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A Qualitative Analysis of Decision-Making for Total Knee Replacement in Patients with Osteoarthritis

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Abstract

Objective—Variation in the utilization of total knee arthroplasty (TKA) for patients with osteoarthritis has been well documented. Conceivably, patient preferences may play a major role in these differences; however, this has not been adequately assessed. The purpose of this study was to conduct a qualitative analysis of decision-making factors influencing preferences for TKA in patients with knee osteoarthritis.

Methods—We conducted six focus groups of patients with knee osteoarthritis from diverse ethnic backgrounds attending primary care clinics affiliated to the largest private outpatient institution in Houston, TX. All groups were lead by race-concordant facilitators. The group discussions were centered on factors considered to be important in the decision-making for TKA. Thematic analysis was conducted, using a grounded theory approach aided by qualitative software.

Results—Several themes emerged from the groups' discussions. Positive and negative personal experiences played a major role in decision-making. Generally, participants had good expectations about improved function and quality of life, but a number of fears were identified, the most prevalent being fear of a lengthy recovery, followed by fear of complications and of anesthesia. Additional emerging themes included trust in surgeon, financial concerns, and worries about general health.

Conclusions—The attitudes and beliefs of patients with knee osteoarthritis about TKA are largely based on personal experiences, expectations, and fears, and they are largely influenced by their close social environment. These findings emphasize the need for open doctor-patient communication around individual experiences to achieve satisfactory shared decision-making for TKA.

Osteoarthritis is a prevalent source of disability in elderly individuals, particularly that of the knee or the hip (1–3). There are not currently any therapies that are known to stop or reverse the progression of osteoarthritis, so treatment of the disease is largely centered around managing its symptoms. Patients with moderate-to-severe osteoarthritis who do not respond to therapy may elect to undergo elective surgery to replace the knee (total knee arthroplasty) or the hip (total hip arthroplasty). These surgeries are known to have substantial benefit to patients, proving effective in terms of alleviating pain, improving function, and improving quality of life (4–6).

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Variation in the utilization of total knee arthroplasty (TKA) by patients with osteoarthritis has been observed across several different studies (7–11). These studies show that utilization of TKA varies markedly by race/ethnicity, gender, and geography. White patients are more likely to undergo TKA than are African-American or Hispanic patients (7–9). Although women have been found to be more likely overall to undergo TKA than men are in some studies (7;8), when the higher prevalence of osteoarthritis of the knee in women is taken into consideration (2; 12), female patients with osteoarthritis have been found to underutilize TKA when compared to male patients with osteoarthritis, often not receiving the surgery until they are at a more advanced stage of disease (10;11). Regional variations in utilization of TKA that cannot be entirely explained by prevalence of osteoarthritis have also been observed (7;8). Overall, variation is observed in studies of total joint replacement across ethnicity (13–17), gender (10;16;18), and geography (19).

The observed differences in utilization by cannot be explained by the prevalence of knee osteoarthritis, which is mostly similar in the groups compared, or is even slightly higher in minorities than in whites (12;20) and significantly higher in women than in men (2;10;12). Nor are they likely to be wholly explained by differences in perception of pain and function, which has been observed to be concordant between white and African-American patients with osteoarthritis (21). Differences also cannot be wholly explained by differences in access and socioeconomic status. Although socioeconomic status does influence utilization of TKA (7; 22), disparities persist in utilization of TKA, and more broadly speaking, in total joint replacement, even after adjusting for the effects of socioeconomic status and in populations with equitable access to care (10;13;14;20). Alternative explanations may include patient preferences, tolerance for risk, social environment, and knowledge; patient comorbidities; physician recommendations; and doctor-patient interaction. Previous studies have identified patient concerns (23), patient preferences (19), patient beliefs (24;25), patient perceptions (26), patient expectations (27;28), patient familiarity with the procedure (27;29), and physician opinion of the procedure (30) as having an impact on patient decisions to consider joint arthroplasty.

Since TKA is an elective surgery, patient preferences may play a major role in differences in utilization. Most often, patients with osteoarthritis are managed in primary care, and primary care physicians often initiate discussions with patients about surgery, to evaluate potential referral to an orthopedic surgeon for further evaluation. This study used focus groups, a methodology frequently relied upon in exploratory qualitative studies to elicit personal perceptions and descriptions of lived experience (31;32). Our objective was to identify decision-making factors which influence patient preferences for TKA, and that should therefore be considered in the discussions that primary care physicians have with their patients when considering surgery.

METHODS

In order to examine the decision-making factors influencing preferences for TKA in patients with knee osteoarthritis, we conducted six focus groups of patients with knee osteoarthritis from diverse ethnic backgrounds attending primary care clinics at the same outpatient institution, Kelsey-Seybold, Houston, TX. Patients participating in the focus groups were recruited from a larger pool of participants in a previous survey related to knee osteoarthritis (33). To be eligible for the study, patients had to meet the following inclusion criteria: a physician diagnosis of knee osteoarthritis; no previous knee replacement; race (African-American and non-Hispanic, Hispanic, or white and non-Hispanic); age (55 to 80 years); adequate cognitive status as determined by the interviewer; and English language proficiency.

Two groups were conducted with African-Americans, two groups with Hispanics, and two groups with whites. All focus groups were led by race-concordant facilitators and were conducted in English. This strategy was important, because it has been shown in previous focus groups of patients with osteoarthritis that African-Americans, particularly males, raise fewer issues than other participants, and speak the least (23). The group discussions were centered on factors considered to be important in the decision-making for TKA, exploring four major themes: (1) current problems with knee arthritis; (2) awareness of TKA as a treatment option; (3) decision-making processes in considering TKA; and (4) expectations about TKA. Eleven questions with probes were developed for use in the focus groups. However, due to redundancy, after the first group meeting, one question was eliminated, and a second set of 10 questions were used with the remaining groups (Table 1). Transcripts were recorded for each group discussion.

The purpose of qualitative research is not generalization, but rather a rich, in-depth description and interpretation of the phenomena being studied. In this study, thematic analysis was conducted, using a grounded theory approach, meaning that a preliminary theory of how patients with knee osteoarthritis make decisions about whether to have TKA, is derived from the patients' discourse (33). The transcripts were reviewed for accuracy by the research team and subsequently entered into Atlas.ti © (SCOLARI, Sage Publications), a qualitative software program that facilitates the investigators' ability to organize, code, and sort patients' verbatim responses. A team of at least two coders was assigned to independently review each transcript. Each coding team discussed their assigned transcripts on a line-by-line basis. The research team as a whole agreed upon definitions of emergent themes, which were refined as each subsequent transcript was reviewed. Themes were then clustered in order to recognize patterns within the data. This step of clustering themes is usually what is done as part of building a grounded theory, rather than simply listing a long list of individual themes.

RESULTS

A total of 37 patients participated in the focus groups, 14 males and 23 females; 13 were white, 15 African-American and 9 Hispanic. The characteristics of the participants are shown in Table 2. The mean duration of the focus group discussions was 105 minutes. Though the number of participants was relatively small, the amount of discourse produced by these focus groups was extensive, resulting in 215 pages of transcripts.

Several themes emerged from the groups' discussions. The most common frequent themes related to decision-making and the number of times each was brought up by patients are shown in Table 3.

Patients obtained information about TKA from different sources which often included non-professional contacts, such as relatives or acquaintances, the media (e.g. television), and the Internet.

"Well, I've heard on television and my sister-in-law and a friend of mine that had both knees done. That they have had good response from it. All I've heard is positive about it."

"So I guess other people's horror stories have frightened me."

"I read just about anything and everything and I saw, I don't know what magazine it was now, but I did read the article and it had a profile of the knee showing how they cut -- well, cut off literally and replaced and bolt and just the idea of that is just so" "Grueling" "Uh-huh. It's mind boggling, I mean, in a negative way for me."

Primary care physicians were the most common source of professional medical information. Many participants expressed desire for additional information about the surgery and what to expect. Lack of knowledge hindered their decision-making.

“I would like to know all that information before the operation, if the doctor would take his time and explain all these things --tell me what could go wrong.”

”But they don't explain the after effect. When you go home, is there gonna be somebody to help you out? Are you gonna be able to have that motivation to do your physical therapy yourself? How are you gonna get to the doctor? Do you live by yourself? Do you have help? That's what they don't explain to you. They say, Oops, yeah, it's a piece of cake.”

Both positive and negative personal experiences played a major role in decision-making, and included TKA experienced by relatives, friends, or acquaintances.

“I changed doctors and I started going to her doctor because she really had success with her knee surgery.”

“She couldn't get in the car and I worked up the courage to ask her if she had had the knee replacement surgery. She said, “Yes, honey, and don't get it done.” Her scar went like that, across the knee. It was -- her knee was totally deformed.”

“He's now in a wheelchair with -- has to have a 24-hour person helping him. They got -- his knees got infected ... I mean that's a reality, you know, that's something I've experienced personally, it's not something I read somewhere.”

Previous personal experience with surgery, including non-orthopedic procedures, also played a role in patients' preferences about knee surgery.

“I think one of the reasons that I don't have a fear of that surgery, I had bunionectomies – I don't know how close it would be as far as operations but I had twice— bunionectomies and they did a very good job.”

“Well, I had heart surgery and I tell you what, when they roll you out of that room, going in that operating room, you don't know if you're coming back there or not. I tell you, and that's very frightening.”

Financial issues were often discussed, and most participants expressed concerns about the cost of surgery, although in general they stated that financial difficulties would not affect their final decision to undergo knee surgery.

“As I stated earlier, I would borrow -- if I didn't have the money and the pain was bad enough, I would have it done, I'd get the money.”

“You know, whatever it takes, you know, draw it out of my 401k, something. I'd do something. I wouldn't let money stop me.”

Participants had good expectations about improved function and quality of life, sometimes perhaps unrealistic.

“You could do all the things you didn't do. I imagine, for me, I could go back to the gym every day.... I know I could go play tennis..... Do all those little things you used to do.”

A number of fears were also identified: fear of a lengthy recovery, fear from complications and from anesthesia, concerns about longevity of prosthesis, and worries about how the surgery may affect their other health problems.

“But that would be my main concern; if I have the surgery, do you think you can handle all these other ailments?”

The concepts of readiness for surgery and surgery as last resort as perceived by the patient or the physician was also important and often brought up as the threshold for decision-making.

“Like I said, uh, to me surgery is the last resort. If I'm at a point where I can't walk no more and I have to crawl, then I might consider surgery.”

“Well, I m just waiting for the doctor to tell me when he' s ready. I m going to have mine as soon as he tells me.”

The relationship between patients and their physicians was often discussed and included issues of communication, informativeness, and trust.

“You know, sometime you go to see a doctor, they talk to you maybe a minute then you go -- -- they get a bunch of people one after the other one. You wait like 20 minutes or one hour, they come and talk to you five minutes (snaps fingers) and they leave. But I have a doctor my knee and the clinic, -- he's Hispanic doctor. He takes time talk to you and explain and I like the way he helped me. So, I trust him.”

“Some doctors are good doctors, but they make mistakes and some doctors can explain better than other doctors. They've got their own ways. They're like anything else, carpenter, some carpenter's good; some carpenters not that good”

“You have to be concerned about the doctor that is doing the surgery. How many times? Is this the first time he's doing it on you or has he done it a hundred times? You know? Yeah, that's a very good one. The experience of the doctor, the orthopedic doctor who is doing the surgery, has a lot to do with it.”

Although many patients expressed a desire for partnership in decision-making, others preferred to a more passive role.

“You have to do what the doctor says to do.”

“I'd let the doctor make the decisions. I'd like to think if I pick a good enough doctor he is going to do the right stuff.”

Finally, conflicts in opinions between, patients and families, and sometimes doctors, were also a concern for some participants, hampering satisfactory decision-making.

“One daughter is a nurse and strange enough, she's the one that says, "Don't do the surgery." My other daughter says, "Mama, why don't you go on and do the surgery?" My boys don't care. I mean, they are not opinionated about it.”

“Well, my doctor -- I've gone to three, different doctors and each one has told that they would not recommend knee surgery because my back is the reason that my knees are in the shape that they're in, and it's extended to my hips.”

DISCUSSION

It is well known that variation by geography, race, and gender occurs in patients with osteoarthritis in the utilization of total joint arthroplasty (7–11;13–19). This variation cannot be completely accounted for by differences in the prevalence of osteoarthritis, in health care access, or in socioeconomic status (10;12–14;20). TKA is an elective surgery, so patient preferences may be important among the other factors that determine differences in utilization. This study qualitatively explored decision-making factors influencing preferences for TKA in patients with knee osteoarthritis.

Our study found that the attitudes and beliefs of patients with knee osteoarthritis about TKA are largely based on *personal experiences*—both positive and negative; *expectations* about the outcome of the surgery; *fears*, including those relating to recovery time, complications,

anesthesia, and the longevity of the prosthesis, and their *interactions with their doctors*. The patient's close social environment strongly influenced their attitudes and beliefs about TKA, and much of the patients' narratives related to others' stories and testimonials, that were incorporated to the group discussion.

The role of physician-patient communication was prominent throughout the focus groups, and participants expressed the importance of trust in physicians' opinions and in their technical abilities as a recurrent theme. Some participants expressed desire for additional information about the surgery and what to expect post-operatively, and felt dissatisfied with their current knowledge. Yet, some participants were more comfortable with delegating decision-making to their physicians.

The concept of readiness was repeatedly included as the threshold for decision-making, sometimes described as a point in time when no other alternatives would be viable. This concept was important to us, because TKA improves pain and function, and it is conceivable that some patients may choose surgery at an earlier point in their disease to improve their quality of life. Yet, the concepts of readiness and surgery as last resort were prominent throughout, suggesting that patients will 'hold off' until late stages. This finding can also help understand why joint replacements may be underutilized on the basis of appropriateness alone.

Most of the research related to patient decision-making in TKA and total joint replacement, has examined variations across race, mostly using survey methodology (23;24;26;27;34;35). Only one survey, conducted by our group, included Hispanics (34). Our current analysis examines overall attitudes and decision-making towards TKA because most major themes were similar across ethnic groups. A separate narrative report outlines the differences in perception observed between the three ethnic groups in more detail (36). In brief, these included four specific themes: differences in explanations of illness, potential changes in lifestyle, trust and skepticism, and financial issues. However, the major issues identified in the overall analysis were prominent for all ethnic groups. In prior studies, African-American patients differed from white patients in several ways: they were less likely to know someone who had undergone/benefited from the surgery, had less familiarity with the surgery, were more likely to have concerns/lower expectations about postsurgical outcomes, more likely to perceive prayer as being helpful, less likely to perceive joint replacement as helpful, and more likely to perceive other alternative and traditional treatments as efficacious (23;24;26;27;34;35). Our qualitative study did not identify African-American patients as having more concerns, or fewer expectations. This could potentially be due to the use of focus groups with race-concordant facilitators in this study allowing a more open and comprehensive examination, the more in-depth explanations encouraged within the groups that is not possible in surveys, or our small sample size.

A few other studies have yielded results that were concordant with the ones presented in this paper. Mancuso et al. (28) identified similar patient expectations to the ones listed herein in TKA relating to improved physical function, improved well-being, and relief of symptoms. Chang et al. (23) conducted focus groups of white and African-American participants, to investigate the concerns of patients who were considering TKA. Their study was different from ours in that they included patients recruited at an orthopedic clinic who were already considering TKA, and only examined their worries about surgery. They identified several concerns similar to those found in this study, including timing of surgery, longevity of prosthesis, physician trust, and financial concerns. In our study, patients were recruited from primary care practices, and some had considered surgery but other had not. The goal of our study was broader, in that we wanted to examine what factors were important in their decision-making, and not only their worries about surgery. Nevertheless, the surgical concerns described

by Chang et al, were also identified in our study, which in addition to African-Americans and whites, also included Hispanic patients.

Focus groups were utilized as this study's research methodology because they are an efficient method of examining patients' experiences and opinions, particularly when they are complex. This study assesses in depth the factors that may be most important in patient decision-making about TKA. However, this study is constrained by several limitations. This study may be limited in its generalizability. All of the patients participating in these focus groups were drawn from a single outpatient institution, and the sample size was relatively small. It is not possible to assume that the decision-making factors identified by the patients in this study can be generalized to the population of patients with osteoarthritis who are considering TKA at large. However, this study did successfully identify factors in patient preferences that may apply to other patients with similar characteristics who are in similar settings, and information of this nature may not have been obtained without this type of qualitative methodology.

In conclusion, based on the findings of this study, a number of factors influence patient decision-making; patient experiences, fears, and expectations, and physician trust are prominent among these. Our findings emphasize the need for open doctor-patient communication around individual experiences to achieve satisfactory shared decision-making for TKA. Doctor-patient interactions and subsequent patient decision-making could be improved by developing and using decision aids for patients, and educating physicians about patient concerns and expectations. This would ultimately improve patient understanding of the risks and benefits of TKA and allow patients to make an informed decision about the procedure.

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Table 1

Focus Groups Topics, Questions, and Probes

<p>Current Problems with Knee Arthritis</p> <p><u>Question 1:</u> What bothers you the most about the arthritis in your knee?</p> <p>Probes (if necessary): Emotional and social, as well as physical problems?</p>
<p>Awareness of Surgery as a Treatment Option</p> <p><u>Question 2:</u> What do you know about knee replacement surgery as a treatment for arthritis?</p> <p>Probe (if necessary): Where did you get the information?</p>
<p>Decision-making Factors</p> <p><u>Question 3:</u> Have you ever thought about having knee surgery?</p> <p>Probe (if necessary): If not, why?</p> <p><u>Question 4:</u> Has anyone suggested that you consider having this surgery?</p> <p>Probe: Doctors (primary care, specialist, surgeon), family, friends</p> <p><u>Question 5:</u> Do you know of anyone who has had this surgery?</p> <p>Probe: If so, how has talking with that person influenced you?</p> <p><u>Question 6:</u> What concerns or needs would keep you from having knee surgery if your doctor recommended it?</p> <p>Probe: How about money concerns or family concerns?</p> <p><u>Question 7:</u> What things would you take into account in deciding whether to have knee surgery?</p> <p>Probes (if necessary): Benefits? Risks? Expense? Other concerns? People you'd like to consult with? Other information needed (examples)?</p>
<p>Expectations</p> <p><u>Question 8:</u> What fears or concerns do you have about what may happen with a knee replacement surgery?</p> <p>Probe: Any fears or concerns?</p> <p><u>Question 9:</u> If you were to decide to have knee surgery how do you expect your knee condition would change after the surgery?</p> <p>Probe: Expectations of good outcomes? Expectations of bad outcomes?</p> <p><u>Question 10:</u> If you were to decide to have knee surgery how do you expect your life would change after the surgery?</p> <p>Probe: Expectations of good outcomes? Expectations of bad outcomes?</p>

Table 2

Demographic characteristics of the focus group participants

Ethnicity FG	White	White	AA *	AA *	Hispanic	Hispanic	Total
Total patients	7	6	8	7	4	5	37
Gender							
Male	3	3	4	0	1	3	14
Female	4	3	4	7	3	2	23
Age, mean (yrs)	62.6	67.0	61.4	65.6	63.8	65.4	64 yrs
Education Level							
<8 th grade	0	0	0	0	1	1	2
High school	1	0	1	0	0	2	4
Trade/technical	0	1	1	2	1	0	5
Some college	4	2	5	1	2	2	16
BA/BS	2	2	0	1	0	0	5
Advanced	0	1	1	3	0	0	5
Disease duration, mean (yrs) **	4.4	7.8	6.3	5.3	11.0	7.3	7 yrs

* AA – African American

** Disease duration estimated from duration of knee pain

Table 3

Themes in Decision-Making

Theme	Total
Source of Information - How or from whom patients receive their information about knee osteoarthritis; includes physicians, others, media and Internet.	98
Expectations - Refers to patients' anticipated outcomes and their importance in making the decision to undergo surgery.	80
Readiness - Patients' subjective perception about how ready they may be for surgery; perception that they reach a state where the best option might be surgery.	75
Fears - Unpleasant emotions and apprehensions that patients have regarding knee surgery.	72
Expenses/Willingness to Pay - Refers to what patients would/could spend on knee surgery.	57
Good Experiences - Positive experiences that may impact patient expectations for knee surgery. Can be personal experiences, such as previous surgeries, or knowledge of surgical experiences in others.	52
Trust in Doctors - Perception that the doctor is qualified and will act in their best interest; includes physician's judgment and experience.	41
Bad Experiences - Negative experiences that may affect patient expectations for knee surgery. Can be personal experiences, such as previous surgeries or knowledge of surgical experiences in others.	34
Concern, Longevity of Prosthesis - Length of time the prosthesis will last.	20
New Technology - Patients' comments about expectations for new technology for the treatment of knee arthritis; improved procedures.	16
Skepticism - Attitude of doubt, or a disposition to incredulity toward healthcare in general or toward knee surgery specifically.	15
Surgery as Last Resort - Patients' expressed desire for other options instead of knee surgery; surgery as last option after other treatments.	15
Concern, General Health - Concerns about other medical conditions, which may have an impact on the patients' outcomes during and/or after surgery.	14
Desire for Surgery Information - Desire for information relating to treatment and surgery procedures.	14
Second Opinion - Advice from another physician; includes patients' struggles with different information.	9
Decision Conflict - Patient and relative or family disagree about the need or readiness for surgery.	7