Arthritis symptoms, information sources, and a constantly shifting threshold of risk-benefit ratios influenced elderly patients' decisions about total joint replacement

Clark JP, Hudak PL, Hawker GA, *et al.* The moving target: a qualitative study of elderly patients' decision-making regarding total joint replacement surgery. *J Bone Joint Surg Am* 2004;**86-A**:1366–74.

Q What are the decision making processes of elderly patients with severe arthritis who are unwilling to consider total joint replacement (TJR) surgery?

DESIGN

Qualitative.

SETTING

Toronto, Ontario, Canada.

PATIENTS

17 patients (age range 59–81 y, 53% women) who had severe arthritis (confirmed by Western Ontario and McMaster Universities Osteoarthritis Index scores ≥ 39 out of 100 points and x rays), and were unwilling to consider surgery.

METHODS

Patients were interviewed for a mean 2.5 hours using a semistructured interview guide to elicit the sources and nature of information they received about TJR and potential sources of support; and the preferences, motivation, and needs that were important when considering the general management of arthritis and TJR. Transcribed interview data were analysed using qualitative content analysis.

MAIN FINDINGS

3 themes described patients' decision making processes. (1) *Factors influencing decisions.* Patients differed in terms of the relative importance they placed on symptoms and information sources. (a) *Symptoms.* Pain was the most important and frequent symptom causing disability. Changes in the nature or frequency of pain motivated patients to consider "doing something" to ease their suffering. Despite perceiving pain as severe, they didn't think it was "bad enough" to consider TJR. For some patients, arthritis pain was perceived as expected, natural, and not treatable with surgery. (b) *Information sources.* Some patients believed that they were not candidates for TJR because of poor or incomplete information from medical sources about TJR and its utility for them personally. Peer based information sources, particularly others who had undergone TJR, were highly trusted and influential in shaping perceptions of TJR but sometimes led to misconceptions, greater uncertainty, fear of TJR, and unwillingness to have surgery. (2) *Weighing of costs and benefits.* In making the choice, patients weighed perceived benefits against perceived costs. Fear of postoperative pain or dysfunction, and concerns about household security and social support were important to many patients. Concerns about negative outcomes (ie, efficacy and perceived risks) also detracted from the desirability of TJR. Pain relief, improved physical function, and greater independence were important benefits. (3) *Trading off process.* (a) Managing severe arthritis meant *accommodating it* (ie, restricting activities and "learning to live with it"). Decision making involved weighing the costs and benefits of TJR with reference to a constantly changing decision threshold of pain ("a moving target"). Unwillingness to have TJR often resulted from an ongoing process of deliberation and deferral rather than an explicit decision. (b) *Quality, not extension of life.* Patients perceived TJR as an elective procedure that could

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improve quality of life (QOL) rather than length of life and placed a low relative value on arthritis treatment compared with other illnesses (eg, hypertension). Considering TJR as a way of improving QOL in the context of a diminishing life expectancy was challenging for patients.

CONCLUSIONS

Pain, disability, and peer based information sources influenced elderly patients' decision making about total joint replacement (TJR). Patients viewed the pain and disability of arthritis as severe but not "bad enough" to consider TJR. Patients engaged in an individualised process of recognising and weighing the perceived costs and benefits of TJR. They managed arthritis pain and disability by adapting to it. The choice to undergo TJR was a function of ongoing deliberations and continuing deferrals in response to ever changing thresholds of pain rather than an explicit decision.

Commentary

The study by Clark *et al* is useful to nurses who help patients make decisions about elective treatments. The investigators looked beyond statistical models of patient decision making that focus on expected utility to examine the individualistic and subjective processes that patients used when considering TJR. The study showed that patients did not always fully understand the benefits and risks of the proposed treatments. Nurses who care for such patients can provide, reinforce, and target relevant information to patients' particular levels of understanding and healthcare needs. In fact, research has shown that such tailored educational content is more useful to patients than standardised content.¹

The study by Clark *et al* showed that patients valued information from peers who had faced similar treatment choices for TJR. Because experienced nurses are aware of the similarities among patient experiences, they can provide comparable types of input. Patients value such experiential knowledge shared by nurses.²

Most importantly, when making decisions about TJR, patients in the study by Clark *et al* considered the effect of their pain on present circumstances, the personal toll of surgery, and the anticipated effect of TJR. Nurses who "know their patients" may be particularly well suited to provide advice about elective treatments. Both patients and nurses value care that is tailored to patients' feelings and perceptions of the way in which illnesses and treatments affect patients' lives.³

In summary, the findings of Clark *et al* can be linked with those of other studies to suggest ways that nurses can improve the care of patients making decisions about elective treatment. These include sharing experiential knowledge with patients, individualising care, and tailoring teaching.

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