

Clinical Trial

“I was considering surgery because I believed that was how it was treated”: a qualitative study on willingness for joint surgery after completion of a digital management program for osteoarthritis



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SUMMARY

Objective: To explore, using a qualitative approach, reasons for patients' continued willingness or their shift in willingness for total joint replacement (TJR) surgery, following participation in Joint Academy, a Swedish, digital, non-surgical treatment program for osteoarthritis (OA).

Design: Nineteen patients with hip or knee OA were interviewed after finishing their first 6 weeks in the treatment program, using a semi-structured interview guide. The interviews were transcribed verbatim and analyzed using a systematic text condensation method.

Results: Analysis of the interview data revealed three main categories of reasons provided for the participants' decisions regarding surgery:

1) Various reasons for participating in Joint Academy with three sub-categories: (a) longstanding pain affects daily life, (b) last chance for improvement and (c) mandatory treatment to be eligible for total joint replacements (TJR); 2) Willingness for TJR following treatment, which included four sub-categories: (a) surgery – the last resort, (b) reduced pain and improved functioning, (c) no perceived improvements after treatment, and (d) trust in healthcare providers; and 3) Expectations of TJR. The shift in willingness towards or away from TJR was mainly due to the perceived success of Joint Academy in improving their functioning.

Conclusion: Several patients reconsidered their options and had changed their attitude to TJR after participation in a digital program aimed at reducing OA symptoms and improving functioning. These results highlight the importance of providing patients with adequate information about non-surgical management options to facilitate shared decision-making, and possibly reduce the need for surgery.

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Background

Osteoarthritis (OA) is a major cause of pain and disability¹, with significant consequences for the affected individual and substantial financial costs for society^{2,3}. The prevalence of radiographic hip and knee OA in the United States is estimated to be 27% and 19%⁴, respectively. Furthermore, knee OA alone represents approximately

2% of all reported sick days in Sweden and significantly increases the risk of long-term sick leave and disability pension for the affected individual⁵.

The number of total joint replacements (TJR) in OA is continually rising as it is considered an effective treatment for end-stage OA⁶. TJR is a common treatment in hip and knee OA, entailing significant costs for society^{7,8}. Yet, one third of all OA surgeries are deemed to be inappropriate, i.e., TJR is performed even though the patient has only mild symptoms^{9,10}. Approximately one fifth of the patients who undergo TJR are dissatisfied with the outcomes after surgery^{11,12}. Identifying the patients for whom TJR would be most beneficial is challenging since consensus criteria for surgery

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referral are not well established^{13–15}. Furthermore, previous research reports willingness for surgery to be the most important criterion for TJR in patients with hip and knee OA¹⁶. Several factors that are not related to structural OA severity, such as education level, social network and surgery expectations, may affect the willingness for surgery^{16,17}, indicating that willingness to consider surgery alone may not be an optimal referral criterion. This is further emphasized in a study by Skou et al., where only 26% of the patients that initially were willing to consider surgery and were on a waiting list for TJR, underwent surgery within 1 year of receiving non-surgical treatment⁶.

In a recent quantitative study¹⁸, we reported that after participation in Joint Academy, a digital, non-surgical management program for OA^{19,20}, one third of the patients that had been willing to consider surgery before entering the program changed their views and no longer saw surgery as a treatment option. On the other hand, 6% of the patients changed their mind in favor of surgery at follow-up. The shifts in attitude for or against surgery were mainly attributed to participants' improvement in functioning and OA symptoms after program completion¹⁸. However, a recent systematic review of qualitative studies on willingness to undergo TJR in patients with OA, reported factors such as expectations and experiences of surgery, trust in clinicians and social aspects to be important in the decision-making process²¹, factors that were not investigated in our previous study. The aim of the present study was therefore to explore patients' perspectives on their continued willingness to have TJR after participation in Joint Academy and/or possible shift in willingness for TJR, to gain a deeper understanding of factors that may contribute to the decision-making process with regards to TJR after participation in non-surgical OA management.

Method

Setting and sampling

This study was conducted in Lund, Sweden. In Sweden, approximately 80% of those suffering from symptomatic knee or hip OA do not receive adequate treatment²². Joint Academy was developed to reach out to this broader population in need of OA management^{19,20}, and is a digital version of the Swedish evidence-based face-to-face self-management program, 'Better management of patients with OsteoArthritis' (BOA)²². The digital program comprises OA education (instructional videos on OA, physical activity and weight management), individualized neuromuscular exercises with increasing difficulty in relation to patient's progress, and an opportunity to chat asynchronously with an assigned physical therapist for feedback and questions. All together the education strives to give the patient an understanding of the rationale behind doing exercises that time to time may be painful. An invitation with written information about the study was emailed to a strategically selected sample²³ of 73 individuals out of all patients ($n = 462$) who completed their first six weeks in the digital osteoarthritis treatment program between November 2015 and January 2018. The sample was selected to reflect patients of different sex, age, functional limitations, disease severity and willingness to have TJR surgery. The inclusion criterion was clinical hip or knee OA, previously diagnosed or diagnosed by an orthopedic surgeon involved in Joint Academy. Exclusion criteria were 1) reporting other joints than hip or knee as the primary joint for OA symptoms and 2) not understanding and/or speaking Swedish.

The study was approved by The Regional Ethical Review Board in Lund, Sweden (Dnr 2017/651; Dnr 2017/980).

Data collection

In depth interviews were performed by one of the authors (AC) and a physical therapy student, using a semi-structured interview guide. The interview guide consisted of open questions related to (1) experiences of the physical and psychological consequences of osteoarthritis, (2) experiences of Joint Academy, the digital treatment, (3) expectations of TJR, and (4) the willingness to have TJR surgery. Follow-up questions were used frequently, such as "Can you give me an example?" and "Can you explain what you mean a bit more?" (See [Online resource 1](#) for interview guide).

As Joint Academy is a digital treatment option, patients who participated in the program were located in different parts of Sweden. Therefore, the interviews took place in conference rooms (face-to-face), via Skype or by telephone, depending on the patients' home location and access to Skype. The interview guide and follow-up questions were pilot tested and then subjected to minor editing. The interviews lasted approximately 30–40 min. They were recorded and transcribed verbatim. The transcripts were then analyzed using systematic text condensation according to Malterud²⁴. This method is based on Giorgi's phenomenological analysis²⁵, and is a method that is suitable when doing cross-case analyses of the meaning of people's experiences. Data collection stopped when no further information was added.

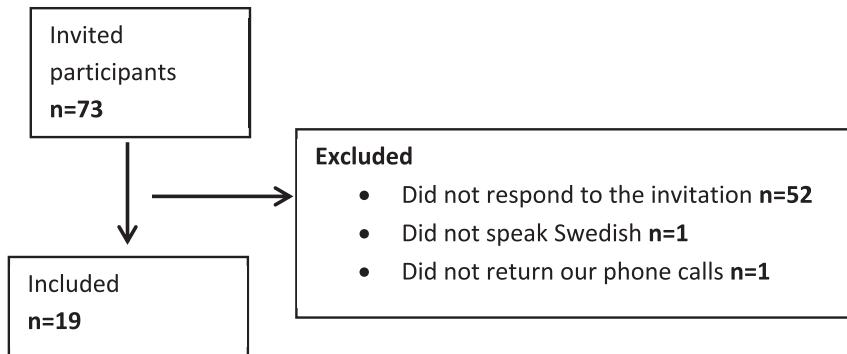
Data analysis

The interview transcripts were read several times to obtain a general impression of the content and to identify primary topics. Next, meaning units were identified and formulated into codes, representing central and essential aspects of the statements. During this phase, two of the authors (AC, CSH) worked individually to identify as many perspectives and experiences as possible in the data. In the next stage, all authors worked together with the coded data to construct one set of data by removing duplicates and data that did not meet the aim of the study. Thereafter, the coded data were arranged into sub-categories, and the content of the meaning units of each category was reviewed. The sub-categories were then organized into categories. The content of each category was formulated to describe the meaning and representation of the data. To validate the categories and make sure that no important aspects had gone unnoticed, the clusters were referred back to the raw data and read once again. Finally, the re-contextualized data were expressed as an interpretation of the meaning of each category and representative quotes were selected for each category/sub-category ([Online resource 2, Table 1](#)).

Results

Twenty-one participants agreed to participate and gave their written informed consent prior to participation. One participant did not speak Swedish and one did not return our phone calls, leaving nine men and ten women (median age (q1, q3); 66 years (57–71)) eligible for interview ([Fig. 1](#)). Of those, ten participants reported hip and nine participants reported knee as the primary OA location (See [Table 1](#) for participant characteristics). As reported previously¹⁸, 31% shifted their willingness for surgery away from TJR and 6% in favor of TJR after finishing this program. Hence, patients who considered having TJR at both baseline and follow-up ($n = 10$), those who considered having TJR at baseline but had reconsidered at follow-up ($n = 4$) and those who did not consider TJR as an option at baseline but had reconsidered after completion of the program ($n = 5$) were included.

Analysis of the interview data revealed three main categories of reasons provided for the participants' decisions regarding surgery:

**Fig. 1.** Flow chart of the inclusion process.**Table 1**
Characteristics of the participants (n = 19)

Characteristics	n = 19
Age mean (min–max)	65 (45–80)
Sex	
Women n	10
Men n	9
Retired n	10
OA location	
Hip n	10
Knee n	9
Pain baseline (min–max)	6.1 (1–9)
Physical function baseline (min–max)	8.6 (1–14)
EQ5D-3L index baseline (min–max)	0.59 (0.29–0.76)

OA = osteoarthritis, pain was assessed with the Numeric Rating Scale (NRS) from 0 to 10, where 0 indicate no pain with higher numbers indicating more severe pain, physical function was assessed using the 30-s Chair Stand Test reflecting the number of repetitions of sitting to standing from a chair during a period of 30 s. EQ5D-3L = EuroQol – five dimension descriptive system assessing health-related quality of life - a higher EQ-5D-3L index indicates better health-related quality of life.

- 1) Various reasons for participating in Joint Academy, with three sub-categories: (1) longstanding pain affects daily life, (2) last chance for improvement and (3) mandatory treatment to be eligible for TJR;
- 2) Willingness for TJR following treatment, with four sub-categories: (1) surgery – the last resort, (2) reduced pain and improved functioning, (3) no perceived improvements after treatment, and (4) trust in healthcare providers;
- 3) Expectations of surgery (Fig. 2. See [online resource 2, Table 2](#) for additional quotes).

Various reasons for participating in Joint Academy

The interviews revealed three main reasons for joining Joint Academy. The two most common reasons were the experience of long-lasting pain that had a significant effect on the participants' quality of life and that the treatment was perceived as the last chance for improvement before surgery. Another reason was that the program was considered as a mandatory treatment to be eligible for TJR.

Longstanding pain affects daily life

A majority of the participants described how long-lasting pain had started several years ago, yet they did not realize that they might have a serious disorder. From being merely subtle symptoms,

the pain had now escalated to a point where pain was a major part of their everyday life.

"It came in episodes, the osteoarthritis I think. I mean, it has crept its way into my body and has evolved over several years, without me knowing what it was. But all of a sudden it was really, really painful." (I8)

The perceived OA symptoms had a significant impact on all the participants' everyday life. Before joining Joint Academy, many individuals described movement restriction and reduced flexibility in various activities, and that they were not able to perform even the simplest of activities, such as cutting their toenails, putting on socks and picking up things from the floor. Their ability to sleep was significantly affected by the OA symptoms, which consequently resulted in a constant feeling of tiredness. Furthermore, the joint pain prevented them from participating in activities that they previously had been able to perform and they also described that the OA affected not only themselves, but also other people that were close to them.

"Yes, there were periods in my life when I had to use crutches, two crutches. And I couldn't move around very much. I had a hard time sleeping at night. I had to move backwards to be able to get down the stairs ... and the pain at night was very different. Not being able to sleep, that was the trigger ... this affected my husband too, since I was so ill. He could say "Would you like to go for a walk with me?" And I said "yes". I could walk 100 m, then I had to sit down. And then another 100 m and sit down again. That's not quality-of-life ... neither for him nor me." (I11)

Some participants described their life to be exhausting and characterized by resignation and helplessness.

"I was, from time to time you know ... I couldn't go to town without thinking of how to be able to get home again, when it was at its worst. I did also think of surgery and everything, but only to get better. I was feeling really bad due to the situation." (I8)

Last chance for improvement

Several participants expressed that the program was perceived as their last fragile hope before TJR surgery. The participants experienced their situation to be unbearable as it was, and they did everything they possibly could to reduce their symptoms and get better.

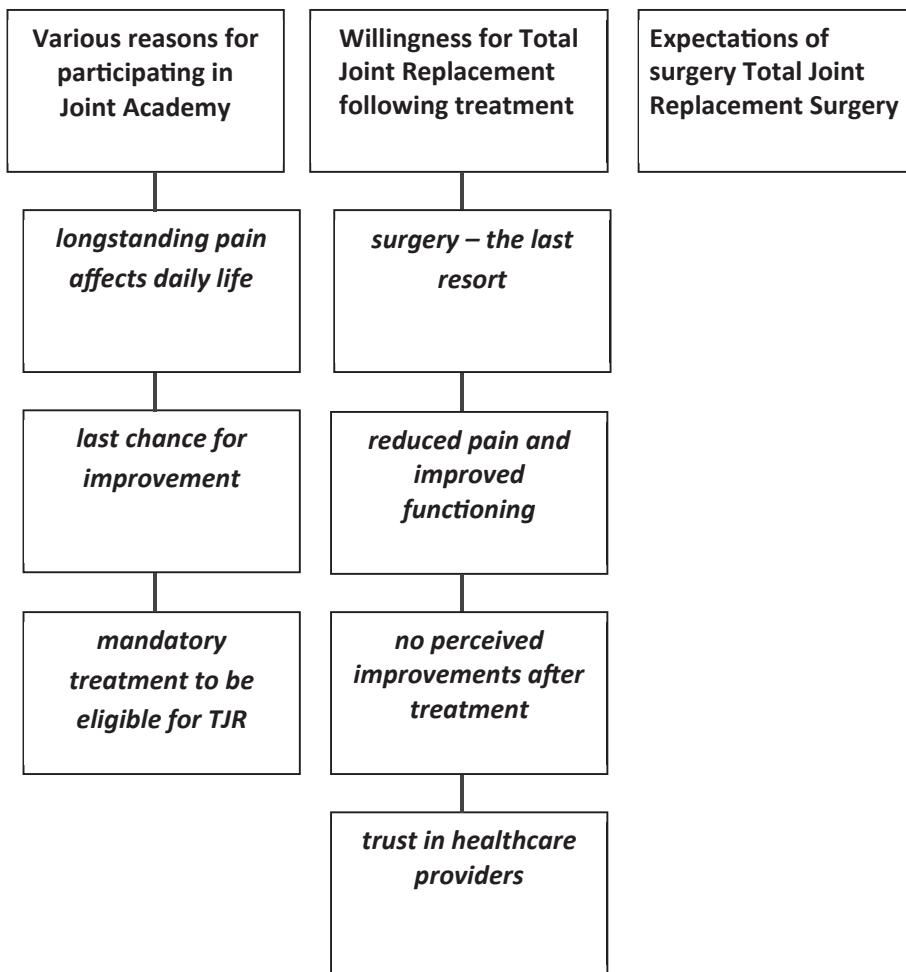


Fig. 2. Overview of the categories and subcategories describing willingness to have Total Joint Replacement Surgery in people with osteoarthritis.

"It was the last thing I wanted to do [i.e., have surgery]. I really didn't want to do that so that's why I did everything that came my way in the hope of not having to undergo surgery." (I15)

Mandatory treatment to be eligible for TJR

A few participants expressed that Joint Academy was something they had to go through to be eligible for surgery. They really wanted to have a TJR, but they acknowledged the guidelines of osteoarthritis healthcare, and accepted that they had to try non-surgical treatment before any decision about TJR could be made.

"And if I understand things correctly, they think that you should go through a program like this before surgery. To see if it helps." (I1)

Willingness for TJR following treatment

The participants commonly referred to TJR as the last resort, when nothing else worked. However, at follow-up, approximately 50% of the participants included in this study had changed their attitude towards either accepting or declining TJR. The reason for this shift was often described in relation to perceived improvements after finishing the program. Those who experienced improved functioning and reduced symptoms or even

disappearance of symptoms felt that they wanted to postpone TJR surgery. However, those who did not experience any reduction in pain nor improved functioning were eager to have TJR. Differences in opinion regarding eligibility for surgery between the patient and the healthcare providers were also revealed.

Surgery – the last resort

All participants who still considered having surgery at follow-up described surgery as the last resort. They had tried everything else yet their symptoms were so severe that they were no longer able to cope with the pain and had now reached a point of no return, where there was nothing else to be done.

"Well, of course ... having surgery always involves a risk, but I made up my mind ... If it all goes wrong, then I will deal with it then. But I feel like I have no reason to worry as it can't get any worse ..." (I13)

Reduced pain and improved functioning

Some of the participants, who had desired surgery before entering Joint Academy, thought that this was the only option. However, all who had reconsidered and no longer wanted TJR after treatment, cited reduced OA symptoms as the main reason for changing their attitude. After completing the program these

patients described reduced pain and improved functioning in their daily activities and that they had gained more knowledge and insight regarding their illness and different treatment options.

"I was considering surgery because I believed that was how it was treated. That's what you do when you have osteoarthritis and have pain, you replace your knee joint. That was the knowledge I had. But then in the program I have learned that surgery is also a trauma and could possibly cause more osteoarthritis, which is not good. And now, I have had this good result from the exercises, so surgery is definitely not an option anymore." (I8)

No perceived improvements after treatment

For the participants who changed their attitude in favor of surgery after completion of their first six weeks in the program, a lack of improved functioning and no reduction in OA symptoms after completion of the program were mentioned in most cases. One participant also expressed fear of postponing the surgery, and thereby miss potential benefits from the surgery, i.e., why suffer if they don't have to.

"I didn't get any better. I had more and more pain. Instead of the exercises being easy in the beginning with a gradual increase in difficulty, I had to go back to the beginning in some exercises. And I felt that this is not beneficial ... like ... now surgery is the only option ... Yes, everybody I have spoken to that has had surgery has said "Why did I wait so long?" And I was thinking, I do not want to become one of those ... waiting too long and becoming bitter over it ... why did I wait so long?" (I3)

Trust in healthcare providers

Approximately one fourth of the participants expressed that they would prefer a TJR but that their orthopedic surgeon or physiotherapist advised against it. Their healthcare providers had explained to them that their symptoms were not severe enough for surgery. Under such circumstances the participants often experienced a lack of empowerment and a feeling of not being listened to.

"I think I am much worse now, and due to that it might be needed (surgery). But that is like an orthopedic judgment. If the orthopedist says that I don't have enough symptoms, then I'm powerless. It's him that is qualified, not me. ... It's me that feels the pain ... but it's him that is the doctor, if I put it like that." (I17)

Expectations of TJR

A majority of the participants expressed that their main expectations of surgery were a desire to go back to their normal life; the ability to participate in the activities they used to do before their illness had worsened. Half of the participants had positive experiences from previous successful surgery in other joints or referred to acquaintances that had undergone surgery, and were functioning as before, which influenced their high expectations of the TJR.

"That I would be able to regain my mobility and be able to do things that I can't do at the moment. To take walks, ride my bike, to be just as mobile as I used to be. To have a normal life." (I11)

"And there are numerous people that are very satisfied with the result of their surgery. The consequences on their quality-of-life and pain and so on. So my expectation is that I could go back to my old life again, if you like." (I19)

"If I put it this way, the surgery I had when I got my knee replacement was really good, it was tremendous ... and now I think that it has to be the same good result if I have a hip replacement as well". (I17)

Discussion

In this study, we explored the attitudes towards TJR and the individual reasons for continued willingness or any shift in willingness to have surgery after participation in a digital non-surgical management program for OA. Patients' shifts in willingness for surgery were mostly explained by their perceived improvement in OA symptoms and functioning, or if they felt no effect from the treatment.

Samson *et al.*, have previously identified two main reasons for patients with hip and knee OA choosing TJR: patients that waited until their symptoms were so severe that they could no longer cope with them, and patients that wanted surgery to prevent the symptoms from getting worse²⁶. That finding was also supported in the current study, in that the participants who desired surgery after completion of the program commonly referred to surgery as the last resort. They had tried everything else and since they had not received the results they had hoped for by joining the program, TJR surgery was their only remaining option. Similarly, the other reason for a change in attitude in favor of TJR was fear of waiting too long. They wanted surgery before their symptoms became so severe that they could no longer continue with their everyday activities. In contrast, participants who changed their mind and no longer considered surgery as an option after the program perceived significant improvement in functioning and OA symptoms. This shift in attitude may have been due to the program improving knowledge of their condition and how to manage their symptoms coupled with the effect of the included exercises.

Although the participants in this study made several different decisions about their willingness for surgery following the Joint Academy program, it is interesting to consider what comprises the decision-making process. Elwyn *et al.*²⁷, suggested that there are two important aspects of the decision making process: deliberation and decision-making. In the deliberation stage, all information that is available to the individual patient is considered, and different options and their consequences are reviewed, leading to the final decision²⁷. Therefore, adequate information is a prerequisite for the patients' ability to make a decision that will meet their expectations of the outcome. However, previous research shows that far from all OA patients are given appropriate information regarding their treatment options, and that surgery is often the first line of treatment for these patients^{22,28,29}. The result from this study highlights the importance of such information, especially since some patients seem to go back to the deliberation stage, reconsidering their options and changing their attitude to TJR surgery after completing the treatment program. Given this, a non-surgical treatment program, which includes education and exercise may potentially reduce or delay the need for TJR in this group of patients. Future research needs to delve deeper into what options are available for patients, what is offered before surgery and what is given priority, to reach the goal of improved identification of those in real need of TJR. Furthermore, despite consensus guidelines on what type of

treatment should be offered first, i.e., non-surgical³⁰, there is still a lack of knowledge on how to effectively implement these guidelines.

Another interesting result was the trust placed in healthcare providers. The patients relied on their doctors' professional opinion that their symptoms were not severe enough to require surgery, although they did not necessarily agree with this opinion. In such cases, the patients expressed feelings of powerlessness and that hope of ever getting better was lost. The doctor–patient relationship has previously been reported as playing a significant role in the decision process regarding TJR in patients with OA^{16,21,26,31}. While the patients seem to trust their orthopedist's competence and experience to evaluate their need for TJR^{26,31}, they also expressed feelings of anxiety and disempowerment if the doctor disagreed with their desire to have TJR²⁶. The result from the current study revealed similar discrepancies between the wishes of some patients and their orthopedists after completion of the non-surgical treatment program. There is limited evidence for the effect of shared-decision making interventions on patient-relevant outcomes, such as decision regret and physical and health-related quality of life³². Still, this result highlights the importance of acknowledging the patient's treatment preference early in the process, and to respond to these preferences with adequate information, enhancing the patient's confidence in the health-care providers. In this way the patient can also understand potential discrepancies and participate in a truly shared decision-making process^{33–35} regarding any TJR in OA.

Positive and negative personal experiences of surgery, or experiences of friends or family, have been shown to influence the expectations on future TJRs in individuals with hip and knee OA^{16,21}. These results were also reflected in the current study, indicating that previous experiences and expectations of surgery play an important role in the decision-making process regarding TJR in these patients, even after non-surgical treatment has been completed.

Our aim was to investigate the underlying reasons for still considering a TJR or reasons for a possible shift in willingness for TJR after a 6-week participation in the non-surgical treatment program. The participants differed in age, sex, functional limitations and disease severity. Although all of them provided rich and relevant data, which gave valuable understanding of the willingness for TJR, the results may not be fully transferable to the entire population of persons with OA. For example, none of the patients that were unwilling to consider surgery at both baseline and at follow-up participated in the current study. Their participation may have revealed additional experiences and expectations-based factors that formed their decision to not have a TJR. Another important consideration when interpreting the results of this study was that the treatment program was digital and the participants were located all over Sweden. It was therefore only possible to perform face-to-face interviews in two cases. All other interviews were conducted either by Skype or by telephone, which may have resulted in less depth in the interviews due to a loss of visual input. On the other hand, this may also be considered as a strength of this study. Due to the digital nature of the program, this study was not limited to a single setting since we were able to recruit individuals representing different regions across Sweden increasing the applicability of the results.

In an effort to reduce the possible effect of bias related to the interviewers' experiences³⁶, continuous discussions were held to ensure that we remained aware of our backgrounds as clinicians and researchers throughout the analysis of the data. These discussions helped us to stay neutral to the data by reminding us that our decisions may be influenced by our previous experiences. In addition, we have presented a signature after each quotation to

show the representation of the participants, thereby adding transparency and trustworthiness to our findings.

Conclusion

This qualitative study adds deeper insight regarding factors that contributed to the individual decision-making process for TJR after participation in a non-surgical OA treatment program. Many patients seem to go back to the deliberation stage, reconsidering their options and changing their attitude to surgery, in either direction, after completing a digital OA management program aimed at improving functioning and reducing OA symptoms. Specifically, this result highlights the importance of providing patients with adequate information about non-surgical management options to potentially reduce the need for TJR and to improve the identification of those for whom a TJR may be truly beneficial.

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Authors' contribution

Anna Cronström, PhD contributed to the design of the study, conducted part of the interviews, was responsible for the analysis and interpretation of the data and was in charge of writing the manuscript. Leif E Dahlberg, PhD contributed to the conception and design of the study, to the interpretation of the data, and provided feedback on drafts of this paper. Håkan Nero PhD contributed to the conception and design of the study, to the analysis and interpretation of the data, and provided feedback on drafts of this paper. Catharina Sjödahl Hammarlund, PhD contributed to the conception and design of the study, to the analysis and interpretation of the data, and provided feedback on drafts of this paper. All authors have read and approved the final manuscript.

Conflict of Interest

HN is a physiotherapist and part-time consultant at Joint Academy AB and LED is the co-founder and Chief Medical Officer of Joint Academy AB. No other relationships or activities exist that appear to have influenced the submitted work.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

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Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.joca.2019.04.004>.

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