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A Qualitative Study of Factors Underlying Decision Making for Joint Replacement among African Americans and Latinos with Osteoarthritis

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Abstract

To support patients in making decisions that align with their unique cultural beliefs, an understanding of factors underlying patient preferences is needed. We sought to identify psychosocial factors that influenced decision making among African-American and Hispanic patients referred for knee or hip arthroplasty. Thirty-six participants deciding on surgery were interviewed. Responses were audio-taped, transcribed, and read. Codes were assigned to the raw data and then clustered into categories that were analyzed to yield overarching themes. This process was repeated independently by two corroborators. Six categories described the mental calculations made in patients' decision-making processes: 1) self-assessment of fit for surgery based on age and comorbidity, 2) research and development of mental report cards of their surgeons, 3) reliving of social network experiences, 4) reliance on faith and spirituality for guidance, 5) acknowledgment of fear and anxiety, and 6) setting expectations for recovery. This study advanced the understanding of how decisions about joint replacement are constructed and identified cultural levers that can be targeted for intervention. Developing culturally tailored health information that addresses some of our findings and disseminating messages through social networks may reduce the underutilization of joint replacement among racial and ethnic minority populations.

Keywords

patient-centered care; disparity; surgical decision making; total joint arthroplasty

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I. Introduction

Patient-centered care has gained prominence as a key measure of quality care among orthopaedic surgeons. To provide this degree of care, physicians must understand factors that are important to their patients and must coordinate a health care team that supports and integrates patients' values in the decision-making process. This is particularly relevant to culturally diverse populations who may have unique views on health care decision making.

This study provides an emic perspective on factors influencing patients' decision making regarding total knee or hip replacement (TKR or THR, respectively). Osteoarthritis (OA) is an optimal case for highlighting shared decision making because it is highly prevalent, has the potential for significant morbidity, and requires patients to make choices about the best approaches for treatment. Numerous studies have documented disparities in joint replacement among African Americans and Hispanics compared with whites.^{1,2} Even after adjusting for age, sex, and insurance, African Americans and Hispanics have lower rates of knee and hip replacement.²⁻⁶ The reasons are complex and include patient-level factors (e.g., past experiences),⁷ provider factors (e.g., physician-patient communication style), and system-level factors (e.g., access to care).⁸

Previous OA studies presented patients with hypothetical scenarios to explore willingness to undergo arthroplasty.³ This study includes participants with a clinician-confirmed OA diagnosis who were in the process of making a decision about surgery. This provides a better understanding of practical considerations.⁴ The objective was to explore sociocultural factors that might influence African-American and Hispanic patients' decisions regarding joint replacement. To eliminate access to care as a confounder, all participants were insured and under the care of an orthopaedic surgeon.

II. Methods

Participants were recruited from two surgeons' practices comprised of racially and ethnically diverse patients. Eligibility was based on the following: 1) assessment of clinical and radiographic evidence of advanced OA, 2) the surgeon's indication of the patient as a candidate for TKR or THR, and 3) the patient's self-identification as African American or Hispanic.

Interviews were conducted in English or Spanish based on the participant's choice. Participants were queried on items such as the impact of OA on their day-to-day lives, their perceptions of their relationship with their surgeon, and their expectations of joint replacement surgery.

Data analysis included data immersion, creation of codes, and categorization.⁵ This process was iterative and used new evolving theory in the context of existing data until no new findings emerged, or when analytical saturation occurred.⁶ Participant responses were audiotaped and transcribed verbatim. For data immersion, all transcripts were read line by line. Codes were then assigned to all of the responses. Codes are descriptive labels that represent key concepts being conveyed by the data, and could be actual responses, selected words from the transcripts, or words that represent key concepts.⁹ The codes were grouped

into categories that were analyzed to identify spheres of influence in the decision-making process. To ensure trustworthiness of data, detailed notes of the coding process were maintained as field notes, all steps were conducted independently by a second reviewer for corroboration, and half of the interviews were reanalyzed to determine “fit” into the categories. When discordance was found, raw data were reviewed by a third corroborator, and new categories were derived until consensus was reached.^{7,8}

The Western Ontario and McMaster Osteo-arthritis (WOMAC) Index (version LK 3.0) was used to describe pain level and limitations prior to the interview.^{10,11}

III. Results

Thirty-six patients participated in individual semi-structured interviews (Table 1). The average age was 67.8 ± 10 years, 78% were African American, 17% were Hispanic, and 80% were women. More than half (55%) of the participants made $< \$40,000$ annually, and the majority (70%) were receiving Medicare and/or Medicaid. Nearly half (45%) had a college degree or higher; 14% had not completed high school. Patients averaged a mean (\pm SD) score of 50 ± 15 on the WOMAC index of OA with scores on pain, stiffness, and physical function of 12 ± 3 , 5 ± 2 , and 33 ± 10 , respectively. We reviewed 210 patient responses and six categories emerged, each describing a mental calculation that patients made in the decision-making process: 1) self-assessment of fit for surgery based on age and comorbidity, 2) research and development of mental report cards of their orthopaedic surgeons, 3) drawing from social network experiences, 4) reliance on faith and spirituality for guidance, 5) acknowledgment of fear and anxiety, and 6) setting expectations for recovery.

A. Self-Assessment of Fit for Surgery Based on Age and Comorbidity

Participants conducted a self-assessment as to whether they deemed themselves fit for surgery. This assessment was largely based on their age and underlying comorbid conditions. Responses were mixed regarding at what age surgery should be precluded and pain be accepted. There was also a discussion about whether pain was normal with aging. Some participants more readily accepted pain and decreased function as part of aging, while others felt they should not be in pain regardless of age.

“I know when you get older you are supposed to get a little slower, and you do have a little pain, but at 55, the pain that I am in, I don't feel that I should be in yet.”

Diabetes was a commonly cited comorbid condition; others included coronary artery disease, hypertension, and mental health conditions. Some participants felt that their multiple comorbidities could increase their likelihood of an adverse outcome or that the comorbid condition itself could be exacerbated. This diminished their enthusiasm for surgery.

“If I wasn't a diabetic, I probably would have it (surgery), but I know being a diabetic, healing takes longer, and I know that.”

“But with me, since I have been on so much medication, I had a heart attack, I am a diabetic, I have taken medication for high blood pressure, and I almost had a nervous breakdown, and with all of that, that bothers me, and I just feel that if I go

through with the surgery, that will affect my nervous system and make me have another breakdown.”

B. Background Research and Development of Mental Report Cards of Providers

In deciding whether they would pursue surgery, participants did research into their surgeons' backgrounds. Their perceptions were derived from this research and from recommendations and referrals from providers. Participants also sought information from the internet and MEDLINE searches for surgeons' publications. These elements were used to create mental report cards of their providers and to decide to be treated by this particular surgeon.

“I looked at the research that he's published and I was interested in it and it looked to me like he's, you know, he's clearly up on what's going on in the field, and what sorts of advances are being made and clearly thinking about the process and what work[s] and what doesn't.”

“In choosing an orthopedist I looked around and I talked to the surgeon and got recommendations and I looked at websites and MEDLINE and things, so yes, in general the people that we've dealt with I've felt like definitely have both aware of us as people and have our best interest in mind.”

C. Drawing from Social Network Experiences

Participants infused events that had happened within their social networks into their narratives. Knowledge of others, who had a successful joint replacement experience, emerged as a powerful influence. Social network narratives focused on good or adverse outcomes and timing of surgery. Sources included people in their community or church, as well as family members.

“There are a lot of people where I live that have had knee surgery and they are doing fine, so I figure I should just go ahead and have the surgery.”

“There was a person at our church and he said, ‘I was in pain for 5 years, you see, and if I knew it like I know, I would have done it way before.’”

Knowledge of others who had negative outcomes was an important consideration in the decision making regarding surgery. Some social network experiences pertained to nonorthopaedic procedures. Nevertheless, they seemed to influence participants' thought processes regarding orthopaedic surgery.

“Surgeries for me, I am really cautious, because there was an incident that happened with my husband and with my son, and I think that had a lot to do with me. Because my husband was a diabetic and he was on dialysis. His kidney was repaired. My son was tested and he was the perfect match, but when they went into surgery, they were taking a kidney out of my son, my husband - the doctor said they could not put [it] in because something kept breaking, I am not sure. So, that was a big disappointment, and I felt that they should have tested my husband to see if he could have received the kidney. That was in '97, and my husband lived 2 years after that. And that just did something to me.”

D. Acknowledgement of Fear and Anxiety About the Procedure

Participants acknowledged fear and anxiety about surgery. Fears included fear of anesthesia and its potentially fatal consequences, fear of pain, fear that their comorbid conditions would impact their ability to withstand the procedure, fear of being intubated, and fear of “going to sleep.” The influence of social network experiences resurfaced as they described their fears and anxiety.

“I’m not scared of the surgery, but they put a tube up your nose and down your throat and I hate that because it is very painful.”

“I was really afraid of that and I kept thinking in my mind that I was going to go to sleep and never going to wake up.”

“I am not frightened with the surgery; believe it or not, I am frightened with the anesthesia simply because I have had two members in the family who did not come out of anesthesia and that’s frightening.”

E. Reliance on Faith and Spirituality for Guidance and Support

Although not queried directly, references to God, spirituality, and/or religion emerged throughout the interviews. Participants described a strong reliance on God and their faith as sources of support. This category had several dimensions: 1) God working through the surgeon, 2) God determining destiny/ God will heal, and 3) the role of prayer. Some expressed that their locus of control was in a higher power, their future was in God’s hands, and they have little control over what happens. Of note, their faith in God did not diminish their trust in their surgeons; rather, their faith reinforced their belief in the provider. Some participants relied on their faith in deciding the timing for surgery.

“I do believe that God is the one, and He heals and He also gives the doctors the faith that they can do it.”

“God gives [doctors] their quality to do the work. I mean faith-wise it’s all in God’s hands.”

“The best doctor can mess up at the last moment on me, whereas with everything else he had a straight record. So, my faith is really in God, and once I trust them, then I just say that everything is in His hands and He will help the doctors, the nurses, the scrub people, and the whole staff and I’ll be in good hands.”

“I have to pray on it for the Lord to steer me in the right direction... if this is the time for me to have the knee replacement, you know, let me know and that’s to let my spirit be at peace. So, once He lets me know that, then I can go forward.

F. Setting Expectations for Recovery

Expectations for recovery varied from patients desiring to be more independent without the use of a cane to regaining their previous level of function. For some, surgery was a way to restore their quality of life and to return to normalcy: “*I just want to get back to my life.*” Expectations of surgery were influenced by social network experiences and discussions with

their provider. Some expectations were also defined by a timeframe. Despite expectations for improved function, there was also an expectation of pain.

“I’m expecting to be, maybe not pain-free, but not in severe pain, but I am expecting to be able to go up and down the steps to go on with my life.”

“Yeah, because they talk about the pain afterwards, but I know that I will have to take it easy at first and then get adjusted to whatever they put in there. I will go slowly. I won’t be walking up and down in the house probably, but I will try to walk around with my cane until I feel like I am ready enough to try it on my own. But after I get well, like 4 months later, I want to be the same person I used to be.”

III. Discussion

Shared decision making involves conversations between patients and providers about options, needs, preferences, values, and potential out-comes.¹² An understanding of factors that affect a patient’s decision is necessary to implement the best model of care, especially in populations whose views may be based on social or cultural experiences. This study used a qualitative approach to provide insight into the factors underlying attitudes toward THR or TKR among African-American and Hispanic adults. Six distinct yet interrelated categories emerged that described factors that influence the decision-making process. Three overarching themes emerged as lessons learned from the study, and provide a basis for recommendations for enhancing provider-patient communication around joint replacement.

The first theme is that patients’ decisions are framed prior to the provider-patient encounter. Prior to discussing surgery with their providers, patients may conduct a self-assessment of whether they deem themselves as appropriate candidates for surgery. Therefore, when they come to the encounter, they may already have made up their minds that they are not suitable candidates. Many participants described their age and comorbidity as barriers to undergoing surgery.

For other patients, the degree of pain is an important factor regardless of their age. Therefore, asking patients whether they consider themselves as a candidate for surgery provides an opportunity for correcting any misperceptions regarding the influence of age and comorbidity on outcomes. Patients may be reassured that providers also make a pre-operative assessment that addresses their comorbid conditions. This validates the patients’ concerns and may reduce barriers for discussion. Decision making may be supported by incorporating success stories of patients with similar comorbid conditions and similar age.¹³

An important lesson is that the process of shared decision making must anticipate and consider these antecedent factors. Patients’ perceptions of pain and expectations for recovery may also be formed prior to the provider-patient encounter. Fear of pain was described in previous studies as a determinant of quality-of-life outcomes. Lavernia et al.¹⁴ reported that among patients undergoing THR and TKR, African-American adults experienced higher fear of pain before surgery when compared with whites. This greater aversion to surgery may reflect the influence of social network experiences, mistrust of medical care, or lingering effects of racial and ethnic discrimination.^{10,11,15,16} Another study found that Hispanic veterans were less likely than white veterans to receive nonsteroidal anti-

inflammatory drugs with COX-2 selectivity for pain and both Hispanic and African-American veterans received fewer days' supply of analgesics than white veterans.^{17,18} It is unclear whether prior experiences with pain management impact perceptions for this surgery. This can best be addressed in prospective studies following patients.

The fear of being cut resonated in the patient narratives. One participant stated “*And a lot of people just don't wanna be cut.*” Participants in a qualitative study by Figaro et al. made similar assertions.¹⁹ This fear may not be related to prior surgical experiences, but rather experiences of members of their social network or simply visceral perceptions of being cut. Discussions on these difficult, yet important, aspects of surgery are important to allay patients' fears.

A second dominant theme was that faith and spirituality play a vital role in the lives of these participants. Discussions of faith and spirituality may be uncomfortable in the provider-patient interaction; however, shared decision making can only be effective if patients fully disclose their beliefs. Eliciting the patient's locus of control may help providers to frame culturally tailored interventions. Participants described a strong reliance on God for guidance and support. While patients may not always make their religious beliefs known to their providers, faith and spirituality remain a major driving force. This is particularly relevant to communities of color who may be more likely to have greater reliance on their faith.

In a cross-sectional survey of veterans, of which 44% were African American, Ang and colleagues found that African Americans were twice as likely to report relying on their faith.²⁰ Studies also found that African Americans and Hispanics are more likely to use prayer as a coping mechanism.²¹ A qualitative study among African Americans with OA also noted that faith and belief in God were important factors.²¹ Building alliances with community, faith-based organizations can help providers gain a better understanding of factors that influence patients' decision making. Working with faith-based organizations may also dispel misperceptions regarding surgery. Responding with respect to a patient's reference to faith is an important aspect of providing patient-centered care. Patients should feel comfortable discussing their preferences in light of their faith or religious beliefs. Decision aids that incorporate discussions or references to God, faith, or spirituality may help in these discussions.

A third theme was that participants' perceptions result from a dynamic exchange of information that occurs between the patient, their social network (actual and internet), and their providers. Social network experience is an important factor in the perception of need for joint replacement.²² McHugh and Luker, in a qualitative study of 27 patients, found that hearing of experiences of joint replacement from others in their social networks influenced treatment selection for total joint replacement.²³ Experiences of members in one's social network affects the patient's willingness to undergo surgery as well as his or her expectations and may be a clue to understanding differences in joint replacement. Patients' expectations varied from being active to just not having to use a cane.²⁴ These expectations are drawn from sources that may include social network experiences or prior research.

Therefore, patients may come to the encounter with preconceived ideas about the provider and with expectations of outcomes. Providers may wish to elicit the influence of social networks by querying patients about their sources of information, asking questions discerning patients' knowledge and perceptions, such as "From whom do you get your information about osteoarthritis and its treatment?" or "What have you heard about this procedure?" This provides another opportunity to point patients to internet sites describing patient experiences or resources as decision aids. A pilot study among veterans with OA found that while the introduction of a decision aid did not change willingness to consider joint replacement, it improved the stage of decision making and reduced decision conflict.²⁵

Limitations may impact the ability to extrapolate beyond this group of participants. The sample was small, yet consistent with qualitative research.²⁶ In a review of qualitative research on knee OA, the median sample size was 20.⁴ The sample had few Hispanic patients and men, which limits the ability to analyze data across race, ethnicity, and sex. The study only included patients seen by two African-American surgeons. It is unknown to what extent this may have influenced perceptions, patients' selection of a specialist, and decisions to have surgery. We recognize that the inclusion of Hispanic and African-American patients without a Caucasian control group provided limitations, but sought to identify those ethnic minorities most at risk for disparities. Future studies can provide direct comparison as we understand more about how patients of different backgrounds make surgical decisions. The cross-sectional nature of the study limits the ability to determine whether participants ultimately did choose to have the procedure and whether certain categories of responses correlated best with decision making. Notwithstanding these limitations, this study provides insight into potential avenues for interventions that may enhance provider-patient communication around joint replacement.

IV. Conclusions and Clinical Relevance

The results of this study provide insight into factors that underlie the decision making of ethnic minorities. The goal of this qualitative study was to understand from the minority patient's unique perspective what factors play a role in his or her decision making regarding elective total joint replacement. These data point to opportunities for intervention and strategies to support the decision-making process regarding joint replacement. The findings provide a framework for a more effective provider-patient discussion. Asking patients about their own self-assessment as surgical candidates and responding in a culturally and linguistically appropriate manner may facilitate greater sharing of information. Asking patients to recount experiences of their social networks with surgery including nonorthopaedic procedures may provide insightful information about their fears and expectations. In addition, inquiring about their source of information or locus of control may help broach sensitive or personal topics such as faith and spirituality. This can also help providers address misconceptions, and enable patients to set realistic goals. Knowing where patients are in their thought processes and meeting them there with openness and cultural humility is important for achieving quality patient-centered care and may help to stem the racial and ethnic gaps in total joint replacement utilization by minorities.

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Table 1
Research participant characteristics (N=36)

Characteristic	Value
Age (yr)	67.8±10.0
Female sex	29 (80.6)
Race/ethnicity	
African American	28 (77.8)
Hispanic	6 (16.7)
Not specified	2 (5.6)
Annual income (\$)	
<20,000	14 (38.9)
20,000–40,000	6 (16.7)
41,000–60,000	7 (19.4)
>61,000	5 (13.9)
Not specified	4 (11.1)
Education level	
More than fifth grade, did not finish high school	5 (13.9)
High school or GED	14 (38.9)
College or trade school	14 (38.9)
More than college	2 (5.6)
Not specified	4 (11.1)
On Medicaid or Medicare	
Yes	25 (70)
No	6 (17)
No information	5 (14)
Number of people living in the household	2.2±1.2
WOMAC Index	50.0±15.0
Pain subscale	12±3.1
Stiffness subscale	5±2.5
Physical function	33±10.6

Data are presented as *n* (%) or mean ± SD.