"You're Perfect for the Procedure! Why Don't You Want It?" Elderly Arthritis Patients' Unwillingness to Consider Total Joint Arthroplasty Surgery: A Qualitative Study

PAMELA L. HUDAK, BScPT, PhD, JOCALYN P. CLARK, MSc, GILLIAN A. HAWKER, MD, MSC, FRCPC, PETER C. COYTE, MA, PhD, NIZAR N. MAHOMED, MD, ScD, FRCSC, HANS J. KREDER, MD, MPH, FRCSC, JAMES G. WRIGHT, MD, MPH, FRCSC

Objective**. To explore the process by which elderly persons make decisions about a surgical treatment, total joint arthroplasty (TJA). **Methods**. In-depth interviews with 17 elderly individuals identified as potential candidates for TJA who were unwilling to undergo the procedure. **Results**. For the majority of participants, decision making involved ongoing deliberation of the surgical option, often resulting in a deferral of the treatment decision. Three assumptions may constrain elderly persons from making a decision about surgery. First, some participants viewed osteoarthritis not as a disease but as a normal part of aging. Second, despite being candidates for TJA according to medical criteria, many participants believed candidacy required a level of pain and disability higher than their current level. Third, some participants believed that if they either required or would benefit from TJA, their physicians would advise surgery. **Conclusion**. These assumptions may limit the possibility for shared decision making. **Clinical Implications**. Emphasis should be directed toward thinking about ways in which discussions about TJA might be initiated (and by whom) and considering how patients' views on and knowledge of osteoarthritis in general might be addressed. **Key words:** patient decision making; qualitative study; arthritis; total joint arthroplasty.* ***(Med Decis Making 2002;22:272–278)

Total joint arthroplasty (TJA) is an accepted, cost-effective, and efficacious treatment for severe hip or knee arthritis when nonoperative medical treatments such as medications, exercise, and physical therapy have failed to provide sufficient improvement.[1–4] Approximately 90% of individuals experience dramatic long-term improvement in pain and physical functioning following joint arthroplasty.[1,5] Patients who delay the procedure until late in the disease course may have less optimal results.[5]

A large population-based study demonstrated significant unmet need in the use of TJA in Ontario.[6,7] Unmet need in these studies was defined as patients with moderate to severe arthritis, no contraindication to surgery, and willingness to consider the procedure. A finding of those studies, although not the focus of the work, was that of all patients identified as ideal candidates, only 10% reported themselves as being "willing" to consider TJA. The contrast between the medical assessment of these elderly individuals as "perfect clinical candidates" for TJA and participants' unwillingness to consider TJA led us to question how elderly arthritis

Received 9 October 2001 from the Hospital for Sick Children and the Department of Medicine, St. Michael's Hospital, Toronto (PLH); the Department of Public Health Sciences, University of Toronto, and the Centre for Research in Women's Health, Sunnybrook and Women's College Health Sciences Centre, Toronto (JPC); the Departments of Medicine and Health Policy, Management and Evaluation, and Clinical Epidemiology and Health Care Research Program, University of Toronto, and Sunnybrook and Women's College Health Sciences Centre, Toronto (GAH); the Department of Health Policy, Management and Evaluation, University of Toronto (PCC); the Departments of Orthopaedic Surgery and Health Policy, Management and Administration, University of Toronto, and the Toronto Western Hospital (NNM); the Departments of Orthopaedic Surgery and Health Policy, Management and Administration, University of Toronto, and Sunnybrook and

patients make decisions about joint arthroplasty surgery.

Shared decision making, versus more traditional authoritative models of the patient-practitioner relationship, advocates information exchange between the practitioner and patient, who then deliberate together and decide on the best treatment option.[8–12] Decision support interventions providing structured, explicit descriptions of the possible outcomes and associated risks of alternative treatment options have been advocated to supplement counseling from practitioners.[13,14] Although the experience of chronic illness, including the loss of autonomy often associated with advancing age, has been well described in the literature,[15,16] little attention has been directed toward understanding how the experience of a chronic, non-life-threatening condition intersects with the making of decisions about invasive procedures such as surgery, particularly among elderly persons. The objective of this study was to obtain subjective accounts of elderly patients' decision making as it related to the consideration of a surgical procedure, TJA, for severe hip or knee osteoarthritis. Our focus was on the *process* of decision making—the way of deciding, not only what is decided. In this article, we explore how this process fits with the model of shared decision making.

Methods

SETTING

The study took place in Toronto, Ontario, a large urban, ethnically diverse city. Ethics approval was obtained from both the university and hospital's research ethics review committees.

Women's College Health Sciences Centre, Toronto (HJK); and the Departments of Surgery and Public Health Sciences and Clinical Epidemiology and Health Care Research Program, University of Toronto, and the Hospital for Sick Children, Toronto (JGW). This work was presented at the annual meeting of the Society for Clinical Epidemiology and Health Care Research, San Diego, California, May 2001, and the 6th International Qualitative Health Research Conference 2000, Banff, Alberta, April 2000. Financial support for this study was provided in part by grants from the Medical Research Council of Canada (MT-15469) and the Canadian Arthritis Society (99/093; renumbered to 99/0143 in 2001). The funding agreement ensured the authors' independence in designing the study, interpreting the data, and writing and publishing the report. Revision accepted for publication 14 February 2002.

Address correspondence and reprint requests to Dr. Hudak, Department of Medicine, St. Michael's Hospital, 4-036, Queen Wing, 30 Bond Street, Toronto, Ontario, Canada M5B 1W8; phone: (416) 864-6060, ext. 2016; fax: (416) 864-6043; e-mail: hudakp@smh.toronto.on.ca.

A purposive sample of elderly individuals with arthritis was obtained from individuals identified in a prior population-based survey.[6] Patients had severe disabling arthritis confirmed on physical and radiographic examination, with no contraindications to surgery. Trained physical therapists presented participants in their homes with a standardized description of the consequences of not having surgery, alternative treatments, and risks and benefits of arthroplasty (including the projected life span of the replaced joints). Participants were told, "In people with complaints like yours, TJA [knee or hip] might be a good treatment for you to consider if you haven't already," and then asked about their willingness to consider having TJA. Only participants who reported they would probably or definitely not consider surgery at the time of this assessment were eligible for inclusion in our study.

DATA COLLECTION

One of the investigators conducted in-depth, face-to-face interviews with each participant guided by a semistructured interview schedule (interview schedule available from authors on request). The general guiding question of our study was, "What issues are important to patients when thinking about surgical treatment?" Interviews considered (1) the sources and nature of information about TJA and (2) the values and preferences important to individuals in considering TJA. All interviews took place in the participants' homes, except for 1 that was conducted in a private office at the hospital's research unit. Interviews lasted 2 to 3 hours.

Data collection was discontinued after 17 interviews because although the details and examples in participants' accounts were often unique, there was sufficient information from which to identify themes relevant to our objective. Participants ranged in age from 59 to 81 years (mean 69). Nine participants were women. Nine participants lived alone, seven of whom were women. One participant had had a previous total knee arthroplasty.

ANALYSIS

All interviews were tape-recorded and transcribed verbatim. The method of data analysis was qualitative content analysis—the process of identifying, coding, and categorizing patterns.[17] Analysis began with the identification of key themes and patterns using the process of coding. Coding is the means of generating concepts from and with the data.[18] Codes are labels that describe, in an abbreviated way, the different topics and

underlying assumptions in the data. The analytic process began inductively and was iterative (i.e., the data were reviewed multiple times, and codes were added and changed as new data were collected and new topics and relationships identified). Credibility and rigor of the analysis were aided by coanalysis of transcripts by 2 of the researchers (PH, JC), continual reexamination of the interview data throughout the research process, and ongoing discussion with the senior investigator (JW).

Results

DEFERRAL

Among this group of appropriate candidates unwilling to consider TJA, a key finding appears to be the notion of "decision" itself. Rather than implying a decision endpoint (i.e., yes or no), we found that some elderly patients' decision making involved ongoing deliberation of the TJA option, often resulting in a *deferral* of the treatment decision. Although TJA had not been chosen as a treatment option *now*, the possibility remains that it could be chosen at some point in the future. The TJA decision was being put off to some ill-defined future point in time when an equally ill-defined threshold of pain and/or immobility might be reached. These participants did not appear to have a definite or distinct plan for when they would make this decision. Moreover, it seemed that some were hopeful that things would get better and a decision would never actually be required. Responses such as "not bad enough," "not at that point yet," "if it comes to that," "if there is no other choice," and "I'm holding it off at this stage" highlight the process of deferral.

These accounts suggested that rather than view patients' unwillingness to consider TJA as a decision, many patients are involved in an ongoing and subjective *continuum* of decision deliberation. Deferral, when it occurs as part of this continuum, is not a decision per se, nor is it a rejection of the procedure. For some patients, current "unwillingness" to undergo TJA actually meant "no, not now," "no, I'm not sure" or "no, I haven't really considered it," and not simply "no, not ever."

Charles et al.[10] described treatment decision making as 3 distinct stages that, in practice, often occur iteratively: information exchange, discussion with regard to treatment preferences, and choice of a treatment. The results of this study suggest that decision making may be more complicated and, at least for some elderly individuals with arthritis, decisions are often deferred. The procedure is neither accepted nor rejected, with no discrete "choice" or end point to the decision-making process.

ASSUMPTIONS

Many would assume that a reasonable option for these patients would have been to consider TJA, given they were told of its known efficacy and high probability of relieving pain and restoring mobility. This was particularly perplexing because more than 90% of individuals stated they were unwilling to even consider surgical treatment. What rationale is underlying how elderly persons think and act when it comes to TJA? According to Ingham,[19] "the extent to which what might be regarded by some outsiders as the rational, or sensible, attitude to hold or action to perform, is constrained . . . by basic taken-for-granted assumptions within particular social worlds" (p. 104). The possibility that decision making may be constrained by patient assumptions led us to look at participants' responses from the point of view of what underlying assumptions appear to be operating in elderly persons' views with regard to TJA. Specifically, do patients consider their arthritis a "problem," do they see themselves as candidates for treatment, and finally, should they be pursuing treatment?

THE NATURE OF ARTHRITIS

This study evaluated decision making for osteoarthritis, a non-life-threatening, chronic disorder that is largely "managed" rather than "cured." For the moment, some participants in this study had adjusted to the changes to their physical bodies and lifestyles that accompanied their arthritis. The following patient, for example, considered herself in relation to others her age and concluded that she is fortunate:

> I'll be 80 in December . . . there's a lot of people who don't get around at my age anyway. So I feel that I do really well. (Participant 7, age 79)

Others talked about the expectation of pain with age, as well as the legitimacy of being stiff:

> When you're this age and you have an ache, well so what? You expect to have aches when you're this age. (Participant 3, age 78)

These excerpts highlight the view held by some participants of arthritis as something one lives with, to be expected in the later part of one's life course, and not necessarily something that should be "fixed." The issue is

not that these participants did not recognize a problem, but rather they did not see their arthritic pain or associated functional limitations as problems or a disease that warranted attention or required fixing. Charmaz[15] described the process of "normalizing illness," which means "making [the illness] routine, and treating whatever changes and improvisations are created as ordinary" (p. 283). Persons who have normalized their arthritis may be less likely to initiate conversations with their health care providers or express dissatisfaction with their arthritis treatment. This may have important implications for, and indeed may preclude, shared decision making between the practitioner and the elderly patient. Moreover, this would seem to potentially detract from a full consideration of TJA, including proper referral to a specialist.

CANDIDACY

Many patients believed that they needed to be in constant pain and virtually unable to move before they would consider themselves a TJA candidate. Surgery was often viewed as a last resort option, turned to only when pain and immobility could no longer be tolerated.

> I will go on not having it or not even considering it [TJA] unless I feel I just can't get around at all. (Participant 12, age 73)

> If I was in just constant pain, I would take it [TJA]. (Participant 8, age 75)

> When the time comes it gets that bad, I'll decide for the surgery. But right now I can limp around with it, and let it stay that way. I'll take the pain-killing pills to ease the pain, and you live that way.

These quotes highlight how patients may have different assumptions than health care practitioners about the point at which one becomes a candidate. Our intent in highlighting these differing assumptions is not to suggest that it is unacceptable for patients to deviate from a gold standard definition of candidacy as defined by medical criteria but, rather, to demonstrate how views about what constitutes candidacy can differ between patients and health care practitioners. From the elderly person's perspective, it makes sense to defer both a decision with regard to surgery and the surgery itself if you do not think you are a candidate for surgery. These people did not think they were "putting off" surgery but, rather, waiting until the "time is right." Alternatively, deferral may be suggestive of a presumption that others are more needy of the procedure—an entitlement or fairness conjecture by patients. There were at least 2 individuals in this sample for whom fairness was an issue:

> I'm too old, and my health isn't that great. And it would seem to me and I'm not trying to be, you know, pick me. It's just that other candidates with better health deserve the operation more than I do. (Participant 11, age 64)

Deferral, then, is potentially tied to the meanings people have about what constitutes an "appropriate" candidate for TJA.

The taken-for-granted assumption that one needs to be in almost constant pain and virtually unable to move before seriously considering TJA implies that some patients may be unlikely to raise the issue of their hip or knee problems and TJA as a treatment option with health practitioners until very late in the course of their disease. Once again, the potential for shared decision making is potentially foreclosed because discussion of TJA is not initiated.

DECISION MAKING PROCESS

Some elderly patients' process of, and preferences for, information gathering and synthesizing strongly suggest a need for physician responsibility for information sharing. In addition, a desire for a more authoritative model of patient-practitioner interaction and treatment decision making may be present. For example,

> I have to talk to the [doctor], if it's gonna get worse I told him, the pain, everything . . . then I have to talk to him. Then he'll tell me what to do. (Participant 14, age 59)

> (In response to the question, "What does it mean, that at some point you'll need it [TJA] but not now?"): I don't know if I need it. If I go to the doctor or specialist and they say you have to have it [TJA], I have it. I'm the best patient. (Participant 8, age 75)

If a patient is waiting for his or her physician to either initiate a discussion or make a direct recommendation about TJA and the physician does not, then deferral or rejection of TJA may reflect not so much an active consideration of the pros and cons of the procedure by the patient but, rather, the patient's preferred interaction with health care practitioners. It may also be that today's elderly patients lack a precedent for shared decision making. At any rate, there appears to be a large

enough gulf between some elderly patients' descriptions of the decision making process as it relates to TJA and the components of shared decision making models to cast doubts on the efficacy of such a model in all situations.

INFORMATION AND FEARS

Although this research focused on patient assumptions that could preclude initiation of a discussion about TJA with their health practitioner, participants' descriptions of their information sources and fears suggest that improved communication about TJA is also needed.

Many participants showed evidence of poor information or trust in TJA itself, despite having received detailed risk/benefit information as part of the population-based survey. This casts doubt on their receptiveness to the utility of TJA in their individual cases, as well as on the effectiveness of the manner in which the information was presented.

Participants often drew preferentially upon lay sources of TJA information, such as the satisfaction accounts of others who had undergone the surgery, to form perceptions of TJA's efficacy. Although some had heard that the surgery was "marvelous" and like having "new bones," others learned that surgical outcomes were not always ideal. According to one participant,

> What I understand, boys who have had a replacement were never any good afterwards . . . they could never perform their jobs like the way they used to. (Participant 10, age 63)

Risk assessments were also formed on the basis of peer accounts, and these appeared to detract elderly patients from accepting TJA:

> When I go to the mall, and with the people I was discussing it with said, "don't go for hip replacement . . . it's dangerous."

These examples highlight how the experiences and stories of peers strongly influence an individual's consideration of TJA. Although these information sources may be inaccurate—leading to (or exacerbating) uncertainty, misconceptions, and fear—they did seem to powerfully shape perceptions and attitudes toward the surgery and may override information provided in a shared decision making context.

Finally, the following quote highlights how fear and information needs can be linked:

> I was afraid to go for the surgery, so I never asked. (Participant 5, age 63)

Fears stemming from misinformation, lack of information, or misperceptions may all contribute to patients' failure to initiate a discussion with their health practitioner about TJA.

Discussion

Research on decision aids, in addition to defining the specific message and most appropriate means of conveyance, needs to consider how information is processed and understood.[20,21] Understanding how information is processed and understood, particularly in patient subgroups (e.g., elderly individuals considering surgery such as TJA), is important because it may illuminate how the decision making process might be optimally approached and facilitated. Shared decision making can only occur if a discussion about treatment options for arthritis occurs. If an elderly person assumes either that arthritis is not a disease requiring invasive treatment or that he or she is not (based on self-assessment) a candidate for TJA, the initiation of, or request for, a discussion concerning treatment options such as TJA may never occur. Alternatively, the practitioner sensing a patient's "reluctance" may fail to initiate or engage in a discussion about TJA.

The normalization of arthritis appears, in part, to be at issue for many elderly persons. Whose role or right is it to challenge patients' views of arthritis as a normal part of aging? Given what we know about the efficacy of TJA, should health care practitioners more aggressively pursue treatment of arthritis with elderly patients? To do so is essentially to ask patients to redefine their conceptions of illness—to define themselves as "sick" (when they may not think they are)—and subsequently to make decisions about treatments such as an invasive procedure such as TJA. Individuals who have more or less resigned themselves to their hip and knee osteoarthritis may be viewed as demonstrating resistance to the currently prevalent view of fixing or managing the body[22] by their acceptance of a less active, slower-paced life.

There are at least 2 separate issues here. The 1st issue is that patients need to know when they have a treatable condition, and informing them of this is a responsibility of health care practitioners. Given that some elderly persons are heavily reliant on their practitioners to advise them on their health, practitioners may need to initiate discussions about arthritis and various treatment options, including surgery. To do so, health care practitioners (and in particular general

practitioners who are often the gatekeepers for specialist referrals) need to be clear and up to date with respect to the known expected benefits and potential risks of various treatments in terms of physical functioning and quality of life. This does not mean that health care practitioners should direct patients to receive surgery,[23] but rather that specialists should be consulted to clarify patients' potential candidacy. With respect to TJA, part of their role may be to demystify the surgical intervention so as to cast it as health enhancing rather than an "end-of-the-road" treatment. The results presented here suggest that communication about the procedure needs to be better, alongside initiation of such a discussion. Although more factual information about the procedure alone may be insufficient to address or redress taken-for-granted assumptions concerning candidacy or arthritis itself, it is still necessary that persons have full and accurate information about this treatment option sooner in the evolution of the condition and not only at the extremely debilitated end of the spectrum. Particularly if earlier intervention is likely to be more efficacious for some patients,[5] this point is crucial.

The 2nd issue has to do with how practitioners interact with elderly patients around treatment choices, such as whether to have TJA. Some of our participants' accounts suggest it is insufficient to assume and expect all elderly patients' preferences to include a shared decision making process. Rather, some appear to desire more direction from their physicians. This finding is consistent with others[24] who have reported that patients more than 60 years old were more likely to prefer a directed (vs. shared) style of decision making. Once again, the responsibility falls to health care practitioners to be sensitive to the unique needs of individual patients, acknowledging that these needs may differ even within an individual depending on the context of the decision. No single approach or directive is appropriate here.

Our study has some potential limitations. Although one might argue that our participants may simply be unwilling because they had not received sufficient information about TJA, or that the discussion of decision making was hypothetical in that it did not occur in the context of a current exchange between patient and surgeon, we think this was not the case. All participants had had a discussion with a trained therapist who provided standardized, detailed, and up-to-date information on the pros and cons of TJA. Furthermore, at least 10 of our 17 participants had discussed TJA with a physician (and sometimes also a surgeon) at some point in time. Despite these interactions, 90% of individuals were unwilling to even consider TJA, suggesting that this was not simply an issue of needing more information.

A 2nd limitation is that the extent to which these assumptions are prevalent in the larger population is not available from our data. This exploration of assumptions underlying elderly persons' accounts of decision making about TJA and the influence of these assumptions on shared decision making is an attempt to illuminate what appears to be a complex, multifaceted process. These assumptions are not exhaustive, and others may also be operating. Although like most qualitative studies the sample size was small, 1 or more of these assumptions could be seen, to varying degrees, in virtually all participants' accounts. Furthermore, and more important, these assumptions are provocative enough to warrant serious consideration when developing future interventions targeted to the more than 90% of people who might benefit from TJA yet appear unwilling to even consider the procedure.

Conclusion

This qualitative study illustrates a contrast between the model of shared decision making and elderly patients' subjective accounts of their decision making process. The current emphasis on shared decision making and decision aids needs to be considered in light of the needs of elderly persons. Rather than focusing exclusively on the development of sophisticated aids to facilitate shared decision making, emphasis should be directed toward thinking about ways in which discussions about TJA might be initiated (and by whom) and considering how patients' views on and knowledge of osteoarthritis in general might be addressed.

References

1. Hawker GA, Wright JG, Coyte PC, et al. Health-related quality of life after knee replacement. J Bone Joint Surg Am. 1998;80:163–73.
2. Chang RW, Pellisier JM, Hazen GB. A cost-effectiveness analysis of total hip arthroplasty for osteoarthritis of the hip. JAMA. 1996;275:858–65.
3. Bunker JP, Frazier HS, Mosteller F. Improving health: measuring effects of medical care. Milbank Q. 1994;72:225–58.
4. Liang MH, Cullen KE, Larson MG, et al. Cost-effectiveness of total joint arthroplasty in osteoarthritis. Arthritis Rheum. 1986;29: 937–43.
5. Fortin PR, Clarke AE, Joseph L, Liang MH, Tanzer M, Ferland D, et al. Outcomes of total hip replacement: preoperative functional status predicts outcomes at six months after surgery. Arthritis Rheum. 1999;42:1722–8.
6. Hawker GA, Wright JG, Coyte PC, Williams JI, Harvey B, Glazier R, et al. Differences between men and women in the rate of use of hip and knee arthroplasty. N Engl J Med. 2000;342:1016–22.

7. Hawker GA, Wright JG, Coyte PC, Williams JI, Harvey B, Glazier R, Wilkins A, Badley EM. Determining the need for hip and knee arthroplasty: the role of clinical severity and patients' preferences. Med Care. 2001;39:206–16.
8. Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med. 1999;17:285–94.
9. Charles C, Gafni A, Whelan T. Shared decision making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med. 1997;44:681–92.
10. Charles C, Whelan T, Gafni A. What do we mean by partnership in making decisions about treatment? Br Med J. 1999;319:780–2.
11. O'Connor A, Drake ER, Fiset V, Page J, Curtin D, Llewellyn-Thomas HA. Annotated bibliography: studies evaluating decision-support interventions for patients. Can J Nurs Res. 1997;29(30): 113–20.
12. Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. Br Med J. 1999;319:766–71.
13. O'Connor AM, Rostom A, Fiset V, Tetroe J, Entwistle V, Llewellyn-Thomas H, et al. Decision aids for patients facing health treatment or screening decisions: systematic review. Br Med J. 1999;319:731–4.
14. Deyo RA, Cherkin DC, Weinstein J, et al. Involving patients in clinical decisions: impact of an interactive video program on use of back surgery. Med Care. 2000;38:959–69.
15. Charmaz K. Experiencing chronic illness. In: Albrecht G, Fitzpatrick R, Scrimshaw S, eds. The Handbook of Social Studies in Health and Medicine. Thousand Oaks, CA: Sage; 2000. p. 277–92.
16. Evans JG. Prevention of age-associated loss of autonomy: epidemiological approaches. J Chronic Dis. 1984;37:353–63.
17. Patton M. Qualitative Evaluation and Research Methods. 2nd ed. Beverly Hills, CA: Sage; 1990.
18. Coffey A, Atkinson P. Making Sense of Qualitative Data: Complementary Research Strategies. Thousand Oaks, CA: Sage, 1996.
19. Ingham R. Some speculations on the concept of reality. Adv Med Sociol. 1994;4:89–111.
20. Mischler EG. The Discourse of Medicine. Norwood, NJ: Ablex; 1984.
21. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med. 1999;49:651–61.
22. Featherstone M. The body in consumer culture. In: Featherstone M, Hepworth M, Turner BS, eds. The Body Social Process and Cultural Theory. London: Sage; 1993. p. 170-96.
23. Nettleton S. The sociology of lay-professional interactions. In: The Sociology of Health and Illness. Cambridge, UK: Cambridge Polity Press; 1995. p. 131-59.
24. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. Br Med J. 2000;321:867–71.