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A bird can't fly on one wing: patient views on waiting for hip and knee replacement surgery

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Abstract

Objectives To obtain patients' perspectives on acceptable waiting times for hip or knee replacement surgery.

Methods A questionnaire with both open- and close-ended items was mailed to 432 consecutive patients who had hip or knee replacement surgery 3–12 months previously in Saskatchewan, Canada. A content analysis was used to analyse the text data from the open-ended questions.

Results The sample of 303 (response rate 70%) was 59% female with a mean age of 70 years (SD 11). The median waiting time from the decision date to surgery was 17 weeks. Individuals who rated their waiting time very acceptable (48%) had a median waiting time of 13 weeks compared with a median waiting time of 22 weeks for those who rated it unacceptable (23%). The two most common determinants of acceptability were patient expectations and pain and its impact on patient quality of life. The median maximum acceptable waiting time was 13 weeks and median ideal waiting time, 8.6 weeks. Seventy-nine per cent felt that those in greater need (higher severity) should go before them on the waiting list. Patient ratings of maximum acceptable waiting time were based on: pain and loss of mobility, time needed to prepare for surgery, and severity at the time of seeing the surgeon. In consideration of changing their surgeon to one with a shorter waiting list, 68% would not.

Conclusions Patient views on waiting times are not only related to quality of life issues, but also to prior expectations and notions of fairness and priority. Understanding patient views on waiting for surgery has implications for better management of waiting times and experiences for joint replacement.

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Introduction

Long waiting times for scheduled health services are a reality in countries with publicly funded health care. Canadians have identified long waits as the primary barrier to specialized services. In a recent population health survey 17% of respondents who waited for all non-emergency surgeries reported their waiting time as unacceptable.[1] When that waiting exceeds societal expectations, the public perceives vulnerability and loses confidence in the ability of a publicly-funded healthcare system to deliver timely and accessible care, and looks to explore other means of healthcare provision.

Two of the most common, present-day, scheduled surgical procedures are hip and knee replacement surgery for end-stage arthritis. When the pain and disability of those so afflicted worsen to the point that interventions such as activity limitation, use of a cane, analgesics and anti-inflammatory medications no longer help to ease the pain, a decision may be made for joint replacement surgery. If the patient is otherwise healthy enough to withstand the operation, the patient is placed on a surgical waiting list. Not surprisingly, pain and loss of mobility affect the quality of life of patients on waiting lists for hip or knee replacement, patients for whom other treatment measures have failed. Although the effectiveness of joint arthroplasty is well documented, clinical evidence on the effect of waiting on quality of life and health outcomes is less clear. Recent evidence suggests that pain increases and function deteriorates with longer waits.[2–4] Moreover, individuals with more preoperative pain and poorer function tend to have poorer postoperative pain relief and function.[2,5]

In an attempt to reduce waiting times and restore public confidence, benchmarks or guidelines for acceptable waiting times for care have been implemented or proposed in some countries.[6,7] They have been based largely on consensus decisions with physician input, but there is little published literature on the rationale and evidence used to formulate these benchmarks.[8,9] It is increasingly recognized that patient perspectives on how long is reasonable or acceptable to wait should be considered as an important input to these benchmarks. Although some papers have reported average or median waiting times that are acceptable to patients,[10,11] there is little knowledge of the rationale behind patients' evaluation of the acceptability of their wait.

Thompson and Sunol hypothesized that expectation is linked to satisfaction with health services.[12] They described four types of expectation: normative, a subjective evaluation of what should or ought to happen; ideal, the desired or preferred outcome; predicted, the realistic or anticipated outcome; and, unformed, when individuals are unable or unwilling to articulate their expectations. A maximum acceptable waiting time can be viewed as the normative view or what patients feel should happen, while an ideal waiting time is a desired waiting time.

The purpose of this study was to obtain patients' perspectives on acceptable waiting times for hip or knee arthroplasty and to examine patient views on issues associated with waiting. This article explores patient views on both maximum acceptable waiting times and ideal waiting times. The maximum acceptable waiting time should provide information towards establishing an outer bound for benchmark waiting times while the ideal waiting time may inform an inner bound of a range of acceptable waiting times.

Methods

A questionnaire was mailed to 432 consecutive patients who had a hip or knee joint replacement in three of the four health regions in Saskatchewan that provide hip and knee arthroplasties. Inclusion criteria were all individuals, 18 years and older, who had a scheduled hip or knee arthroplasty within the past 3–12 months; whose urgency was assessed with the Western Canada Waiting List Priority Criteria Score;[13] and who were registered in the Saskatchewan Surgical Patient Registry. The Registry, implemented in 2003, is a comprehensive provincial database of all patients on the surgical waiting list and

includes data on waiting times and priority scores.[14] The initial mail out was followed by two reminder letters and surveys with stamped self-addressed return envelopes. Ethics approval for the study was obtained from the University of Saskatchewan Research Ethics Board.

The questionnaire included both open- and close-ended questions. The open-ended questions were placed near the beginning of the survey to lessen the influence of the other questions on their answers. In addition to demographic variables, the survey questionnaire assessed patient views on the acceptability of their waiting times, maximum acceptable waiting time, ideal waiting time, fairness, priority, and whether they would consider going to an orthopaedic surgeon with a shorter waiting time (Table 1). Waiting time was defined as the interval from the decision date (when the patient and surgeon decide to proceed with the replacement surgery) to the actual date of surgery. The questionnaire items were based on the research questions and a literature review. In addition, a checklist of potential problems while waiting (yes/no response) was adapted from the Access to Health Care Services in Statistics Canada Survey.[1] All items were pre-tested with three individuals who had undergone joint replacement. Pre-testing involved completion of the questionnaire followed by an interview to probe their comprehension and interpretation of the items.

Content analysis was used to analyse the text data from the open-ended questions.[15] The primary researcher (B.C.S.) coded the data and identified themes. A second researcher (C.S.) independently coded a random sample of 30 cases for each item. Themes were compared and discussed and a consensus was reached on the final themes. A parallel paper reporting on a comparison of patient and surgeon maximum acceptable waiting times for levels of urgency is in preparation.

Table 1 Questionnaire items

In your view, what should be the maximum acceptable waiting time for you or a person like yourself to wait for hip or knee replacement surgery? Describe your reasons for choosing this length of time.
In the best of all possible worlds, what would be the ideal length of time that you would choose to wait for surgery once you and your surgeon decided to go ahead with your surgery?
How acceptable is the length of time that you actually waited for your most recent surgery? Explain the reasons for your answer.
How fairly did you feel you were treated in regard to the length of time that you waited for your most recent joint replacement surgery? (very fairly to very unfairly)
If another person had more severe pain than you and more difficulty in carrying out their usual activities, should they go before you on the waiting list?
If you had a choice of going to another orthopaedic surgeon with a shorter waiting time, would you consider changing your surgeon? Explain the reason for your answer.
How was your life affected as a result of waiting for surgery? (a checklist of responses with yes or no options)

Note: waiting time was defined on the survey as 'the length of time from when you and your surgeon decided to go ahead with the surgery until the day that you had your surgery'.

Results

Three hundred and three individuals returned completed surveys (70% response rate). The sample of 303 was 59% female with a mean age of 70.24 years (SD 11.06). The sample was similar in age and sex to the 432 eligible individuals (59% female, mean age 70 years, SD 12). The median actual waiting time for the 303 patients was 17 weeks, the median maximum acceptable waiting time, 13 weeks, and the median ideal waiting time, 8.6 weeks. Mean values were similar. Forty-eight per cent felt their waiting time was very acceptable, 29% somewhat acceptable and 23% unacceptable. For levels of acceptability, the median actual waiting time ranged from 13 weeks (very acceptable) to 22 weeks (unacceptable) (Table 2).

When asked how fairly they felt they were treated in regard to the length of time that they waited for their surgery, 58% answered very fairly, 22% somewhat fairly, 11% neither fairly or unfairly, 5% somewhat fairly and 4% very unfairly. Seventy-nine per cent of patients agreed that if another person had more severe pain and more difficulty in carrying out their

Table 2 Actual waiting times for levels of acceptability

Acceptability of waiting time	*n*	%	Actual waiting time		
			Median	Mean	SD
Very acceptable	142	48.0	13.21	15.61	11.22
Somewhat acceptable	87	29.4	19.57	19.27	10.20
Unacceptable*	67	22.6	21.71	26.95	29.67

*The categories somewhat unacceptable and very unacceptable were combined because of small numbers in each category.

usual activities, they should go before them on the waiting list. If given a choice of going to another orthopaedic surgeon with a shorter waiting time, 68% would not consider changing their surgeon, 15% would and 17% were uncertain.

Patients were given a list of potential problems and asked how their life was affected as a result of waiting for surgery. The most common problems were related to deterioration in pain and function, while the least common were loss of work and income (Table 3).

Reasons for acceptability of the length of wait

Seventy-four per cent of respondents ($n = 224$) gave an explanation for the acceptability of their waiting time. Reasons were coded, grouped into themes and are summarized in Table 4. Examples of patient responses are included to exemplify each theme and include responses from patients who rated their waiting time both acceptable and unacceptable.

Table 3 Percentage of respondents who checked yes for each statement

How patient's life was affected as a result of waiting	%*
Hip or knee problem got worse	91.3
Pain got worse	90.0
Problems with usual activities	88.1
Increased use of pain medication	86.7
Family or friends worried	76.9
Increased dependence	68.7
Worried	64.4
Problems with activities of daily living	64.2
Did not go out of town	53.7
Problems caregiving	53.5
Overall health got worse	51.3
Personal relationships suffered	41.4
Loss of work	25.7
Loss of income	13.3

*Because multiple responses were allowed, the total exceeds 100%.

Table 4 Reasons for acceptability of waiting time

Theme	Waiting time acceptable		Waiting time not acceptable	
	n	%	*n*	%
Expectation	61	36.3	8	15.1
Pain and loss of mobility	36	21.4	32	60.4
Judgement (long, short, reasonable)	25	14.9	4	7.6
Taking your turn	9	5.4	0	0.0
Time to prepare for surgery	7	4.2	0	0.0
Medical reason	7	4.2	1	1.9
Health system reason	4	2.4	2	3.8
Long wait to see surgeon	3	1.8	2	3.8
Difficult to plan life	1	0.6	1	1.9
Other	19	11.3	3	5.7

Note: percentage is out of 224 respondents who provided a reason for acceptability. Because of multiple responses, the total may exceed 100%.

Expectations

Thirty-six per cent of patients who felt their waiting time was acceptable and 15% of those who rated it unacceptable compared their actual waiting time with their expected waiting time. Their expectations were based on what their surgeon told them, stories that they heard, their anticipation of expedited surgery once they had been converted from the elective to urgent waiting list and their past experience with waiting. Some examples of patient comments included:

> They put me on the urgent wait list and I felt that 6 months was quite the wait for an urgent surgery.

> I was expecting a 2-year wait and I waited 8 months.

> My surgery actually took place sooner than expected according to what other people say they had to wait. But not soon enough according to pain and the fact that the longer I waited the more serious the injury became.

Pain and loss of mobility

Twenty-one per cent of patients who felt their waiting time was acceptable and 60% of those who felt it was unacceptable gave a reason that included pain, loss of mobility or problems resulting from these, such as medication use and side effects, loss of work and difficulty sleeping. Twelve patients felt that their joint had deteriorated over time or that their joint problem precipitated other general health problems or exacerbated pain in other arthritic joints.

> Complete deterioration of the hip joint, mobility was extremely limited, pain was severe and general health and well being was at extreme risk!

> Three years of pain and disabilities is much too long. I totally destroyed the knee by the time surgery was done.

Judgement

Some patients expressed an opinion or conclusion as to the acceptability of their waiting time but did not provide a further explanation or rationale. Fifteen per cent of patients who rated their waiting time acceptable and 8% who rated their waiting time unacceptable judged the acceptability of their waiting time as a short wait, too long a wait, or a reasonable wait.

Taking your turn

Five per cent of patients who felt their waiting time was acceptable explained their wait in the context of others on the waiting list. They understood that there were others in the queue who were also waiting and they accepted the notion of taking their turn.

> You have to wait your turn.

> Other people are in pain too. Maybe their surgery should have been done after waiting 2 and 3 years.

> I was in great pain that was getting worse by the week but I realized that there was a list of people with similar problems.

Other reasons included: needing time to prepare for surgery, medical reasons and system-related reasons such as cancelling of surgery by the hospital. Five patients noted that the wait to see the specialist was long and two referred to difficulties in planning one's life when they didn't know the date of surgery.

Reasons for a maximum acceptable waiting time

When patients were asked the reason for choosing the length of time for a maximum acceptable waiting time, 209 of 303 (69%) patients gave an explanation for their response. The two most frequent themes related to pain and loss of mobility (52%) and needing time to prepare for surgery (20%) (Table 5).

Pain and loss of mobility

Fifty two per cent ($n = 108$) of respondents referred to issues related to pain, loss of mobility and their consequences, including deterioration of the joint while waiting, medications and increased medication use, effect on health, loss of work and difficulty sleeping.

> I mean a bird can't fly on one wing. Same goes with a human trying to work when your bad knee gives way and you fall.

> When your knee joint wears out and is popping out of place, you're in pain with every step or movement, and it is grinding bone on bone, you can't sleep, 3 or 4 months is long enough.

Table 5 Reasons for maximum acceptable waiting time

Theme	*n*	%
Pain and loss of mobility	108	51.7
Need time to prepare for surgery	41	19.6
Depends on severity of condition	30	14.4
Reasonableness of waiting time	20	9.6
Effect of time spent waiting	15	7.2
Taking your turn	10	4.8
As soon as possible once the decision is made	9	4.3
Up to the surgeon	4	1.9
System-related	4	1.9
Health-related	3	1.4
Expectation compared with previous joint replacement	3	1.4
Life on hold	2	1.0
Other	8	3.8

Note: percentage is out of 209 respondents who provided a reason for acceptability. Because of multiple responses, the total exceeds 100%.

> I feel that 8 months should be the outside maximum because of the chronic long term pain. For someone who has not ever lived with chronic long term pain, you can empathize but never fully understand. The reliance on narcotics is very heavy.

Time needed to prepare for surgery

Twenty per cent ($n = 41$) of patients felt they needed time to prepare for surgery. These included preparing mentally (expressed as getting used to the idea and getting brave), organizing things at home or at work, arranging for help following surgery and giving the joint a chance to improve without surgery.

> Sometimes a person gets herself ready ahead of time, as in mind, body, soul, for the actual waiting period for surgery.

> It would give you time to become prepared, to accept the fact that you need the surgery, and get your life organized before the date.

Severity of condition

Fourteen per cent ($n = 30$) felt that those in more pain or disability should have a shorter waiting time. Some were in extreme pain by the time they saw their doctor. This was due to either a long wait to see the surgeon or because they put off making the appointment.

> It depends on the severity of the hip. It also depends on how long you wait before going to your family doctor.

> In most cases 3 months is probably an acceptable length of time. However it certainly depends upon the level of pain, deterioration of the joint, and level of mobility.

> Nobody enjoys surgery so you wait as long as you can before deciding to have the surgery done.

> Most people would not wait as long as I did to see the surgeon or rheumatologist. Being a physical therapist, I believed I was doing all I could to help myself and then it was bone on bone and I could not walk before I even saw my family doctor.

Reasonable length of time

Ten per cent ($n = 20$) described a maximum length of time in terms of what they felt was a reasonable wait.

> Pain curtails many of your everyday activities and affects your quality of life. It is difficult to do shopping, keep appointments, and have much of a social life. 6 months is not an unreasonable wait. I'm willing to tolerate the discomfort up to that time.

Taking your turn

Five per cent ($n = 10$) of patients compared their situation to others and expressed an understanding there are others on the waiting list who might be in worse or less pain than they are.

> I always figure there's other people that need it worse than I do.

Other reasons were health related (e.g. need time for first joint replacement to heal), system related (e.g. need more resources), uncertainty (e.g. life is on hold), and two patients compared their wait time to that of their previous joint replacement.

Reasons for consideration of changing to surgeons with shorter waiting time

The majority of patients would not consider changing their surgeon to one with a shorter waiting time. For those who would not change their surgeon, the most common reasons were satisfaction with their surgeon and surgery, confidence and trust in their surgeon, competence and skill of the surgeon, and the bedside manner of their surgeon.

> My surgeon did an excellent job and I trust him implicitly.

> Once you know a doctor, confidence in him is essential.

For those who would change their surgeon, it was usually because of unbearable pain. For those patients who were not sure, their answers were conditional on the amount of pain, the

length of their waiting time and on a recommendation from their family doctor.

> If my pain was unbearable, I'd consider going to a surgeon with a shorter waiting time.

Discussion

This paper used both open- and close-ended survey questions to study patients' attitudes towards waiting for hip and knee replacement surgery. The methods are complementary and allowed us to gain a greater understanding by capturing a more complete and contextual portrayal of patient perspectives.

Patient perception of actual waiting time is an important issue in interpreting acceptability of waiting time. Twenty-three per cent of patients felt that their waiting time, as defined on the questionnaire, was unacceptable. One must appreciate that waiting time is defined in this context as the interval between decision and actual surgical dates. It does not take into account the additional interval of time prior to the decision date that patients endured the consequences of end-stage arthritis. For example, one patient commented that she had had knee problems for 15 years but was too young at that time for a knee replacement. Often patients have waited many months to see the orthopaedic surgeon and may have had the problem for many years before seeing their family doctor. Two patients commented that they had switched doctors and were previously on another waiting list.

Reasons for the unacceptability of waiting times were largely associated with joint pain and its effects on mobility and other aspects of quality of life. This is consistent with other studies of patients waiting for joint replacement surgery.[16–18] The consequences of living with the pain and decreased mobility of osteoarthritis included concerns with increased medication use, problems with usual activities, difficulty sleeping, deterioration in the hip and knee problem, and deterioration in health. Similar to our findings, Snider *et al.* found that 47% of patients on the waiting list for hip or knee replacement felt that their wait contributed to a deterioration in their health.[11]

Approximately 20% of respondents explained the acceptability of their waiting time by comparing their waiting time to what they expected. How long patients expected to wait can be interpreted as an anticipated outcome, based on what they actually believe will happen, likely conditioned by the environment in which they wait. Patients described the source of these expectations as their surgeon, reported experiences from other people and a general belief that patients wait a long time for surgery. In our study, descriptions of the sources of expectation are congruent with models that explain the formation of expectancy: direct personal experience, the suggestion of others, observing others or beliefs.[19] Yet, expectations are not always well formed due to a lack of information about surgery, a concern expressed by some patients. In a Swedish study, patients waiting for joint replacement expressed frustration at the lack of information about when surgery would take place.[16] Patients may have a general idea of how long they might wait, but more often, they live a 'life on hold', waiting with uncertainty as to when they will have surgery.

Although patients had expectations based on what they believed would happen, their reasons for a maximum acceptable waiting time related not only to their pain and disability but also to other factors such as needing time to prepare and the severity of one's condition. The majority of patients agreed that patients in worse pain and more difficulty in carrying out their usual activities should have priority. In a UK study on patient views about who should have priority for knee arthroplasty, half of the patients accepted that there has to be a waiting list because of high demand and limited resources.[20] Similar to our study findings, most patients felt that those with more pain or lack of mobility should have priority and that a fair process should include factors specific to a patient's circumstances, such as length and degree of suffering, ability to work and to provide caregiving.

Almost 20% of respondents described needing time to prepare for surgery as a reason for their

maximum acceptable waiting time. This may help to explain why half of the patients viewed an ideal waiting time as greater than 2 months. Other patients described living with their problem a long time before going to a doctor. One explanation for the postponement could be a reluctance to undergo surgery, as expressed by some patients. In one community-based study, over 40% of individuals with severe arthritis who were not on a wait list for arthroplasty were either probably or definitely unwilling to undergo arthroplasty.[21]

Most patients would not consider changing their surgeon to one with a shorter waiting time, indicating that they had confidence in their surgeon and were pleased with the results of the surgery. Considering that the sample for this study had completed surgery, it raises the question of whether patients would feel the same or would consider changing their surgeon at some point in the referral or pre-surgery process.

A limitation of the study is that no open-ended questions were used to elicit patient views on the rationale for an ideal waiting time. Another limitation was that not all patients returned the questionnaire. However, demographic characteristics of the individuals who did respond were similar to those who did not. Finally, the perspectives were those of patients who had completed the waiting trajectory and are likely to be different from those who continue to wait for surgery. Our ongoing research agenda is addressing some of these study limitations by examining the views of both patients waiting and post-surgery. An important question will be the effect of the timing of assessment on patient views on the acceptability of waiting times.

In summary, this study shows that patient views on acceptability of waiting times are multifaceted. When there is little known about a subject, open-ended questions allow respondents to explain their perspectives in their own words. As there is little research in this area, our study provided a formative understanding of patient attitudes and reasons behind the acceptability of waiting times.

This research has important implications for the management of waiting times and the waiting experience for joint replacement. The acceptability of waiting times is related not only to quality of life and the length of waiting but also to other issues such as prior expectations and perceptions of fairness. More in-depth qualitative methods would allow one to explore these perspectives in more detail. Finally, little is known of strategies that may more effectively manage patients while they wait, such as providing the certainty of a scheduled date, contacting patients on the waiting list, and reassuring and reassessing them at regular intervals.

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