Rheumatology Advances in Practice, 2023, **8(1)**, rkad111
https://doi.org/10.1093/rap/rkad111
Advance access publication 13 December 2023
Original Article

British Society for Rheumatology
RHEUMATOLOGY ADVANCES IN PRACTICE
OXFORD

Clinical science

Exploration of adverse consequences of total knee arthroplasty by patients and knee specialists: a qualitative study

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Abstract

Objectives: A successful outcome according to the knee specialist is not a guarantee for treatment success as perceived by patients. In this study, we aimed to explore outcome expectations and experiences of patients with OA before and after total knee arthroplasty (TKA) surgery and knee specialists that might contribute to the negative appraisal of its effect, and differences in views between patients and knee specialists.

Methods: Semi-structured interviews were held in Belgium and the Netherlands. Twenty-five patients (2 without indications for TKA, 11 on the waiting list for TKA and 12 postoperative TKA) and 15 knee specialists (9 orthopaedic surgeons, 1 physician assistant, 1 nurse practitioner and 4 physiotherapists) were interviewed. Conversations were audio recorded, transcribed verbatim, and analysed using thematic analysis following the grounded theory approach. Separate analyses were conducted for patients and knee specialists.

Results: Patients were focused on the arduous process of getting used to the prosthesis, lingering pain, awareness of the artificial knee and limitations they experience during valued and daily activities, whereas knee specialists put emphasis on surgical failure, unexplained pain, limited walking ability and impairments that limit the physical functioning of patients.

Conclusion: This study provides a comprehensive overview of potential adverse consequences from the perspective of both patients and knee specialists. Improving patients' awareness and expectations of adaptation to the knee prosthesis needs to be considered.

Lay Summary

What does this mean for patients?
Many people with serious complaints owing to knee osteoarthritis benefit from knee replacement surgery. This is not the case for ∼20% of these people. 'No benefit' or 'not happy' can mean too much pain, not being able to bend the knee, limited walking ability or a rehabilitation that takes too long. There are many different opinions, and the view of the orthopaedic surgeon can be different from that of the patient. We interviewed patients and knee specialists on the negative consequences of a knee replacement surgery and described whether these views differed. We found that patients were more focused on the difficult process of getting used to the prosthesis, lingering pain, awareness of the prosthetic knee and limitations they experience during valued and daily activities, whereas knee specialists were more focused on surgical failure (i.e. infections, prosthetic loosening), unexplained pain and impaired physical functioning. We concluded that the difficult process of adapting to the knee prosthesis should be discussed better with patients during preoperative consultation.

Keywords: total knee arthroplasty, poor outcome, qualitative study.

Key messages

- A comprehensive overview of adverse consequences after total knee arthroplasty is provided.
- Patient and physician perceptions of adverse consequences after total knee arthroplasty may differ.
- Patients need to be better prepared for difficulties in adaptation to the knee prosthesis.

Received: 17 July 2023. **Accepted:** 5 December 2023

Introduction

Total knee arthroplasty (TKA) is considered to be a successful and cost-effective intervention for treatment of advanced symptomatic OA [1]. However, despite improvement in knee pain and disability, 15–20% of the patients report being dissatisfied with their prosthetic knee owing to insufficient pain relief, loss of function and limitations in physical functioning [2–5]. To improve the dissatisfaction rate, a clear and valid definition of what a poor outcome after TKA entails is needed. Currently, various dichotomous definitions consisting of one or more outcome dimensions are used to quantify the proportion of patients with a poor response to TKA [6].

Importantly, the various current definitions for poor outcome reflect the perspective of physicians and researchers. Previous research shows that a successful outcome according to the physician is not a guarantee for treatment success as perceived by patients [3, 7, 8]. A definition of poor response that is supported by patients and physicians is crucial to allow benchmarking across (inter)national institutions for quality improvement and will facilitate improved (shared) decision making.

Recently, in a qualitative study using nominal group technique, patients identified refractory pain after total joint arthroplasty as more important than surgical failure (i.e. complications, revisions) [9]. However, group responses/themes about failure were ranked and prioritized by 42 postoperative patients from only one high-volume centre. That study did not provide insight into differences between the views of physicians and patients about TKA failure. Hence, the primary purpose of our multicentre, qualitative study was to explore outcome expectations and experiences of patients with OA and knee specialists [i.e. orthopaedic surgeons, physician assistants (PA), nurse practitioners (NP) and physiotherapists] after TKA surgery that might contribute to the negative appraisal of its effect. Our secondary aim was to explore whether these views differ between patients and knee specialists.

Methods

Study design and setting

A cross-sectional, multicentre qualitative study was performed using semi-structured interviews. To support our objective of exploring outcome expectations and experiences on adverse consequences of TKA, methods of a constructivist grounded theory approach [10] with thematic analysis [11] were applied. The interviews were held with OA patients and with health-care providers with expertise on knee replacement surgery and its rehabilitation. Ideally, patients and knee specialists from all over the world should have been interviewed, but given that interviews should be conducted in the native language, this study was limited to participants in the Netherlands and Belgium. Patients were recruited from one Belgian and two Dutch hospitals; knee specialists were recruited from various hospitals and physiotherapy practices in Belgium and the Netherlands. The Standards for Reporting of Qualitative Research checklist [12] was used to ensure complete and transparent reporting (Supplementary Table S1, available at *Rheumatology Advances in Practice* online).

Participants

Interviews with patients

Purposive sampling for patients was based on age, sex, patient subgroup, outcome experiences and recruiting hospital (Supplementary Table S2, available at *Rheumatology Advances in Practice* online). Three different patient subgroups were captured: subgroup 1, knee OA patients without surgical indication; subgroup 2, patients scheduled for TKA; and subgroup 3, patients 1–5 years after TKA. Patients in subgroup 1 were included because they might have different outcome expectations regarding a TKA procedure compared with patients scheduled for TKA. Regarding the latter subgroup, purposive sampling was directed towards achieving different outcome experiences (success/failure) and rehabilitation duration (1–5 years). An a priori decision was made to limit follow-up to 1–5 years, because outcomes of pain and physical functioning 1–5 years after TKA are reasonably stable [13–15]. Physicians working in the three recruiting hospitals were asked to invite eligible patients. Eligibility criteria for patient selection can be found in Table 1. Interviews with Dutch patients were held at their homes. Patients in Belgium were interviewed during individual online meetings as a consequence of the regulations during the coronavirus disease 2019 pandemic. Interviews were audio-recorded, and additional field notes were made during and after the interviews.

Table 1. Eligibility criteria by patient subgroup

Subgroup 1: patients with knee OA without surgical indication
• Patients with self-reported knee OA or knee pain (for >3 months)
• ≥18 years of age
• Dutch as native language
• No surgery for contralateral TKA
• No hearing or speech impairment
• Able and willing to participate and provide informed consent
Subgroup 2: patients with knee OA scheduled for TKA
• Patient with a clinical diagnosis of knee OA and scheduled for TKA in one of the three participating hospitals
• ≥18 years of age
• Dutch as native language
• No surgery for contralateral TKA
• No hearing or speech impairment
• Able and willing to participate and provide informed consent
• Dutch patients: living <50 km from one of the two participating hospitals
• Belgian patients: willing to be present at UZ Gent on the day of the interview
Subgroup 3: patients 1–5 years after TKA
• Patients with a primary TKA for 1–5 years
• Surgery performed in one of the three participating hospitals
• ≥18 years of age
• Dutch as native language
• No hearing or speech impairment
• Able and willing to participate and provide informed consent
• Dutch patients: living <50 km from one of the two participating hospitals
• Belgian patients: willing to be present at UZ Gent on the day of the interview

TKA: total knee arthroplasty.

Interviews with knee specialists

Purposive sampling for knee specialists was based on health profession and working environment (Supplementary Table S2, available at *Rheumatology Advances in Practice* online). Knee specialists were included as follows: orthopaedic surgeons, performing ≥30 primary TKA procedures a year; physiotherapists (specialized in knee rehabilitation) involved in the care of ≥10 TKA patients a year; and orthopaedic PAs and NPs (both in the Netherlands) with ≥50% of their patient contacts with TKA patients. Within the sample of knee specialists, we sought

variety in current working environment (university, general or specialized hospital and physiotherapy practice), working experience in TKA surgery and care. Orthopaedic knee specialists with Dutch as their native language, working in the Netherlands or in Belgium, were recruited through the research team. Participants were invited via email or telephone to participate and were also asked to nominate potential other knee specialists (snowball sampling) [16]. Knee specialists were interviewed face to face at their hospital office, physiotherapy practice or during a conference.

Data collection

An interview guide was developed based on a review of the literature on poor outcome after TKA and clinical expertise of the research team (Supplementary Table S3, available at *Rheumatology Advances in Practice* online) [6]. The questions had an open-ended format and were adapted to the specific subgroup of participants (Table 2). The interview guides were discussed with the patient research partners, then pilot-tested on one postoperative patient and one orthopaedic surgeon, leading to minor changes in the wording of interview guides. All interviews were conducted between May and November 2020 by one researcher (M.E.M.t.M., PhD candidate), who had formal interview training and had no pre-existing relationship with any of the participants. The interviewer had previous experience in working with TKA patients as a research nurse and as a researcher. Before the interviews started, participants were asked to fill out a short questionnaire to collect participant characteristics. A summary of the interview was sent to the interviewee after each interview as a member check to assure data validity. Two patients responded and confirmed that they recognized their experiences in the summaries.

Data collection ended after 25 patient interviews and 15 interviews with knee specialists, because data saturation had been reached (no new information emerged from the last two interviews).

Table 2. Main topics of patients' interview guide, with one example question and some probing questions

Topic	Example question
Outcome of TKA	What are important outcomes of TKA for you? • Why are these important outcomes for you? • Could you tell me more about this?
Expectations of the outcome	To what extent have your expectations regarding TKA outcome been fulfilled? • Why are these expectations not fulfilled? • How realistic were these expectations?
Less successful outcome	When do you consider the result of TKA less successful? • Why is the result less successful for you?
Unsuccessful outcome	When do you consider the result of TKA unsuccessful? • Why is the result unsuccessful for you? • What do you think is the worst-case scenario?
Dissatisfaction with the outcome	What would be reasons for you to be dissatisfied with your TKA? • Which factors play a role in this? • Could you explain to me?
Time point for outcome	What is for you the optimal time after surgery to assess the success of TKA? • How do you determine whether the prosthetic knee is not working for you? • Could you explain to me?

TKA: total knee arthroplasty.

Data analysis

Audio recordings were transcribed by a commercial third party (Secretaresse Hulp), anonymized, and checked for accuracy against the original audio recordings. Transcripts were analysed using Atlas.ti version 8.4.25 (Atlas.ti Scientific Software Development, GmbH Berlin, Germany). Data for patients and knee specialists were analysed separately. Following the grounded theory approach with thematic analysis, coding was performed in three steps: open, axial, and selective coding [10]. The first step started with reading and re-reading the transcripts for familiarization. Relevant fragments were selected in the interviews, and each fragment was given a label (open coding). Second, these open codes were categorized (axial coding). From these axial codes, the core themes were identified (selective coding). To support the coding process, field notes were made during the interviews. Data collection and data analysis were continuously alternating in a cyclic process. To enhance trustworthiness [17], the first three interviews in each group (patients and knee specialists) were coded independently by two researchers (J.E.V. and M.E.M.t.M.). The remaining interviews were coded by one researcher (M.E.M.t.M.). Throughout this process, three researchers (J.E.V., C.H.M.v.d. E. and M.E.M.t.M.) continuously and repetitively reflected on, compared, discussed, refined and adjusted the codes in order to determine the number and wording of themes carefully, in an iterative design. The identified themes were discussed thoroughly until consensus was reached in the research team (comprising a Dutch orthopaedic surgeon, a Belgian orthopaedic surgeon, a psychologist, a physiotherapist and a nurse). Finally, quotations were extracted that related to the subthemes. Quotations were translated into English in collaboration with a professional translator.

Ethics

This study was conducted in accordance with the ethical standards in the 1964 Declaration of Helsinki. The ethical Review Board of the Radboud University Medical Centre, Nijmegen in the Netherlands exempted the study (ref. no. 2019/5283) from ethical approval according to the Medical Research Involving Human Subjects Act. In Belgium, the institutional ethics committee of the Gent University Hospital granted approval (BC-07096). All participants gave informed consent.

Results

Participant characteristics

In Tables 3 and 4, respectively, the characteristics of the patient and knee specialist samples are shown. The duration of the interviews varied from 25 to 85 min [mean (S.D.): 51.2 (11.8) min] in patients and from 25 to 59 min [mean (S.D.): 44.7 (8.7) min] in knee specialists.

Table 3. Characteristics and clinical details of Dutch and Belgian patients

Characteristics	The Netherlands	Belgium
Interviews, *n*	18	7
Subgroup, *n*		
Patients with knee OA without surgical indication	2	NA
Patients with knee OA scheduled for TKA	8	3
Patients 1–5 years after TKA	8	4
Age in years, median (25th–75th percentile)	64 (62–69)	61 (57–66)
Woman, *n*	12	4
Level of education[a], *n*		
Primary and secondary	10	6
Tertiary	8	1
Currently employed, *n*	4	0
General health score[b], median (25th–75th percentile)	47 (29–53)	43 (34–52)
Pain[c], median (25th—75th percentile)	38 (26–53)	36 (27–46)
Physical functioning[d], median (25th–75th percentile)	55 (39–60)	54 (38–62)

[a] Primary: primary education; secondary: lower secondary education, upper secondary education; tertiary: short-cycle tertiary education, bachelor's or equivalent, master's or equivalent.
[b] Position marked on visual analogue scale (100 mm) from best health (left side: 0/100) to worst health (right side: 100/100).
[c] Position marked on visual analogue scale (100 mm) from no pain (left side: 0/100) to worst pain (right side: 100/100).
[d] Position marked on visual analogue scale (100 mm) from no problem (left side: 0/100) to much difficulty (right side: 100/100).
TKA: total knee arthroplasty.

Table 4. Characteristics and working experience of Dutch and Belgian knee specialists

Characteristics	The Netherlands	Belgium
Interviews, *n*	12	3
Orthopedic surgeon, *n*	6	3
General hospital	3	2
Specialized hospital	2	NA
University hospital	1	1
Physician assistant/nurse practitioner, *n*	2	NA
General hospital	2	–
Physiotherapist, *n*	4	NA
General hospital	1	–
Physiotherapy practice	3	–
Experience in TKA surgery, treatment and/or rehabilitation, median (25th–75th percentile), years	10 (7–12)	16 (14–22)
Number of performed primary TKA surgeries per year, median (25th–75th percentile)	100 (24–185)	100 (65–100)

TKA: total knee arthroplasty.

Main results

Four themes and 15 subthemes were identified (Table 5). Each theme is described in detail below, separately for both groups of participants. In Table 6, quotations from patients and knee specialists are displayed for each subtheme.

Lingering pain

Negative outcome expectations for preoperative patients were no improvement in pain throughout the day and night and pain that limits patients in resuming valued activities. Postoperative patients reported that the typical preoperative OA pain had disappeared postoperatively, but some patients reported that it had been replaced by a new, different type of pain. Most patients experienced this new type of pain during the first postoperative period (6–8 weeks); some of them had a lot of pain or a burning sensation in the knee and could not sleep at night, whereas others described the pain as muscle ache or nagging pain. Some patients did not obtain adequate pain relief because they discontinued taking pain medication owing to side effects (e.g. nausea or vomiting), whereas other patients preferred not to use any pain medication other than paracetamol. Up to a year, a number of patients experienced pain flares during and/or after physical activity, such as climbing stairs, walking long distances (e.g. 1 h) and during and/or after more strenuous exercise, such as hiking in the mountains or sports (e.g. golf, fitness). Patients described these pain flares as an irritating or cramping sensation and interpreted this as a signal to take a rest for the remainder of the day.

Knee specialists reported that they have concerns when patients continue to have a lot of pain, beyond an acceptable level for the patients, or when the cause of pain remains elusive. These patients are seen more often at the outpatient clinic and sometimes receive additional treatment (i.e. additional follow-up consultations or guidance from the pain specialist). Knee specialists sometimes felt that nothing could be done for the patients.

Stagnating mobility

Most negative outcome expectations and experiences of both pre- and postoperative patients were focused on limitations during physical functioning and in resuming valued activities. In addition, preoperative patients mentioned a decline in walking ability and continued reliance on a cane, crutch or walker as negative outcome expectations. Postoperative patients described poor function of the knee in terms of a tight feeling in the knee, a feeling of knee stiffness and an unreliable knee. They felt hampered in their mobility and, consequently, in their activities of daily living and leisure activities, such as climbing stairs, walking long distances, gardening, cycling, playing tennis or shopping. Patients indicated the inability to resume valued activities in and around the house as an adverse consequence of TKA. Some patients found it disappointing that they could not return to an active lifestyle.

Negative outcomes for knee specialists were non-fulfilling conditions that hamper patients in their mobility. Knee specialists considered an extension or flexion limitation, (mid-flexion) instability or stiffness of the knee as a negative outcome, particularly when an extension limitation affected the ability of a patient to walk and made walking tiresome. In patients with stiffness within 3 months post-TKA, the patient's knee needs to be manipulated under anaesthesia with the purpose of regaining a full range of motion. In addition, knee specialists and especially physiotherapists were concerned when patients remained limited in their walking ability; that is when they were not able to walk independently for a short distance or when they were not able to walk without pain or discomfort.

Complications and revision surgery

Some patients experienced surgical complications, such as a swollen knee, a chronic inflammation of the knee, thrombosis, stiffness of the knee or a prosthesis infection that resulted

Table 5. Themes and subthemes identified in thematic analysis

Theme	Subtheme	Apply to
Lingering pain	Pain during the first postoperative period	Patients
	Pain medication to ease the pain	Patients
	Pain flares during and/or after physical activity	Patients
	Continued unacceptable pain to the patient	Knee specialists
Stagnating mobility	Limitations in physical activities	Patients
	Not fulfilling conditions for mobility	Knee specialists
	Limited walking ability	Knee specialists
Complications and revision surgery	Revision surgery	Patients and knee specialists
	Complications	Patients and knee specialists
	Surgical technical limitations	Knee specialists
Getting used to the prosthetic knee	Disappointing first postoperative period	Patients
	Movement anxiety	Patients
	Lingering pain creates uncertainty	Patients
	Unhelpful thoughts	Patients
	Awareness of the prosthesis	Patients

in a negative experience after TKA. Some of the study patients experienced a manipulation under anaesthesia or revision surgery (i.e. debridement, antibiotics and implant retention) because of infection.

Knee specialists mentioned several complications that might contribute to a negative experience for patients: swollen knee, reactive knee (redness, swelling, heat), deep venous thrombosis, wound-healing disorders, vascular injury, severe stiffness, aseptic loosening, infection and malrotation of the prosthesis. Early revision surgery is a clear indication of poor response to TKA according to knee specialists.

In addition, orthopaedic surgeons mentioned surgical technical shortcomings, such as malposition, loosening of the prosthesis, malalignment and mechanical failures, contributing to a negative experience for the orthopaedic surgeon.

Getting used to the prosthetic knee

For most patients, the first postoperative period was hard, exhausting, disappointing and sometimes with emotional impact owing to unexpected pain, surgical complications, medication side effects and being dependent on help from other people. Patients worried whether their pain was normal and comparable to other patients and whether the knee was recovering properly. Some patients who experienced a difficult recovery after the first postoperative period and the ones with pain persisting after 6–9 months experienced uncertainty on several domains; some experienced movement anxiety. They worried about the future, slept poorly and were distressed. Patients had struggles with adjusting to their prosthetic knee in daily life. One patient took early retirement, whereas others were able to return to work but later than initially planned and/or with temporary adjustments. Adaptations (in duration, frequency, bracing and other support measurements) related to movement and sport were mentioned, or more generally, accepting that not everything is possible with the prosthetic knee and adjusting their level of activity. Some patients struggled with unhelpful thoughts that limited their motivation to practise physiotherapy exercises and their hope that the knee would become better. Other patients were eager to engage in different tasks despite their pain and limited knee function and refused to be affected negatively by their prosthetic knee. More in general, several patients mentioned that being aware of the prosthesis all the time was an unexpected, unpleasant experience. Preoperative patients expected to be recovered within 3–6 months, whereas most postoperative patients indicated that they were recovered in 6–7 months, but for some it took longer. Two patients indicated that they had recovered fully only after 2 years. Knee specialists indicated that patients should take into account a rehabilitation duration of 1 year.

Discussion

In this interview study, potential adverse consequences after TKA from the perspective of patients and knee specialists were identified. The findings of this study highlight that knee specialists put emphasis on surgical failure, unexplained pain, limited walking ability and impairments that limit the physical functioning of patients, whereas patients were focused on the arduous process of getting used to the prosthesis, lingering pain, awareness of the artificial knee and limitations they experienced during valued and daily activities.

In line with previous research [18, 19], our study showed that the process of getting used to the prosthesis, the experiences of adjusting physically and mentally to the prosthesis, were in the top of the mind of patients. Especially in patients for whom rehabilitation took longer than anticipated, this process of adapting to their artificial knee was dominant in their stories. Patients for whom additional efforts at improvement did not result in their expected outcome expressed deep frustration with what they perceived to be a lack of adequate guidance or help from the health-care providers. In contrast, knee specialists expressed in their stories that the process of getting used to the prosthesis was part of the postoperative process and did not explicitly acknowledge that the process of recovery can contribute to a negative experience. These differences in views between patients and knee specialists might contribute to discrepancies in their perception of poor response to TKA.

Patients' experiences of lingering pain and limitations in performing valued and daily activities also contributed to their negative appraisal of the TKA procedure. Comparable results were found in previous studies that focused on asking patients what results matter the most to patients undergoing a knee or hip replacement [9, 20, 21]. Patients ranked three outcomes as their highest priorities: pain relief, functional recovery and improved quality of life [20]. Another study by Whitebird *et al.* [21] identified the ability to walk without pain or discomfort, pain relief and returning to an active lifestyle as important outcomes. Although both studies ([20] and [21]) focused on pain relief, many patients discussed pain

Table 6 Subthemes and quotations

Subtheme	Participant[a]	Quotation
Pain during the first postoperative period	Preoperative patient 5, 67	I would not be satisfied if the pain has not decreased or remained the same.
	Postoperative patient 12, 62	I slept poorly during the first few weeks, purely because of the new knee. It felt like a burning sensation. Every time I wanted to turn over in bed, I woke up, and then it took me a while to find a comfortable position again. Those nights were actually the most disappointing for me.
Pain medication to ease the pain	Postoperative patient 21, 68	I couldn't tolerate the pain medication after the surgery. As a result, I relied on paracetamol during the first few weeks. It was terrible because the pain was unbearable.
Pain flares during and/or after physical activity	Preoperative patient 3, 59	If pain prevents me from resuming my daily activities, I would not be happy. I just want to be able to go up and down the stairs with a laundry basket and take care of the garden myself.
	Postoperative patient 10, 46	After about an hour at the gym, or after an hour of swimming, I start experiencing a sense of irritation, indicating that I need to stop. At that point, I prefer to sit down with my legs up, and take a moment of rest for my knee.
Continued unacceptable pain to the patient	Knee specialist 10, nurse practitioner	These patients have a lot of pain all the time, and if you want to bend their knee, everything hurts. I find that worrisome! Then I think TKA might have been a bad choice.
Limitations in physical activities	Preoperative patient 14, 48	In the past few years, I already had to limit my activities. If I experience even greater limitations in my activities after the operation, then the knee prosthesis has been of no use to me. I would like to resume my work in a department store, and it would be nice if I could go out with my children again.
	Postoperative patient 7, 67	I constantly feel like I'm going through my knee, that makes it difficult to rely on my knee. Therefore, I don't dare to climb stairs or to go out for a long walk.
Not fulfilling conditions for mobility	Knee specialist 14, orthopaedic surgeon	After 8 weeks, I want patients to reach 110° of flexion and 0° of extension. If patients have less than 90° of flexion and/or 10° or more of extension at that point, I am not satisfied.
Limited walking ability	Knee specialist 2, physiotherapist	Training the quadriceps function and gait pattern is crucial. If patients start walking longer distances with an abnormal gait pattern, they will experience difficulties. Moreover, learning a new gait pattern can be challenging.
Complications	Postoperative patient 17, 62	The knee went red, warm and swollen. I started with antibiotics because there was an infection going on.
	Knee specialist 15, orthopaedic surgeon	There are mild and severe complications, an aseptic loosening is an example of a serious complication.
Revision surgery	Knee OA patient without surgical indication, 2, 72	The surgeon said that the prosthesis could have a lifespan of 15–20 years. So, if a reoperation is required within 10 years, I would be disappointed.
	Postoperative patient 11, 64	I was able to flex the knee up to 70°, and there was no further progress. I waited for another 4 weeks, but I didn't make any progress, not even a millimetre. The extension of the knee also deteriorated over time, leading to the decision to manipulate the knee under anaesthesia.
	Knee specialist 7, physiotherapist	Early revision surgery as a consequence of, for example, arthrofibrosis or prosthetic loosening, is perhaps one of the most objective measures of failure.
Disappointing first postoperative period	Postoperative patient 6, 72	The first 3 months really disappointed me. I thought: 'A new knee, wound healed and done!' However, that wasn't the case. We cooled the knee with ice for at least 6–7 weeks.
Movement anxiety	Postoperative patient 8, 64	Exercising was scary because I was anxious to bend the knee. I was afraid that something would tear. I had to trust my knee and allow it to relax in order to achieve further flexion. It was ultimately a matter of building confidence.
Lingering pain creates uncertainty	Postoperative patient 10, 46	When the pain persists for such a long time and the physiotherapist refers you back to the surgeon, it can create a sense of insecurity. You start to wonder if the pain will ever go away.
Unhelpful thoughts	Postoperative patient 11, 64	There is progress happening, and that's what keeps me going. It's my mindset, and it's important. You almost need psychological support to avoid falling into a slump when things are going so poorly.
Awareness of the prosthesis	Postoperative patient 16, 57	I didn't expect to feel the prosthesis every day. This possible experience was not communicated to me prior to the operation. While it is possible to adapt and live with it, this sensation was unexpected for me.

[a] Patient participant indexed by the patient identification number and age or knee specialist participant indexed by the knee specialist's identification number and profession.
TKA: total knee arthroplasty.

specifically in relationship to specific activities, such as mobility and walking. The association between pain and performing valued activities is also reflected in our findings, because patients reported experiences of pain flares during and/or after physical activity. Knee specialists in our study tend to put more emphasis on surgical failure, unexplained pain, limited walking ability and impairments that limit the physical functioning of patients. Remarkably, surgical failure is not incorporated in any of the definitions for poor response after TKA used in the literature [6]. Our findings indicate that, besides complications and revision surgery, lingering pain, limitations in walking ability and the ability to perform (valued) activities of daily living and/or work are relevant outcome domains for measuring poor response to TKA according to both patients and knee specialists.

There is evidence that TKA patients tend to have overly high expectations going into surgery [22, 23]. Knee specialists in our study confirmed that some patients persist in unrealistic expectations on the outcome of a TKA, even after comprehensive preoperative consultation. Most knee specialists in our study mentioned that they discuss these (unrealistic) expectations with their patients. Nevertheless, it is important to encourage patients to list what they would like or expect to do post-TKA [24]. Knee specialists must council them appropriately regarding the relative probability that they would be able to accomplish each of their stated goals [24]. In the event of a discrepancy between what the patient expects and what knee specialists know TKA can deliver, the first step is for the knee specialist to explain the extent to which the expectations of the patient are realistic [24]. This should be seen as an essential component of preoperative consultation.

These findings have several important clinical and research implications. Our findings can inform shared decision making for TKA. We found that lingering pain, impaired mobility and the inability to resume valued activities are important adverse consequences of TKA. The identified adverse consequences of TKA could be incorporated into a tool where patients can tick or prioritize consequences they find relevant to discuss with their orthopaedic surgeon. Such a tool will assist patients to state their personal preferences, goals and expectations explicitly. The orthopaedic surgeon can use the checklist as a conversation guide for discussing the treatment options, their risks and benefits, and to discuss the expectations, constraints and information needs of patients [25–29]. Furthermore, a guidance can be created to advise related health-care professionals on informing patients about the adverse consequences of TKA and exploring conservative treatments before seeing an orthopaedic surgeon. Our study provided a full picture on the variety of potential adverse consequences of TKA that could contribute to a negative appraisal of its effect. However, we did not identify the relative importance of these consequences. Future research should focus on the prioritization of adverse consequences of TKA for patients with OA that might contribute to poor response, from the perspective of both patients and knee specialists.

One of the strengths of this study is that, to our knowledge, this is the first study to investigate the expectations and experiences of patients and the perceptions of knee specialists on adverse consequences that might contribute to the negative appraisal of the TKA procedure. Another strength is that the interviews were conducted by a PhD candidate who did not have a relationship with the interviewed patients before the study, reducing the risk of response bias. Furthermore, purposive sampling and participant recruitment from two hospitals in the Netherlands and one in Belgium allowed the inclusion of a wide variety of participants, leading to a thorough evaluation of all possible experiences that might contribute to the negative appraisal of the TKA procedure. Another strength is the involvement of patient research partners in the study design.

Potential limitations must be considered while interpreting the findings. Firstly, our results describe a process that unfolds over time, but data were collected at one time point and thus, for postoperative patients, relied on recall by the participants of their TKA journey. However, some patients indicated that they could now reflect better on that period than they could during the rehabilitation period. We attempted to minimize recall and salience bias by asking patients about their own experiences, about previously mentioned experiences of other participants and by asking probing questions about all sorts of details. Secondly, cross-cultural comparison between participants in the Netherlands and Belgium was not feasible owing to the small sample size. Thirdly, signs of non-verbal communication during the interviews with patients in Belgium could have been missed because these interviews were online as a consequence of the regulations during the coronavirus disease 2019 pandemic. However, we used video conferencing software, which is seen as the closest to the gold standard of interviewing [30]. Fourthly, only patients and knee specialists who were able to communicate (read and speak) in Dutch were included to ensure that all interviews could be conducted in the native language. Thus, cultural differences and different health-care systems can make these results less generalizable.

In conclusion, our study provides a comprehensive overview of potential adverse consequences from the perspective of both patients and knee specialists. Our findings highlight that knee specialists put more emphasis on surgical failure, unexplained pain, limited walking ability and impairments that limit the physical functioning of patients, whereas the experiences of patients were more focused on the arduous process of getting used to the prosthesis, lingering pain, awareness of the artificial knee and limitations they experienced during valued and daily activities. Aspects associated with the difficult process of adapting to the prosthesis need to be addressed during shared decision making.

Supplementary material

Supplementary material is available at *Rheumatology Advances in Practice* online.

Data availability

The deidentified data underlying this article will be shared on reasonable request to the corresponding author.

Author contributions

The authors declare the following contributions to the preparation of the manuscript: study conception and design (M.E.M.t.M., J.E.V., P.J.C.H. and C.H.M.v.d.E.); data collection (M.E.M.t.M., S.v.O. and J.M.H.S.), data analysis, Tables 1–6 (all authors) and interpretation of data (M.E.M.t.M., J.E.V. and C.H.M.v.d.E.); drafting of the manuscript (M.E.M.t.M.); critical revision of the manuscript for important intellectual

content (all authors); final approval of the manuscript (all authors). All authors take responsibility for the integrity of the work and agreed to submit the article for publication.

Funding

This work was supported by Smith & Nephew as the institution of one or more of the authors (M.E.M.t.M., J.M.H.S., P. J.C.H. and C.H.M.v.d.E.) has received funding to provide us with research support for staff and materials. Smith & Nephew had no role in the design and conduct of the study; collection, management, analysis and interpretation of the data; preparation and review of the manuscript.

Disclosure statement: The authors have declared no competing interests. The institution of the authors reports received grants from Smith & Nephew and Stryker outside of the submitted work.

Acknowledgements

The authors are grateful to the patients and knee specialists who were willing to participate in this research and thank nurse practitioner Keetie Kremers for her efforts in patient recruitment in one of the three participating hospitals. The authors also thank Manorma Dwarkasing and John van de Langenberg (patient research partners) for their contribution to the study. The preliminary results of this study were presented at EULAR 2021 and some other conferences.

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