

CHAPTER FOUR

Qualitative Research

Research methods that delve deeply into experiences, social processes, and subcultures are referred to as qualitative research. As a group, qualitative research methods:

- Recognize that every individual is situated in an unfolding life context, that is, a set of circumstances, values, and influences
- Respect the meanings each individual assigns to what happens to and around him or her
- Recognize that cultures and subcultures are diverse and have considerable effect on individuals

Qualitative researchers feel strongly that a person's experiences, perceptions, and social interactions are not reducible to numbers and categories—they are much too complex and situated in the context of a person's life. They believe that the researcher attempting to understand experiences, perception, and social interaction must enter into a person's life-world and let the participant's words and accounts lead the researcher to understandings that would remain hidden without deep and open-minded exploration (Munhall, 2007). Thus, qualitative researchers go into their exploration with as few assumptions as possible.

Data Collection and Analysis

The data collection techniques used to understand subjective realities include:

- Nonintrusive, often prolonged, observation
- Conversational interviews
 - ✓ Open-ended questions
 - ✓ Careful listening
 - ✓ Follow-up questions
 - ✓ Helping persons to be reflective about their experiences
 - ✓ Requesting elaboration
- Validation (when making an interpretation of observations or what was said, ask the informant if the interpretation is accurate)

Often, detailed notes are kept or interviews are recorded and subsequently transcribed. The researcher spends considerable time going back and forth through the notes to identify important connections. As the researcher gains greater insight into the issue, the questions asked of subsequent study participants may change (Swanson, 2001). The researcher works inductively, that is: moving from details to a slightly more general encompassing phrase or concept, and finally to a set of themes or patterns that portrays important aspects of the experience, social process, or culture.

The term *qualitative research* actually refers to methodological traditions and methods with diverse aims, data collection techniques, and analysis techniques. The methodological traditions were developed in disciplines such as sociology and anthropology—and nursing has adopted them (see Table 4–1).

The phenomenological research tradition is useful in gaining insight into human experiences, whereas the grounded theory tradition enables researchers to understand the fundamental social processes involved in healthcare situations, say, the workings of emergency care transports or how families make the decision for a child to have an organ transplant. The ethnographic research tradition creates descriptions of healthcare subcultures, such as chronic renal dialysis units or Alzheimer support groups—from the insider perspective. Two other qualitative research traditions are discourse analysis and historical analysis. Discourse analysis is used to analyze the dynamics and structure of conversations, such as patient–provider dialogue. Historical research examines past events and trends, usually through records, documents, articles, and personal diaries from the past.

Table 4-1 QUALITATIVE RESEARCH METHODS

TRADITION	COMMON AIM IN NURSING STUDIES	DATA COLLECTION TECHNIQUES	DATA ANALYSIS TECHNIQUES
Phenomenologic research	To produce understanding of the lived experience of persons with a particular health condition or situation	<ol style="list-style-type: none"> 1. Select persons who are living or have lived the experience. 2. Set aside preconceived ideas. 3. Engage in dialogue with each participant. 4. Explore the person's life-world. 5. Assist person to be reflective about his or her experiences and what they mean to him or her. 6. Stay in the setting until no new insights are emerging and all issues are understood. 	<ol style="list-style-type: none"> 1. Transcribe interviews. 2. Look for segments in the account. 3. Identify significant phrases. 4. Group phrases with common thoughts into themes. 5. Confirm themes with the participants.
Ethnographic research	To produce a rich portrayal of the norms, values, language, roles, and social rules of a health or health care culture or subculture	<ol style="list-style-type: none"> 1. Immerse self in the culture/setting, typically for long periods of time. 2. Observe social interactions. 3. Seek out and informally question good informants. 4. Analyze documents. 5. Take detailed notes. 	<ol style="list-style-type: none"> 1. Identification of social rules and understandings. 2. Analysis of social networks. 3. Confirmation of interpretations. 4. Produce a coherent account of the culture. 5. Check out description with key informants.

(continued)

Table 4-1 (CONTINUED)

TRADITION	COMMON AIM IN NURSING STUDIES	DATA COLLECTION TECHNIQUES	DATA ANALYSIS TECHNIQUES
Grounded theory research	To produce a theory (i.e., a tentative, coherent explanation) about how a social process works	<ol style="list-style-type: none"> 1. Gain access to the social setting. 2. Observe social interactions. 3. Conduct informal interviews. 4. Keep field notes. 5. Identify useful written materials. 6. Stay in the setting until no new insights are emerging and all issues are well understood. 	<ol style="list-style-type: none"> 1. Intermix data collection and analysis. 2. Name what is happening in the data with codes. 3. Analyze the use of language. 4. Proceed from concrete codes to theoretical ones. 5. Constantly compare new data with previously acquired data. 6. Generate hypotheses and check them out with participants.

Each of these traditions requires techniques for collecting and analyzing data appropriate to its purposes. After looking across the rows of Table 4–1, which will give you a sense for each tradition, look down the columns and note how the purposes and methods of these traditions differ.

Qualitative Description

Not all questions in nursing and healthcare can be investigated in a clinically useful way using the methods of one of the traditions just described. As a result another method that draws on features from the traditional approaches has evolved. This somewhat eclectic approach is called *qualitative description* (Neergaard, Olesen, Andersen, & Sondegaard, 2009; Sandelowski, 2000, 2010; Thorne, Kirkham, & MacDonald-Emes, 1997). The goal of qualitative description is to produce a straightforward description of participants' experiences in words as similar to what the participants said as possible. Most often, but not always, the participants are patients. Commonly used methods of qualitative description include, but are not limited to the following:

1. Sampling for diversity
2. Data collection by interviews of individual or focus groups
3. Data analysis by qualitative content analysis
4. Generation of themes or patterns that capture what has been said

Even quantitative data collection and analysis techniques can be incorporated into a study using the qualitative description method.

Understanding how *qualitative content analysis* is done is key to understanding this qualitative research method. If you think about it, you will realize that qualitative data collection produces an abundance of data—pages and pages of transcripts of interviews and dialogue or of written material. To extract meaning from all this raw data, researchers identify sections of data that convey an idea and assign it a word or phrase code that conveys its essence. The code should be data-derived, i.e., generated from the data itself (Sandelowski, 2000). In assigning a code to a section of transcribed narrative or a section of a diary, the researcher is always aware that she is making an interpretation and therefore must be careful that the code does not change the original meaning of what was said.

Content analysis is not a linear, constantly forward-moving process. Rather, it is dynamic and reflexive. If none of the previously used codes captures the meaning of a section of text, the researcher will create a new code.

The new code may or may not lead the researcher to revise the coding of already coded text.

A list of codes can be informative, but it may be more useful if coding is taken a step further. That step involves identifying similarities in the codes; it may be possible to group similar codes without losing the meaning of the first round of codes. This broader grouping may be a category, a chronological order, or a theme. Again, the researcher is on guard to not lose the meaning of the original data and codes.

Original quote → Code
Several similar codes → Theme

Importantly, even though qualitative description is somewhat eclectic in the methods used, researchers who use it remain committed to rigor of method by using methodological principles widely recognized by other qualitative researchers. In summary, qualitative description is a very pragmatic approach to doing qualitative research. It is characterized by using a combination of methods that will produce a useful description of the experience, perceptions, or events of interest. Any interpretation produced should not be far removed in meaning from the data provided by the study participants.

Uniqueness of Qualitative Studies

Some findings from qualitative research are useful in their own right, whereas others produce hypotheses that require further study using quantitative methods. Certainly, in-depth descriptions of patients' experiences of illness and health care are directly useful to nurses in understanding what their patients are experiencing and in communicating helpfully with them. They may also be useful in developing nursing assessment guides and teaching plans.

Other findings from qualitative research are hypotheses about associations and causal relationships at work in the situation of interest. These hypotheses require further study using quantitative methods—to acquire knowledge regarding the degree to which the identified associations are true across different segments of the population or to test possible causal relationships identified by the qualitative study.

At first, qualitative research methods may seem “unscientific” to you. Although it is true that they are very different from what most people view as “scientific,” the reality is that these methods have been developed to acquire insights into subjective experiences and social processes—complex human realities that cannot be broken apart, manipulated, and examined the way physical realities can be. The rich and nuanced understandings of human experiences and social interaction produced by qualitative methods cannot be achieved using methods that reduce human characteristics to numbers and the context of human lives to the status of “variables.”

Qualitative studies are sometimes criticized for having small sample sizes or for not being objective. These criticisms are based on a lack of understanding of what qualitative studies aim to produce and how their methods produce unique and valuable forms of knowledge for the clinical professions. Both qualitative and quantitative research methods have a place in the scientific toolbox of the clinical professions. Just as a house cannot be built with only one type of tool, e.g., saws, so it is that producing the full range of knowledge required for clinical practice requires the use of both qualitative and quantitative research methods.

Exemplar

Reading Tips

I want to call your attention to the structure of this chapter. I do so because the same structure will be used in the rest of the chapters in Part I of the book. Each chapter is made up of three sections:

1. Introductory information about the featured method in an opening section such as you have just read about qualitative methods
2. A reprinted Exemplar article of an actual study using the featured method
3. A Profile and Commentary on the exemplar article

The Jacobson et al. (2008) article uses qualitative description methods; do pay attention to the full-page box called *More on Methods and Analysis* in the article. The Profile and Commentary that follows the article will refer quite a bit to the information provided in that box.

Exemplar

Patients' Perspectives on Total Knee Replacement

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Abstract

Objective: Because patients' perspectives on total knee replacement (TKR) surgery have rarely been the topic of research, this study sought to describe their pre- and postoperative experiences. **Methods:** Using a qualitative descriptive design, researchers collected data from a convenience sample of 27 patients who were about to undergo or had recently undergone TKR. Preoperative data were obtained in focus group sessions (n = 17); postoperative data were obtained in individual interviews (n = 10). All data-collection sessions were tape-recorded and transcribed, and transcripts were analyzed. The researchers isolated themes by identifying recurrent words and phrases and then sorted the data into thematic categories. **Results:** Four main themes emerged. First, many participants delayed surgery for months to years, despite increasing pain and limitation. Second, once participants decided to proceed with surgery, they entered a period of waiting and worrying about what would happen during and after surgery. Third, both pre- and postoperative participants struggled with the need for independence, as well as with learning to accept the new knee. And fourth, patients experienced postoperative pain associated with surgery and rehabilitation, yet reported having hope that they'd regain function. **Conclusions:** These findings suggest that patients need to be better educated and supported before and after TKR surgery. More research is needed to shed light on how patients' experiences influence their decisions about the surgery and its outcomes.

Key Words

total knee replacement
total knee arthroplasty
patient response to surgery
pain
functional ability
patient education

Total knee replacement (TKR) is one of the most common orthopedic operations in the United States,^{1, 2} but few researchers have examined patients' experience of the procedure. The operation, performed to improve function and relieve pain in people with osteoarthritis or rheumatoid arthritis, involves resurfacing damaged bone and cartilage and replacing them with plastic or metal parts.² Yet numerous studies of total joint replacement (of the hip or knee) indicate that eligible patients delay or decline the procedure for reasons that aren't well understood.^{3, 4} One recent literature review reported that a significant proportion of people who were eligible for joint replacement were unwilling to consider surgery.⁴ It concluded that patients' expectations of outcomes are significantly influenced by factors such as sex, race, ethnicity, and socioeconomic status and that patient education materials "may not address the concerns of many individuals." (For more on total knee replacement, see *Facts About Total Knee Replacement Surgery*.)

Facts About Total Knee Replacement Surgery

- The first hinged knee prosthesis, made of ivory, was inserted in 1891 by German surgeon Themistocles Gluck to replace a tubercular joint.¹
- According to the Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project (HCUP) (<http://hcupnet.ahrq.gov>), the number of total knee replacements (TKRs) performed in the United States almost doubled between 1995 (293,086) and 2005 (549,867).
- The proportion of patients ages 40 to 49 years and 50 to 59 years having TKRs increased by 95% and almost 54%, respectively, from 1990 through 2000.²
- Significantly fewer eligible black patients elect to have TKR than do eligible white patients.^{3, 4}
- According to the HCUP, acute care discharge disposition for TKR in 2005 was 41% to another institution such as a rehabilitation center or nursing home, 32% to home health care, and 26% to home.
- Indications for TKR include "radiographic evidence of joint damage, moderate-to severe persistent pain not adequately relieved by an extended course of nonsurgical management, and clinically significant functional limitation resulting in diminished quality of life."³
- Advances in implant composition and placement techniques have increased the popularity of TKR surgery. The longevity of the implant depends on individual factors such as the amount and type of postsurgical activity and the patient's weight, age, and sex.⁵⁻⁸

References

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One orthopedic surgeon who has written on this topic, Peter Bonutti, put it this way: “Maybe we don’t understand what our patients care about.”⁵ He cited two studies’ findings that one-third of patients who’d had TKR were dissatisfied with it, and he identified the need to consider the procedure from the patient’s, rather than the surgeon’s, point of view. The difference in perspective was highlighted in another study of 108 patients who underwent 126 TKRs: patients’ subjective and physicians’ objective assessments of outcomes correlated poorly.⁶ The researchers concluded that “surgeons are more satisfied than patients.”

In 2003 the National Institutes of Health held the Consensus Development Conference on Total Knee Replacement, calling in particular for research into patients’ decisions about surgery and the factors that affect outcomes.⁷ Members of the expert panel also suggested that the use of qualitative rather than quantitative methods might reveal a fuller range of experiences. And a British review examining qualitative research concluded that it “has particular strengths in uncovering evidence that is discrepant with researchers’ or practitioners’ prior assumptions” and revealing “significant but unanticipated factors.”⁸

Methods

In seeking to describe patients' experiences with TKR, we used a qualitative descriptive design, collecting data from 17 preoperative and 10 postoperative patients during focus group and individual interviews, respectively. The focus group session immediately followed the hospital's joint-replacement class. Because of the limitations imposed by postoperative recovery and the variety of care sites, we collected data on patients' postoperative experiences during individual interviews. Table 1 shows the demographic characteristics of the sample. (For additional details about the methods, see *More on Methods and Analysis.*)

Table 1 PARTICIPANT CHARACTERISTICS (N = 27)

DEMOGRAPHIC	MALE (N = 13)	FEMALE (N = 14)	TOTAL (N = 27)
Mean age, in years (SD)	66.5 (12.8)	65.6 (11.9)	66.03 (12.1)
Range in years of age	45–83	49–83	45–83
Race, n (%)			
African American	1 (7.7)	2 (14.3)	3 (11.1)
White	12 (92.3)	12 (85.7)	24 (89.9)
Marital status, n (%)			
Married	8 (61.5)	7 (50)	15 (55.6)
Widowed	3 (23.1)	2 (14.3)	5 (18.5)
Divorced	1 (7.7)	1 (7.1)	2 (7.4)
Single	1 (7.7)	4 (28.6)	5 (18.5)

SD = standard deviation

Note: percentages in the middle columns are percentages of the column totals (n) rather than the total cohort (N). Demographic data are not categorized by pre- and postoperative samples because the study did not investigate the differences between these groups; rather, it sought to fully describe patients' experiences.

Results

We identified four overarching themes in patients' experiences of TKR, which we named “putting up and putting off,” “waiting and worrying,” “letting go and letting in,” and “hurting and hoping.” Our purpose was to describe overall experience; we did not compare and contrast the data from the pre- and postoperative samples.

Putting up and putting off characterized the period before the decision to have surgery was made. It typically lasted for years and involved “putting up” with knee pain and resulting limitations and “putting off” TKR by modifying activities, using adaptive equipment, and undergoing less drastic treatments.

Putting up: pain limits what you can do. Participants described a gradual increase in knee pain, which they usually characterized as constant and aggravated by walking and other movements. Sometimes the joint gave out unexpectedly when they were walking or climbing stairs. They frequently described the knee as “bone on bone” with “no cartilage.” Some reported that the knee was bending to the side or “bowing out.”

One participant said, “Pain limits what you can do,” a sentiment echoed by many. Another said,

I’m tired of it. . . . I am a very active person. My favorite comment is ‘I can’t.’ I can’t take the trash to the street. I can’t cut the grass. . . . I am a car salesman. I feel like a flat tire, and in my business you can’t have a flat tire.

Knee pain limited participants’ ability to perform many daily activities, including dressing, cooking, cleaning their homes, shopping, using stairs, dancing, and playing golf. Many activities required careful planning, such as bringing crutches or a wheelchair, premedicating with analgesics, and planning routes.

If I went to the store, I had to know exactly what I could get and just hold onto the shopping cart. . . . [Eventually] I could only go to the stores that had [electric shopping carts]. I really couldn’t even walk. . . . [The physician] even encouraged me to get handicapped parking, which I did.

Outings often resulted in fatigue and prolonged or exacerbated pain. Some participants described crying because of the pain and becoming depressed and isolated. As the condition worsened, participants began to limit their activities to those that required little walking or could be accomplished with frequent rest breaks or the use of mobility aids. Some relied on others for transportation; some obtained handicapped parking permits. One participant took her cell phone everywhere, even inside her own home, so that she could “call someone in case I get stuck.” Others described modifying the way they approached tasks—for example, placing pillows under the knees when kneeling, sitting or lying down instead of kneeling, and crawling instead of walking.

For some, knee pain and functional limitations changed how they viewed themselves or how they believed others viewed them. They considered themselves active people who had been forced into inactivity. They saw their knee problems as constricting, and even controlling, their lives.

Putting off: getting to the point. Most participants delayed surgery for as long as possible, and for many, that was years after the option was first presented.

It was something I knew I had to do, but you just keep hoping that it will get better. . . . You get to the point where finally you figure, “I got to do something.”

Some said that they’d put off surgery because they’d hoped that medical science would eventually offer a less drastic alternative or because they wanted to first try to strengthen their knees. Most participants said they wished they hadn’t delayed surgery for as long as they had and would advise others not to wait so long. But that view was not universally shared. One postoperative participant “wanted to make sure that . . . there wasn’t any doubt, that [surgery] was my only recourse.”

During this period, participants often received treatments such as cortisone or hylan G-F 20 (Synvisc) injections. These gave transient relief to some; others said the treatments either weren’t effective or worsened their condition. Participants referred to these treatments as “Band-Aids,” “just temporary,” or “a prelude to having [TKR] done.”

Waiting and worrying. Once participants decided to proceed with TKR, they entered a period of waiting and worrying about what would happen during and after surgery.

Waiting: let’s get it over with. As participants prepared for TKR, they became anxious to put the surgery behind them: “I put this off for years. I can’t wait to get it over with.” They described the waiting period as one filled with apprehension; one spoke of “anxiety that is cursing my life.”

Many participants prepared by maintaining or increasing their activity level, believing that would aid recovery: “The better shape you are in, the better you get through surgery.” Some worked to get “everything in as much order as [they] possibly can” to prepare for a postoperative period of limited functioning.

Worrying: ‘something can go wrong.’ Participants reported having concerns about anesthesia, surgery, and complications. Many viewed anesthesia as particularly risky. Participants were given the choice of a spinal or a general anesthetic. Most chose general, even if they felt it was riskier and would prolong recovery; they didn’t want to be aware of any aspect of surgery.

I had general anesthesia, it was my choice. . . . [I’m] a nurse; I didn’t want to wake up in the middle and hear things. . . . I’ve been scrubbed in for

orthopedic surgeries so I kinda know the sounds and noises, and I didn't want to wake up and hear the jigsaw or anything.

Some expressed a generalized fear about surgery:

"Any time you have surgery, anything can happen." Specific fears involved the risk of complications, such as a blood clot, infection, or death. Some had had complications with prior procedures or knew someone who had, which led to their current fear.

More on Methods and Analysis

Design. The qualitative descriptive method entails collecting data and presenting findings in everyday language, with minimal inference and interpretation by researchers, unlike other qualitative methods (such as grounded theory).¹ As Sandelowski states, this method is "especially amenable to obtaining straight and largely unadorned . . . answers to questions of special relevance to practitioners."¹

The study was approved by the institutional review boards at the university where the first author (AFJ) worked and the hospital where the patients were scheduled for their operations, a large urban medical center with an active orthopedic surgery department. All participants were informed of the nature of the study and signed consent forms. At the end of data collection, each participant was paid \$25.

Sample. Data were obtained from a convenience sample of 27 patients (see Table 1, page 55) who either were scheduled for total knee replacement (TKR) surgery within one month or had undergone the surgery within the previous two months. Preoperative data were obtained in four focus group sessions in which a total of 17 patients participated; postoperative data were obtained in individual interviews with 10 patients. Inclusion criteria were being able to speak English, being 21 years of age or older, having had no previous total joint replacement, and either being scheduled for (preoperative sample) or having undergone (postoperative sample) a single TKR within the periods specified. Exclusion criteria were having cognitive impairment, rheumatoid arthritis of the operative joint, or significant postoperative complications (such as surgical site infection or thrombophlebitis). In addition, participants in the preoperative sample could not be in the postoperative sample, to avoid the possibility that participation in a preoperative focus group might influence postoperative views. Participants were recruited into both samples until data saturation occurred (with the additional interviews yielding only redundant information).

Instrument. All data collection sessions were tape-recorded and transcribed, with the transcripts serving as the units of analysis.

Preoperative focus groups. Four different focus groups with patients scheduled to undergo their first TKR within one month were held. The focus groups were moderated by one of the authors (RPM), a clinical psychologist with extensive experience in facilitating group discussion. One or two other research team members, RNs with research experience (AFJ and EF), served as assistant moderators, organizing participant recruitment and consent, keeping track of time, observing and recording nonverbal cues, and making other field notes.

Focus group participants were recruited from among people attending a class on total joint replacement, which was held in a conference room of the hospital where they would have the surgery. The nurse leading the class (not a research team member) mentioned the study at the end of class and invited attendees scheduled for a single TKR to remain if they wanted more information. Those who were interested met with one of us (AFJ), who explained the study. Participants signed a consent form and remained for the focus group session, at which participants and moderators were seated around a conference table. The session started with the moderator explaining basic concepts and expectations (for example, that there are no right or wrong answers in descriptive research and that it's hoped that everyone will participate).

The moderator then facilitated the discussion. First, to discourage “group think” (a phenomenon marked by a failure to express views that differ from the perceived group consensus), participants were asked to write down their three main concerns for later discussion. Next, the moderator prompted discussion by asking questions that progressed from the general (such as “As you’ve been thinking about the surgery, what’s been on your mind the most?”) to the more specific (such as “What are some of your concerns?”). (The complete list of *Questions for Focus Group and Interview Sessions* is available at <http://links.lww.com/A422>.) Follow-up questions were based on the participants’ responses and were asked as they arose during the sessions. Each focus group session lasted about one hour, after which the moderators held a debriefing session to review responses and note emerging themes.

Postoperative interviews. Potential participants—patients who had undergone TKR in the previous two months—were identified by the orthopedic unit’s patient care coordinator, an RN, who notified them of the study and obtained their permission to be contacted by the research team. Those who were interested in participating signed a consent form and scheduled a date for the interview with the research team member (NB), an RN graduate assistant with perioperative experience. Interviews took place on the post-acute rehabilitation unit or the patient’s home. The researcher

interviewed the patient using open-ended questions. Interviews ranged from about 15 minutes to about 60 minutes in length.

Data analysis. Transcripts from the focus group, debriefing, and interview sessions were first read through. Next, each transcript was read and analyzed using principles of qualitative content analysis, an approach that’s “oriented toward summarizing the informational contents of [the] data” with minimal inference and interpretation.¹ Using the study’s stated purpose as a guide, the researchers selected relevant sections of the transcripts, defined themes by identifying recurrent words and phrases, sorted the data into the thematic categories, and drew conclusions. Two members of the research team (AFJ and KD) analyzed the data independently and met periodically to compare findings and resolve category coding discrepancies (“check coding”). Codes were repeatedly revised as similarities and differences were noted across categories, until the final categories were considered robust and complete with agreement between coders.

References

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But some said they had no concerns. Many said they tried to maintain a positive attitude, believing a negative one would worsen their outcome.

I sure don’t want to be negative going into it. . . . I mean, it’s either go [in] up, or go in down and out. And if you go in down and out, there’s . . . a worst-case scenario, that you will have complications.

One factor contributing to worry was having too little information about the operation: “I have no idea how long it will take. . . . Everything is ambiguous. . . . Please tell me what you are going to do.” Most wished they’d received more information from their surgeons preoperatively and had better understood what to expect during recovery. One postoperative participant said that understanding the “backward-and-forward” nature of recovery beforehand would have made it “less scary and less traumatic than afterwards thinking, ‘Why, what’s wrong?’” (For more, see *Questions Participants Had About Surgery*.)

Questions Participants Had About Surgery

- When can I take a shower?
- How can I get up and down stairs?
- Will they give me a temporary wheelchair card for my car?

- How much pain will I have?
- When can I drive?
- What will the incision look like?

Some participants reported feeling well prepared for surgery and recovery. Those who'd received detailed and graphic information from their physicians appreciated it: "He was very explicit about what . . . the surgery would entail. [The surgeon] was great. . . . He let me hold the [replacement] joint in my hand."

Letting go and letting in. Pre- and postoperatively, participants struggled with the need for independence and with allowing others to help, comfort, and support them. "Letting in" also involved learning to accept the knee implant as part of their bodies.

Letting go: accepting a loss of control. Participants described themselves as independent people who found it difficult to rely on others: "I had to accept the loss of control." Many said they'd needed increasing assistance in performing activities of daily living preoperatively. Participants worried about being dependent on others, usually family members, while recovering.

When you're used to being the caregiver, that's hard, having somebody take care of you. . . . The first night I came home from the hospital . . . I went to the bathroom and I made a mess and I couldn't clean it up. . . . That night [my partner] was fine, he didn't mind cleaning up my mess or doing all that, but I asked him to just leave the room and just let the music play and shut out the lights. I put the pillow over my head and I cried.

Sometimes, participants resisted relinquishing control and exercised their independence, ignoring the advice of clinicians or family members. One participant planned to sip ginger ale after surgery during the period when fluids weren't allowed, believing that it would relieve postoperative nausea. Some planned to get out of bed on their own right after surgery: "I can't be tied down." One planned to bring his pajamas to the hospital, saying he couldn't sleep in anything else. A participant with diabetes planned to adhere to his usual diet after surgery, rather than the one prescribed.

Religion helped some participants; one spoke of God: "He will take care of this." Others articulated a philosophical acceptance: "Life is a road and you have to go down it, and this is something that I have to do."

We observed that letting go was accompanied by letting in—receiving encouragement from others, establishing trust with clinicians, and accepting the new knee.

Letting in: accepting encouragement. Many participants knew others who'd undergone TKR and found their accounts of successful outcomes encouraging: "It is wonderful . . . just thinking that I am going to come out the same way." Some of these acquaintances had spoken about wishing they'd had the procedure years earlier and being happy with the results; they told our participants that after TKR they'd "feel brand-new." But reports of negative outcomes (such as continuing pain or poor knee function) left participants feeling frustrated or fearful, and many said they tried to avoid hearing such stories: "I don't want any negativity around me right now. I want the positive stuff."

Several participants said that having more opportunities to talk with people who'd had the surgery or with providers would have increased their confidence going into surgery.

Don't let me just read it in a book or in a pamphlet or whatever. That's all well and good, but I want to talk to somebody. I want to bounce things off of them. I want to put myself more at ease. I want to get rid of that stress.

They would also have appreciated a structured peer-support group: "[It helps] knowing that other people have the same discomforts that I have. . . . You know, misery loves company and I'm sure we can compare notes."

Letting in: trusting the team. Participants spoke favorably of physicians who took the time to explain the surgery and answer questions. They valued a direct approach: "He's the nuts-and-bolts type of doctor that I like"; "He's not into fooling around. He tells you what's happening." They related having "100% confidence" in their physicians and their recommendations. Many chose a surgeon based on the recommendations of friends and family; some had solicited opinions about surgeons from others who'd had TKR.

Participants also noted the caring and skills of nurses and other hospital workers, especially those who had helped with transferring and walking. They appreciated nurses who assessed their pain and suggested or administered analgesia. They felt cared for by nurses who "hovered over" them or helped with personal care.

Letting in: accepting the new knee. Participants referred to how "bad" their own knees were and asked questions about the new one. (For more, see *Questions Participants Had About the New Knee*) Postoperative participants

said their muscles needed to “learn” to work with the new knee, which they described as stable and strong.

I just feel like it’s part of my knee. I don’t feel like there’s anything metal in there, or there’s anything different, and if you hold one of those joints in your hands, they’re real heavy. But I don’t feel it at all. . . . In fact, it feels more steady than [the other] leg, to stand on it.

Questions Participants Had About the New Knee

- What is it made of?
- How long will it last?
- What if the implant wears out?
- Is it heavy?
- Can I get through airport security?
- Do they use the original kneecap?
- Can I kneel on it?
- Will I sink if I go swimming?

Many wished they had seen an actual model. One preoperative participant had, but only after asking the surgeon to show it to her. Another asked his surgeon whether the operation would be videotaped so that he could watch it later.

Hurting and hoping. During the recovery period patients were in pain, and they hoped that regaining lost function would make it worthwhile.

Hurting: pain is the thing. Pain was a prevalent theme. Preoperatively, participants anticipated postsurgical pain; as one said, “The pain is the main thing with the knee.” They expressed the hope that adequate analgesia would be given; some discussed pain management preoperatively with the surgeon or anesthesiologist. One quoted her anesthesiologist’s advice to take pain medications at regular intervals rather than as needed, “because if you let that pain get ahold of you, it is really hard to get rid of.” Another’s physician had said, “Take pain medicine when I tell you to take it and you won’t hurt.”

Many preoperative participants said that postoperative pain was inevitable and that they would endure it.

I don’t care how much pain medicine you give—it’s still going to hurt. The pain medicine’s going to wear off. And I know I’m probably going to go through . . . about two weeks of just a lot of pain. And then once that passes, the healing begins, it gets better.

All who underwent surgery reported immediate postoperative pain that was intensified by movement of the leg and by physical therapy. For some, the pain level diminished daily. Several reported being pleasantly surprised to find that they were in less pain than they'd anticipated: "I thought it would be a lot more painful than what it was. . . . I thought it would be a different type of pain." Yet others described severe, continuous pain. One explained how she would prepare someone else considering TKR for post-surgical pain.

Even if they give you morphine, the pain's still there. . . . I think that would be one thing I would tell a patient: that we can relieve the pain afterward, but you're gonna have pain. And the pain medications will ease it a little bit, but it will never take it away completely.

Pharmacology was the primary pain management strategy—nonpharmacologic measures such as meditation, walking, transcutaneous electrical nerve stimulation, and topical application of ice were less frequently reported. Some participants' care teams advised them about pharmacologic strategies preoperatively. Some noted that nurses' postoperative strategies helped. For example, a home health care nurse advised a participant to take smaller doses of oxycodone with acetaminophen (Percocet) more often, rather than larger doses at greater intervals, with good results: "That really worked for me." Another participant said, "I feel really good in the morning because they medicate me during the night. . . . They said they should give it to me before I start to hurting real bad." But another described losing sleep because of pain and repeatedly asking for analgesia.

I . . . just cried this morning 'cause it hurt so bad I couldn't stand it. And I couldn't get no more pills. . . . Just wish I could get a doctor in here to . . . give me something a little stronger.

Some participants worried about potential problems with analgesics (such as constipation, nightmares, becoming addicted, breakthrough pain, and reduced mental acuity), and some reported adverse effects.

Hurting: rehabilitation is work. Preoperative participants viewed the rehabilitation period as necessary to returning to normal life, saying that they knew it would involve "slow, hard work." Postoperative participants described physical therapy regimens including exercise, walking, and other measures as a necessary stage: "You have to give it dressing aids (a trouser pull, for example) were used. Regular supervision was important to ensure adherence to the physical therapy program.

My second physical therapy session in outpatient was tough. . . . They put you on your stomach and they bend your knee. . . . They try to break up the scar tissue, and push on it until you scream. . . . I know they have to do it. I know I can't do it all on my own.

Some made steady progress: "I expected to be able to get up and walk right away, and I did." One found rehabilitation to be "not as bad as what I figured it would be," as did others. But many voiced frustration over a lack of progress. How long is it gonna take? 'Cause I haven't felt like anything has changed. Everybody says it looks like it has, but I can't see that and I don't feel that.

Hoping: eyes on the prize. Participants envisioned a timeline for recovery, although the duration of the timeline varied, and some patients were more specific than others. Many predicted that they'd be independent, able to return to work, or both within three weeks. Some predicted it would take several months to a year. They emphasized the need to stay motivated during recovery: "Gotta keep your eye on the prize." They talked about pushing themselves or being pushed by providers or family members.

Since I couldn't go outside much, [the physical therapist] told me, "Just walk." So I walk from one end of the house to the other. I try to keep walking.

Participants believed that if they didn't perform the prescribed rehabilitation exercises, their new knees would be "stiff" or painful or wouldn't bend. Some said they thought that if they didn't bend their knees as prescribed, the surgeon would "take you back to surgery and bend it for you."

So I'm telling myself, and I'll tell somebody else, "Don't give up until you get full mobility back." Because if you don't gain it in this window of time . . . you're not gonna. You can't decide a year from now, "I'm gonna rehabilitate my knee and get more mobility." It's gone.

Many identified having a positive attitude, before and after surgery, as being necessary. One referred to this as "mind management."

Hoping: back to normal. Participants articulated specific activities they hoped to be able to perform as a result of the surgery, especially those they had been capable of doing "without having to think about it" and without pain, such as housework, gardening, and walking the dog. (For more, go to <http://links.lww.com/A423>.) The phrase "normal human being" was often used.

I'm going to be back out hiking and biking and doing all those things I haven't been able to do. Get down on the floor with my grandkids. I have no fear that it's not going to be good; I know it's going to be good.

Discussion

Many of our 27 participants reported delaying the surgery for months to years, despite increasing pain and limitation. Similarly, prolonged “enduring” was identified in a qualitative study of nine people in New Zealand who had had TKR surgery.⁹ While our study included only people who ultimately did have the operation, their comments suggest that possible reasons for delay include the hope that the knee would get better on its own or that surgical advances would offer less drastic alternatives to total joint replacement. The latter reason echoes findings from a 1997 study of 30 people with osteoarthritis of the hip or knee, in which women were more likely than men to delay surgery because they expected that technology would improve.¹⁰

Once participants decided to proceed with surgery, they typically anticipated it with anxiety and felt a desire to “get it over with.” Common sources of anxiety were general fears about anesthesia, surgery, and complications. Another frequent concern was their lack of information about the implant and what surgery and recovery would entail. In contrast, two quantitative surveys of patients planning to undergo total joint replacement identified more specific concerns, the most prominent of which involved postsurgical pain and mobility and the ability to care for oneself.^{11, 12} This discrepancy may result from the selection of items included in the quantitative surveys and the forced-choice responses they entailed. In our study, participants' responses were not so restricted.

Although we conducted the preoperative interviews after patients had met with their surgeons and attended the hospital's joint-replacement class, our findings strongly suggest that patients wanted more information. But does additional information improve outcomes? A recent review of nine studies involving a total of 782 patients about to undergo joint replacement suggests that it does not. The researchers concluded that “there is little evidence to support the use of preoperative education . . . to improve [most] postoperative outcomes,” although they said that “there is evidence that preoperative education has a modest beneficial effect on preoperative anxiety.”¹³ Similarly, a Swedish study found that giving patients specific information about pain management before TKR lessened their anxiety.¹⁴ Such educational programs are increasingly common, but because they don't report on the theoretical or empirical basis for their design, the mechanisms that might explain their effectiveness remain

obscured, limiting their applicability.^{15,16} More research is needed. Approaches tailored to a patient's age, race, and sex may be most effective.^{11, 12}

Many participants indicated that they would have liked to have talked with others who had had successful TKR; those who had done so reported feeling that it was helpful. Other qualitative studies of people considering total joint replacement have described similar findings.^{10, 17} Further investigation into the efficacy of formal peer-support interventions-which have been effective in other patient

populations (such as people with cancer¹⁸ or diabetes¹⁹)-for people preparing to undergo TKR is warranted.

The adequacy of participants' postoperative analgesia was inconsistent. For some, acceptable pain control was obtained with strategies such as routine dosing (rather than dosing as needed) and consultation with providers. Some comments reflected acceptance of postoperative pain, which was perceived as inevitable. Because preoperative expectations of postoperative pain and doubt about one's ability to manage it can increase pain levels,²⁰ effective pain management strategies should be developed and shared with patients before surgery.

Limitations. The study has several limitations. Participants were recruited by convenience sampling from one health care institution, and their experiences may not be representative of all patients in all geographic regions. Another limitation was a lack of control over variables (such as the surgeon, the surgical technique, and the analgesic regimen) that could influence participants' experiences. And although we attempted to encourage participants to respond candidly, the fact that we identified focus group moderators and interviewers as health care professionals may have altered some of the responses we received.

Further Considerations

Our study revealed four themes reflecting patients' experiences of anticipating and recovering from TKR, extending the findings of several other studies in this population.

Findings from this and similar studies suggest that patients need better education and support and highlight the role of the health care team, particularly nurses and physicians, in providing both. Patients aren't prepared to make the decision to undergo TKR, and they don't know what to expect in the postoperative period. Anxiety and pain, which were common before and after surgery, may adversely affect outcomes. Participants emphasized the benefits of peer support and of having competent and caring surgeons, anesthesiologists, and nurses. Descriptive and interventional studies should be conducted to evaluate strategies designed to eliminate or reduce the negative

aspects of TKR (such as preoperative pain and anxiety) and promote positive influences (such as peer support). More research focusing on the patient's perspective is also needed to explore how patients' experiences influence their decisions about TKR surgery and affect their outcomes.

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Profile and Commentary

Study Purpose

In the introduction, the authors set forth the reasons *why* they conducted this study, namely that patients' subjective experiences of having a total knee replacement (TKR) are not well understood. The lack of understanding is reflected in the findings of several previously conducted studies. The authors cite several studies in which patients were found to delay having a TKR for a long time even though they were having considerable pain and functional limitations. Also, two studies found that after surgery a third of the patients were dissatisfied with their outcomes. The goal of the study was to describe patients' experiences before and after uncomplicated TKR. The restriction to patients with uncomplicated results is important as it limits the variation in the data; patients with complications undoubtedly have very different views than patients with smooth postoperative recoveries.

Methods

How the study was done is described in a short section in the body of the report and in greater detail in the box called *More on Methods and Analysis*.

Ethics Review The study was approved by the Institutional Review Boards at the university where the first author worked and the hospital where the patients were seen. An institutional review board (IRB) is a group of people appointed by a university, hospital, or other healthcare organization who are charged with the responsibility of ensuring that the rights of human subjects are protected when a study is conducted under their auspices. Federal law requires that IRBs be nationally registered.

A researcher must receive IRB approval prior to beginning a study and provide reports to the IRB about the ongoing status of the research. In reviewing proposals, IRBs consider the following information:

- How informed consent (knowledgeable choice to participate or not) will be ensured
- Whether pressure or coercion to participate in the study is completely absent
- How participants in the study will be informed about the purpose of the study, the basis of subject selection, the experimental treatments, assignment to treatment groups, and risks associated with each treatment

- How participants will be protected from discomfort and harm and treated with dignity
- How privacy, confidentiality, and anonymity will be ensured

Importantly, an informed consent document must be signed and dated by the participant or the participant's legal guardian. The informed consent document must include a statement giving the researcher access to the participant's protected health information, if that is needed to conduct the study.

Some studies, by their very nature, involve minimal risk of violating human rights, whereas others are very sensitive. Studies involving infants, children, reproductive issues, imposed pain or distress, and risks are considered sensitive, and thus the procedures of the study must be spelled out in great detail. Only individuals who are 18 years of age or older and legally competent can give their own informed consent. Parents or guardians must give consent for minors. The capacity of persons with cognitive and mental limitations to give consent is considered carefully by IRBs.

Recognizing the great diversity of studies, an IRB chairperson or committee designates a study as (1) exempt from review, (2) eligible for expedited review, or (3) requiring complete review (U.S. Department of Health and Human Services, 2005). The criteria for *exempt from review* status are spelled out in a U.S. Department of Health and Human Services policy. If the risk is minimal, an expedited review can be carried out by the IRB chairperson or by one or more experienced reviewers. A study that has greater than minimal risk must receive full review by the entire IRB. From the exemplar article, we don't know if this study underwent expedited review or full review; we do know that it was approved.

Design In the text and the box we are told that the researchers used qualitative descriptive methods with the goal of conveying what patients said in everyday language.

Sample Seventeen patients participated in preoperative focus groups, and 10 participated in postoperative individual interviews. Focus group participants were excluded from postoperative interviews to avoid having the preop focus group discussions influence what the patients said in the postoperative interviews. Note the inclusion and exclusion that were used to assure full participation in the focus groups and interviews and to control extraneous influences (e.g., postoperative complications). The sample size

was not predetermined; rather, recruitment of new participants was closed when no new information was being contributed (i.e., data saturation). A brief demographic profile of the sample participants is provided in Table 1.

Data Collection The preoperative focus group participants were recruited during classes on joint replacement held in the hospital; the focus groups were held immediately after the classes. The moderators, who were experienced in leading group discussions, used prompts that at first encouraged participants to say what was on their minds but subsequently asked participants to talk about more specific issues. Do look at the questions used for the focus group and the interview sessions that are provided at the online site given in the article. I would say that the questions are slightly more focused than what might be used by some other qualitative researchers. The postoperative interviews were held within 2 months of having undergone the TKR; they lasted 15 to 60 minutes. Transcripts of both the focus group dialogue and the interviews were produced to facilitate analysis.

Data Analysis The researchers analyzed the data of transcripts using the principles of qualitative content analysis. They marked sections of the data relevant to understanding the patients' experiences and perceptions with word or phrase codes that conveyed the meaning of the section or comment. The codes were then grouped into themes based on similarity of the ideas expressed. Do note that the researchers took steps to control their own pre-conceptions during this interpretation process.

Results

Four overarching themes comprise *what* was found. Under the heading for each of these themes, the researchers provide general statements portraying participants' experiences. These statements expand on the abbreviated theme labels. Illustrative participants' quotes that led to the development of each theme are also provided. Notice how these quotes give life to the more abstract overall description. This is how it should be—the linkage between the themes and the quotes should ring true. The themes should not seem forced. The researchers provide these quotes to demonstrate to the reader that the themes did indeed arise out of the data and are close to it. Each reader then makes a judgment about the credibility of the themes.

Discussion

In the Discussion section, the researchers link their findings to findings from other studies. This is crucial to producing a coherent and broad body of knowledge about the issue. These authors (1) link their finding to similar finding in a New Zealand study; (2) contrast their findings to two qualitative surveys of patients planning to have total joint replacement; and (3) discuss the implications of participants' views that they would have liked more information preoperatively. To further place the findings in a larger knowledge context, the limitations of the study, as perceived by the researcher themselves, are set forth. Finally, clinical implications and issues needing further research are offered.

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