped… to have confidence in the doctor…it's very important they tell you what you're up against" (Group 2). These broader concerns about trust and communication skills ran throughout the focus groups.

3) Discussion of the alternatives and 4) Discussion of the potential benefits and risks of the alternatives—These elements refer to discussion of feasible options (such as medical versus surgical treatment) and the risks and benefits of each (side effects, costs, and so on). Participants generally felt these elements were present in the videotapes. One said:

> "I think he really discussed them, telling her what the options, the medicine…what they were going to do at the surgery…." (Group 1)

However, some felt the patient in the videotape was not adequately informed about alternatives to surgery, and connected this with lack of an established, trusting relationship:

> "I saw him really leading her and not giving her much option… [T]hat surprised me, that her internist wouldn't have sent her over to… get a beginning relationship before… trying to deal with it." (Group 5)

Another connected his own physician's failure to discuss alternatives to surgical treatment with insufficient medical knowledge: "He didn't know of any medication or anything else." (Group 4)

Participants also voiced dissatisfaction with physicians' failure to discuss risks of medication use. One said, "…they hardly ever talk about side effects." (Group 4) This failure led to questioning of the extent of physicians' knowledge:

> "… one [medication] could counteract the action of the other one… and I don't think the doctors really know…" (Group 4)

While most participants appreciated physicians' reviewing alternatives, risks, and benefits, some felt physicians conveyed this information only out of self-interest, again invoking the theme of trust:

> "They give you options because the doctors want to protect themselves… he relieves himself of all responsibility." (Group 5)

These comments reflect varying attitudes towards the discussion of alternatives, risks, and benefits, yet taken together they underscore not only the importance of these IDM elements, but also the need to discuss them in the setting of a trusting patient-physician relationship.

5) Discussion of uncertainties associated with the decision—Discussion of uncertainties includes acknowledgment of what cannot be fully predicted, such as the course of a disease or the chance of complete recovery from surgery. Participants supported discussion of uncertainties, but also described a need for their physicians to help them navigate the unknown.

One participant spoke positively about her physician's acknowledgment of uncertainty associated with a diagnosis:

> "She said, 'I notice I've got patients coming in with that a lot…[w]e're going to have to do more study on this type of thing that's coming up.'" (Group 2)

Others focused more on the uncertainty of surgical risk:

> "[M]y doctor did say… 'I don't want you to have surgery because I want you to, because every surgery's a risk.'… He pointed out… that any time you go into the hospital there's a risk. That took away some of the fear that I would have had the way he presented it.." (Group 5)

This physician's honesty about the risks associated with surgery, combined with his reassurance that he had the patient's best interests in mind, decreased the patient's apprehension about her decision.

Some participants pushed their physicians to guide their choices in the face of uncertainty:

> "he had told me that…maybe if they operated I could die on the table. I said, "What would you do?" He says, "I'd have it done. I'd take a gamble.' Which I did, and it worked out fine." (Group 5)

For this participant and others, discussion of uncertainties was appreciated; however, they often wanted their physicians to resolve uncertainties by giving definitive recommendations. Though these comments illustrate a differing attitudes towards discussion of uncertainties, they again underscore the theme of trust, with patients relying on physicians' advocacy and guidance in the face of the unknown.

6) Assessment of the patient's understanding—Comments about assessment of understanding referenced concerns about cognitive abilities. Participants recounted positive experiences with physicians who assessed understanding:

> "She will ask me questions, you know, just to hear how I would explain whatever's wrong with me…" (Group 1)

> "They'll find out what you know, and then that's the way they'll talk about it… I think they talk …from what they think you know." (Group 1)

Conversely, many participants – including the one cited earlier who urged his physician to "break it down into layman's terms" -- described frustration with physicians who did *not* convey information in a way that they could understand. Others doubted their ability to recall information accurately, describing being "very forgetful" (Group 3), or claiming "nobody hears [what the doctor is saying] the same." (Group 1)

Through recounting positive experiences with physicians who did assess understanding and negative experiences with those who did not, and in discussing their own concerns about ability to comprehend medical information, participants endorsed the IDM element of assessing patients' understanding.

7) Exploration of patient preference—Participants spoke positively of physicians who explored and acknowledged their preferences. One said simply, "She likes my opinion." (Group 1). Another described this interaction about medication:

> "[[S]he wanted to put my on medication, [but I wanted to try it with my diet]. Then… I got frightened I'd have a stroke, and so I went in and I said 'Look doc, I've been doing it my way. Now I'm ready to do it your way.'" (Group 1)

Another appreciated her orthopedist's attention to her preferences about having surgery:

> "‥on my first visit the doctor made it very clear that he was never going to tell me whether I needed hip surgery. I would tell him, and… then we'd talk about it seriously." (Group 5)

While these and other participants preferred very directive roles in their medical decisions, others deferred to their physicians' guidance, including the earlier-cited participant who asked his physician "what would you do?" Though participants varied in the amount of guidance they wanted in making a decision, the appreciation of having their preferences heard and understood was a common theme.

In the survey question on the value of individual IDM elements done after these discussions, 97–100% ranked each IDM element as "very important" or "somewhat important"; details are not shown given minimal differences between the elements.

3.3 New elements in informed decision making

Two additional IDM elements emerged from these groups: the need for the opportunity to involve a ‘trusted other’ in a decision, and need for discussion of the impact of a medical decision on a patient’s daily life.

Many participants described a need to involve other people in their medical care. In questionnaires, 83% of participants agreed with involving family members in their decision. Focus group discussions elicited multiple reasons for family involvement. One was the desire to remember and understand information:

> “My daughter takes me to my doctor appointments… if it’s needed, because I’m very forgetful… I take her with me, she will understand and help me to understand.” (Group 3)

> “[I]t’s always better for two people to hear what the doctor’s saying, because nobody hears it the same.” (Group 1)

Some felt a *responsibility* to include family members who could be impacted by decisions, for instance with caretaking duties:

> “[S]he was going to have somebody take care of her, and sometimes the family hears so much about different things. I would like for my family to hear the doctor…Make me feel more comfortable.” (Group 3)

Some participants also voiced concerns about making their families feel overly responsible for decision-making and for care duties:

> “You have to explain to them what is happening, but… so that my children would not feel responsible for what would happen to me in the future I would have to make…that decision.” (Group 2)

> “[I]f anything happens I would not want to burden my children with the thought that this could have been prevented and might not have been extremely, extremely necessary.” (Group 2)

For some, the ‘trusted others’ included other physicians as well as family. This participant appreciated the presence of his daughter and multiple physicians in making a decision:

> “When I was doing my surgery, I got two doctors…[T]he doctor tell me that the medication don’t work no more, and the other doctor, he was a surgeon… And then…I bring my daughter… That’s a good discussion that we have together.” (Group 2)

Though having ‘trusted others’ help navigate medical decisions was important to many participants, the identities and roles of the trusted others varied, suggesting that physicians should explore with patients not only *who* else should be involved in decisions, but *how* these others should be involved.

The second new element of informed decision-making was discussion of a decision in the context of a patient’s daily life. The comments above illustrate participants’ concerns about medical decisions’ impacts on family members, in their roles as advisors and caretakers. Additional comments noted practical concerns about daily demands on family members. One participant said his physician had disregarded his wishes *not* to involve his family in conversations about his care following his cancer diagnosis, but he had come to realize that their involvement was appropriate, given their need to know what to anticipate:

> "[W]hen I found out that I had cancer, and they notified my family, one of the purposes was that they knew what to expect out of the treatment.… so I guess it was okay." (Group 4)

Participants also pointed out the importance of discussion about the impact of medical decisions on their own daily lives. Commenting on the videotaped discussion, a participant pointed out appreciatively that the physician had said

> "[A]pproximately you know how long [until] she would be back on her feet, even, you know? Be in the hospital a couple of days, perhaps, and then back on her feet with a cane." (Group 1)

Other participants wished the physician in the video had spoken more about the recovery:

> "I think they could have gone into a little more on how long it takes after this surgery, what you're able to do…" (Group 4)

> "I think the pain from the hip is gone almost immediately, and it would have been nice if he'd got that across." (Group 5)

In the same group, another participant suggested physicians rarely address discuss the impact of medical decisions on older patients' daily lives:

> "I think young doctors should learn more about older people, the effects of operations on them. Are they physically able to stand this, and what'll be the effect afterwards? Because some doctors don't really study on older people." (Group 4)

4. DISCUSSION AND CONCLUSION

4.1 Discussion

In this focus group study of older adults we found strong support for existing IDM elements. While participants overwhelmingly endorsed IDM criteria in questionnaires, focus group comments elicited additional dimensions of the criteria and brought out two new IDM elements: 1) inviting the involvement of trusted others, and 2) exploring the impact of the decision in the context of the patient's life. Our analysis also revealed ways in which the existing and new IDM elements relate to older adults and their concerns about cognitive ability and increasing dependence on others.

Current classifications of decision making describe a spectrum of patient empowerment and involvement, ranging from a unidirectional, "paternalistic" flow of information and decisions from the physician to the patient, to a model in which a patient, armed with adequate information, controls the decision making process [9, 35]. Focus group participants' endorsement of our IDM criteria lend weight to the interactive, bi-directional aspects of decision-making – assessing understanding, eliciting patient preferences, involving 'trusted others', and framing decisions within the contexts of patients' lives. At the same time, the broad range of preferred roles described by participants underscores the need to discuss with patients what kind of involvement they would like to have.

We found intriguing the number of comments implying that informed decision-making depends not only on the fulfillment of a set of criteria, but also on physician communication skills that address older patients' concerns. These concerns included having difficulty understanding information, having trouble trusting doctors, and having inadequate time to speak with doctors. These comments bring the overlap of IDM with patient-centered communication into sharp relief. Stewart's "patient-centered clinical method" includes in its six dimensions "understanding the whole person," which includes the perspective of the "bio-psychosocial model to define the appropriate contexts for understanding a patient's problem" [36], echoing participants' desire to discuss decisions in the contexts of their daily lives. In Krupat's "Four Habits" framework for patient-physician communication, one habit concerns eliciting the patient's perspective and "show[ing] interest in the impact on patient's life" [37, 38]. Participants in our study have shown us the relevance of these communication behaviors in the context of decision making, further demonstrating the interconnectedness of effective communication and high quality IDM. We have modified our previously published IDM model to include these two new elements.

There are some limitations to our findings. Remuneration of participants may have biased responses in favor of endorsing the IDM elements. Because of the small focus groups, our findings may not be representative of the population of interest, or there may be the appearance of consensus where no true agreement exists. While participants in this study were highly engaged in the conversations, it was often difficult to keep participants focused on the IDM elements. Nevertheless, participants clearly recognized and validated the elements' importance.

In addition, each focus group shared a community and, often, an ethnic background, leading to minimal within-group diversity that may have affected responses. Further, participants were relatively healthy and functional, and very few were over age 85. In the general population of older adults, age, medical complexity, and prior contacts with the health care system might bear significantly on views of decision-making; thus, the selection of relatively young seniors at a relatively functional level may limit this study's generalizability.

Despite the above challenges, these focus groups provided valuable insight into older patients' views of informed decision making. Our use of rigorous qualitative analysis with three independent coders increases our confidence in our findings. Furthermore, the consistency of themes across focus groups adds to our sense that the findings are real and meaningful. Finally, the complementary nature of the themes we discovered and the broader themes of patient-centered communication are reinforcing in their own right.

4.2 Conclusion

The quality of patient participation in clinical decision making has been improved greatly by the availability of theory-based, valid and reliable metrics. This study has added further weight to our confidence that the IDM elements provide a meaningful measure of the quality of informed decision-making, and suggested two additional elements that extend our understanding of the dimensions of IDM for older patients.

4.3 Practice Implications

Our findings have important implications for future empirical work on IDM, and for models of how best to enhance informed participation of older patients in decision making in clinical practice. Increased physician attention to existing IDM elements and the two new elements we propose here can improve older patients' participation in informed decision-making. Further, these elements continue to provide a framework for improved quality of patient-physician communication, with beneficial implications related to adherence, treatment acceptance, and patient satisfaction.

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Table 1

Demographics of focus groups to assess older patients' views of informed decision making

Group (N)	Group 1 (10)	Group 2 (11)	Group 3 (8)	Group 4 (10)	Group 5 (10)	Group 6 (10)	Total (59)
Age[*]	%	%	%	%	%	%	%
65 –74 yrs	60	82	25	30	40	0	41
75 – 84 yrs	30	18	50	60	60	80	49
85 and older	10	0	20	0	0	10	7
Sex (female)	80	73	100	50	70	30	66
Race[**]							
Hispanic	0	100	13	10	0	0	22
African American	100	0	100	0	0	0	31
White	0	73	0	100	100	100	64
Other	0	27	0	0	0	0	5
Education							
Less than high school	30	64	63	10	0	0	27
High school diploma/GED	70	27	25	70	60	60	53
College degree or higher	0	0	13	20	40	40	19

[*] Responses may not total to 100% due to missing data and rounding

[**] Some participants self-identified with more than one race

Table 2

Focus group participants' self-reported health and medical care.

Question	n (%)
Self-reported health	
Excellent or very good	17 (29.3)
Good or fair	37 (63.8)
Poor	4 (6.9)
Have a regular doctor or clinic	55 (96.5)
Currently taking any prescription medications	53 (91.4)
Had an operation in the past 5 years	23 (39.7)

Table 3

Focus group participants' preferred level of involvement in medical decision-making

Statement	**N**	**Response category**	**n (%)**
I prefer that my doctor offer me choices and ask my opinion	57	Strongly or moderately agree	55 (96.5)
		Slightly agree	1 (1.7)
		Slightly disagree	1 (1.7)
I prefer to leave decisions about my medical care up to my doctor	59	Strongly or moderately agree	43 (72.9)
		Slightly agree	6 (10.2)
		Slightly disagree	6 (10.2)
		Strongly or moderately disagree	4 (5.1)
I prefer to rely on my doctor's knowledge and not try to find out about my condition on my own	58	Strongly or moderately agree	40 (69.0)
		Slightly agree	4 (6.9)
		Slightly disagree	2 (3.4)
		Strongly or moderately disagree	12 (20.7)

Table 4

Focus group participants' preferences about involving others in care: "When making a decision about medical procedures, like surgery, I would rely on the experience or opinion of…"

Answer	**N**	**Strongly or moderately agree**	**Slightly agree**	**Slightly disagree**	**Stongly or moderately disagree**
Doctor	57	54 (94.7)	1 (1.8)	1 (1.8)	1 (1.8)
Self	50	39 (78.0)	4 (8.0)	2 (4.0)	5 (10.0)
Family	52	35 (62.3)	11 (21.1)	2 (3.8)	4 (7.7)
Friends	51	11 (21.6)	20 (39.2)	4 (7.8)	16 (31.3)

Table 5

Prior and additional elements in Informed Decision Making

Prior criteria for informed decision-making	Additional IDM criteria from focus groups
1. Discussion of patient's role in decision-making	8. Provision of opportunity to involve trusted others
2. Discussion of the clinical issue or nature of the decision	9. Discussion of the decision's impact on a patient's daily life
3. Discussion of the alternatives	
4. Discussion of the potential benefits and risks of the alternatives	
5. Discussion of uncertainties associated with the decision	
6. Assessment of the patient's understanding	
7. Exploration of the patient's preferences	