

What are the Essential Elements to Enable Patient Participation in Medical Decision Making?

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BACKGROUND: Patient participation in shared decision making (SDM) results in increased patient knowledge, adherence, and improved outcomes. Despite the benefits of the SDM model, many patients do not attain the level of participation they desire.

OBJECTIVE: To gain a more complete understanding of the essential elements, or the prerequisites, critical to active patient participation in medical decision making from the patient's perspective.

DESIGN: Qualitative study.

SETTING: Individual, in-depth patient interviews were conducted until thematic saturation was reached. Two analysts independently read the transcripts and jointly developed a list of codes.

PATIENTS: Twenty-six consecutive subjects drawn from community dwelling subjects undergoing bone density measurements.

MEASUREMENTS: Respondents' experiences and beliefs related to patient participation in SDM.

RESULTS: Five elements were repeatedly described by respondents as being essential to enable patient participation in medical decision making: (1) patient knowledge, (2) explicit encouragement of patient participation by physicians, (3) appreciation of the patient's responsibility/rights to play an active role in decision making, (4) awareness of choice, and (5) time.

LIMITATIONS: The generalizability of the results is limited by the homogeneity of the study sample.

CONCLUSIONS: Our findings have important clinical implications and suggest that several needs must be met before patients can become active participants in decisions related to their health care. These needs include ensuring that patients (1) appreciate that there is uncertainty in medicine and "buy in" to the importance of active patient participation in decisions related to their health care, (2) understand the trade-offs related to available options, and (3) have the opportunity to

discuss these options with their physician to arrive at a decision concordant with their values.

KEY WORDS: patient participation; medical decision making; shared decision making; health care.

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INTRODUCTION

Shared decision making (SDM), where patients play an active role in decisions related to their health care, is being increasingly thought of as the model of choice for complex medical decisions involving more than 1 rational treatment option.¹ This is especially true for value sensitive decisions, such as treatment for breast and prostate cancer or screening for colon cancer.^{1,2} Patient participation in medical decision making may result in increased patient knowledge, satisfaction, adherence with treatment, and improved outcomes.³⁻⁸ Furthermore, interactive discussions between physicians and patients about possible options improve patient satisfaction with provider care even among patients preferring a more passive role in decision making.⁹

Despite the benefits of the SDM model, not all patients prefer an active role in decision making. Nonetheless, among patients who do prefer an active or collaborative role, many do not attain the level of participation they desire. Studies have shown that less than half of patients achieve their preferred role in clinical practice¹⁰⁻¹³ with many acquiescing to a more passive role than desired.^{10,14,15} Although investigators have described the predictors of patient participation in SDM,¹⁶⁻¹⁸ less is known regarding why patients fail to participate at their desired level.

We conducted this study to gain a more complete understanding of the essential elements, or the prerequisites, critical to active patient participation in medical decision making, from the patients' perspective. Identification of these factors is needed before methods can be developed to promote and facilitate SDM in clinical practice for patients who prefer to be active participants. In contrast to most previous studies, we allowed patients to discuss situations in which they perceived an important decision had to be made, and did not query patients on specific scenarios. We chose qualitative methods to elicit the patient's perspective because of its potential to clarify complex issues and to identify new concepts not previously addressed in the literature.

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METHODS

Participants

Participants were drawn from a larger study examining patient treatment preferences for osteoporosis.¹⁹ The sampling frame for the larger parent study was men (over the age of 65) and postmenopausal women who had recently (within 2 weeks) undergone bone densitometry from 6 centers in the greater New Haven, Connecticut area. Subjects for this qualitative study were drawn consecutively from the group of patients whose bone densitometry measures were too high to make them eligible to participate in the parent study. We attempted to reach 44 individuals to participate in this study. Of these, 12 individuals could not be reached after 3 attempts by phone, and 6 refused to participate. Twenty-six (59%) agreed to be interviewed for this study. Other eligibility criteria included the ability to speak and understand English. All participants gave informed consent and the Yale University Institutional Review Boards approved the protocol.

Interviews

Individual face-to-face interviews were chosen over focus groups for this study because interviews allow for more in-depth exploration of each respondent's experiences and thoughts. Using a semistructured discussion guide, the interviews followed a funnel structure, progressing from broader and open-ended questions to more structured questions with specific probes to clarify issues as needed.²⁰ A formal discussion guide was developed based on pilot interviews with 2 participants. The guide included 14 open-ended questions on participants' experiences with medical decision making (see Appendix). Unless participants had covered a topic without being prompted, all participants were asked each of the 14 questions. Further prompts were used as required to encourage discussion with patients tending to answer with brief responses.

Interviews were conducted until thematic saturation was reached. The interviews were audiotaped and transcribed by a professional transcription service. Study investigators read each transcript as it became available creating a preliminary list of themes. Data collection ended when no new themes or ideas arose during an interview. Each interview ran for up to 90 min and was conducted by the same Ph.D. level senior research scientist (SMCG) with extensive experience conducting qualitative interviews. Demographic data (age, gender, race, highest level of education attained, marital and employment status) were collected at the beginning of each interview using a self-administered paper and pencil questionnaire. All questions offered a defined set of responses except for age.

Analysis

The analysts (SMCG and LF) independently read all of the transcripts and developed an initial list of codes.²¹ The independent coding was subsequently jointly reviewed by the analysts. Transcripts were then reread to confirm the list of codes and create subheadings.²² The constant comparative method approach was employed to ensure that the analysts defined and applied the codes in a consistent manner across all transcripts. Using 2 readers ensured that a broader range

of codes was identified. QSR*NUDIST (Sage Publications Software, Thousand Oaks, California) was used to identify and sort the relevant text across the transcripts for each code.²³ All codes related to enabling active patient participation in decision making were retained and are presented in this paper. Demographic data were summarized using descriptive statistics (SAS Software, version 8.0, SAS Institute Inc., Cary, North Carolina).

RESULTS

Participant Characteristics

A total of 25 women and 1 man were interviewed between April 2004 and June 2005. The mean age of the participants was 61 (range 49 to 76). All were Caucasian, 69% were married, 50% had a graduate degree, and 23% were retired.

Main Themes

Five elements were repeatedly described by respondents as being essential to enable patient participation in medical decision making: (1) patient knowledge, (2) explicit encouragement of patient participation by physicians, (3) appreciation of the patient's responsibility/rights to play an active role in decision making, (4) awareness of choice, and (5) time. As illustrated in the following paragraphs, these domains overlap, but each emphasizes distinct goals that must be fulfilled to enable patient participation in decision making.

Patient Knowledge. Participants repeatedly emphasized that being adequately informed was absolutely essential to be able to participate in the decision-making process with their physicians:

You only spend so much time in a doctor's office, and if you don't understand something it's always good to either go to the library and get some more information or talk to another doctor to get another opinion so that you know as much about it as you can before you make a decision. (Interview #6)

If you don't know, then how do you make the choice. You can't because you don't have the information. (Interview #7)

For example, 1 respondent commented that she saw her role as being very limited in making decisions about the treatment of her breast cancer because she was not adequately informed.

They asked me how do you like this or what do you think of that, and I would usually say—I will take your advice—because the average lay person knows nothing you know. (Interview #19)

Several participants pointed out that they had considerable difficulty dealing with the amount and complexity of the information they received:

Because there's so much information to take in that I think it can be hard to process it. (Interview #16)

Doctors talk so far over their heads. They've got to have someone ... that can interpret what the doctor is saying, and that can ask questions. (Interview #8)

(Someone needs to point out) here's what you really need to sit up and pay attention (to) and here are the factors you ought to ask about, so that you have a little more guidance about what is important and what isn't important. (Interview #23)

Explicit Encouragement of Patient Participation by Physicians.

Beyond providing and clarifying complex information, participants in this study felt that physicians should facilitate patient participation in decision making by enabling patients to ask questions:

You don't want to go see a doctor that says this is what you have to have done, who doesn't give you a chance to ask questions. (Interview #24)

I think that's where the relationship with a doctor comes in. I feel like I can question things that my doctor says, if I don't understand I can ask him about it so that I can make an informed decision. (Interview #16)

Others emphasized the patient-physician relationship as being an important partnership in which to evaluate choices:

I think that I'm actually very happy with being able to get most of my medical care from somebody that I feel I have a good relationship with, is knowledgeable, can share with me how other patients have done and really help me make informed decisions. (Interview #16)

There has to be a back and forth conversation because it's your life. The more comfortable you feel, the more open you'll be to talking about other options. (Interview #6)

Several subjects also discussed the importance of physicians' attitudes in enabling patient participation. For example, the following quotes illustrate that some patients may avoid active participation so as not to annoy their physician:

Some people fear that they are going to antagonize the person that is taking care of them and that somehow that is going to impact their care. (Interview # 7)

Well if you're at odds with what the doctor prescribed, you know they won't like it. (Interview # 19)

Appreciation of the Patient's Responsibility/Rights to Play an Active Role in Decision Making. Many of the participants felt that patients had a responsibility to actively participate in decisions involving their health:

A patient has to be involved. It's their body and ultimately they are the ones who are going to be carrying out whatever decision's been made because they're the ones living with it day to day. (Interview #20)

It's very important for the doctor to make it clear what those side effects are and what the risks are. But it's also important for the patient to make sure they understand. (Interview #18)

You really have the responsibility of educating yourself as much as possible. (Interview #9)

Several patients described an inverse association between level of trust in their physicians and the importance of active patient participation.

If she doesn't feel secure with what the doctor says, then she should ask a lot of questions, but I just feel that I have good doctors and I take their advice. (Interview #19)

If you've gone to a doctor long enough, if he has a good reputation that would lean me more to take his decision as the right decision. (Interview #24)

Some respondents thought that patients' rights to participate were related to payment for services:

It's my body; I should have the right to make decisions on the treatment. (This) might annoy the doctor, but you're paying them. (Interview #2)

Similarly, another respondent described feeling as though she and her family did not have the right to participate in decisions about treatment for her father because they were not paying for the medical bills:

We felt like we were helpless in the decision making. One, because he was in a situation where we weren't paying any medical because of where he was, so they made you feel like you didn't have any say in the decision. (Interview #1)

Awareness of Choice. To participate in decision making, patients must first acknowledge that there is uncertainty in medicine. In this study, patients' perception of choice appeared to be related to context. Patients realized the importance of patient participation for decisions which were clearly value-based. For example:

Like if I was in a breast cancer situation and we're dealing with whether it's a mastectomy or a lumpectomy and this is purely personal...I would never leave the decision to the doctor. (Interview #1)

In contrast, in other situations patients failed to perceive a "choice" and therefore deferred to their physicians as illustrated by the following quotes:

I don't think I had a choice. I thought I had to do what the doctor wanted me to do. (Interview #5)

I think we were young and scared and I think if we were a little older and wiser we might have gotten other opinions. It's whatever they told us, that's what we believed. (Interview #1)

I just figured I didn't have a choice. (Interview #3)

The preceding quotes all refer to clinical contexts with more than 1 available treatment option in which the SDM model would have been appropriate.

Time. The lack of time spent with patients during medical encounters is frequently cited as a barrier to providing effective healthcare. In this study, at the end of the interview, when specifically prompted to describe additional barriers to enabling active patient participation in medical decision making, "time" was the only factor discussed by participants. Limited time was seen as a barrier to becoming informed and as a barrier to processing information to derive preferences:

A lot of them don't explain things—they don't have the time or they don't take the time. (Interview #12)

It just doesn't feel like there's ever room in the system anymore for real dialogue. In other words, that's what gets in the way. Time...Time sadly. (Interview #5)

Participants also felt that lack of time limits the extent to which physicians can help their patients process information.

They (patients) bring things in from the Internet, and then time is taken up wading through a lot of stuff, which may not even be of importance. So...when there is a little bit of time it is confused by all of the outside information that patients have. (Interview #11)

To overcome this barrier, 1 respondent suggested that patients might consider rescheduling their appointment to ensure that their physician had enough time to spend with them:

Calling ahead and saying, I have a lot of questions today and I might need a little more time with the doctor. Is this the best time or should I reschedule for another day? (Interview #18)

DISCUSSION

In this study, participants were able to describe several factors that they considered essential in order for patients to be able to participate in medical decision making. These fundamental issues share overlapping features, but each highlights specific processes which need to be addressed in order to promote SDM in clinical practice.

Participants repeatedly emphasized the importance of being adequately informed to participate in decision making. They noted that if they weren't informed, they had little choice but to defer to their physician. They also stressed that merely obtaining information was necessary, but not sufficient, to become an informed patient. To achieve the latter, resources are needed to help patients process the large amount of complex, and at times conflicting, information they receive from diverse sources.

Although one might expect that trust in physician would be positively associated with active patient participation, subjects in this study felt that their participation was most important when they had less trust in their physician. This finding is consistent with those of Kraetschmer et al.²⁴ who also found an inverse association between preferred role in decision making and trust and suggests that patients may fail to recognize the value of their input in situations where they have complete trust in their physician. Alternatively, patients having high levels of trust may believe that their physicians understand their values and know what's best for them.

In 2004, Robert McNutt published a commentary describing patients' responsibility to participate in decision making regardless of their preferences.²⁵ This view was shared by some of the participants in this study who felt that it was the patient's responsibility to become informed and to participate in decisions affecting their health care. It is interesting to note that some felt that they had the right to participate because they were "paying" patients. This latter view, in conjunction with the finding that some patients worried that their participation might annoy their physicians, emphasizes the need for healthcare professionals to explicitly encourage patient input.

Some participants did not even realize that there were choices to consider. Unless patients understand the concept of uncertainty in medicine and the possibility of there being more than 1 rational option, there is no reason for patients to want to participate in decision making. When specifically prompted to discuss obstacles to SDM in clinical practice, almost all participants described the lack of time as being a barrier. As high quality decision-making processes require adequate time, and time constraints in medicine are pervasive and unlikely to change, further efforts, such as the more widespread use of decision aids,²⁶ are needed to inform patients outside of the patient-physician relationship.

Limitations of this study lie primarily in the generalizability of the results. Given the homogeneity of the study population, future studies are needed to replicate and expand our results. Although we conducted interviews until thematic saturation was reached, i.e., until no new themes arose, our sample was composed primarily of well-educated postmenopausal women, thereby limiting the generalizability of the themes discussed in this group. However, this demographic group is among those most likely to want to

actively participate in SDM, therefore the factors discussed in this study are likely relevant for patients desiring an active role in SDM. Because men and women have different attitudes towards healthcare, future studies should explore whether men perceive supplementary or dissimilar themes as being essential to enable active patient participation in decision making. In addition, it is important to expand such studies to include patients with more varied educational backgrounds because less well-educated patients would likely identify additional needs to ensure a level of participation commensurate with their preferred roles.

Despite these limitations, our findings have important clinical implications and suggest that several needs must be met before patients can become active participants in decisions related to their health care. These needs include ensuring that patients (1) appreciate that there is uncertainty in medicine and buy in to the importance of active patient participation, (2) understand the trade-offs related to available options, and (3) have the opportunity to discuss these options with their physician to arrive at a decision concordant with their values. The common features underlying all these factors are the need for patients to be adequately informed and for physicians to give patients the opportunity to participate.

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APPENDIX

Discussion Guide

Attitudes Towards Shared Decision-making Study. The purpose of this study is to understand communication between patients and their doctors around treatment decisions. We are interested in understanding how patients and their doctors make decisions about treatment for an illness or a medical condition. The information gathered through this study will be used to develop strategies to help patient and doctors communicate more effectively.

I will be asking you 14 questions. They are all open-ended questions and there are no right or wrong answers. The first 6 questions are about your own experiences in making decisions about medical care. They are not necessarily specific to osteoporosis.

1. To begin, I am going to ask you to think back to a time when an important decision had to be made about your

treatment for an illness or a medical condition. [NOTE: Do not include small decisions, such as having a blood test.] IF PARTICIPANT CANNOT THINK OF A DECISION FOR THEMSELVES, ASK ABOUT A PARENT, CHILD, OR SOME OTHER PERSON THEY CARE FOR.
Please tell me about that situation.

Tell me very *briefly* about the illness or condition.
Also, just *briefly*, how did you find out about this illness or condition?
What was the decision that had to be made about treating this condition?
How was the decision made?
What was your role in the decision-making process?
What were you told to do?
What did do about it?
Who did you talk to about this decision?
Why did you choose to do this?
Who helped you to make this decision?
What information did you gather about making this decision?
How did you get this information?
Are there other things you have considered doing?

2. Thinking back about this decision and other decisions related to your health care, to what extent do you feel that you have shared in the decision making with your doctor(s)? Why? PROBE: To what extent do you feel you have had a role in, or participated in the decision making?
3. Thinking back over times when you faced a decision about medical care, was there ever a time when you wished you had a bigger role in the decision-making process? PROBE: Why did you wish you had a larger role?
4. Now, thinking back about times when you faced a decision about medical care, was there ever an instance when you wished you were asked to make fewer decisions or have less of a role in the decision-making process? PROBE: Why?
5. Have you ever disagreed with your doctor about a treatment plan that was suggested to you? PROBE: How did you handle this disagreement?
6. Have you ever been told by a doctor to try a treatment option that was impractical for you? How did you respond to this? PROBE: Has a doctor ever disagreed with you about something you wanted to try?

The next 4 questions are about the value or importance you place on elements of the decision-making process.

7. In a situation where there are choices about treatment, how important is the physician's recommendation to you in making a decision?
8. How important is it for the patient and doctor to share a similar outlook, such as values about health or use of medicine? Why? PROBE: Think about a situation where there are 2 medicines approved for an illness, medicine A and medicine B. What would you do if you wanted to take medicine A but the doctor recommended medicine B?
9. How important do you think it is for your doctor to have a clear understanding of what issues are most important to you when deciding which treatment to take?
10. How important is it that a physician explains clearly the financial costs of a course of treatment? Why?

The next set of questions covers your beliefs and attitudes about patient involvement in treatment decisions.

11. I will begin this set by asking you to talk about the pros and cons of having a patient participate in the decision-making process. What are your thoughts about having a patient be part of the decision? Why? PROBE: What is the best way to make a decision about how to treat an illness or a medical condition? Why? PROBE: What are the pros and cons of each approach? Why?
12. Every treatment has a chance of helping, as well as a chance of causing side effects. Who should decide whether the treatment is worth the risk? PROBE: Who should decide what side effects the patient should put up with?
13. In general, do you think there any barriers in our health care system which make it difficult for patients to participate in their health care? Why?
14. What do you think could be done to improve the decision-making process for you?

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