

# Quality of Life After TKA for Patients With Juvenile Rheumatoid Arthritis

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**Abstract** Total knee arthroplasty frequently is required during early adulthood in patients with advanced juvenile rheumatoid arthritis. We queried patients on issues of importance to them, asked whether they were satisfied with surgical outcomes, and ascertained their postoperative status. We retrospectively reviewed 14 adult patients (22 knees) with severe juvenile rheumatoid arthritis who were treated with primary total knee arthroplasty between 1989 and 2001. All patients were evaluated by pain and stiffness visual analog scales, range of motion, the Patient-Specific Index, Hospital for Special Surgery knee score, WOMAC Osteoarthritis Index, EuroQuol in five dimensions, and SF-36 Health Survey. Preoperative scores were assessed by recall. Patients had a minimum followup of 2 years (mean, 8 years; range, 2–13 years). Quality of life improved after TKA as measured by the Patient-Specific Index. Eighteen of 22 patients rated themselves satisfied with the functional outcome of their surgery; all patients were satisfied with

pain relief. Final SF-36, EuroQuol in five dimensions, and WOMAC scores were low compared with age-matched population norms. A mean postoperative flexion arc of 77° (range, 30°–130°) was observed. Total knee arthroplasty had a major positive impact on quality of life as reported by patients.

**Level of Evidence:** Level IV, therapeutic study. See the Guidelines for Authors for a complete description of levels of evidence.

## Introduction

Juvenile rheumatoid arthritis (JRA) is a chronic, inflammatory, disabling condition distinct from its adult counterpart with onset before 16 years and an incidence of approximately 10 per 100,000 population [25]. The knee is the most common joint involved in JRA and is a major factor in diminished function for these patients. Diminished function may be severely limiting to physical, social, and emotional development in childhood, adolescence, and young adult life. In early adult life, full-thickness articular cartilage damage in the lateral component of the knee frequently results in intolerable flexion and valgus deformity of JRA. Arthroplasty of the knee then is indicated to reduce pain and improve function [4, 8, 26].

Implantation of knee prostheses in the third and fourth decades of life in patients who have a long life expectancy raises concerns about the potential need for revision surgery at a young age. Hargreaves et al. [12] reported wound healing problems in 26% of patients with JRA. A search of computerized medical databases located 10 additional studies of outcomes of TKA in patients with JRA [4, 7, 8, 18, 23, 24, 26, 29, 32, 33]. Unlike the reports of 55% to 80% improvement in pain after TKA in JRA [8, 23, 24, 26,

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Each author certifies that his or her institution has approved the human protocol for this investigation, that all investigations were conducted in conformity with ethical principles of research, and that informed consent was obtained.

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32, 33], improvements in functional outcome measures and other instruments have been less positive than generally seen in TKA for osteoarthritis. These studies showed mean Knee Society scores from 82 to 92 and functional scores from 39 to 76 (on a scale of 0–100) at 4 to 6.5 years postoperatively [4, 24, 33], Jergensen's functional outcomes scores of 68 to 85 (on a scale of 0–100) [7, 8], and Hospital for Special Surgery knee scores of 80 to 84 (on a scale of 0–100) [26, 32]. A marked improvement in ambulation was reported after surgery. Whereas 88% to 100% of patients required walking aids or wheelchairs before surgery, 73% to 100% of patients did not require walking aids at 3.5 to 7 years' followup [7, 8, 24, 25, 33]. However, these studies did not analyze patient satisfaction or quality of life. It has been our clinical impression that patients with JRA who are profoundly disabled by multiple impairments usually highly value the beneficial effect of TKA performed for appropriate indications despite continuing to experience residual disability.

Clinical measures of health status, focusing on physiologic and physical measurements, reflect clinicians' perceptions of disease but often correlate poorly with patients' perceptions of health [38]. Other measures therefore have been designed to have direct relevance to patients' lives [2, 22, 38], such as patient-specific indices, in which the patient chooses the questionnaire items. Examples of such instruments include the McMaster Toronto Arthritis Questionnaire and the Patient-Specific Index (PASI) [39], which have been previously reviewed and compared with seven other patient-specific instruments [16]. The PASI asks patients to evaluate the severity of a given list of symptoms, degree of difficulty of a given list of activities, and importance of a given list of problems. The final two questions are completely open-ended, permitting patients to identify and rate any two symptoms and any three activities to form the last five patient-generated items, or PASI-pg.

We asked what issues were of importance to adult patients with JRA before and after TKA, as determined by a patient-specific index, the PASI-pg, and whether patients were satisfied with the surgery. We also asked what their postoperative status was, as evaluated radiographically, clinically, and by standardized outcome measures that are widely used in evaluation of TKA.

## Materials and Methods

We retrospectively evaluated 14 consecutive patients (22 knees) diagnosed with either severe polyarticular-onset JRA (13 patients; 20 knees) or systemic-onset JRA (both knees of one patient) admitted for elective primary TKA between 1989 and 2001 (Table 1). Indications for surgery

**Table 1.** Baseline characteristics of patients with juvenile rheumatoid arthritis who underwent TKA

Characteristic	Number of patients (%)
Number of patients	14 (22 knees)
Mean age at surgery (years)	33 (range, 15–42)
Gender	
Female	12/14 (86%)
Male	2/14 (14%)
Mode of juvenile rheumatoid arthritis onset	
Pauciarticular	0/14 (0%)
Polyarticular	13/14 (93%)
Systemic	1/14 (7%)
Marital status	
Single	7/14 (50%)
Married or common law	7/14 (50%)
Highest level of education	
Primary	1/14 (7%)
Secondary	8/14 (57%)
University/college	5/14 (36%)
Employment status	
Full-time	2/14 (14%)
Part-time	1/14 (7%)
Not working	11/14 (79%)
Type of prosthesis (% cemented)	
Femoral implant	15/22 (68%)
Tibial implant	19/22 (86%)
Patella resurfaced	15/22 (68%)
Mean followup (years)	8.0 (range, 2–13)

included JRA with severe, painful, and disabling arthritis of the knee. Key outcome measures were evaluated after a minimum followup of 2 years (mean, 8 years; range, 2–13 years) and compared with historical controls from the literature. All patients signed a consent form to participate in the study. We obtained prior approval by our research ethics board.

All surgical procedures were performed by one of the authors (ERB). Exposure was through a midline incision and a medial parapatellar arthrotomy. Because of bone deformity and contracted, inelastic soft tissue, it frequently was difficult to rotate the patella, in which case it initially was subluxated without rotation to gain access to the joint. A quadriceps tendon snip usually was avoided but was performed when necessary. Osteotomy of the anterior tibial tubercle was not performed because of concerns regarding osteoporosis and potential poor fixation. There was typically little or no synovitis. Although the entire skeleton was usually small, a variable deformity consisting of relative overgrowth of the epiphyses with relatively large condyles and a thick, squared-off patella was found, which

contributed to the restricted range of motion. Five knees had ankylosis. The soft tissue capsule was restrictive over the large condyle. To optimize range of motion, the excessive anteroposterior diameter of the femoral condyles was reduced by generous bone resection while maintaining the posterior condylar aspect. Anterior femoral bone was removed without notching the metaphysis, and excess posterior bone was resected by choosing the next smaller femoral component when possible. The posterior cruciate ligament could not be made isometric in a reliable manner because of the unusual shape and size of the condyles and because of the flexion and valgus deformities encountered, so it was resected and posterior stabilized implants were used. Flexion and valgus deformities were managed with posterior and lateral soft tissue releases. Lower limb alignment often was difficult to achieve because of concomitant hip and hindfoot deformity. Patellar resurfacing was performed in 15 of 22 knees (Table 2) either to address articular surface damage and poor articulation with the femoral component or to reduce the anteroposterior diameter of the patella and promote flexion. All implants used since 1992 were cemented. Implants included Osteonics<sup>®</sup> (12 knees; Stryker Orthopaedics, Mahwah, NJ), PFC<sup>®</sup>

(four knees; DePuy Orthopaedics, Inc, a Johnson and Johnson company, Warsaw, IN), Miller-Galante<sup>®</sup> I (one knee) and II (three knees) (Zimmer, Inc, Warsaw, IN), and Howmedica PCA<sup>®</sup> (two knees; Stryker Orthopaedics) (Table 2). Substantial soft tissue releases sometimes were necessary, and we addressed soft tissue and bone causes of tightness in the knee to promote range of motion. We used prosthesis systems that included small components when operating on smaller patients.

Patients were asked to return for followup and were evaluated retrospectively by one independent observer (BMJ).

Patient data gathered included patient demographics with age, gender, education level, and employment status, and mode of JRA onset (systemic, polyarticular, pauciarticular) and number of other joints involved. Intraoperative data from the operative record included the prosthesis type, the type of fixation used, soft tissue releases performed, and intraoperative complications. An independent observer (BMJ) interviewed patients and performed a clinical examination at followup. Preoperative pain and stiffness were estimated with a visual analog scale (VAS) by patient recall. Postoperative data included pain and stiffness at

**Table 2.** Cemented and uncemented prostheses used for TKA

Patient number	Joint side	Femoral component	Patellar resurfacing	Patellar component	Tibial component	Prosthesis*
2	Right	Cemented	No	NA	Cemented	PFC
2	Left	Cemented	No	NA	Cemented	PFC
3	Right	Cemented	No	NA	Cemented	Miller-Galante II
5	Right	Uncemented	Yes	Cemented	Cemented	Howmedica PCA
7	Right	Cemented	Yes	Cemented	Cemented	Osteonics
7	Left	Cemented	Yes	Cemented	Cemented	Osteonics
13	Right	Uncemented	No	NA	Cemented	Osteonics
16	Right	Uncemented	No	NA	Uncemented	Miller-Galante II
16	Left	Cemented	Yes	Cemented	Cemented	PFC
21	Left	Uncemented	Yes	Cemented	Cemented	PFC
24	Right	Cemented	Yes	Cemented	Cemented	Osteonics
27	Right	Uncemented	Yes	Uncemented	Uncemented	Miller-Galante I
27	Left	Uncemented	Yes	Cemented	Cemented	Miller-Galante II
28	Left	Cemented	No	NA	Cemented	Osteonics
28	Right	Cemented	Yes	Cemented	Cemented	Osteonics
29	Left	Cemented	Yes	Cemented	Cemented	Osteonics
29	Right	Cemented	Yes	Cemented	Cemented	Osteonics
32	Left	Cemented	No	NA	Cemented	Osteonics
33	Left	Cemented	Yes	Cemented	Cemented	Osteonics
33	Right	Uncemented	Yes	Uncemented	Uncemented	Howmedica PCA
34	Left	Cemented	Yes	Cemented	Cemented	Osteonics
34	Right	Cemented	Yes	Cemented	Cemented	Osteonics

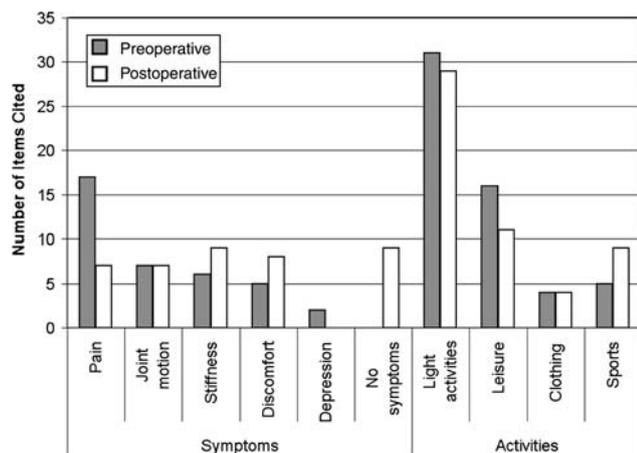
\* Prostheses included Osteonics<sup>®</sup> (Stryker Orthopaedics, Mahwah, NJ), PFC<sup>®</sup> (DePuy Orthopaedics, Inc, a Johnson and Johnson company, Warsaw, IN), Miller-Galante<sup>®</sup> I and II (Zimmer, Inc, Warsaw, IN), and Howmedica PCA<sup>®</sup> (Stryker Orthopaedics); NA = not applicable.

followup, postoperative range of motion, and late complications. Objective outcomes were assessed with the Hospital for Special Surgery (HSS) knee score [14] and range of motion of the knees.

Each participant completed a questionnaire, which included the SF-36 Health Survey [34, 35], the EuroQol in five dimensions (EQ-5D) [5, 9], the Meaning of Illness Questionnaire—Self Report [6, 36], and the WOMAC Osteoarthritis Index (Version 3) [3] to evaluate the patients' subjective outcomes, and the five patient-generated items from the PASI-pg [39], which included two symptoms and three activities, each scored separately [16]. The PASI-pg questionnaire asks open-ended questions for patients to identify and rate any two symptoms and any three activities. Additionally, patients were asked to recall issues that led them to have TKA, and a recall PASI-pg was completed at followup describing preoperative issues of importance to the participants. To evaluate patient satisfaction with the surgery, the questionnaire (Appendix 1) also included items from the Group Health Association of America Consumer Satisfaction Survey adapted for knee pain [31] and the Patient-Doctor Interaction Scale [30].

We (ERB, BMJ) assessed anteroposterior and lateral radiographs of the surgically treated joint(s) with the Knee Society radiographic evaluation form [10] and the Aglietti index for patellar height [1]. Interobserver correlation coefficients were computed for the radiographic analysis (femoral or tibial subsidence, radiolucent lines, overhang, or undersizing) and a mean agreement of 91% with a mean  $\kappa$  value of 0.73 (substantial agreement) were obtained.

Descriptive analyses were completed on demographic information and clinical and radiographic outcomes.



**Fig. 1** A comparison is shown of symptoms and activities most frequently identified by patients with JRA in the patient-generated PASI-pg ( $n = 20$ ) after TKA (Postoperative) and in recall of preoperative issues (Preoperative). Issues were coded into general categories using the headings of the International Classification of Functioning, Disability and Health [37].

Quality of life at followup was measured with the SF-36, EQ-5D, WOMAC, Knee Society score, and PASI-pg scores. WOMAC scores and subscores for pain, stiffness, and function of the patients with JRA were normalized on a scale ranging from 0 to 100. We used the Wilcoxon signed rank test at the  $\alpha = 0.05$  level of significance to compare SF-36 scores of the study population with the normal population of the same age [13, 34, 35]. The PASI-pg patient-generated items were coded into general categories according to the headings of the International Classification of Functioning, Disability and Health [37]. We used ranked statistics to determine the items identified most frequently by patients in the symptoms area of the score and in the activities area of the score; the ranked statistics were used to reduce dependence on absolute numeric scores, which may not have a common meaning in patient-specific measures such as the PASI-pg [16].

## Results

The PASI-pg questionnaire identified changes in items generated by patients with JRA after TKA when compared with preoperative items generated by patient recall, indicating an improvement in quality of life (Fig. 1). The patients identified six symptom areas, including pain, joint motion, stiffness, discomfort, depression, and no reported symptoms, and four activity areas, including light household, leisure, clothing, and sports, as important and relevant to their lives. The issues most frequently cited by the patients when recalling their preoperative status differed from those raised by the patients at postoperative evaluation, showing a shift away from pain and toward greater activity. Pain was selected by 19 of 22 patients with JRA in their recall of preoperative salient issues compared with only eight at followup. Although no patients reported having no symptoms before surgery, nine of 22 reported having no symptoms at followup. Furthermore, the ability to perform sports was selected as important by only five of 22 patients preoperatively but by nine patients at followup, reflecting a shift in the level of activity that could be considered by the patients and representing a clinically important change in quality of life.

Patients' reported satisfaction with the surgical outcome was high. Regarding the knee, 20 of 22 reported their pain at a level permitting daily activities, and all patients were satisfied with pain relief. Eighteen of 22 rated themselves as satisfied by knee surgery, and 12 to 20 patients were satisfied with their ability to perform heavy activities of daily living (Table 3). Overall, 16 of 22 patients said their needs were addressed.

We identified radiolucent lines greater than 2 mm for six knees (Table 4). The tibial components were generally

**Table 3.** Satisfaction of patients with pain relief and activities of daily living at a mean followup of 8 years (n = 22 knees)

Item/Activity	Completely satisfied/satisfied	Neither satisfied nor dissatisfied	Dissatisfied
Pain relief	22 (100%)		
Ability to perform light activities such as housework	20 (91%)	2 (9%)	
Ability to perform heavy activities such as gardening or lifting	12 (55%)	2 (9%)	7 (32%)
Comfort in walking	19 (86%)	3 (14%)	
Balance or steadiness on their feet	17 (77%)	4 (18%)	1 (5%)
Ability to perform self-care activities such as bathing and dressing	14 (64%)	4 (18%)	4 (18%)
Ability to participate in recreational activities	13 (59%)	3 (14%)	5 (23%)
Overall, needs were addressed	16 (73%)	6 (27%)	

appropriately sized (Table 5). The mean patellar thickness was 16.48 mm (range, 9–23 mm) and the height was 0.49 mm (range, 0.08–0.87 mm). No patient had symptoms suggestive of component loosening. The postoperative mean flexion was 77° (range, 30°–130°). Four knees had flexion contractures at final followup (5°, 10°, 20°, 30°, respectively). Patients indicated their pain and stiffness at followup was low to moderate (Table 6). One patient had a very stiff knee associated with a very limited range of motion. That patient underwent arthroscopy and manipulation 3 weeks postoperatively. No patients had revisions or were scheduled for revision at the time of followup.

At followup, the HSS knee scores (Table 6) indicated excellent results for nine of 22 patients with JRA, good for nine, fair for three, and poor for one. Followup SF-36 scores for patients with JRA were low with a physical component summary of 32.09 (standard deviation [SD], 9.73) and mental component summary of 48.37 (SD, 12.62) (Fig. 2). Followup EQ-5D scores for patients with JRA were low on the range of possible scores (Table 6), and Level 2 and Level 3 EQ-5D scores, indicating a moderate or extreme problem, respectively, were found in 18 of 22 patients with JRA for mobility, self-care, and usual activities. The patients also had relatively low WOMAC scores at followup (Table 6), with a mean of 66.

**Table 4.** Radiolucent lines and radiographic subsidence at final followup (n = 22 knees)

Radiolucent lines/Radiographic subsidence	No	Yes	Zone						
			1	2	3	4	5	6	7
Radiolucent lines (> 2 mm)									
Femoral	21 (95%)	1 (5%)	1	0	0	0	0	0	0
Tibial (mediolateral)	21 (95%)	1 (5%)	1	0	0	0	0	0	0
Tibial (anteroposterior)	17 (77%)	5 (23%)	4	1	0				
Patellar	21 (95%)	1 (5%)	1	0	0				
Radiographic subsidence (> 3 mm) (for all 3 components)	22 (100%)								

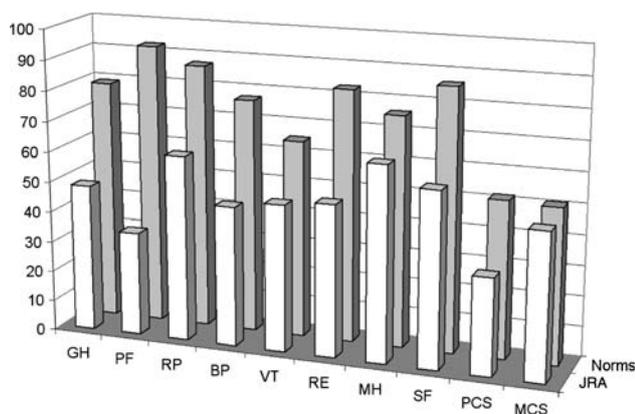
**Table 5.** Radiographic observations of tibia at final followup (n = 22 knees)

Radiographic observation	Finding absent	Finding present	< 2 mm	2–5 mm	> 5 mm
Tibia					
Lateral overhang	19 (86%)	3 (14%)	1	1	1
Medial overhang	19 (86%)	3 (14%)	1	2	0
Lateral undersize	16 (73%)	6 (27%)	3	3	0
Medial undersize	17 (77%)	5 (23%)	2	3	0

**Table 6.** Outcome measures for patients with juvenile rheumatoid arthritis at followup

Outcome measure	Mean score (SD)	Range	Possible range
VAS pain	1.95 (2.33)	0–7	0 (none)–10 (severe)
VAS stiffness	3.31 (3.04)	0–8	0 (none)–10 (severe)
<b>HSS</b>			
Knee score	81	50–95	0 (poor)–100 (excellent)
Pain subscore	29	25–30	10 (severe)–50 (none)
Function subscore	54	26–73	0 (poor)–100 (excellent)
<b>EQ-5D</b>			
Health state score	0.52 (0.23)	0.02–0.74	0 (poor)–1.0 (excellent)
VAS score	73 (15)	40–95	0 (poor)–100 (excellent)
<b>WOMAC</b>			
Total score	66	31–96	0 (poor)–100 (excellent)
Pain subscore	80	30–100	0 (poor)–100 (excellent)
Stiffness subscore	72	38–100	0 (poor)–100 (excellent)
Physical function	61	29–96	0 (poor)–100 (excellent)
<b>Meaning of Illness Questionnaire</b>			
Factor 1 (impact)	2.6 (1.4)	0–4	0 (high)–6 (low)
Factor 2 (stress and attitude of harm)	1.3 (1.1)	0–4	0 (high)–6 (none)
Factor 3 (degree of stress and change in commitments)	3.0 (1.4)	0–5.2	0 (negative)–6 (positive)
Factor 4 (challenge, positive attitude, motivation, and hope)	4.1 (1.0)	2.8–5.6	0 (poor)–6 (hopeful)

SD = standard deviation; VAS = visual analog scale; HSS = Hospital for Special Surgery; EQ-5D = EuroQoL in five dimensions.



**Fig. 2** SF-36 scores for patients with JRA at followup were compared with the population norms for people 25 to 34 years old [13, 34, 35]. GH = global health,  $p = 0.0019$ ; PF = physical functioning,  $p = 0.0014$ ; RP = growth physical,  $p = 0.0014$ ; BP = bodily pain,  $p = 0.0029$ ; VT = vitality,  $p = 0.0125$ ; MH = mental health,  $p = 0.15$ ; SF = social functioning,  $p = 0.0086$ ; PCS = physical component summary score,  $p = 0.0014$ ; MCS = mental component summary score,  $p = 0.15$ .

## Discussion

We asked what the issues of importance were to adult patients with JRA before and after TKA, as determined by a patient-specific index, the PASI-pg, and whether patients

were satisfied with the surgery. We also asked what their postoperative status was, as evaluated radiographically, clinically, and by standardized outcome measures that are widely used in evaluation of TKA.

Limitations of the study include the assessment of preoperative scores by patient recall, with Level IV evidence and deficient statistical power. Recall can be affected by current patient status and the perceived need to justify having had the surgery. Recall of pain is controversial. In a prospective study evaluating the accuracy of postoperative recall of preoperative pain related to endometriosis, Redwine [27] reported accurate recall; 6 to 18 months after surgery, more than 80% of patients recalled their preoperative pain level within 1 point on a 5-point scale for 10 of 11 symptoms. Patients who did not undergo reoperation tended to slightly inflate their postoperative assessment of preoperative pain. In knee and hip arthroplasties, a tendency to retrospectively exaggerate preoperative pain has been noted [17, 20]. In a study by Mancuso and Charlson [20], patients who completed a Hip Rating Questionnaire before and several years after THA tended to recall more pain, better walking, and better function than they reported before surgery. In our study, although our pain evaluation at final outcome is likely valid, it is likely that the recall evaluation of preoperative pain is somewhat greater than would have been obtained preoperatively, and thus the very large differential in preoperative and postoperative pain

may be somewhat higher than would have been recorded if a prospective assessment had been available. In contrast, our data regarding differences in function likely underestimate the actual improvement observed. This study addresses deficiencies in applying standard outcome measures to this patient group. We show that standard outcome measures do not capture issues of importance to the patient with JRA after TKA. Therefore, we offer a different category of outcome measure, ie, patient-generated outcomes, in addition to standard outcomes, to capture issues of importance. The condition is sufficiently uncommon that no published randomized prospective trials of TKA in patients with JRA exist.

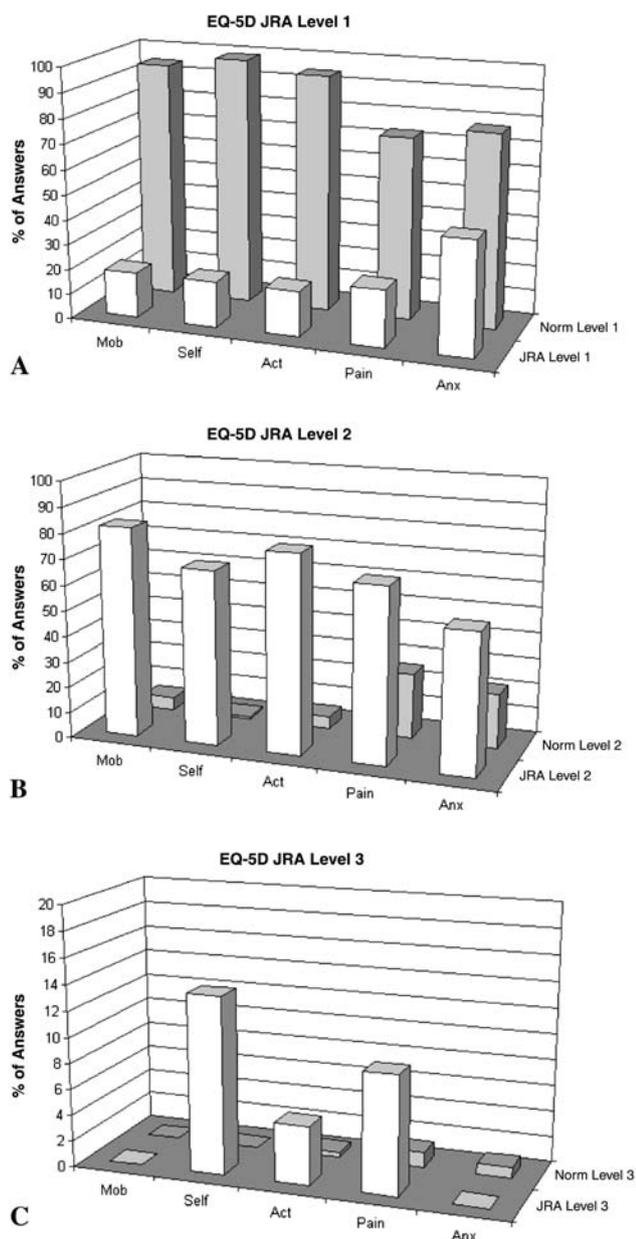
The PASI-pg questionnaire we used suggested symptoms and activities selected by patients shifted in frequency of selection between preoperative and final assessments. Pain was selected as a key issue preoperatively by 19 of 22 patients with JRA, as compared with eight patients at followup. The ability to perform heavier activities such as sports was selected as a key issue by five of 22 patients preoperatively, shifting to nine of 22 at followup, reflecting a shift in the level of activity that would be considered by the patients. We interpret the shift in issues reported by the patients to be indicative of clinical improvement. These issues, which were identified by the patients, were not captured in any other standardized instruments we used.

The majority of patients (18 of 22) were satisfied with the outcome of their surgery, although they had a high mean impact factor score and severe mean stress and attitude of harm score as evaluated by the Meaning of Illness Questionnaire (Table 6). Benefits of TKA in patients with JRA have been documented [4, 7, 8, 26, 29], but our study quantifies satisfaction and quality of life after TKA in different domains of daily life. Palmer et al. [23] reported on eight patients undergoing TKA with a mean followup of 15.5 years, and three of 15 TKAs were rated as unsuccessful. Parvizi et al. [24] reported on 13 patients undergoing TKA with a mean followup of 10.7 years, and Thomas et al. [33] reported on 10 patients undergoing TKA with a mean followup of 6 years, but these studies did not comment on patient satisfaction. Lybäck et al. [18] reported an overall “subjective contentment” of 75% of the patients. In our study, after surgery, all patients rated themselves as satisfied with pain relief, but satisfaction ratings were much lower for self-care activities (bathing and dressing), heavy activities (gardening, lifting), and recreational activities. The differential in preoperative and postoperative VAS pain scores, even if more modest than measured by recall evaluation, is indicative of how important pain is to these patients and their satisfaction with the surgery.

Our data showed a postoperative mean knee flexion arc of 73° (range, 20°–120°), with four knees having a flexion

contracture after surgery (mean, 16°). Other authors have reported an improvement in range of motion. Boublik et al. [4] reported a mean flexion arc improvement of 26°, with a mean postoperative flexion arc of 103° (range, 65°–135°); Carmichael and Chaplin [8] reported a mean postoperative flexion arc of 73° (range, 15°–120°), with a mean residual flexion contracture of 17°; Thomas et al. [33] reported a mean flexion arc improvement of 33°, with a mean residual flexion contracture of 7°; and Palmer et al. [23] reported a 43° increase in mean arc of motion (range, 36°–79°). However, Parvizi et al. [24] reported TKA did not increase range of motion in a series of 15 patients younger than 20 years who underwent TKA, and Stuart and Rand [32] reported a modest decrease in knee flexion after TKA in 26 patients (44 knees) younger than 40 years. The range of motion reported in patients with JRA would be considered unsatisfactory for patients with osteoarthritis. However, it appears acceptable to patients with JRA based on their satisfaction report. The improvement in subjective pain scores cannot be directly compared with reported scores because only qualitative descriptions of pain have been published. Boublik et al. [4] stated “dramatic” pain relief was the “single most important contributor to the improved knee score.” Subjective stiffness was cited as one of the three major preoperative symptoms by almost ½ of the patients with JRA in our PASI-pg, but we found no references in the literature for comparison.

Outcome scores for these patients with JRA were lower than those reported for patients with osteoarthritis using standardized measures. Followup SF-36 scores for patients with JRA were considerably worse in all domains compared with the reference 25- to 34-year-old population norm [13, 34, 35], with the exception of the mental health domain (Fig. 2). Patients with JRA had EQ-5D scores that were moderately lower than the reference value of 83 for the population norms for people 30 to 39 years old (SD, 10) [15] (Fig. 3), and 82% of patients with JRA had Level 2 or 3 scores for mobility and self-care (indicating moderate or extreme problems) compared with less than 5% of the normal population [15]. Patients with JRA also had lower WOMAC global scores at followup (66) than patients with osteoarthritis 6 months after TKA (77), despite the fact they had similar pain and stiffness subscores [19]. The principal difference was in the physical function subscore, which includes some general daily activities, such as climbing stairs, going shopping, and heavy domestic duties. It is likely this subscore was low in patients with JRA because of the involvement of other joints of the lower or upper limbs. In addition, our HSS knee score results were considerably inferior to the 90% excellent results reported for posterior-stabilized primary



**Fig. 3A–C** EQ-5D scores for patients with JRA at followup were compared with the population norms for people 30 to 39 years old [15]: (A) Level 1, indicating no problem; (B) Level 2, indicating some problem; and (C) Level 3, indicating an extreme problem. Mob = mobility; Self = self-care; Act = usual activities; Pain = pain/discomfort; Anx = anxiety/depression.

TKA in 137 consecutive cases in a general orthopaedic population [11]. Nevertheless, TKA in this group of patients with advanced JRA provided worthwhile patient-reported benefits, notwithstanding limited postoperative function as determined by traditional outcome measures.

The SF-36, EQ-5D, WOMAC, and HSS scores did not reflect what these profoundly disabled patients identified as positive outcomes. This is expected, because severely affected patients with JRA often have associated polyarticular upper and lower limb joint involvement and lifelong soft tissue contractures that impact their scores. Neer et al. [21] referred to the difficulty of evaluating the outcome of an operation in a polyarticular condition (referring to rheumatoid arthritis) stating, “the use of the term unsatisfactory in the rigid clinical rating system does not depict the true value of the procedure.” Because patients generally reported satisfaction despite results in the poor range on generally accepted objective outcome instruments, the question of how to evaluate the impact of an intervention in one joint in a patient with severe multiple joint involvement is problematic. A patient-specific index [28, 39] may better reflect a patient’s perception of quality of life and should describe the effect of a condition on those aspects of life considered by the patient of greatest importance [16, 28], thereby providing a useful additional measure of outcome in certain patient groups, such as severely disabled patients with JRA.

A midterm review of TKA in this uncommon and severely affected group of patients showed a quality of life and ability to perform activities of living acceptable to our patients, and satisfactory pain levels. The PASI-pg captured issues missed by standardized instruments currently in wide use, indicating patients with JRA who have severe polyarticular involvement highly value TKA despite poor results on standard outcome measures. Surgeons treating this group of patients need not be discouraged, in setting indications for TKA, by low postoperative scores in commonly used outcome measures.

**Acknowledgments** We thank Dagmar Gross for assistance in the preparation of the manuscript.

**Appendix 1. Questionnaire, including Satisfaction Questions**

***JRA***  
***TOTAL KNEE REPLACEMENTS***  
***REVIEW***

*Inclusion criteria:*

JRA diagnosis (systemic, polyarticular, or pauciarticular)

THA or TKA surgery 5 years ago or more

Signature of a consent form

- Thank you for participating in our study. This study is doing a detailed description of the level of function and the outcomes of surgery 5 years or more after your hip surgery. Most of the questions deal with how you are functioning and dealing with the outcome of your surgery.
- Your responses are important to the success of this study. We thank you for taking the time to answer these questions.

*This section asks some general information about you:*

D1. What are the first three letters of your postal code: \_\_\_ \_\_\_ \_\_\_

D2. Please indicate your birthdate (DD-MM-YYYY)? \_\_\_ / \_\_\_ / 19\_\_

D3. What is your gender? (*Please check one*)

- Female [F]  
 Male [M]

D4. Please indicate your current marital status: (*Please check one box only*)

- Single/ Widowed [1]       Married [2]       Common Law/ Living with someone [3]       Separated [4]       Divorced [5]       [6]

a. How many people live in your household?

- 1       2       3       4       5       >5

D5. What language is spoken at home? (*Please check all that apply to you*)

- English [E]  
 French [F]  
 Other: \_\_\_\_\_

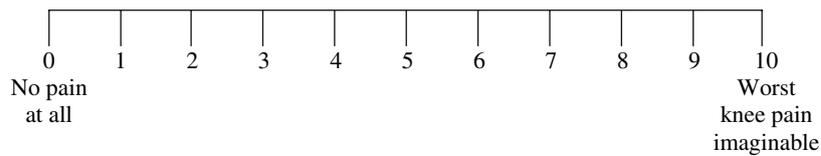
[0]

- D6. What is the highest level of education that you received? *(Please check one box only)*
- Primary/Elementary school (e.g., completed, or did some elementary school) [P]
  - Secondary/High school or equivalent (e.g., graduated from high school) [S]
  - Post Secondary or equivalent (e.g., graduated from College or University) [U]
  - Other: \_\_\_\_\_ [O]
  - Unsure [X]
- D7. Have you filed for workers' compensation (WSIB/WCB) related to your disease?
- Yes, I have filed for a WSIB/WCB claim, received it in the past, but I am not receiving compensation now. [1]
  - Yes, I have filed for a claim and I am currently receiving compensation. [2]
  - Yes, I have filed a claim and am waiting for it to be processed/accepted. [3]
  - No. [4]
- D8. Are you currently working full or part-time for pay or profit?
- Full-time [F]                       Part-time [P]                       Not working [N]
- D9. If working, please indicate your present occupation: \_\_\_\_\_
- D10. How many hours, on average do you work each week: \_\_\_\_\_ hours [WH]
- D11. What is your height? \_\_\_\_ feet \_\_\_\_ inches OR \_\_\_\_ metres [HF/HM]
- D12. What is your weight? \_\_\_\_\_ pounds OR \_\_\_\_ kilograms [WP/WK]

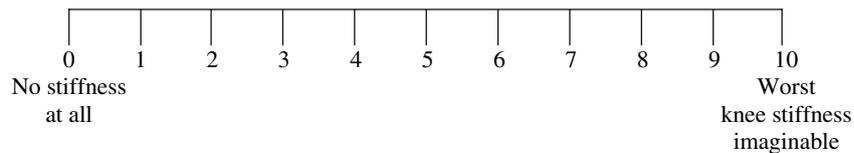
***This section asks about your current symptoms or function***

- S1. Is your knee joint at a level now where you can ignore or cope with it and do whatever it is you need to do in your daily life *(check one box)*
- Yes, I can cope with my knee problem at this level [1]
  - No, my knee problem is not at a level where I can cope with it [2]
- S2. Which statement best describes you right now *(check one box)*
- I am better with no symptoms or residual effects of my affected knee joint [1]
  - I am better and have some residual effects, but I have figured out ways to avoid them [2]
  - I am better and have some residual effects, but I can cope/live with them [3]
  - I am not better at this point in time [4]

VAS1. How would you rate the intensity of your knee pain over the last week? *(Please draw a mark on the scale)*



VAS2. How much stiffness in your hip did you have over the last week? *(Please draw a mark on the scale)*



***This section asks about your satisfaction of the results of your knee surgery***

S3. How satisfied are you with the results of your operation for your knee (*check one box*)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very satisfied	Somewhat satisfied	Somewhat dissatisfied	Very dissatisfied
[1]	[2]	[3]	[4]

S4-9. How satisfied are you with the results of your knee surgery in terms of (*check one box for each statement*)

	Very satisfied [1]	Somewhat satisfied [2]	Somewhat dissatisfied [3]	Very dissatisfied [4]
Pain relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being able to do light activities such as housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being able to do heavy activities such as heavy yard work or lifting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being able to walk comfortably	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balance or steadiness on your feet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>[GHAACSS III]</b>				
Being able to do self-care activities such as bathing and dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being able to do recreational activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

S10. My needs were addressed (*check one box*)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
[1]	[2]	[3]	[4]	[5]

**[PDIS]**

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