Patient participation in decision making fulfills the ethical principle of patient autonomy and the legal requirement of informed consent. Studies published to date, however, have reported significant variability in how much patients want to participate in this process. For example, in a recent large population-based survey, Levinson and others found that 52% of respondents preferred to leave the final decision up to their doctor. Moreover, Kiesler and Auerbach found that the common belief that matching patients’ preferred level of involvement will lead to positive outcomes was not consistently supported by research with the currently available measurements.

Deber and others hypothesized, and subsequently demonstrated, that variability in patients’ desire to participate in decision making is in part due to the failure of survey questions to adequately differentiate between problem-solving tasks (i.e., determining the correct diagnosis and delineating appropriate treatment choices) and decision-making tasks (i.e., choosing a treatment or intervention from a rational set of options). In point of fact, in Levinson and the study by Levinson and others, the vast majority of patients wanted to be offered choices, even though many preferred to leave the final decision up to their doctor. This discrepancy suggests that the variability in patient participation noted in previous studies may be due in part to limitations in study design.

Patient and physician beliefs differ in many respects, including how they conceptualize illness, how they prioritize long-term outcomes, and how they rank available treatment options. Likewise, it is also possible that physicians and patients differ in how they conceptualize participation in decision making. If this hypothesis is correct, current instruments...

Purpose. Variability in reports of patients’ preferences to participate in decision making may be due in part to a lack of understanding about how patients conceptualize their participation. The authors sought to learn more about how patients view their involvement in decisions related to their health care. Methods. The authors conducted individual interviews to allow patients to frame the decision-making process from their own perspective. The constant comparative-method approach to analysis was employed to ensure that the analysts defined the codes in a consistent manner. Results. Twenty-six persons were interviewed. The main themes discussed by the participants reflecting how they viewed their involvement in medical decision making are the following: 1) decision making is often an ongoing process in which patient participation may change over time, 2) decision making is performed within an extended social context, 3) the decisions patients report being involved in are often distinct from those traditionally studied (choice of treatment or screening strategies), 4) patient involvement in decision making occurs in response to physicians’ recommendations, and 5) patients make choices in the context of their specific illness perceptions. Conclusions. Participants in this study view their participation in decision making as including ideas distinct from those traditionally discussed by researchers. These findings suggest that the variability in patient participation noted in previous studies may be due in part to limitations in study design. Key words: medical decision making; qualitative study; patient participation. (Med Decis Making 2007;27:533–538)
may not accurately reflect patients’ preferences to participate in decision making. Given this background, we performed a qualitative study to better understand how patients view their involvement in decisions related to their health care.

METHODS

Data Collection

A qualitative study was chosen as the best approach to elicit patients’ descriptions of their own experiences and their interpretations of these experiences related to decision making in their own medical care. We wanted to allow patients to frame the decision-making process from their own perspective and to avoid imposing any assumptions about how the process is defined. Individual face-to-face audiotaped interviews were chosen over focus groups for this study because interviews allow for more in-depth exploration of each respondent’s individual experiences and thoughts. By using extensive in-depth probing, we hoped to uncover a broader and more detailed understanding of the patient perspective.

Participants

Participants were drawn from a larger study examining patient treatment preferences for osteoporosis. The sampling frame for the larger parent study was men older than 65 years and postmenopausal women who had recently (within 2 weeks) undergone bone densitometry from 6 centers in the greater New Haven, Connecticut, area. The vast majority of patients referred to these centers are women. Participants 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 larger, parent study. Other eligibility criteria included the ability to speak and understand English.

Interviews

Using a semistructured discussion guide, the interviews followed a funnel structure, progressing from broader open-ended questions to more structured questions with specific probes to clarify issues as needed. Opening with broader questions helps to elicit concepts or topics of greatest salience to the participants, an important feature of qualitative as opposed to structured interviews. The guide included 14 open-ended questions on participants’ experiences with medical decision making (see the appendix). Participants were first asked to think back to a time when an important decision had to be made about treatment of an illness or medical condition and then specifically prompted as necessary to discuss their involvement or lack of involvement in the decision-making process.

Each interview ran for up to 90 min and was conducted by the same PhD-level senior research scientist (SM), who has extensive experience in qualitative research and interviews. All participants gave informed consent, and the Yale University Institutional Review Boards approved the protocol. The interviews were audiotaped and transcribed by a professional transcription service. Demographic data (age, race, education, marital and employment status) were collected at the beginning of each interview using a self-administered questionnaire. All questions offered a defined set of responses, except for age.

Analysis

The constant comparative method of analysis was employed to ensure that the 2 coders defined and applied codes in a consistent manner across all transcripts. The analysts (SM and LF) independently read all of the transcripts and developed an initial list of codes. We stopped interviewing patients when we noted that no new ideas were discussed after 3 consecutive interviews. After all the interviews were conducted, codes were refined with subheadings on a 2nd reading of the transcripts and applied to specific sections of each transcript. QSR-NUDIST (Sage Publications Software, Thousand Oaks, CA) was used to identify and sort the relevant text across the transcripts for each code. Sections were reread to identify patients’ concepts related to their participation in decision making. The demographic data were summarized using descriptive statistics (SAS Software, version 8.0; SAS Institute, Cary, NC).

RESULTS

Participant Characteristics

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

The main themes that arose during the interviews, related to how participants conceptualize their participation in medical decision making, noted that decision making 1) is often an ongoing process, 2) involves an extended social context, 3) includes decisions distinct from those traditionally studied, 4) occurs in response to physicians’ recommendations, and 5) occurs in the context of patients’ illness perceptions.

An ongoing process. Some patients described their involvement in the decision-making process as one that occurred over time. For example, one respondent observed,

Sometimes a patient might say, well, I want to do a little bit more research, or maybe I want to consult with this other physician. (Interview 13)

Another respondent described a series of conversations she had with her doctor about which medicine to take to lower her cholesterol. After beginning with one drug, she reviewed the formulary of her insurance company to find the cheapest medicine and then requested that her doctor change her medicine. She then continued to evaluate the tradeoffs involved in this treatment decision, as illustrated by the following quote:

Once I started taking it, I started questioning. You know, reading up on it and finding out. But it can cause liver damage and that frightened me. I asked him to explain … what is the risk-benefit ratio here? (Interview 2)

Some participants described their experiences, usually related to cancer treatment, as including multiple decisions over time related to diverse domains, including attitudes toward screening or follow-up as well as curative and palliative treatment. For some, their preferred role in the decision-making process changed over time. For example, one woman described how a friend had participated actively in many decisions related to her breast cancer until she no longer felt strong enough to contribute:

But when she got there she was just kind of exhausted from making decisions and really worried and really just wanted people to tell her what to do. (Interview 10)

Involves an extended social context. Some participants in this study viewed active patient participation in decision making as occurring within, or as part of, a larger social unit. For example, some viewed themselves as supporting family members:

My sister and I have been instrumental in helping both parents make decisions when it was necessary in their older life. (Interview 14)

I wasn’t a patient’s annoying spouse. I was a member of the team taking care of him, is what I felt like. (Interview 2)

Others highlighted the need for someone to assist them:

They really need somebody to be there to advocate for them…if you don’t really know anything about the system or how things go…if you’re just like, “I’m here; take care of me,” you could get seriously screwed. (Interview 7)

Well if I had questions…usually I brought my daughter with me. Because you know when you go in there you are a little unnerved. You might not ask all the questions…and what I don’t ask she will. (Interview 19)

One participant noted that including others in high-stake decisions benefits both patients as well as their support unit:

I think especially if you’re doing it by yourself that the burden is extreme. When you’re in a situation you’re going to make a decision totally on your own without any influence from anyone else...the decision you make affects other people. (Interview 1)

Includes decisions distinct from those traditionally studied. Patients interviewed in this study chose to discuss their participation in decisions related to choice of physicians and whether to accept physicians’ recommendations more often than the choice of treatment or screening. For example,

[He] felt that he would do better switching [medical] groups, and there was a lot of anxiety about doing that, because he’s not a person who does that easily…but in the end we did. It was a difficult decision. (Interview 10)

I had to make a medical decision. Leave the doctor I had gone to for 5 years and go to somebody new. (Interview 4)

The main decision I kept making was that I wasn’t getting anywhere at this particular station. You move on to another guy…hoping that someone would be of help. (Interview 13)
Participants also described making decisions to both acquire and reject health services against their physicians’ advice. Decisions against physicians’ recommendations involved low-risk tests. For example,

But I made the decision that I wanted to go have a stress test anyway because I just think that’s the right thing to do. (Interview 14)

I think I’m going to call and get an ultrasound, just for my peace of mind, and when I went there, they weren’t going to pay for it because my doctor didn’t feel it was necessary so I paid out of pocket. (Interview 11)

In contrast, decisions to reject physicians’ recommendations centered on prescription drugs:

I made the decision not to do Lipitor, even though my cholesterol is 230. The diet and the treadmill and barbells and that’s as good as it’s going to get. (Interview 15)

And I did send away for the pills. I did order them. I got them home, and I looked at them and I go, I’m not taking these. (Interview 7)

[I filled the prescription] about 2 weeks ago, and I still have it. I don’t forget my other pills. It probably is more me than forgetfulness. (Interview 24)

In an example of a decision manifested in a non-action, one woman described that she was told that she had osteopenia and should “take some kind of drug.” In response, she said,

I never called the doctor back. I mean, I know I should. It’s only been about a month, I think, but I don’t want to go on this medication. (Interview 20)

Occurs in response to physicians’ recommendations. In this study, participants uniformly responded that they highly valued their physicians’ recommendations. Some participants viewed the physicians’ recommendations as an important piece of information. In these instances, the physician was viewed as a consultant:

I think the physician’s recommendation is presented to you, and then you have to decide whether you want it or not and how much you agree with him. (Interview 12)

The doctor lays out the risks and benefits, and you take all of that information and put it together with what is important to you. (Interview 9)

He [the physician] suggests and I make the decision. (Interview 2)

Others felt that their physicians’ recommendation stipulated the decision and consequently limited their participation:

He feels what he says should be done. If you have any objections, you can talk about them, but his word is good. (Interview 19)

Sometime he doesn’t say a word when you ask things . . . so you know he’s not going to change. You know he just came out of the Connecticut Magazine as one of the 10 best doctors, so he knows what he’s talking about. (Interview 18)

Occurs in the context of patients’ illness perceptions. In this study, participants highlighted the fact that information and/or recommendations are interpreted based on each patient’s individual illness perceptions.

If somebody comes in and says you have to do this and you just nod and say ok, and go home and don’t do any of it. But . . . if it makes sense to me, then I’ll do it. (Interview 7)

The conclusion I came to was that you’re not getting at the cause of the carpal tunnel if you go for surgery. When this woman suggested that the problem was coming from tightening my shoulder, it made sense to me, and that’s what I started working on, and I did not go back to the orthopedist. (Interview 9)

Others felt that individual patient health beliefs were so important that they should be not only acknowledged by the physician but also concordant with the physician’s personal views. For example,

I’m not a good medicine taker or pill taker. We think alike and that’s very important. (Interview 1)

I think they have to have a similar belief system or I don’t think the patient is going to trust the doctor, and the doctor can’t possibly believe that the patient is going to follow through with the treatment. (Interview 22)

DISCUSSION

In this qualitative study, patients described their participation in decision making using several concepts that differ from those usually included in surveys quantifying patients’ preferences to participate in decisions related to their health care. For example, researchers often query patients on their preference to participate in a particular decision at a discrete point in time. However, in
this study, patients frequently described their participation in decision making as an ongoing process. In fact, the highly educated patients’ description of how they view their role (i.e., to gather information over time and to weigh the consequences of each alternative) is reflective of what experts advocate to promote high-quality decision making.20 Patients in this study also raised the important point that preference for participation may change over time. This issue highlights the limitations of surveying patients on a single occasion but perhaps more importantly indicates that added support may be required to enable patients to participate in difficult decisions when they feel most vulnerable.

Studies examining patient participation in decision making have usually focused on choice of treatment or screening strategies.6,7 In this study, in which participants were given the opportunity to discuss 1 or more decisions of their choice, those discussed most frequently were related to choice of physician and whether to accept physicians’ recommendations, 2 situations in which patients clearly recognize the importance of their input. This finding calls attention to the importance of ensuring that patients appreciate the importance of their contribution before querying them on their preferred role to participate in a specified decision. In addition, investigators have generally queried patients on their preferred level of participation as individuals.6,7 Notably, patients in this study frequently viewed their participation in decision making as occurring within a larger social unit, thereby emphasizing the need to include all relevant stakeholders when surveying patients about their desire to participate in important decisions affecting their health care.

The differences in how patients conceptualize their participation in medical decision making compared with how health professionals conceptualize and study this process are consistent with differences in how patients and health care professionals understand and address medical symptoms.21 Although physicians focus on a disease model that centers on symptoms, testing, diagnosis, and treatment, patients’ illness perceptions center on how they interpret and cope with the effect of their symptoms on their quality of life. The concepts identified in this study are grounded in the patients’ descriptions of their own experiences and illness perceptions.

Although we feel that a qualitative study was the best approach to meet our objective, this approach does preclude quantitative analyses of the data and assessment of the relative importance that patients attach to each of the factors discussed. There are several additional limitations of this study. We did not include personal logbooks, observation methods, official reports, or focus groups to corroborate our results. Participants were enrolled consecutively, and we did not purposely look for deviant cases. Our sample was composed primarily of Caucasian, well-educated, postmenopausal women, which limits the generalizability of our results. Inclusion of a more diverse sample might yield even more discrepancies between the domains considered by patients to reflect active participation and those covered in studies using currently available instruments.

In summary, patients in this study viewed patient participation in decision making as including concepts distinct from those traditionally evaluated. These findings suggest that underestimation of patients’ desire to participate in medical decision making may be due in part to inadequate understanding of how patients conceptualize participation and consequent limitations in survey design. Based on the content of the interviews conducted, future studies examining patients’ preferred role in decision making should consider the following:

1. allowing for opportunities to reevaluate decisions over time in response to acquisition of new information,
2. ascertaining preferences from the appropriate social unit,
3. ensuring that patients understand the value of their input for the decision under consideration,
4. including a reference to the physician’s recommendation, and
5. ensuring that patients’ understanding of the expected course of their disease is based on accurate information so they may evaluate treatment alternatives.

**APPENDIX**

**QUESTIONS USED IN THE DISCUSSION GUIDE**

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.
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]?
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? Why did you wish you had a large 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?

5. Have you ever disagreed with your doctor about a treatment plan that was suggested to you? 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?

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?

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 clearly explains the financial costs of a course of treatment?

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?

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?

13. In general, do you think there are barriers in our health care system that make it difficult for a patient to participate in his or her health care?

14. What do you think could be done to improve the decision-making process for you?

REFERENCES


