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DIFFERENT PERSPECTIVES OF LIVING WITH OSTEOARTHRITIS AND OUTCOMES AFTER KNEE ARTHROPLASTY

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Institutet**

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*Pain is a noise the body gives away
and the mind is an unwilling listener.
The mind strives to silence the pain
to be able to hear the sound of music.
But when the body cannot be silenced
the mind must befriend the pain
or the music will vanish altogether.*

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Different perspectives of living with osteoarthritis and outcomes after knee arthroplasty

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To Gustav and Florence

ABSTRACT

Osteoarthritis (OA) is the most common joint disease affecting the population increasingly with age. Living with OA and pain can cause severe distress in an individual's life and expectations of outcome after joint replacement surgery are generally high. Joint-related pain and functional loss are consequences of OA as the disease progresses and are also indications for surgery. The majority of patients undergoing a knee arthroplasty experience pain relief and are satisfied with the surgical outcome. However, there is an important minority with persistent pain and functional disability that needs to be addressed. The overall aim of this thesis was to investigate and describe individuals' experiences of living with knee or hip OA, and their expectations of and outcomes after knee arthroplasty using both quantitative and qualitative methods.

Methods: *Study I:* Semi-structured interviews were conducted with 12 participants with knee OA who were scheduled for a knee arthroplasty within the next month. The interviews were transcribed *verbatim* and analyzed through qualitative thematic analysis.

Study II: Semi-structured interviews were conducted with the same 12 participants as in study I, approximately one year after surgery. The interviews were transcribed *verbatim* and analyzed through qualitative thematic analysis.

Study III: A total of 108 patients with knee or hip OA scheduled for a joint replacement assessed their preoperative pain and symptoms. Patient reported outcome measures were used: The Knee Injury and Osteoarthritis Outcome Score (KOOS) or the Hip Disability and Osteoarthritis Outcome Score (HOOS), a visual analogue scale (VAS) and the Pain-o-meter (POM), a survey consisting of sensory and affective pain descriptors. Preoperative radiographs were graded and analgesic use was assessed. Differences in pain expression were calculated comparing patients < 65 vs. ≥ 65 years as well as between women and men. A three-way ANOVA was used to assess differences in pain reporting with age, sex and joint as independent factors.

Study IV: Sixty-five consecutive cases, where a stemmed total knee arthroplasty (TKA) was used, were clinically and radiographically evaluated with a mean follow-up of 5 years (range=2–9 years). Prosthetic survival was calculated. Of the 65 procedures, 24 were primary TKA due to knee instability and 41 were revision arthroplasties mostly due to aseptic loosening of the previous prosthesis.

Results: *Study I:* The overriding theme was “It's not just a knee – but a whole life” with three categories: “Change from their earlier lives”, “Coping with knee problems” and “Ultimate decision to undergo surgery”. Knee OA was the main focus in the participants' lives impacting their functional abilities, life quality, and mental well-being. Surgery was seen as the only solution to their problems but expectations regarding outcomes varied.

Study II: The overriding theme of this study was “Striving for a silent knee” with two underlying categories: “The bumpy road to recovery” and “The presence of the future”. Not all participants were fully restored one year after surgery but were hoping for a better future. While some participants had started to accept living with knee problems, others were still hoping to improve.

Additionally, some were pain-free and no longer thought about their knee – the knee had become silent.

Study III: Patients < 65 years of age used more affective words, words with higher pain intensity values, and reported more symptoms (KOOS/HOOS) compared to those ≥ 65 years. However, younger patients had less severe radiographic OA than older adults and no differences were seen in VAS scores and the KOOS/HOOS pain subscale. These differences did not persist in the ANOVA with sex and joint as independent factors. Pain ratings, as measured by VAS, differed between women and men and women rated their pain higher than men. This difference persisted in the ANOVA with joint and age as independent factors. Women also reported more frequent analgesic use than men. No differences were found in radiographic severity of OA or the use of sensory and affective POM-Words between women and men. Using ANOVA with age and sex as independent factors, there was a statistically significant difference in intensity scores for sensory POM-Words where patients with knee OA reported higher intensity scores than those with hip OA.

Study IV: For clinical outcome measures, the knee-related function and health-related quality of life were similar when comparing stemmed TKA used primary or as a revision TKA. However, patients in the primary group generally reported less pain and a greater proportion of these patients were satisfied or very satisfied with the surgical outcomes. The overall five-year survival rate with reoperation as endpoint was 82% (Confidence Interval=72–99) and was similar for primary and revision TKA. There were 12 surgical failures, of which 8 were reoperations due to deep infection. No TKA were loose radiographically but radiolucent lines on either the femoral or tibial side were seen in 36 cases.

Conclusions: Living with OA influences a person's life on many levels. OA pain and functional disabilities lead to reduced spontaneity for engaging in different activities and creates a feeling of loss as the participants are forced to change how they live their lives. How OA affects a person differs between individuals and this should be taken into account when treating patients with OA. Younger patients may be more emotionally affected by pain than older patients and women may experience more pain than men without expressing greater emotional impact. However, pain is subjective and reflective of the individual's own experience. This is why qualitative interviews and qualitative pain measurement may capture these stories more comprehensibly. Patients receiving a knee arthroplasty experience different levels of pain relief and satisfaction with surgical outcome. Some participants experience continued improvement up to one year after surgery, suggesting it may be valuable to provide continuous support throughout the postoperative period and to extend the postoperative follow-up to achieve the best possible outcome. Even after major orthopedic surgery, as with a stemmed TKA, overall patient satisfaction is high, with patients experiencing less pain. A stemmed TKA can be regarded as a good alternative when indications exist.

SAMMANFATTNING

Artros är den vanligaste ledsjukdomen och drabbar främst knän, höfter, rygg, fingrar och stortår. Cirka 25 procent av Sveriges befolkning över 45 års ålder lever med artros i någon led. Förekomsten ökar med stigande ålder, men behandlingskrävande sjukdom finns även hos yngre. Knä- och höftartros innebär nedbrytning av ledbrosk och påverkan på omgivande strukturer som ligament, muskler, ledhinnor och skelett. Detta leder till olika grad av smärta, ledrelaterad funktionsnedsättning och inskränkt livskvalitet. I Sverige utförs årligen cirka 15 000 knäprotesoperationer och cirka 18 000 höftprotesoperationer. Indikationerna för operation är kvarstående smärta och funktionsnedsättning efter icke-kirurgisk behandling.

Syftet med avhandlingen var dels att undersöka upplevelserna av att leva med knä- och höftartros hos patienter som ska opereras med en protes, dels att undersöka upplevt och uppmätt resultat efter en knäprotesoperation. För detta användes både kvalitativ metod och kvantitativa utfallsmått.

Metod: *Studie I och II:* Vi intervjuade tolv personer en månad före planerad knäledsoperation samt ett år efter genomförd operation om deras upplevelser av att leva med knäartros samt om deras förväntningar på och upplevelser av operationsresultatet. Intervjuerna skrevs ut ordagrant och analyserades med kvalitativ tematisk analys.

Studie III: Sammanlagt 108 personer med knä- eller höftartros, planerade för protesoperation, fick skatta sin ledrelaterade smärta och funktion med självskattningsformulär (Knee injury and Osteoarthritis Outcome score/Hip Disability and Osteoarthritis Outcome Score), en visuell analog skala (VAS) samt ett kvalitativt smärtskattningsinstrument, ”Pain-o-Meter”, där patienten fick välja ett fritt antal förutbestämda ord för att beskriva sin smärta. Dessa ord har en förutbestämd intensitet (grad 1–5) som gjorde att vi kunde kvantifiera patienternas skattade fysiska och emotionella påverkan av smärtan. Vi graderade patienternas artros på röntgen och frågade dem hur de använde smärtstillande läkemedel. Vi undersökte om det fanns skillnader i smärta och symptom dels mellan patienter under och över 65 år, dels mellan kvinnor och män.

Studie IV: Extrastabiliserade knäproteser används ibland vid svår knäledsartros eller ledgångsreumatism eller om en tidigare knäprotes inte längre fungerar som den ska. Vi undersökte 65 fall där extrastabiliserade knäproteser använts. Klinisk undersökning och bedömning av röntgenbilder gjordes i snitt 5 (2–9) år efter operationen. Av de 65 undersökta fallen fick 24 extrastabiliserade knäproteser som förstagångsprotes på grund av instabilitet i knäleden, medan 41 fick en tidigare protes utbytt (revision), främst för att den tidigare proteserna inte längre satt helt fast.

Resultat: *Studie I och II:* Vi fann att personer som lever med knäartros upplever påverkan på hela livet och inte bara knäet. Knäet blev huvudfokus i personernas liv och påverkade fysisk aktivitet, livskvalitet och välbefinnande vilket i sin tur gav minskad spontanitet att göra vissa saker och försämrade sociala relationer. Att byta ut knäleden sågs som den enda vägen att ta, men förväntningarna på operationsresultatet varierade mellan personerna. Inte alla personer

var helt återställda ett år efter operationen. Vissa hade förväntningar på att den framtid de hade tänkt sig fortfarande skulle infinna sig medan andra hade börjat acceptera att leva med en del kvarstående knäproblem. För vissa var framtiden redan närvarande, vilket innebar att de var helt återställda och inte längre tänkte på knäet: knäet hade tystnat.

Studie III: Vi fann att personer under 65 år använde fler emotionella ord med högre intensitet för att beskriva sin smärta samtidigt som de hade lägre grad av artros på röntgen jämfört med dem över 65 år. Vi såg dock ingen skillnad i smärta när de fick skatta smärtan med hjälp av en VAS. Mellan kvinnor och män såg vi omvända resultat: Kvinnor skattade sin smärta högre med VAS jämfört med män, men det fanns inga skillnader i röntgengrad, vilka ord som användes för att beskriva smärtan eller smärtans intensitetspoäng.

Studie IV: Efter operation med extrastabiliserade knäproteser fann vi att knärelaterad funktion och hälsorelaterad livskvalitet var densamma oavsett om den användes som primär- eller revisionsprotes. Däremot hade personer, för vilka proteserna använts som primär protes, mindre smärta och dessa personer var i högre grad nöjda eller väldigt nöjda med resultatet jämfört med dem som fått en protes utbytt. Av 65 fall genomfördes 12 reoperationer under uppföljningstiden, vilket gav en protesöverlevnad med reoperation som slutpunkt på 82 procent. På röntgen kunde man i 36 fall se uppklärningszoner. Detta kan indikera att proteserna inte sitter fast, men av dessa 36 fall bedömdes ingen av proteserna sitta löst.

Konklusion: Att leva med artros innebär att leva med smärta, vilket påverkar en person på flera nivåer. Smärta och funktionsnedsättning vid artros leder till minskad spontanitet inför vissa aktiviteter och ger en känsla av saknad, då personer med artros tvingas ändra hur de lever sina liv. Hur artros påverkar en person är individuellt, vilket bör tas i beaktande när sjukvården behandlar dessa patienter. Yngre personer kan bli mer emotionellt påverkade av artrossmärta än äldre och kvinnor kan uppleva mer smärta än män utan att det ger större emotionell påverkan. Smärta är dock subjektiv och sann för den egna individens upplevelse, varför kvalitativa intervjuer och kvalitativ smärtskattning möjligen kan fånga individens egna upplevelse på ett mer fullständigt sätt än endast kvantitativt skattad smärta. Personer som får en knäprotes upplever i varierande grad smärtlindring och nöjdhet med resultatet efter operation. Vissa upplever fortsatt förbättring även ett år efter operationen och det kan vara av värde med kontinuerligt stöd och utökad uppföljning från sjukvården under tiden efter operation för att uppnå bästa möjliga resultat. Även efter stor proteskirurgi, som extrastabiliserade knäproteser innebär, är patientnöjdheten överlag hög med minskad smärta. Detta kan därför utgöra ett bra alternativ när indikationerna finns.

LIST OF SCIENTIFIC PAPERS

The following papers will be referred to by their roman numerals.

I. Nyvang J, Hedström M, Andreassen Gleissman S.

It's not just a knee, but a whole life: a qualitative descriptive study on patients' experiences of living with knee osteoarthritis and their expectations for knee arthroplasty.

International Journal of Qualitative Studies on Health and Well-being 2016;11:30193. doi: 10.3402/qhw.v11.30193

II. Skogö Nyvang J, Hedström M, Iversen MD, Andreassen Gleissman S.

Striving for a silent knee: a qualitative study of patients' experiences of undergoing knee replacement surgery and their perceptions of fulfilled expectations.

International Journal of Qualitative Studies on Health and Well-being 2019;14(1):1620551. doi: 10.1080/17482631.2019.1620551

III. Skogö Nyvang J, Naili JE, Iversen MD, Broström EW, Hedström M.

Younger age is associated with greater pain expression in patients with knee or hip osteoarthritis scheduled for a joint arthroplasty.

BMC Musculoskeletal Disorders 2019;20(1):365. doi: 10.1186/s12891-019-2740-8

IV. Weiss RJ, Thorsell M, Stark A, Nyvang J, Hedström M.

2- to 9-year outcome of stemmed total knee arthroplasty. Similar failure rates in patients when used primary or as a revision.

Acta Orthopaedica 2014;85(6):609–13

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ANOVA	Analysis of Variance
ASA	American Society of Anesthesiologists
BA	Body Awareness
BOA	Better management of patients with Osteoarthritis
CCK	Constrained Condylar Knee
CFR	Canal Filling Ratio
CI	Confidence Interval
EQ-5D	EuroQol 5 Dimensions
HKA	Hip-knee-ankle
HOOS	Hip disability and Osteoarthritis Outcome Score
HRQoL	Health Related Quality of Life
ICC	Intraclass Correlation Coefficient
JSN	Josefina Skogö Nyvang
K	Kappa values
K&L	Kellgren & Lawrence
KOOS	Knee injury and Osteoarthritis Outcome Score
MDI	Maura D Iversen
MH	Margareta Hedström
NSAID	Non-Steroidal Anti-Inflammatory Drugs
OA	Osteoarthritis
OARSI	Osteoarthritis Research Society International
POM	Pain-O-Meter
PRO	Patient reported outcome
QoL	Quality of Life
RH	Rotating Hinge
ROM	Range of Motion
SAG	Sissel Andreassen Gleissman
SD	Standard Deviation
SHAR	Swedish Hip Arthroplasty Registry

SKAR	Swedish Knee Arthroplasty Registry
SOASP	Supported Osteoarthritis Self-management Programme
THA	Total Hip Arthroplasty
TJA	Total Joint Arthroplasty
TKA	Total Knee Arthroplasty
UKA	Unicompartmental Knee Arthroplasty
VAS	Visual Analogue Scale

1 ERRATA

1.1 STUDY I

On page 3 in the article under the heading *data analysis* it was stated that a research assistant transcribed each interview. We would like to revise this statement. The research assistant transcribed interview number eight to twelve and I transcribed interview number one to seven.

1.2 STUDY II

On page 3 in the article under the heading *data analysis* it was stated that a research assistant transcribed each interview. The research assistant transcribed interview number two to twelve and I transcribed number one.

1.3 STUDY IV

Unfortunately, there was a mix-up between different Dnr regarding approval from the Regional Ethical Review Board. The Dnr stated in the article at page 611 belongs to a different study. The correct Dnr is 2009/1879-31/4. Acta Orthopaedica has received an erratum regarding this matter.

2 THESIS AT A GLANCE

Study	Research question	Method	Results	Conclusions
I	How do individuals experience living with knee osteoarthritis (OA) when scheduled for a knee arthroplasty and what are their expectations for future life after surgery?	Twelve semi-structured interviews were conducted with individuals with knee OA, scheduled for a knee arthroplasty, and data was analyzed by qualitative thematic analysis.	Knee OA affects life on many levels and was expressed as the central focus in the participants' lives. Knee arthroplasty was seen as the only solution but expectations regarding surgical outcome varied.	The participants could no longer live as before onset of OA and that generated a feeling of loss. Previous life and expectations for their future life must be taken into account when treating patients with knee OA.
II	How do individuals experience undergoing knee replacement surgery, postoperative recovery and were expectations of surgery fulfilled?	Twelve semi-structured interviews, with the same individuals as in study I, were conducted one year after knee arthroplasty. Data was analyzed by qualitative thematic analysis.	Participants who had continued pain had thoughts ranging from still hoping to improve to accepting living with an aching knee. Those with no pain experienced that the knee had become silent.	Continuous support throughout the postoperative period and a follow-up at one year postoperatively might identify those who need support to continue improvement and those who may need to accept persistent symptoms.
III	How do individuals with knee or hip OA, scheduled for joint arthroplasty, express pain and are there differences in pain expression between patients < 65 years and ≥ 65 years of age, and secondarily between women and men?	One hundred and eight patients with knee or hip OA, scheduled for an arthroplasty, assessed their pain and their joint-related symptoms. Preoperative x-rays were graded and the use of analgesics was recorded.	Younger patients expressed more affective words with higher intensity values in the Pain-o-Meter (POM) than older patients, despite less severe radiographic OA. Women rated their pain higher with a visual analogue scale (VAS) but did not express their pain differently than men.	The POM can be used as an additional pain assessment tool to capture pain more comprehensively and to identify those with emotional distress. Younger patients may be more emotionally affected by their pain than older patients.
IV	What is the rate of implant survival and functional outcome in procedures using stabilizing Total Knee Arthroplasties (TKA) with stemmed components as primary or revision TKA?	Clinical and radiographic evaluation of 65 surgical procedures with a mean follow-up time of 5 (range = 2–9) years.	The five-year survival rate was 82% and overall, there were 12 arthroplasty failures. Patients receiving a primary stemmed TKA had less pain and were more satisfied than those undergoing a revision TKA.	A minority had persistent pain and overall patient satisfaction and health related quality of life (HRQoL) were high. Stemmed TKA can be regarded as a good alternative when indications exists.

3 INTRODUCTION

3.1 BACKGROUND

OA is a common disease of multifactorial genesis that increases with age. The disease affects joint cartilage, synovium and the subchondral bone (Figure 1) leading to joint stiffness, swelling, pain, reduced range of motion (ROM), crepitus and ultimately varying degrees of functional impairment, a restricted lifestyle, and reduced quality of life (1-7). OA affects an estimated 9.6% of men and 18% of women (1). In 2003, OA was predicted to become the fourth leading cause of disability worldwide by 2020 (1).

In Sweden, around 18,000 individuals with hip OA and 15,000 individuals with knee OA undergo a joint arthroplasty yearly, with pain as the main indication for surgery (6, 7). In the United States, 4.2% of the population older than 50 years live with an artificial knee joint and over half of people living with diagnosed OA will undergo a knee arthroplasty (8). The demand for primary total hip and knee arthroplasties is increasing and is estimated to grow 174% and 673% respectively by 2030 (9). Overall satisfaction with surgery is approximately 81% for TKA (10, 11) and 91% for total hip arthroplasty (THA) (11). The majority of the persons receiving a TKA or THA are women and the majority is older than 65 years of age (6, 7).



Figure 1. Medial osteoarthritis of the knee. *Pickit free images*

3.2 LIVING WITH OA OR A KNEE ARTHROPLASTY

OA pain is known to cause severe distress in a person's life, including limitations in physical activity and negative impact on social relationships and emotional well-being (12). Living with constant pain leads to a new body awareness (BA), with shifted attention towards internal bodily awareness, not experienced when living a life without pain (3, 12). Further, individuals with knee OA modify their knee movements in response to pain, leading to changes in physical activity, ultimately affecting social relationships and altered self-perceptions (12). Many quantitative studies and registry studies focus on long-term prosthesis survival and physical complications such as infections, prosthetic loosening, and reoperation (7, 13-15). However, the subjective perspectives regarding experiences of living with knee OA, expectations of knee arthroplasty surgery and surgical outcome have not been sufficiently studied. Patients may experience a lack of function and persistent pain without

having a prosthetic failure and, on the contrary, may be satisfied with their knee arthroplasty despite persistent pain and functional disability. In a previous study, when asked directly about satisfaction with knee replacement outcomes, patients reported good outcomes after knee arthroplasty, but when encouraged to speak more freely they expressed concerns about persistent pain and movement difficulties (16). This highlights the discrepancy between answers obtained from questionnaires and those given in interviews, and consequently the significance of qualitative research. Qualitative research can serve as a foundation for quantitative studies in fields that have not previously been studied. It can also provide in-depth descriptions on different topics and uncover how people act and react in daily life in a way that cannot be captured by quantitative methods (17).

The terms *disease* and *illness* are used to describe different aspects of a disease, where *disease* refers to the pathophysiology and *illness* can describe the symptoms an affected person experience (18). *Illness* is subjective to the person living with the disease and can be investigated through qualitative research. *Disease* and *illness* do not always conjugate and hence it is important that both qualitative and quantitative research are conducted.

3.3 PAIN IN OA

Pain is the most prominent OA symptom. The joint cartilage is aneural and is not itself associated with joint pain. The surrounding structures, including subchondral bone, periosteum, ligaments, synovium and the joint capsule, are highly innervated and when damaged, they lead to painful movement via peripheral sensitization, and pain at rest through both peripheral and central pain sensitization (19, 20). The relationship between the radiographic severity of OA and preoperative pain is weak (21) and lateral tibiofemoral osteophyte grade has been shown to be an independent factor for preoperative function but not pain (22). A visual analogue scale (VAS) is the most common pain assessment tool used in clinical practice. For knee and hip OA there are several validated self-administered questionnaires to assess joint-related symptoms and the Swedish knee- and hip arthroplasty registries (SKAR and SHAR) use the Knee Injury and Osteoarthritis Outcome Score (KOOS) and the Hip Disability and Osteoarthritis Outcome Score (HOOS), of which pain has its own subscale (23, 24).

A previous study examining pain one year after TKA, using both a VAS and the KOOS pain subscale, found that among patients that reported unchanged or worse pain, only 23% did so in both measurements (25). The authors suggested these measures might capture different aspects of pain (25). To better understand the impact of pain on function and satisfaction with care, researchers and clinicians need a tool that can measure pain in a broader perspective. The Pain-O-Meter (POM) is a pain assessment tool that measures pain both quantitatively, by using a VAS, and qualitatively, via sets of sensory and affective words (26). The POM has been validated to describe pain in different patient groups (27, 28), such as those with rheumatoid arthritis (26) who have chronic pain similar to patients with OA. Additionally, pain experiences can be explored through interviews with individuals to learn about the

emotional of impact pain and the overall experience of living with knee OA or with a knee arthroplasty.

3.4 OA IN DIFFERENT AGES AND IN WOMEN AND MEN

The incidence of OA is rising among adults, which leads to a greater use of joint arthroplasties. A fivefold increase in the use of TKA was seen in individuals under 55 years of age between 1998 and 2007 (29), but the risk of surgical complications and prosthesis failure is higher in this group (4-7, 14). Few studies have investigated the impact of age or sex on the experience of living with knee or hip OA. Previously, individuals under 65 years of age have been considered to be “too young” for surgery, which may have led to worse pain and symptoms prior to surgery (30, 31). Further, younger patients have been reported to experience less improvement in pain relief after surgery than older patients (30) and patients < 55 years of age score worse on assessments of emotional well-being than older patients (32). Another study showed contrary results with older age as a risk factor for worse pain and symptoms 1– to 5 years after a TKA compared to younger age (33). Adults between the ages of 45 and 64 years with chronic pain have reported more intense negative emotions compared to those over 65 years of age (34), but the reason for this discrepancy remains unclear.

Sex and gender inequality in health care in different health conditions have previously been reported (35-37). For OA, women have been reported to have worse knee or hip-related pain and function prior to surgery than men (38-40). Some studies report women are less likely to be recommended for total joint arthroplasty (TJA) despite evident indications for surgery (41, 42), while a more recent study showed no difference in recommendations for TKA between women and men (43).

Many different parameters can influence the way a person expresses how they experience a phenomenon such as living with OA. Age and sex may influence how pain is expressed and how individuals with OA are affected by pain.

3.5 INDICATIONS FOR SURGERY AND SURGICAL PROCEDURES

Pain and functional disability are the primary indications for knee and hip arthroplasty in patients with OA. OA is a clinical diagnosis based on a number of clinical features. Pain during movement is thought to be one of the cardinal features, but pain at rest and/or at night becomes more common as the disease progresses (19, 44). For knee OA, other common clinical features include stiffness, reduced ROM, swelling and crepitus (19). Similar to knee OA, hip OA often presents with reduced ROM and additionally groin pain (44). Plain x-rays are used for both hip and knee OA to confirm the diagnosis. However, the correlation between symptoms and radiographic grade of OA is weak (22). Before a joint arthroplasty is considered, patients are offered non-surgical treatment options to reduce pain and increase their functional level. In obese patients, weight loss is recommended to reduce the mechanical load on the joint (19, 44). Further, physiotherapy and pharmaceutical treatments with non-steroidal anti-inflammatory drugs (NSAIDs) and/or paracetamol are offered (19, 44). The Supported Osteoarthritis Self-management Programme (SOASP) includes individually

adapted information and education about OA and physiotherapy (artrosskola) and is a well-established treatment in Sweden. The Better management of patients with OA (BOA) registry reported that 21% of patients with knee OA and 16% with hip OA included in the program were able to quit using joint-related medication after completed treatment (45). Arthroplasty is considered when joint-related pain and functional disability affects the patient's quality of life and when other treatment options are insufficient.

Hip arthroplasties are performed as either total arthroplasty (THA) – where both the femoral head and acetabulum are replaced – or as a hemi arthroplasty – where only the femoral head is replaced. In patients with hip OA it is most common to perform a THA due to disease progression both on the femoral and the acetabular side. The stem of the femoral side is inserted either with or without cement, based on the quality of the femoral bone structure and the patient's age (6). Lower bone quality may require cement to fixate the stem and to minimize the risk of fracture. Different surgical approaches are used depending on the preference at the surgery clinic. The most common surgical approaches are the posterior approach – which accesses the joint from the back – or the anterolateral approach – accessing from the side. Minimally invasive approaches are sporadically used in order to minimize the incisions and to preserve surrounding structures.

Different knee arthroplasty designs are used depending on the severity of the structural changes of the knee joint. Unicompartmental Knee Arthroplasty (UKA) implies an arthroplasty that separately resurfaces the medial or the lateral femoral-tibial compartment (medial or lateral UKA). When the posterior cruciate ligament and the lateral and medial collateral ligament of the knee are maintained, a TKA is most often used where the tibia- and femur condyles are replaced by prosthetic material and a plastic inset is used to serve as synovial surface. Weight bearing x-rays and different angles of the hip-knee-ankle (HKA) are performed as preoperative assessment of the knee joint deformity. In Sweden, the use of cement is the most common way to fixate the components and spinal anesthetics are used in a majority of the cases (4, 7). The knee joint is accessed from the front and the patella is dislocated to one side. The cartilages, meniscuses and anterior cruciate ligament are removed while the posterior cruciate ligament is often preserved as well as the patella.

In patients with severe valgus- or varus instability and/or increased laxity in the flexion gap, a stabilized TKA with stemmed components might be necessary (46). Stemmed TKA models are mainly used for revisions of a previous TKA or in difficult primary cases. Stemmed knee implants can also be classified as constrained condylar prostheses (CCK) or linked rotating hinge (RH) designs. The demand for revision knee implants is increasing and expected to grow by approximately 600% between the years of 2005 and 2030 (9).

3.6 OUTCOMES AFTER KNEE ARTHROPLASTY

Numerous parameters can be used to evaluate knee arthroplasty outcomes. At clinical follow-up, the patient is asked to assess knee-related pain and function and their level of satisfaction with surgical outcomes. Depending on the surgery clinic, patients may also be asked to fill

out self-administered questionnaires such as the KOOS to evaluate pain, symptoms, activities of daily living (ADL), functions in sports and recreation and knee-related quality of life (QoL). Further, a clinical examination is performed where walking ability, alignment, ROM and stability are examined. The visit rarely exceeds 15 minutes and there is limited time to address matters that are not physically measurable. The majority of patients receiving a TKA are satisfied with the surgical outcome. However, 15–20% report persistent joint-related pain and symptoms and are dissatisfied with their replaced joint (10, 47, 48). Predictors of patient satisfaction and postoperative pain and function include preoperative expectations for surgical outcomes (10), postoperative expectations (49), the severity of preoperative disease (50, 51), diagnosis (Rheumatoid Arthritis vs. OA) (50), area deprivation (31, 50), anxiety/depression (50), age (30-32, 51, 52) and sex (51, 53, 54). A few qualitative studies exist regarding knee arthroplasty outcomes and these studies report varying findings. One study found that most participants experienced improvements in pain and function, but for others the overall TKA experience was negative, despite a good postoperative outcome (55). On the contrary, another study reported that participants experienced a good postoperative outcome despite continued pain and immobility (16).

Aseptic loosening of the primary prosthesis has been reported to be the most common indication for a stemmed TKA (56) but recent data from the SKAR (2019) found that infection is now the leading cause for revision knee surgery (7). Infections are a common reason for failure due to the large volume of foreign material implanted in the knee compared to primary implants (15, 46). Additionally, earlier data suggest revision implants are more prone to failure than primary implants (7). Due to the increasing numbers of stemmed knee arthroplasties in Sweden, it is important to gain a better understanding of factors influencing survival rates and functional outcome, and further to determine whether differences exist in patient reported outcomes (PRO) in primary knee replacement or revision total knee replacement.

4 RATIONALE

OA is a well-known cause of pain and functional disability. Living with pain is a major stressor and can cause increased morbidity and mortality. However, pain is subjective and difficult to assess. Pain can also be affected by other parameters in a person's life such as their emotional well-being and life situation. Living with a long-term illness, in this case OA, can cause severe distress and altered self-perceptions. Not all individuals receiving a joint arthroplasty become pain free and without movement difficulties. This implies that not everyone is satisfied with the surgical outcome. However, a person can be satisfied despite continued joint-related symptoms. Qualitative interviews and qualitative pain measurement can provide a broader explanation to the phenomenon of living with OA, how these individuals perceive, and are affected by pain and other symptoms. Further, person-centered quantitative studies can arise from individuals' narratives: The things that are important to an individual with respect to living with disabilities. To learn about the patient's perspective of living with a knee arthroplasty can add to the knowledge about patient satisfaction in relation to the surgical outcome.

There is a lack of qualitative person-centered studies within the orthopedic field and the purpose of these studies was to elucidate this field for the above-mentioned reasons. We also wanted to investigate the outcome after the use of a stemmed TKA in primary and revision cases as this has sparsely been investigated before.

5 AIMS OF THE THESIS

The overarching aim of this thesis was to investigate and describe individuals' experiences of living with knee or hip OA and outcomes after knee arthroplasty using both qualitative and quantitative methods.

The specific objectives addressing the overarching aim were:

- i. To describe patients' experiences of living with knee OA when scheduled for knee replacement surgery (study I).
- ii. To describe their expectations for future life after knee replacement surgery (study I).
- iii. To describe patients' experiences of undergoing knee replacement surgery, either TKA or UKA, and postoperative recovery (study II).
- iv. To determine whether expectations of surgery were fulfilled (study II).
- v. To investigate how patients with knee or hip OA, who were scheduled for joint arthroplasty, expressed pain (study III).
- vi. To investigate whether differences existed in pain expression between younger and older patients (< 65 vs. ≥ 65 years of age) (study III).
- vii. To investigate whether differences existed in pain expression between women and men (study III).
- viii. To gain information on implant survival and functional outcome in stabilizing TKAs with stemmed components (study IV).
- ix. To measure complication rate, patient satisfaction, health-related quality of life, and radiographic results in patients with a stemmed TKA (study IV).
- x. To investigate if there were any differences in patient outcome when a stemmed TKA was used as a primary knee replacement or as a revision TKA (study IV).

6 METHODS

6.1 OVERVIEW OF METHODS

Study	I	II	III	IV
Research question	How do individuals experience living with knee OA, when scheduled for knee replacement surgery, and what are their expectations of future life after surgery?	How do individuals experience undergoing knee replacement surgery, postoperative recovery and were the expectations of surgery fulfilled?	How do individuals with knee or hip OA, scheduled for joint arthroplasty, express pain, stratified by age and sex?	What is the rate of implant survival and functional outcome when stabilizing TKAs with stemmed components are used as primary or revision TKA?
Approach	Qualitative	Qualitative	Quantitative	Quantitative
Design	Interview study	Interview study	Cross-sectional	Retrospective and clinical follow-up
Study population	Individuals with knee OA, scheduled for a knee arthroplasty	Individuals who have received a knee arthroplasty due to OA the previous year	Individuals with knee or hip OA, scheduled for joint arthroplasty	Individuals receiving a stemmed TKA, as primary or as a revision TKA
Study sample	Twelve patients with knee OA, scheduled for a knee arthroplasty within the next month	Follow-up interview with the 12 patients included in study I	One hundred and eight patients (64 women)	Sixty-five consecutive cases
Data gathering	Semi-structured interviews	Semi-structured interviews	POM-VAS, POM-words, self-administered questionnaires (KOOS/HOOS, EuroQoL 5 Dimensions (EQ-5D)), radiology classifications, use of analgesics	Clinical examination, VAS, grading of radiolucent lines, canal filling ratio (CFR), KOOS, EQ-5D, Likert scale for satisfaction, self-reported change in walking distance and the use of walking aids
Analysis	Qualitative thematic analysis	Qualitative thematic analysis	Independent T-test, Mann-Whitney U. χ^2 test, Fisher's exact test. Three-way ANOVA	Kaplan-Meier survival analysis, Wilcoxon signed-rank test, Mann-Whitney-U, χ^2 test

6.2 METHODOLOGICAL ASSUMPTIONS

In this thesis we have used either a quantitative or a qualitative approach with regard to the research questions. Quantitative and qualitative research differ on many levels but both have an important role in describing and understanding the world. Quantitative research is part of the positivistic paradigm, assuming that the world is orderly arranged, allowing us to study the world objectively, whilst qualitative research is part of the constructivist or naturalistic paradigm assuming that there are several interpretations of reality and that individuals construct their own reality within their own natural context (57). While quantitative research answers questions such as ‘How much, how many and how often?’, the questions ‘What, how and why?’ are more often posed in qualitative research. A quantitative approach is appropriate to use in research questions that can be measured or calculated and generalized across time and space, while a qualitative approach is more appropriate to understand, in-depth and holistically, the meaning of a phenomenon (57, 58). It is important to know that qualitative research is not generalizable to a greater population, but that is not its purpose. Quantitative and qualitative methods can complement each other and increase validity of clinical evidence through triangulation (57, 59).

We chose to use both quantitative and qualitative methods in this thesis as pain, the main indication for joint arthroplasty, is subjective and complex to assess. Quantitative assessment of pain via self-administered questionnaires (KOOS/HOOS) and a VAS were used to complement the qualitative pain assessment using the POM (study III). Interviews were used to gather a person-centered perspective on living with OA and a knee arthroplasty (study I and II). Study IV was included in the thesis as this study was the study that led me to start my doctoral studies and because its retrospective nature complements the other methods in the thesis. Finally, there was no data regarding how individuals with a stabilizing TKA with stemmed components assessed their pain and knee-related symptoms.

6.3 STUDY DESIGN AND SUBJECTS

6.3.1 Study I and II

Study I and II used a qualitative descriptive inductive approach to describe the experiences of living with knee OA and following knee arthroplasty. In qualitative research, the process for sampling participants focuses on gathering those with a rich story to tell. Purposeful sampling is used by researchers to decide which participants will be most informative (57). Our goals were to recruit a broad range of participants that had different experiences of living with knee OA, to get a rich description of the phenomenon. In collaboration with the orthopedic surgeon, we invited 12 patients with knee OA from Karolinska University Hospital, who were scheduled for a knee arthroplasty, to be included in study I and II (Table 1). The orthopedic surgeon contacted the participants and asked if they were willing to participate in two interviews, and none declined. The first occurred within a month prior to surgery and the second one year postoperatively. They received written and oral information about the study and were informed of the voluntary participation and the right to withdraw their consent at

any time. Purposeful sampling was used to get maximum variation in age and sex in an attempt to document diversity and important common patterns across the diversity (57). A preliminary number of 10–20 participants was decided before the first interview. The study was concluded with 12 participants, when no new information was expected to occur with new interviews. The information gathered in the interviews was considered to be redundant (57) and the inclusion of participants was stopped.

Study II included the same participants as in study I and the criteria for redundant information did not apply here. Prior to the second interview, the interviewer contacted all participants by telephone and asked again if they were interested in participating, none declined. In total, 12 individuals were included of which 7 were women and 5 men. Prior to the first interview the patients' ages ranged from 47 to 77 years, with a median age of 66 years, and five out of twelve were retired. Prior to the second interview, the participants were roughly one year older than during the previous interview and nine out of twelve had retired from work. Median pain assessed with a VAS was 43.5 (range=4–76) prior to knee replacement surgery and 0 (range=0–43) one year after surgery.

Table 1. Inclusion and exclusion criteria for study I and II.

Inclusion criteria	<ul style="list-style-type: none"> • Scheduled for a primary knee arthroplasty due to OA • Able to speak Swedish well enough to be interviewed in Swedish
Exclusion criterion	<ul style="list-style-type: none"> • Previous knee arthroplasty (study I)

6.3.2 Study III

To investigate how individuals with knee or hip OA who were scheduled for a joint arthroplasty expressed their pain, we found it suitable to conduct a cross-sectional study and use a pain measurement, the POM (26), that could assess pain both quantitatively and qualitatively. The majority of the included patients (n=74) were part of a prospective study evaluating function and gait patterns in patients with knee or hip OA awaiting joint arthroplasty (60, 61). As pain is a prominent symptom for patients with severe knee or hip OA it was logical to also assess pain during gait. The gait laboratory researchers found that younger individuals (< 65 years) expressed pain differently than older individuals during the gait analysis. This impression was the catalyst for the hypothesis in study III. Further inclusion was: patients enrolled in the interview studies (n=12) (study I and II), patients gathered at a preoperative information about surgical procedures for patients scheduled for knee or hip arthroplasty (n=14) and patients gathered for a master's degree where the POM was used (n=8). This resulted in 121 included patients invited to participate. However, 13 were excluded for the following reasons: 4 did not fill out the POM, 1 had an ankle joint arthroplasty, 4 due to caput necrosis (hip), 1 had previously been included prior to his first hip

arthroplasty, 1 had severe problems with a knee but was scheduled for a hip arthroplasty, 1 due to previous Polio disease and 1 did not receive the TJA. Inclusion and exclusion criteria are described in table 2. The remaining 108 patients (64 women) with knee (n=58) or hip (n=50) OA scheduled for a joint arthroplasty, were recruited from two orthopedic departments in Stockholm: OrthoCenter Stockholm Löwenströmska Hospital and Karolinska University Hospital in Stockholm. Patients were considered relatively healthy (all graded 1–2 of the American Society of Anesthesiologists (ASA) classification) (62). Two thirds of the participants were women and the overall mean age was 66 years (Standard Deviation (SD)=8.5).

Table 2. Inclusion and exclusion criteria for study III.

Inclusion criteria	<ul style="list-style-type: none"> • Scheduled for a primary knee or hip arthroplasty due to OA • Were able to understand verbal and written information in Swedish • Being able to walk 10 meters repeatedly without walking-aids
Exclusion criteria	<ul style="list-style-type: none"> • Diseases affecting lower limb function (e.g. neurological diseases and/or diabetes) • Pseudarthrosis or damages to the joint other than primary OA (e.g. caput necrosis)

6.3.3 Study IV

The aim of the study was primarily to gain information on implant survival and functional outcomes in individuals who had received a stemmed stabilized TKA (will be referred to as stemmed TKA throughout the thesis). Since this surgical procedure is fairly uncommon we decided to evaluate procedures that had already been performed. This retrospective study included 65 consecutive cases in 63 patients that had received a stemmed TKA over the last 2–9 years at Karolinska University Hospital or Capio St. Göran’s Hospital in Stockholm, Sweden (Table 3). In 24 cases, the procedure was performed as a primary arthroplasty and in 41 as a revision arthroplasty. The mean age at index surgery was 68 years (SD=12). OA was the primary diagnosis for the majority of the patients. When operated as primary stemmed TKA, instability of the knee joint was the predominant indication, while aseptic loosening was the primary indication for a secondary stemmed TKA. For those who received a secondary stemmed TKA, the mean time that had passed since the primary TKA was 6 (SD=5) years. In 40 cases, a stemmed CCK prosthesis was used and in 25 cases, a stemmed RH prosthesis was used, depending on the integrity of the surrounding soft-tissue structures

providing stability, and bone defects. Clinical follow-up was conducted in 61 cases (4 prostheses were removed).

Table 3. Inclusion criterion for study IV.

Inclusion criterion	<ul style="list-style-type: none">• All cases where a stemmed stabilized TKA had been used the past 2–9 years
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6.4 QUALITATIVE INTERVIEWS AND DATA ANALYSIS

6.4.1 Research team and reflexivity

The research team consisted of three (study I) and four (study II) members: an orthopedic surgeon (MH) with expertise in the OA diagnosis and arthroplasty surgery, an assistant professor (SAG) with great experience in qualitative methods and qualitative research in people living with a long-term illness, and myself (JSN), who has a special interest in the phenomenon of living with OA and how it affects individuals. For the second interview, we included a professor (MDI) in physical therapy and public health with expertise within qualitative methods and OA. The research team discussed and reflected on topics and was active in critical self-reflection to raise awareness of their pre-understanding and to increase reflexivity to minimize the risk of influencing the research with their own pre-conceived assumptions (57).

6.4.2 Semi-structured interviews

An interview – or *inter view* – is an interaction between two persons. The purpose of qualitative interviews is to gain deep descriptions on the interviewees' experiences of a predetermined topic (63). The method was appropriate to use since the aim was to understand the participants' lived experiences of OA. These individuals were the best ones to describe how they experienced a particular phenomenon, in this case living with knee OA. In semi-structured interviews there are predetermined issues to be covered. To facilitate and ascertain that these issues are covered during the interview it is recommended to use an interview guide (57, 63). The interview guide should neither be too general nor too detailed due to the risk of missing information of value. Relevant topics were discussed within the research group and agreed upon, forming the interview guides (Table 4).

Patton (2015) describes the importance of neutrality and being non-judgmental and empathic as an interviewer in the interview setting (57). I conducted all interviews in Swedish. All participants were aware I was a medical doctor and that I was not involved in the decision to undergo surgery, the choice of surgical procedures, or clinical follow-up. The participants were encouraged to speak freely about their experiences.

Table 4. Interview guides for study I and II.

Study I		Study II	
Initial question			
Can you tell me about your experiences of living with knee osteoarthritis?		Can you tell me about your experiences regarding knee replacement surgery and the period thereafter?	
Main topics	<i>Examples of the content of the topics</i>	Main topics	<i>Examples of the content of the topics</i>
Background	<i>Symptom duration, experience of receiving care as expected</i>	Surgical procedure	<i>The experience of the surgical procedure and given care. How did preoperative information relate to reality?</i>
Pain	<i>How does pain influence daily living and social relationships?</i>	Given care at hospital	<i>The experience of given care, pain management and physical therapy.</i>
Physical function	<i>How does reduced physical function influence daily living and social relationships?</i>	Rehabilitation	<i>The experience of rehabilitation conducted with physical therapy and own training.</i>
Given care	<i>How was given care experienced?</i>	Pain and physical function	<i>How was pain and physical function perceived during the year following knee arthroplasty in relation to daily living and social relationships?</i>
Expectations	<i>What are the expectations for surgery with regards to pain, function, quality of life and social relationships and are there any fears?</i>	Social relationships	<i>What have changed?</i>
		Fulfilled Expectations	<i>How well did preoperative expectations correspond to outcome? Was it worth the trouble to undergo surgery?</i>

The interview guide was used to cover all topics but the participants were free to introduce new topics that were relevant to the study aim. In-depth probing questions were posed to exhaust the information on a topic and to ensure that it was understood correctly. All interviews took place at a location that was convenient for the participant. For study I, all interviews but two, took place at a private room at the hospital. One interview was conducted in the participant's home, and the other one at their workplace. For study II, two interviews were conducted in the participants' home, one in a secluded room at a theatre and nine in a private room at the hospital. For study I, a number of interruptions during the interviews were noted: in five interviews there were interruptions from health care personnel opening the door to the room, there was a scheduled short power brake and lastly one interview was interrupted when the participant's husband came home from work. In two interviews the participant's partner decided to quietly attend the interview with permission from the patient (study I). However, neither the interruptions nor the partners were considered to have affected the quality of the interviews. No specific interruptions were noted for interviews in study II. The interviews were recorded and lasted between 25 and 65 minutes (mean=39 minutes) (study I), and between 26 and 63 minutes (mean=43 minutes) (study II).

6.4.3 Qualitative thematic analysis

We decided to analyze the data through qualitative thematic analysis (57) as our aim was to both describe the individuals' experiences and to elucidate and interpret its core meaning. Qualitative content analysis on a manifest or latent level are other commonly used terms. A manifest approach implies that the analysis is conducted closely to the transcriptions, without interpretation, and a latent approach implies the data is interpreted to a higher level (64). Qualitative thematic analysis is another term for qualitative content analysis on a latent level. Each interview was transcribed verbatim by JSN (interview number one to seven in study I, interview number one in study II) or by a research assistant (interview number eight to twelve in study I, interview number two to twelve in study II). Transcribing interviews can be seen as part of the data analysis as it is important to familiarize yourself with the data and to live with the data (57). However, this part is time consuming and due to time limitation, the decision was made to have another person transcribe the tapes. To ensure good quality of the transcripts I read the transcripts while listening to the recordings. Patton (2015) describes qualitative thematic analysis consisting of two parts: descriptive, and interpretive, where themes are formulated (57). In the descriptive part, the transcripts were read and re-read several times to comprehend the overall meaning and how it corresponded to the aim. Notes were made and important key phrases were highlighted and grouped into preliminary codes and categories. The categories were thereafter discussed back and forth between all authors, to ensure internal validity (57) and to decide upon categories. Post-its with key phrases and categories were used (Figure 2) (study I) to easily re-categorize a key phrase, when suitable, and to get an overview of the analysis. Further, messy maps (65) (figure 3) and MAXQDA Standard 12 software (66) were used in study II for the same purpose. Messy maps can be used early in the analysis with the purpose to find key phrases that require further investigation (65) (Figure 3).

Figure 2. Example of analysis process (study I). White stripes represent meaning units and post-its their preliminary codes.

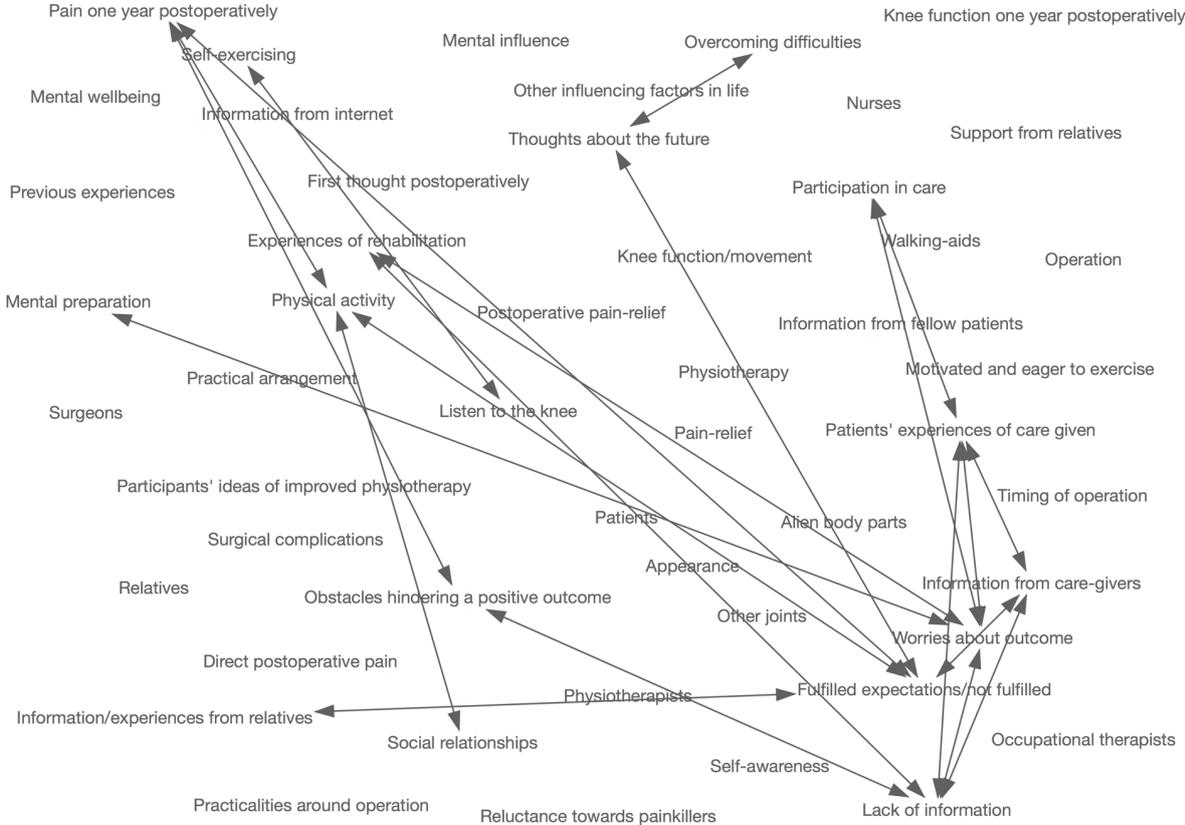
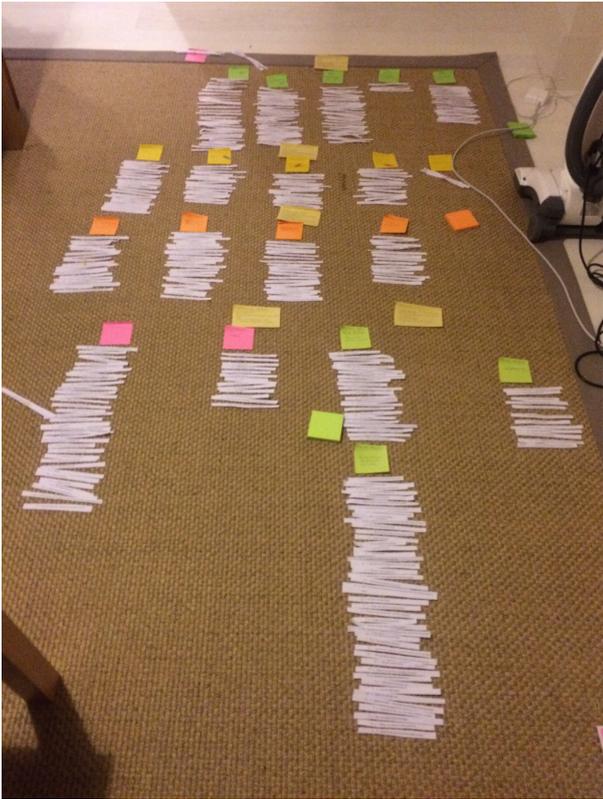


Figure 3. Example of the analysis process at an early phase with messy map (study II).

The categories were again compared to the original transcripts to ensure no important information had been lost in the analysis and, with the aim in mind, underlying meanings of the codes and categories were extracted to interpret the results into themes. Figure 4 describes the analysis process and table 5 demonstrates examples of the analysis process. Writing the manuscript was part of the interpretive analysis and started early in the analysis process in order to structure the findings and visualize data (67). As we wrote, questions arose that forced us to go back to the raw data and our analysis to seek answers and to solve the problems (67).

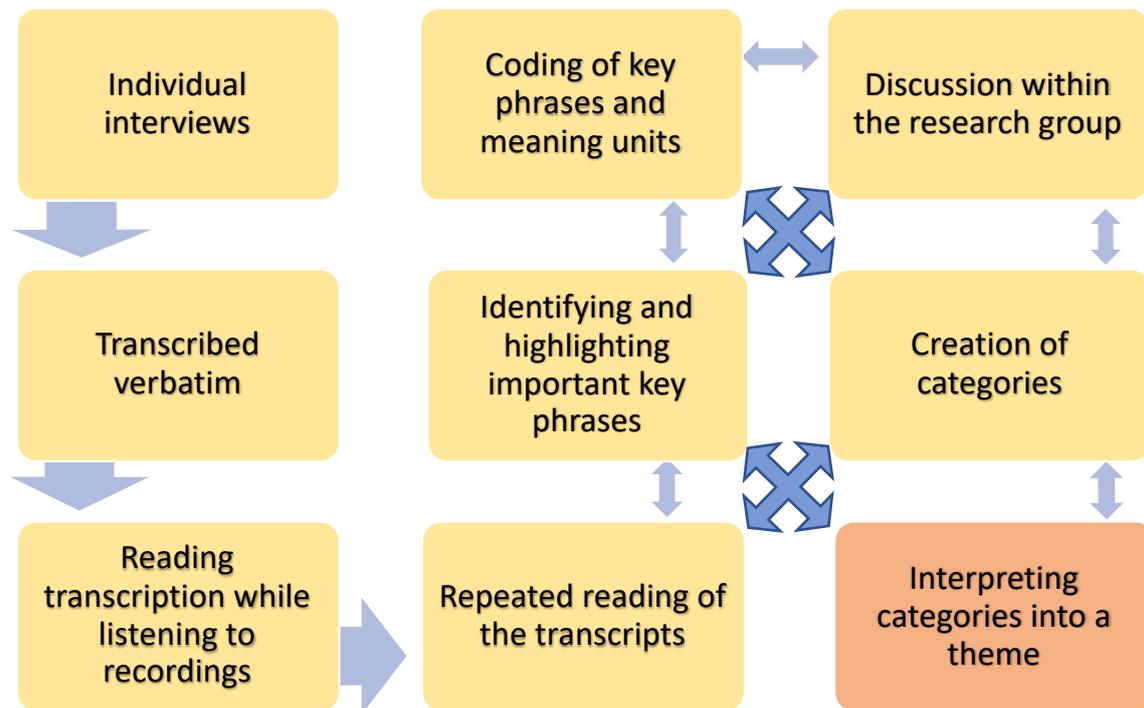


Figure 4. The analysis process during qualitative thematic analysis (study I and II). Double arrows symbolize the process of going back and forth between the analytical steps to ensure no valuable data were missing.

Table 5. Examples of the analytical processes in study I and II.

	<i>Key phrases</i>	Code	Subcategory	Category	Theme
Study I	<i>A friend calls: “you wanna play golf?”. Well, then I have worked hard the previous day so: “no I can’t today, it’s not possible”</i>	Reduced spontaneity	Struggling through everyday life	Change from their earlier lives	It’s not just a knee, but a whole life
	<i>The pain takes away the joy of doing things</i>	Pain affects the mood	Emotional distress		
	<i>I have to take the elevator instead of stairs</i>	Physically reducing pain	Physical coping strategies	Coping with knee problems	
	<i>I should not complain, I am very happy that I feel as good as I do</i>	Positive thinking	Cognitive coping strategies		
	<i>I don’t take many pills, I only do it when nothing else works</i>	Reluctance to taking painkillers	Alleviating pain		
	<i>But I think it was when I saw that there was no cartilage left, then I thought: “now it’s time”</i>	Surgery as the only way out	---	Ultimate decision to undergo surgery	
	<i>The feeling that I would be able to do anything</i>	Expectations			
Study II	<i>I felt confidence right away towards this physiotherapist. And then it’s much easier to cooperate</i>	Trusting health care personnel	Participation in care	The bumpy road to recovery	Striving for a silent knee
	<i>Maybe, you’d like to have more distinct information on what to expect after 3 months, or 1 month and so on</i>	Lack of information	Mental preparation		
	<i>Before, you always thought of or felt the knee. Now, you neither feel it or think about it</i>	Unawareness of the knee		The presence of the future	
	<i>And most of all I don’t want to be in pain. You can understand that right? Well, maybe it will pass. It’s been a year now. Maybe it will be better eventually.</i>	Hoping for a better future	---		

6.4.4 Trustworthiness

Trustworthiness is a term in qualitative research that can be related to validity, reliability and generalizability in quantitative research. Trustworthiness can be evaluated through how the findings were generated (64). The concepts credibility, transferability, dependability and confirmability have been described as criteria for ensuring trustworthiness (68).

Credibility refers to how well the research findings correspond to the original stories told by the participants and to confirm that these stories are correctly interpreted (57, 68). Credibility can be achieved in different ways and starts with the inclusion of participants. We used purposeful sampling to include both men and women of various ages to gather information on different aspects of living with knee OA. Semi-structured interviews were employed as the aim was to describe the variable experiences of living with knee OA or an arthroplasty. The amount of gathered data can facilitate the assessment of whether the data collection procedure is suitable to answer the aim. Our purpose was not to generate a new hypothesis but rather to give rich descriptions on an interpretive level for the phenomenon, thus, we used an inductive qualitative thematic analysis (57). In the data analysis we discussed categories and themes in an iterative manner between all authors, which is a form of analytical triangulation (57). Further, interpreted text were compared to the original text to ensure that no relevant data was missing and the entire data collection and analysis processes were described in detail with suitable quotes to represent original data.

Transferability refers to what extent the reader can judge the findings to be applicable to other contexts (68). We facilitated transferability using a thick description of the method, study sample and analysis. We also described the findings with representative quotes from the participants (64). This can help the reader evaluate the extent this research can be transferred to other patients with knee OA who are scheduled for a knee arthroplasty or who are living with an arthroplasty.

Additionally, dependability refers to how well the research is logical, traceable and documented, and confirmability to what degree data and interpretation are objective (68).

6.5 PATIENT-REPORTED OUTCOME MEASURES

6.5.1 Pain

6.5.1.1 POM (study III)

The participants were instructed to assess their pain when walking from the waiting room using the POM, since loading pain is common among individuals with knee or hip OA. The POM has been validated for different patient groups including patients with rheumatoid arthritis (26) who suffer from chronic pain similar to patients with OA. There are two parts of the POM to assess the pain: POM-VAS and POM-words. POM-VAS ranges from 0–100 on a best to worst scale that helps the health care provider quickly evaluate the pain. POM-words consists of 12 sensory- and 11 affective words and helps the health care provider to form an idea of the qualitative part of the pain (Table 6). The patients were allowed to choose as many

words from the sensory- and the affective group as necessary to describe their pain. Each word has an assigned intensity value, unknown to the patient, ranging from 1–5 where 1 is considered a lighter pain than 5. The values are added separately in the two groups to form intensity scores. Sensory words characterize pain intensity while affective words provide the emotional aspect of the pain experience.

Table 6. Sensory and affective POM-words.

Sensory words (svenska) [value]	Affective words (svenska) [value]
A Cutting (skärande) [5]	M Irritating (irriterande) [2]
B Grinding (molande) [2]	N Frightening (skrämmande) [4]
C Pricking (stickande) [1]	O Troublesome (besvärlig) [3]
D Squeezing (klämmande) [2]	P Suffocating (kvävande) [5]
E Cramping (krampaktig) [4]	Q Killing (mördande) [5]
F Tearing (sönderslitande) [5]	R Unbearable (odräglig) [4]
G Aching (värkande) [3]	S Terrible (fruktansvärd) [5]
H Smarting (svidande) [2]	T Tiring (tröttande) [3]
I Burning (brännande) [4]	U Worrying (oroande) [1]
J Sore (ömmande) [1]	V Excruciating (outhärdlig) [5]
K Gnawing (gnagande) [3]	W Torturing (tortera) [5]
L Pressing (tryckande) [4]	

6.5.1.2 VAS (study I– IV)

The VAS is a 10 cm long stick graded from 0–100 where 0 is no pain and 100 is worst possible pain. The participants were instructed to rate their pain levels using a movable bar and the numeric grading was not presented to the participants. VAS has been shown to be a reliable and valid tool for measuring the pain intensity in children and adults (69). A difference of 15–20 points between groups with OA can be considered of minimal clinical importance (7). The VAS included in the POM was used for study I–III and the participants were asked to assess the pain they had experienced when walking from the waiting room. For study I and II the sole purpose of measuring pain with the VAS was to describe patient

demography. For study IV a VAS was used at follow-up to measure pain at rest and at movement.

6.5.2 Physical Function

6.5.2.1 KOOS and HOOS (study I – IV)

The KOOS and the HOOS are reliable and validated joint-specific questionnaires for knee OA and hip OA, respectively (24, 70). They consist of five joint-specific subscales: Pain, symptoms, ADL, function in sports and recreation, and hip or knee-related QoL. They are used to measure baseline symptoms, including pain and function, and change over time in patients with knee or hip OA (24, 70). Each subscale consists of questions on a Likert scale graded 0–4 (0 equals no problems and 4 extreme problems) and the subscales are scored separately from 0–100 where 0 indicates extreme symptoms. A difference of 8–10 points between groups can be considered of minimal clinical importance (7). Each dimension of the KOOS and HOOS is scored independently. The participants were instructed to fill out KOOS or HOOS preoperatively (study I and III), at the second interview one year postoperatively (study II) and at clinical follow-up (study IV). For study I and II the sole purpose of using the KOOS was to describe patient demography. Reliability is high for both KOOS (Intraclass Correlation Coefficient (ICC)=0.78–0.91) (70) and HOOS (ICC > 0.78) (71). The ICC is a measurement of the agreement of continuous measurements of a scale for two or more raters. Less than 0 is considered poor agreement, 0–0.2: slight, 0.21–0.4: fair, 0.41–0.6: moderate, 0.61–0.8: good, and 0.81–1: very good agreement (72).

6.5.2.2 Clinical examination (study IV)

At the follow-up visit, all patients received a clinical examination including measurements of ROM, medial-lateral stability and patella tracking. They were also asked to assess their level of satisfaction with the outcome of surgery as ‘very satisfied’, ‘satisfied’ or ‘dissatisfied’ and were asked about their use of walking aids and self-reported walking distance.

6.5.3 Health related quality of life

6.5.3.1 EQ-5D (study III and IV)

The EQ-5D is a widely used and generic (non-disease-specific) questionnaire provided by The EuroQoL group to measure HRQoL (73). It consists of five questions regarding patients’ perceived problems in daily living including: Mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The patients’ answers can be transformed into an EQ-5D index score developed by value sets on previous answers from a large population and ranging between -0.594 (worst thinkable health) and 1, interpreted as full health (74). The index score has been reported to be problematic and difficult to interpret (75). There is also a VAS measuring the patients’ self-reported overall health ranging from “worst imaginable health [0] to “best imaginable health” [100]. Only the VAS dimension of EQ-5D was used in

study III and the patients were asked to assess their overall health experienced that same day. For study IV the EQ-5D was presented to the patients at follow-up.

6.6 RADIOLOGY

6.6.1 Kellgren & Lawrence modified grading scale for OA

All preoperative radiographs were independently assessed by two experienced orthopedic surgeons to objectively measure the severity of OA (study III). The Kellgren & Lawrence (K&L) system is a method for classifying the severity of knee and hip OA on a scale from 0 to 4 (76):

- 0: No radiographic features of OA are present
- 1: Doubtful joint space narrowing and possible osteophytic lipping
- 2: Definite osteophytes and possible joint space narrowing on anteroposterior weight-bearing radiographs
- 3: Multiple osteophytes, definite joint space narrowing, sclerosis, and possible bone deformity
- 4: Large osteophytes, marked joint space narrowing, severe sclerosis, and definite bone deformity

In the modified K&L radiographic grading scale, grade 3 and 4 are divided into 3a/b and 4a/b:

Grade 3a is mild joint space narrowing, grade 3b is more severe joint space narrowing but not diminished. Grade 4a is complete loss of joint space but without bone attrition and grade 4b as 4a but with subchondral bone attrition (22).

There are other radiographic grading scales for classifying the severity of OA (e.g. Ahlbäck radiographic grading scale of OA) (77) and none, including the K&L grading scale, have an inter- and intraobserver reliability of Kappa values (K) = 0.81–1, considered to have very good agreement (78). However, the K&L scale was used as it was the scale best known to the orthopedic surgeons that classified the radiographs.

6.6.2 Grading of radiolucent lines and patellar thickness in stemmed TKA

Radiolucent lines around the components of the prosthesis can be regarded as signs of prosthetic loosening depending on the width of the lines. The presence of radiolucent lines at follow-up for revision knee implants were graded according to the Knee Society Roentgenographic Evaluation System (79) (study IV). The femoral- and the tibial components are divided into 5–7 zones each and radiolucent lines are measured in millimeters (grade 0–3). The zone widths are added together, forming a total width for each component. A total width of less than 4 mm is considered non-significant, a width of 5–9 mm should be followed closely and a width > 10 mm is considered a failure regardless of symptoms (79). Patellar thickness was subjectively assessed in three grades: no change, less than 50% reduction or 50–100% reduction of the assumed preoperative thickness.

6.6.3 Canal-filling ratio in stemmed TKA

For a stemmed TKA to be regarded as adjacent to the bone, the CFR needs to be ≥ 0.85 , calculated by dividing the stem diameter at the stem tip by the endosteal diameter at the location of the stem tip (80). The CFR was calculated for all stemmed TKA in study IV.

6.7 STATISTICAL ANALYSES

Continuous data were described with means with SD. Independent t-test (study III) and Mann-Whitney U test (study III and IV) were used to calculate differences between two different groups, depending on data normality. The Wilcoxon signed-rank test (study IV) was used to compare two related samples of which data was not normally distributed. Differences in ordinal outcomes were calculated using Fisher's exact test (study III) and Pearson's chi-squared (study III and IV). A three-way ANOVA was used to test if statistically significant differences remained for the outcome variables with age group, sex and affected joint as independent factors (study III). Skewed variables were log-transformed to meet the assumptions of ANOVA. Kaplan-Meier Survival Analysis was used to calculate survival-rate of the prostheses with reoperation as end-point and 95% confidence interval (CI) was calculated (study IV). All statistical tests were two-sided with a significance level of 0.05. The statistical analyses were performed using the IBM SPSS version 22 and 23 (81, 82) (study III) or PASW statistics package version 18 (83) (study IV).

6.8 ETHICAL CONSIDERATIONS

All studies were conducted according to the declaration of Helsinki (84) and approved by the Regional Ethics Review Board in Stockholm, Sweden. None of the studies included in the thesis were associated with invasive or painful treatments. During recruitment participants were given verbal and written information about the studies and were informed about the right to withdraw their consent at any time during the study period, without any reason. This enabled the participants to voluntarily engage in the studies without feeling obliged. However, the participants may have felt uncertain about refusing to participate and the impact of this on their surgical procedure. We were careful about informing the participants that participation or declining to participate in the studies would not influence the decision about surgery. The participants may not have experienced their care was improved as a result of participating in the studies. However, the studies aimed at improving health care and treatment in a broader perspective to the large group of patients with OA.

When conducting interviews, the interviewer needs to be perceptive about the interviewee's mindset and feelings since matters important to the person, but not immediately related to the topic, may occur and influence the interview. The interviewer needs to know how to handle different situations for the interviewee's best interest and well-being. For study I and II participants were interviewed in a setting convenient for the participants. Being interviewed about a condition that affects a person's life may pose a problem about integrity. The interviews may become emotional and personal, so it was important for the interviewer to be able to identify worries and to offer support through the participant's health care provider or a

counselor, when needed. However, it was also important for the interviewer to acknowledge that she was not a counselor. The interviews could be regarded as a positive experience for the participants as they were given an opportunity to talk freely about how pain and disability affected their lives. Each participant was coded with a unique study identification number in the manuscript, and the age and gender were removed to ensure anonymity. Representative quotations were used to highlight the lived experiences but names were removed.

For study III, participants were asked to complete self-assessment questionnaires and assess their pain according to the POM. We also evaluated preoperative x-rays to grade the level of structural OA. We considered that these measurements would constitute no risk for the participants, but rather give them the opportunity to talk about their pain and disability, which could be a positive experience. All questionnaires and assessments were coded with a unique study identification number to ensure anonymity. No additional radiology was performed and thus the participants were not exposed to unnecessary radiation.

For study IV the participants gave their informed consent to allow reviewing of their medical records. The reviewers were careful about only reviewing parts of the records relevant to the study. The participants were examined at an extra visit to the orthopedic clinic. Primarily, this was considered beneficial to the participants since the main purpose for these extra visits was to identify complications and failures. Patients with these types of stemmed TKAs are regularly closely followed with examinations and radiology due to the increased risk of complications, why the assessments of the study could be regarded as a normal follow-up procedure.

7 RESULTS

7.1 STUDY I

Three categories were formulated with an overarching theme: “It’s not just a knee, but a whole life”. The three categories were: “Change from their earlier lives”, “Coping with knee problems” and “Ultimate decision to undergo surgery”. All participants were scheduled for knee replacement surgery and had thus lived with knee OA in varying amount of time. During this time, living with knee OA had become a large part of their lives: They had lost the ability to do certain things they considered to be part of their normal lives. Social relationships were altered due to this loss and resulted in less spontaneity and a restricted life. The knee restricted their ability to achieve dreams of regaining physical activity but they developed physical and mental strategies to cope with the limitations. Surgery was seen as a way, and the only way, to regain what they considered to be their normal living. However, expectations of outcome after surgery varied from being completely restored to discontinue declining in knee problems.

The category “Change from their earlier lives” was divided into two subcategories: “Struggling through everyday life” and “Emotional distress”. The participants were restricted in their physical activity and were forced to *change how they previously had lived their lives* before onset of OA. A feeling of loss was reported and the participants could only dream of doing certain things. Pain was a major obstacle, not only to physical activity, but also to concentrating, and could result in extreme tiredness, partly due to difficulties sleeping. Work and housework were affected by pain and functional restrictions. Pain was also a major stressor and led to *emotional distress*. Pain was experienced as mentally challenging and could ultimately lead to thoughts about life not being worth living. The participants could not live as they desired and were afraid to fall and hurt themselves, had to sleep during daytime due to tiredness and were reluctant to participate in social events. The younger participants felt older than their chronological age, which affected their overall life.

The category “Coping with knee problems” was divided into three subcategories: “Physical coping strategies”, “Cognitive coping strategies” and “Alleviating pain”. The participants did what they could to avoid pain, using *physical coping strategies*, for example by walking in a way that did not hurt, using walking aids, choosing the elevator or escalator, or simply by restricting how much they walked overall. There was a fear of damaging other joints by modifying their way of walking. There was also a desire to *cognitively cope with pain* by trying to think positively about pain and seeing others with a limp as being worse off. There were different strategies to *alleviate pain*. Some used analgesics regularly while others were reluctant to take them considering possible negative side effects. Preoperative physiotherapy as symptom relieving management was uncommon but postoperative training was believed to be determinant for a good surgical outcome.

When the participants could no longer stand living with OA they *ultimately decided to undergo surgery*. They feared that they would not get well from knee problems if they

postponed surgery and were convinced that surgery was the only way out of misery. The expectations of surgical outcome varied but were often related to dreams of regaining how they previously had lived their lives. Pain relief and regained walking ability were frequently described as expectations. They dreamed of a silent knee.

7.2 STUDY II

Two categories were formulated with an overarching theme: “Striving for a silent knee”. The categories were: “The bumpy road to recovery” and “The presence of the future”. It was not considered to be an easy path to recover from a knee arthroplasty. Surgical complications, medication side effects and worries about the future were described as obstacles but information from caregivers and the participants’ own positive mind-set could facilitate recovery. However, to not be taken seriously from caregivers about their knee-related symptoms could become an obstacle. For those who still had pain one year postoperatively they frequently described how they hoped their future to be. Some still hoped to progress in the recovery process while others had started to accept living with an aching knee. For those who no longer had pain and had regained physical function the future was already present letting them continue living as before the onset of OA: The knee had become silent.

The category “The bumpy road to recovery” was divided into two subcategories: “Participation in care” and “Mental preparation”. The participants that were satisfied with given care did not expect to *participate in care* and were confident in the caregivers’ professionalism. Others had higher demands for participating and were not satisfied with given care or felt they were not taken seriously if they were left out. The participants underwent physiotherapy with varying satisfaction but most believed postoperative training to be necessary to achieve best possible outcome. Most participants were *mentally prepared* of what to expect from the postoperative period and were prepared for pain and other symptoms. They had retrieved this information from relatives but also caregivers but were more trusting towards someone who had themselves gone through the operation. Some participants feared their knee was not healing properly if experiencing unwanted symptoms and would express a lack of information about normal variations of the postoperative recovery. A positive mind-set was a strategy to overcome certain obstacles.

The presence of the future – Some participants reported that the future they had anticipated to arrive one year after surgery was present, meaning they were pain free and could walk unimpeded again. They could forget they had an artificial knee joint and the knee was no longer an obstacle in their lives: The knee had become silent. However, the participants that were not fully recovered still had thoughts about how to make the future better by hoping that their recovery period was longer than normally expected or by starting to accept remaining knee symptoms. Despite continued pain and other symptoms, some participants were eager to continue engaging in different tasks and refused to be negatively affected by their knee. Even though some participants had persistent pain they were still content with the decision to undergo surgery since they had done whatever they could do to get better.

7.3 STUDY III

All patients had moderate to severe radiographic OA as noted by the modified K&L score 3a/b or 4a/b. There were no major differences between those individuals with knee OA compared to those with hip OA in pain measured with a VAS. Figure 5a and b demonstrate overall use of different words in the POM.

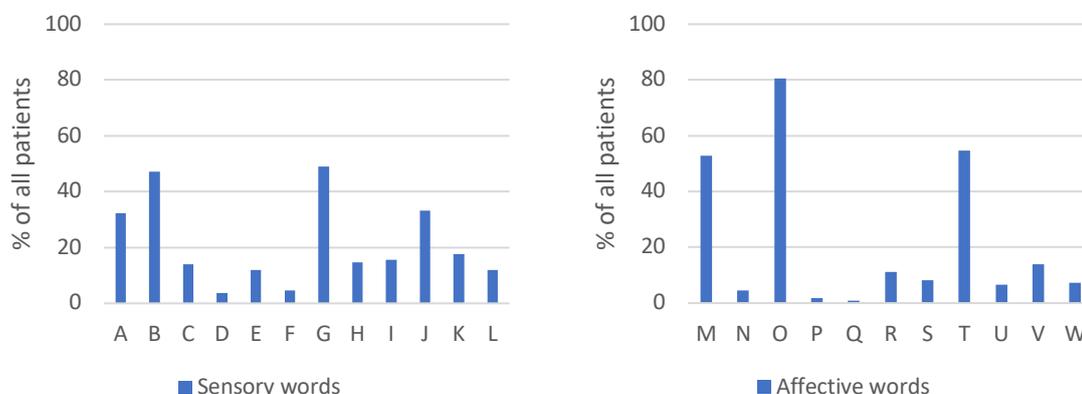


Figure 5a. Overall use of sensory words.

Figure 5b. Overall use of affective words.

The most common sensory words used were cutting (A), grinding (B), aching (G) and sore (J). Aching (G) was used by 49.1% of the patients. The most common affective words used were irritating (M), troublesome (O) and tiring (T). Troublesome (O) was used by 80.6% of the patients. A complete description of letters and words can be found in the methods section in table 6 on page 26.

7.3.1 Differences stratified by age

Patients under 65 years had significantly less advanced structural OA than older patients (27% and 52% respectively, with grade 4b, $p=0.03$), according to the modified K&L OA classification. They also used significantly more affective POM-words (3 (range=1–9) and 2 (range=1–7) respectively, $p=0.02$) to describe their pain. Younger patients presented with significantly greater intensity sensory scores compared to older patients (8 (range=2–20) and 6 (range=0–24) respectively, $p=0.05$), and intensity affective scores (8 (range=3–39) and 5.5 (range=2–27) respectively, $p=0.008$). The affective words troublesome (O) and excruciating (V) were used in 91% and 23%, respectively, among younger patients to describe their pain compared to 73% and 8%, respectively, among older patients ($p=0.03$ and $p=0.045$ respectively).

For the KOOS/HOOS Symptoms subscale, younger patients scored worse compared to the older patients (mean 38 (SD=16) and 46 (SD=19) respectively, $p=0.03$) (Figure 6). No differences were seen between age groups for the remaining subscales of KOOS/HOOS, number of sensory POM-words, EQ-5D VAS or in quantitative pain levels measured with POM-VAS.

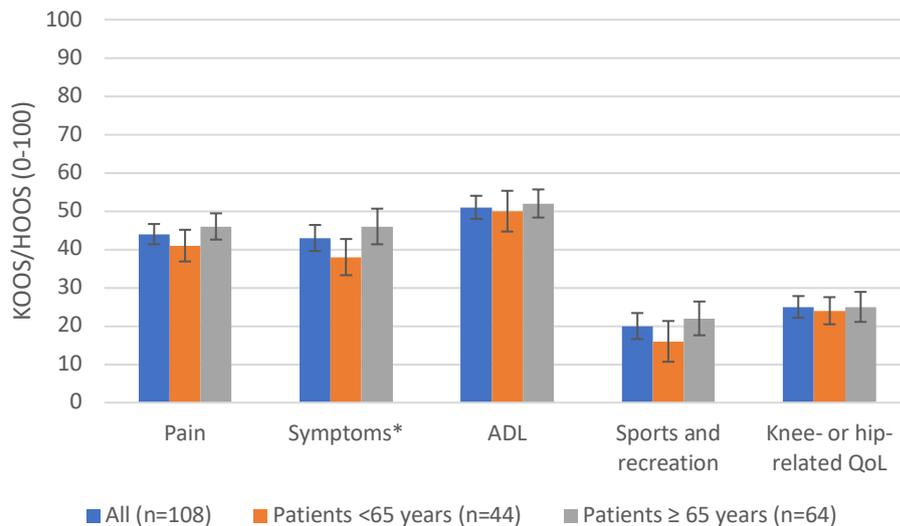


Figure 6. KOOS and HOOS stratified by age. * $p=0.03$ between patients < 65 and ≥ 65 years of age. Error bars represent 95% CI. KOOS: Knee injury and Osteoarthritis Outcome Score, HOOS: Hip disability and Osteoarthritis Outcome Score, ADL: Activities in Daily Living, QoL: Quality of Life.

7.3.2 Differences between women and men

Women rated their pain higher than men: Mean 42 (SD=24) for women versus mean 31 (SD=19) for men ($p=0.011$) with respect to pain intensity using the POM-VAS.

46% of women used analgesics when needed compared to 27% among men ($p=0.03$). No differences were seen between men and women for KOOS/HOOS scores, EQ-5D VAS, pain descriptions in POM-words or radiographic severity of OA.

7.3.3 ANOVA

With sex and age group as independent factors, patients with knee OA reported significantly higher intensity scores for sensory words than those with hip OA ($p=0.015$). No differences remained between younger and older patients with respect to KOOS/HOOS symptoms subscale, number of affective POM-words, and intensity scores for sensory or affective POM-words with sex and joint involved as independent factors. Women reported a higher pain intensity measured with VAS compared to men, with joint and age as independent factors ($p=0.017$).

7.4 STUDY IV

7.4.1 Clinical follow-up

At clinical follow-up 61 cases were reviewed. Four were not included since their prosthesis had been removed. Of 61 cases there were 22 stemmed TKA used as a primary TKA and 39 as a revision replacement. Clinical characteristics were measured and cases operated with a stemmed TKA as a primary TKA were significantly more satisfied with their replaced knee than among the revision group ($p=0.003$). Patients with a primary TKA had less pain at rest (7 (SD=19) and 20 (SD=25) respectively, $p=0.03$) (Figure 7) and at movement (17 (SD=25)

and 42 (SD=34) respectively, $p=0.009$) than patients with a revision TKA. They also scored better for KOOS pain subscale (76 (SD=24) and 58 (SD=28) respectively, $p=0.02$) and KOOS symptoms subscale (83 (SD=18) and 67 (SD=24) respectively, $p=0.02$) (Figure 8). However, the overall patient satisfaction and HRQoL measured with EQ-5D VAS was high and a minority had persistent pain. A greater proportion of patients operated in the revision group had a patella subluxation or dislocation ($p=0.03$), which was not seen in the primary group. No differences were seen between the two groups for body mass index (BMI), ROM, medial-lateral stability, KOOS ADL, sports and recreation or knee-related QoL subscales, or clinical improvement in walking aids or walking distance.

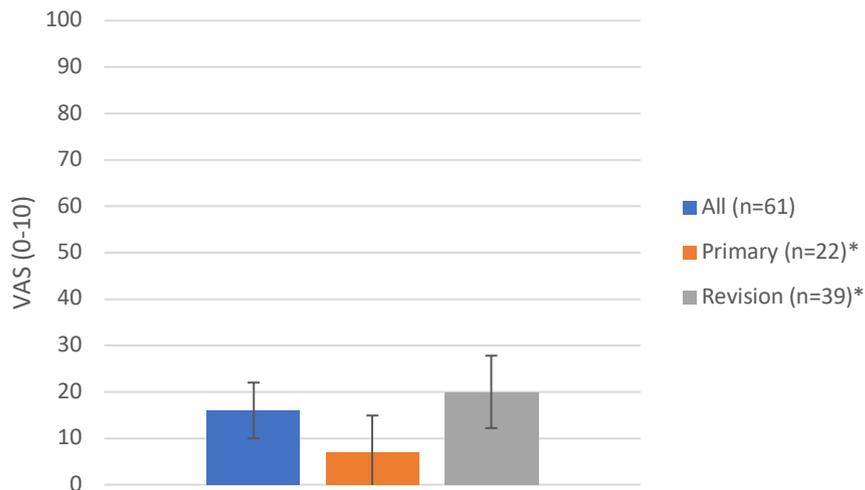


Figure 7. Pain at rest, measured with the VAS, at follow-up in stemmed TKA used as primary or revision TKA. * $p=0.03$ between primary and revision. Error bars represent 95% CI. VAS: Visual Analogue Scale.

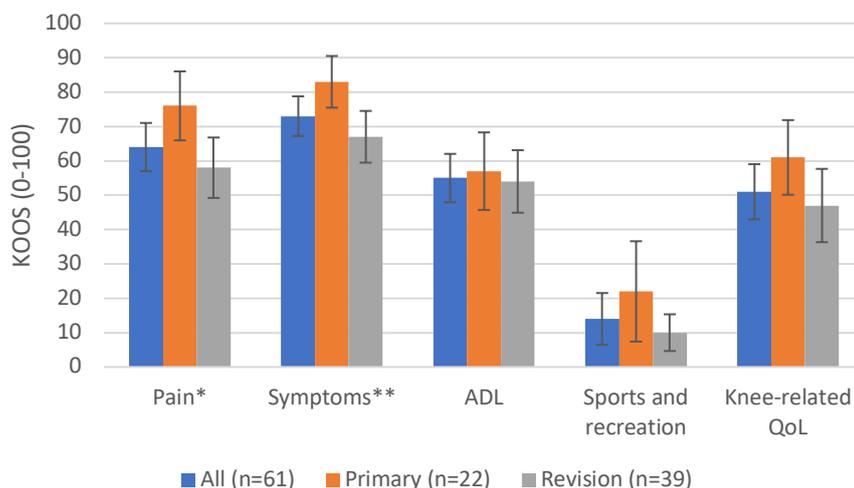


Figure 8. KOOS at follow-up in stemmed TKA used as primary or revision TKA. * $p=0.02$ between primary and revision, ** $p=0.02$ between primary and revision. Error bars represent 95% CI. KOOS: Knee injury and Osteoarthritis Outcome Score, ADL: Activities in Daily Living, QoL: Quality of Life.

7.4.2 Survival and failures

Overall there were 12 failures, which resulted in a 5-year survival rate, with reoperation as endpoint, at 82% (CI=72–99). There were four failures within the primary operated group and eight in the revision group. Of 12 failures, 8 were due to deep infection, of which 1 was primarily converted to a knee arthrodesis and finally amputated due to persisting infection. One received a tumor prosthesis due to implant breakage and two were revised in a two-stage procedure. Four failures were non-septic of which one received a patellar component, one had a hematoma evacuated, one experienced a quadriceps tendon rupture and had to be re-operated, and one had a peri-prosthetic fracture. No differences were seen between the primary and revision groups in implant survival and failure rates.

7.4.3 Radiological assessment

Thin radiolucent lines on the femoral side were seen in 16 cases, and in 30 cases on the tibial side, mainly at the medial plateau. Grade III (>2 mm) was seen in only three cases, but only for one zone each. Primary cases had proportionally fewer radiolucent lines (2/19) than the revision cases (14/37) ($p=0.03$) on the femoral side. However, none of the implants were loose radiographically. For the tibia, the mean CFR was 0.84 (SD=0.08) and 0.89 (SD=0.09) for the femur. Patellar thickness was unchanged in 42 cases, reduced by < 50% in five cases and reduced by 50–100% in six cases.

8 DISCUSSION

This thesis aimed to investigate and describe the experience of living with hip and, particularly, knee OA, the expectations for and outcomes after a knee arthroplasty, using both qualitative and quantitative methods. The first two studies used a qualitative approach to learn about the persons' perspective of the phenomenon of living with knee OA or a knee arthroplasty. Study III had a quantitative approach but used a qualitative pain assessment tool in an attempt to comprehend overall pain experience among individuals with knee or hip OA, scheduled for an arthroplasty. The last study was solely quantitative with the aim to investigate different outcome measures in stemmed TKA, a relatively uncommon procedure performed when a regular TKA is regarded as insufficient. We found that knee and hip OA have substantial effects on a person's life in terms of pain (study I and III) and other experiences (study I). Further, knee replacement surgery is often beneficial to the patient, regardless if it is a "regular" arthroplasty or a stemmed TKA, but complete silence of the knee is not always achieved (study II and IV).

8.1 LIVING WITH LONG-TERM ILLNESS

We found that living with OA affects an individual's life on many levels and leads to a restricted lifestyle with less spontaneity of doing what they desire. Further, it creates a feeling of loss as they continuously need to alter their way of living as the disease progresses. The participants are constantly aware of the knee, which disrupts the unity of body and self. Gadow (1980) described the concept of embodiment as a difference between the "lived body" and the "object body" meaning that a "lived body", who is trustworthy and an instrument to achieve personal goals, can be transformed to an "object body" through illness or injury (85) and hence disrupt the unity of body and self. However, the mind strives to unite body and self to a "lived body" by learning to live with, in our case, an aching body part (12, 85). The participants in our study described cognitive and physical strategies to cope with OA pain but were never completely unaware of the knee, which is similar to previous research (12).

A different view of body and self is BA where the mind focus on and become aware of internal body sensations (86). BA has previously been described in individuals with rheumatoid arthritis, who experience pain not dissimilar to those with OA (87). The participants in study I reported being constantly aware of their knee and that their knee problems were a central focus in their lives. We interpret this as a disruption between body and self and further as negative BA (86). Living with long-term pain and functional disabilities have recently been described in a review article on patients with OA (88). This has also been described for patients with intermittent claudication experiencing great impact on daily life (89). The need to adjust to a restricted life leads to a feeling of loss for their previous life (89), similar to the findings in study I.

For some there was a reunion of body and self and a mind-shift towards less negative BA one year after knee surgery, when they were no longer aware of their aching knee (study II). However, some had persistent knee-related pain and symptoms but were still striving towards

reuniting body and self: Striving for a silent knee. Some were starting to accept living with persistent awareness of the knee, which may be seen as striving towards embodiment (85). Despite persistent knee-related pain and symptoms, most participants were satisfied with the outcome of surgery. They had done what they could to improve by replacing the knee and had also started to accept living with persistent awareness of the knee, as previously described (12). These findings are similar to experiences reported by patients with lower limb trauma going through either surgical reconstruction or amputation of a limb (90).

The VAS is traditionally used for assessment of pain, but as it is numeric and quantitatively measure pain, one can only expect to learn *how much* pain a person experience but not the *quality* of the pain experience. By using the POM we may understand the emotional aspect of pain and further learn how an individual is affected by pain. We have not investigated the POM in relation to BA and embodiment and can only speculate that choosing a great amount of emotional words with high intensity values may correlate to negative BA and the “object body”.

The terms *disease* and *illness* have previously been described in an attempt to distinguish between the pathophysiology (disease) and the effect the disease has on a person’s life (illness) (18). The Osteoarthritis Research Society International (OARSI) has implemented this theory on OA, where structural changes of the joint represent the *disease* and patient-reported symptoms represent the *illness* (91). Qualitative research and qualitative pain assessment can be regarded as instruments to achieve information about how OA affects individuals, hence the *illness*. OARSI also suggested that differentiating between the two terms may support the choice of different treatment methods (91). The fact that there is a discrepancy between radiographic severity of OA and joint-related symptoms support this theory (22). Through qualitative interviews and qualitative pain assessment one can learn about the *illness* OA affecting the individuals.

8.2 DIFFERENT SHADES OF PAIN

8.2.1 Pain assessment

Previous research has suggested that peripheral (nociceptive) and central (neuropathic) sensitization may influence the pain experience (19) but there is no “golden standard” to measure pain sensitization in OA (92). Different measures have been tested to quantify pain experience through different sensory stimuli. Arendt-Nielsen (2017) stated in a review article that OA patients are generally more sensitive to painful stimuli than age-matched controls (92). However, these measures strive to quantify the pain experience and do not consider the qualitative aspect of pain or the emotional impact pain has on an individual. We learned that pain is central in living with knee OA (study I) and that individuals with OA use emotional words such as troublesome, irritating and tiring, and also unbearable and excruciating (study III) to describe the emotional impact they experienced pain to have. These words imply great emotional impact, similar to the reports in study I. Pain assessment remains complex and difficult to assess. We used different assessment tools (VAS, POM-words, KOOS/HOOS) to

measure pain and the result was rarely concordant. As nociceptive and neuropathic pain can cause different pain experiences it would be interesting to assess pain sensitization in relation to what words are used in the POM in an attempt to characterize pain and further to individualize treatment options for pain in OA.

8.2.2 Analgesics use

There was a reluctance to use pain medication, reported by some of the participants in study I. In study III we found that 46% of the cohort reported to use analgesics daily and 39% when needed. Fourteen percent reported to never use pain medication. The proportion who use daily analgesics may be considered low as pain is the main indication for performing joint replacement surgery. In line with this, one previous study interviewed individuals with OA about their experiences on pain medication and reported that they were generally adverse to use them and strived to take as low doses as possible, even lower than what was prescribed (93). One reason for not taking pain medication as prescribed was fear of addiction (93). The participants in our study (study I) rather reported a fear of long-term side effects. Some participants in study II reported receiving insufficient postoperative pain relief, which is known to be a risk factor for persistent post-surgical pain (94). In addition, pain increases the risk for cardio-pulmonary morbidity and mortality in the postoperative period (94).

8.2.3 Influence of age and sex on pain

The primary aim of study III was to investigate differences in pain expression between younger and older patients, and secondarily between women and men, scheduled for a knee or hip arthroplasty. We used the POM in an attempt to comprehensively describe the multifaceted concept of the pain experience. In this descriptive study we found that younger patients used more affective words with a higher intensity value. We cannot draw any conclusions about the reason for this discrepancy in this study. However, we may discuss that since the affective words e.g. ‘troublesome’, ‘excruciating’ and ‘tiring’, represent the emotional aspect of pain, the younger patients may have a greater emotional impact of their OA pain than older patients. We found no differences in KOOS/HOOS knee or hip related QoL, which has been considered to be the most emotionally sensitive subscale, that could explain the difference (95). Previous research suggest that pain may be considered, among older patients, to be a phenomenon related to natural ageing and that pain expression may be influenced by different life-circumstances (34). In line with this, OA has been reported to be considered as natural ageing among older patients while younger patients experience frustration and distress in managing the disease (96). Sixty-five years is the common retirement age in Sweden and another reason may be that younger patients have higher functional demands due to occupational status. This may change if the retirement age is raised. One previous study showed that younger patients with knee OA scored worse on a depression scale compared to older patients (97) and future studies should thus involve depression measures to evaluate the relationship between high pain ratings, measured with the POM, and depression.

Women reported quantitatively more pain as measured with the traditional VAS (study III), consistent with previous research (38, 39, 98), but did not use more affective POM-words than men. However, a difference of 11 points on the VAS measuring pain may not be considered clinically important (7). Similar to our findings, Tonelli et al. (2011) found that among patients with knee OA, scheduled for a knee arthroplasty, women reported higher pain intensity but did not score worse for depression, anxiety or pain catastrophizing (39). To our knowledge, no previous studies have investigated the correlation between POM-words and different scores for depression, thus we cannot draw the conclusion that we would not find any differences in depression scores in study III. However, the affective POM-words may represent the emotional aspect of pain and thus reflect the individuals' well-being. Women also reported to use more analgesics when needed than men, but we found no differences in the grade of OA assessed on plain x-rays. Women have previously been reported to be prescribed more NSAIDs than men (99), but we cannot say that this is the case for our study. In study I we found that the participants were generally reluctant to taking pain medication, which could be a reason for the relatively low part of the patients taking analgesics in study III. This knowledge retrieved from interviews could generate interest for quantitative studies investigating the use of analgesics among individuals with OA with the hypothesis that women and men may use analgesics differently.

Since we included patients with both knee and hip OA in study III we wanted to take into account the influence affected joints may have on the results by performing a three-way ANOVA. We found that patients with knee OA achieved a higher intensity score for sensory POM-words, with age and sex as independent factors. However, there were no differences between the groups for pain intensity measured with VAS or affective POM-words. In hindsight, we should have included patients with only knee or hip OA and a greater number of subjects to minimize the risk of interaction and type II errors.

8.2.4 Transformation of pain from pre- to postoperative

Several factors can influence the postoperative pain experience including, among others, pain sensitization, perioperative pain intensity, pain catastrophizing, co-morbidities and socio-economic factors (92). The participants in study II that reported persistent pain postoperatively reported a change in the pain experience. They reported that the OA pain had been replaced by another type of pain: A less distressing pain. The reason for this change in pain experience remains unclear. It has been suggested that peripheral and central sensitization may be present in people with knee OA and influence pain experience (19, 20), and may persist postoperatively. In contrast to our findings, Jeffery et al. (2011) reported that persistent postoperative pain was experienced as distressful by approximately half of the interviewed patients and others reported acceptance of remaining symptoms (100). They suggested that information regarding postoperative recovery, psychosocial factors and continued improvement in pain and knee-related function were related to patient-perceived favorable results (100). The experience of less distressful postoperative pain (study II) may be related to a continued improvement one year after surgery, reported by some.

8.3 PHYSICAL MANAGEMENT OF OA

Individual-based physiotherapy was uncommon among the participants in study I. The SOASP is a well-established intervention in Sweden for individuals with knee or hip OA with the purpose of reducing joint-related pain and symptoms as well as to postpone joint replacement surgery (45). It includes individual examination from a physiotherapist and further education and information about OA and different self-management interventions, followed by individual or group exercise (45). In a large registry study, 9,825 participants were included to participate in education and supervised exercise with follow-up at baseline, and after 3, and 12 months (101). They found that the intervention led to improved quality of life, reduced pain, decreased intake of painkillers and fewer patients on sick-leave at 12 months (101). In contrast to the participants included in study I, the participants from the registry study were not scheduled for joint replacement (101). It is remarkable that the participants included in study I reported sporadic physiotherapy and we cannot know whether these participants would have postponed knee replacement surgery if they had undergone extensive exercise supervised by physiotherapists.

8.4 ADAPTING TO A NEW LIFE

8.4.1 Expectations vs. outcomes

The expectations of outcome after a knee arthroplasty varied among the interviewed participants but to be pain-free and to be able to walk freely were frequently reported (study I). They dreamed of continuing living their lives as before onset of OA. For some participants, these expectations of outcome were met, and for some they were not (study II). However, those with persistent symptoms were still hoping for a better outcome analogue with their preoperative expectations. Some were starting to accept to live a life with persistent awareness of the knee and that their preoperative expectations would not be fulfilled. They were content that they had gone through with the operation, having done what they could do to improve. In a review article by See et al. (2018) it was common that studies reported patients' unrealistic expectations of outcome after a knee arthroplasty (102). The correlation between unrealistic preoperative expectations and dissatisfaction with postoperative outcome has previously been described (10) and summarized in a review article (103). A majority of patients undergoing joint replacement surgery have been reported to have high or very high expectations regarding the outcome of surgery and it was suggested that enhanced patient-doctor communication may mitigate unrealistic expectations and further increase satisfaction with surgery (104). Additionally, a discrepancy between the patient's and the surgeon's expectations of a good outcome exists and it has been suggested that surgeons lack in their ability to adequately inform about limitations of the planned procedure to mitigate unrealistic expectations (103). In contrast, another review article by Culliton et al. (2012) found no correlation between preoperative expectations and postoperative satisfaction with the surgical result, but rather between postoperative expectations and outcome (49). There was a consistency in suggesting that information and education about realistic expectations is favorable to achieve high satisfaction (10, 49, 103, 105). The participants in study II reported

to have received sufficient information from the surgeon regarding the surgical procedure and what to expect from the post-surgical period regarding pain and movement difficulties. They also reported to rely on information from relatives and other people in their immediate surrounding and appreciate this information even more than that given by health care personnel.

One year after surgery, some expressed a lack of information regarding normal postoperative recovery, which made them insecure about how their knee was healing. The importance of information and education has previously been reported (55, 102, 106). Continuous information and education regarding joint-related symptoms and pain, expected in the normal recovery process, should be offered to prevent unnecessary worrying and distrust in the replaced knee and ultimately enhance patient satisfaction with the outcome of surgery. Nilsson et al. (2019) have described how women with osteoporosis manage daily life and reported that support early in the disease process and continuity in health care encounters were important factors to facilitate managing illness in daily life (107). Preoperatively, surgeons often inform patients that the normal time to recovery is one year. However, the participants in study II often described that they continued to improve in knee-related symptoms and pain relief at one year postoperatively. To achieve the best possible outcome, we suggest that enhanced support should be provided throughout the postoperative period and also after one year, to those who continue to improve. This is in line with previously published research (49, 106).

8.4.2 Stemmed TKA in primary or revision surgery

The majority of patients receiving a stemmed TKA were satisfied or very satisfied. However, 20% of the included cases were dissatisfied. These numbers are comparable to those in a recent retrospective study investigating satisfaction in 163 cases of revision TKA in Asia (108). A satisfaction rate of 80% is in the lower span compared to 80–85% in patients with a regular TKA (10) and 87% of all patients reported in the SKAR (7). The reason for this difference is unknown. Qualitative interviews with patients receiving a stemmed TKA would be of value to better understand the patient's experiences of satisfaction or dissatisfaction. When comparing the patients in study IV to patients with a regular TKA included in the SKAR, postoperative scores were worse in our cohort for all KOOS subscales, except for the symptoms subscale (7). However, pain intensity measured with VAS was comparable for our patient cohort and the SKAR (7).

Peterson et al. (2015) found that 47% of patients reported severe to unbearable pain 3 years after revision knee surgery, which was higher than among patients with a primary TKA (109). In our study, there was a difference in pain at rest and at movement as measured with VAS and for KOOS pain subscale with worse pain among those undergoing revision knee surgery. This indicates that outcome after revision knee surgery may not be as successful as after primary surgery. Since indications for using a stemmed TKA are either severe instability in primary cases or, among others, loosening of the primary prosthesis or infection in secondary cases, different treatment options are limited. To refrain from using a stemmed

TKA is not an option in severe cases and those patients would be worse off without the operation. We consider stemmed TKAs to be a good alternative when indications exist. Preoperatively collected PROs were compared to postoperative values in a previous study on patients undergoing a revision knee replacement, and found a clinically significant improvement up to five years postoperatively (108), suggesting that it is a successful operation, despite lower satisfaction. Since preoperative assessment of PROs was not collected for the patients in study IV we cannot know whether there was an improvement. PROs should be incorporated in preoperative clinical examinations to better evaluate postoperative outcome.

The overall relative risk for revision surgery in patients with a TKA has decreased over the decades (7). In Sweden, between the years 2008 and 2017, 38% of all revisions of TKA, with OA as primary diagnosis, were converted to a new TKA, a stemmed TKA or a hinged TKA (7). Other revisions included, among others, exchange of the plastic component or addition of a patellar component (7). Aseptic loosening and infection are the most common mechanisms of failure in primary TKAs (7, 56), which is in line with our findings (study IV). The overall survival rate in study IV, with re-operation as endpoint, was 82% and infection was the main reason for failure, which is similar to previous findings (110). We found no difference in survival rate between the primary and secondary group, which is inconsistent with previous research suggesting that revision TKAs are more prone to failures than primary TKAs (110). In a recent study by Agarwal et al. (2019) infection and loosening of the revision prosthesis was found to be the most common reasons for failure and they suggested that improvement in infection management and methods for fixation could reduce failure rates (15). We found radiolucent lines on either the femoral or tibial side in two thirds of all cases but no prosthesis was found to be loose. Hence, aseptic loosening was not found to be a major cause for re-revision.

8.5 METHODOLOGICAL CONSIDERATIONS

8.5.1 Study I and II

Strengths of these studies were that all interviews were conducted by one person and that each participant was interviewed twice, which probably allowed them to feel relaxed in the interview setting as mutual trust was already established. Additionally, conducting two interviews with each participant allowed us to follow-up on the first interview and hence retrieve richer information to gain understanding of their life situation.

At the start of the preoperative interviews I was not an experienced interviewer, but as a medical doctor, I was used to gather information from patients. However, I learned with each interview to pose broad questions and let the participants give their view on their life situation with regards to knee problems. The information gathered was rich and detailed, thus this was not regarded as a limitation. The first interview was reviewed by a co-author (SAG), experienced in qualitative interview technique, to make sure all topics in the interview guide were covered and that questions posed by the interviewer were open rather than leading.

There were numerous interruptions at the preoperative interviews (study I) but they were not regarded as disturbing. In two interviews the spouses were present but quiet. This can be regarded as a limitation since the participant potentially may leave out uncomfortable information. However, those interviews did not differ in information richness compared to the other interviews, so we believe it had minimal influence.

There is a potential risk for recall bias in study II where the participants were asked, after a year had gone by, about their experiences of the operation and postoperative care. However, the aims of the study were also to gain information on their experiences of living with an artificial knee joint.

As one year, often informed by orthopedic surgeons, is how long it takes to recover from a knee arthroplasty, we considered this timing of the interview to be appropriate. We cannot know whether the timing of the interviews for study I had any effect on the information gathered in the interviews. We may have received different information from participants if not scheduled for surgery. However, we wanted to investigate the participants' experiences of living with end-stage knee OA and, from a practical point of view, they were easiest to identify from the surgeon's waiting list.

We did not ask about other life-changing events that could have affected the participants' experiences of living with knee OA or a knee arthroplasty, which could be seen as a limitation.

When translating transcriptions from Swedish to English there is a potential risk to lose important information and linguistic nuances. To minimize this risk, we let a native English speaker review the translated quotes for its appropriateness.

One of the inclusion criteria was that the participants should be able to participate in an interview in Swedish, which could be seen as a weakness of the study. If we had included patients with different backgrounds and other native tongues than Swedish we may have received a broader perspective on the phenomenon of living with knee OA or an arthroplasty.

8.5.2 Study III

Patients who were asked to participate, but declined, were not recorded. This may lead to selection bias as those willing to participate may be more prone to talk about their problems. Valuable information may be lost due to a possible discrepancy in pain experience between those willing to participate and those who declined.

All included patients were relatively healthy individuals (ASA 1-2), which may affect the generalizability of the study. However, in SKAR, only 17% of patients undergoing knee replacement surgery in Sweden are ASA 3 or above (7).

The lack of statistically significant differences in pain expression between women and men may be the result of a type II error due to the small number of included patients, which can be regarded as a study limitation. A type II error is a false negative assumption that the null

hypothesis is actually true as a result of low power. Likewise, the non-existing remaining differences between younger and older patients, when adding sex and joint involved as independent factors in the ANOVA, may be due to the small number of patients within each subgroup. Skewed variables were log-transformed to meet the assumptions of the ANOVA. Log-transformed variables are constructed and can thus be difficult to interpret.

A strength of this study was the use of the POM, providing a more complete aspect of pain including the qualitative part. By reviewing what words of the POM that are used the examiner may identify patients using words with high intensity. This is of interest especially for the affective words where the examiner may review those who use intensive affective words more closely and thus enhance patient-care giver communication. The lack of concordance between POM and KOOS/HOOS pain subscale may be due to how the question was posed: Describe your pain when walking from the waiting room (POM) and describe your pain during the last week (KOOS/HOOS).

In hindsight we could have discussed to include only patients with either knee OA or hip OA in the study as we found a statistically significant difference between these groups in the ANOVA. We may also have chosen to divide the affected joint groups into age groups to calculate differences between younger and older patients with knee OA and hip OA, respectively. However, the groups would have been too small to draw any conclusions. Since the KOOS and HOOS are not identical in the number of questions and how they are posed, the two questionnaires may not be comparable and differences should be calculated cautiously.

8.5.3 Study IV

No preoperative pain scores or other clinical data were available due to the retrospective nature of this study. Thus, it was not possible to compare pre- and postoperative data to learn whether the patients had improved in pain and physical function. Further, the lack of preoperative data rules out the possibility to compare preoperative status of our cohort to other patients where a stemmed TKA may be considered. Hence, we cannot use our findings to facilitate the decision of who may or may not benefit from a stemmed TKA.

The follow-up of two to nine years may be considered medium-term and we cannot draw any conclusions on long-term outcome. There might also be differences between patients with a follow-up of two years and those after nine years, differences that have not been investigated in this study.

There is a potential risk for recall bias in the questions of walking aids and walking distance since the patients were asked about the change from pre- to postoperative.

Since this procedure is fairly uncommon all stemmed TKAs were reviewed. They were of different brands and types, which may have affected the outcome. However, in most cases with a CCK design the TC3 prosthesis was used and all RH knees were operated with the S-ROM system.

There is a potential risk of a type II error in the lack of statistically significant differences between the primary and the secondary group due to the small number of included patients. However, this is also a result of the procedure not being very common.

Strengths of the study was that all patients were clinically examined and that radiology was reviewed.

9 IMPLICATIONS AND FUTURE DIRECTIONS

9.1 CLINICAL IMPLICATIONS

Living with knee OA affects individuals' lives on many levels and caregivers should review the patients holistically through person-centered care.

The participants in study II reported that they were still improving in knee-related pain and function at one year postoperatively. Even though this finding may not be generalizable to a greater population this may be interesting for orthopedic surgeons to know at clinical follow-up and to consider longer follow-up time for those with persistent symptoms.

The variation in postoperative recovery between individuals should be considered when informing patients about "normal" postoperative recovery. This information should be individual based, and patients' expectations regarding postoperative recovery and surgical outcome should be taken into account when giving this information.

We have learnt that patients < 65 years of age express pain differently than those ≥ 65 years of age and that they use more affective words. This finding may be useful for orthopedic surgeons in clinical setting when evaluating patients for arthroplasty. The POM can be used as a complement to the VAS in assessment of pain and as a tool to improve patient-doctor communication and to talk about pain.

Patient satisfaction and pain relief in patients receiving a stemmed TKA is good, both when used as a primary or a revision TKA. The indications for a stemmed TKA is either an instable knee where a regular TKA is considered insufficient (primary) or when a prosthesis has failed (revision). Thus, a stemmed TKA can be considered a good alternative when these indications exist, leading to beneficial postoperative outcome.

9.2 FUTURE DIRECTIONS

As the participants from study II reported that they were still improving one year after surgery it would be interesting to do a third interview up to five years after surgery to learn how they have adapted to their artificial knee joint: If they are still improving in knee-related pain and function or if they have accepted living with persistent symptoms.

In-depth interviews with individuals receiving a stemmed TKA would be of interest to learn about their hopes and fears and how the illness affects them. Further, prospective inclusion of preoperative patient data (self-administered questionnaires, pain assessment, clinical features) should be gathered to be able to compare preoperative features to postoperative outcomes in patients with a stemmed TKA.

It would be interesting to do a longitudinal study with comprehensive pain assessment including the POM in individuals with early stage OA to see how pain changes over time and to investigate what treatment options i.e. physiotherapy, pharmaceutical or surgery, may be

better for different types of pain. The differences in pain expression between patients < 65 years of age and those \geq 65 years of age should be investigated further within each group of knee and hip OA and with a larger number of patients. Other parameters, such as socio-economic status, smoking and depression or other life-changing events, that may affect pain, should be taken into account when investigating pain in individuals with OA. Further, to conduct a study using the POM for postoperative pain assessment would be interesting to see what words are used by patients who have persistent postoperative pain and to include a depression scale to correlate to the POM. Due to the lack of statistically significant differences between women and men in our cohort (study III) it would be interesting to include a greater number of patients to see if this lack of difference remains or if study III contains a possible type II error.

10 CONCLUSIONS

- Living with OA is the central focus and impact individuals' lives on many levels. Living with pain and other symptoms force them to alter how they live their lives, which creates a feeling of loss.
- The experiences of living with knee OA and expectations of knee arthroplasty differ between individuals and must be taken into account in the evaluation of treatment methods.
- Information to patients receiving a knee arthroplasty should include the possibility to continued recovery one year postoperatively. A clinical follow-up at one year may identify those with persistent symptoms and relevant resources can be provided to achieve best possible outcome.
- Continuous support and information from health care personell throughout the postoperative period may lead to enhanced patient knowledge about variations of normal recovery and prevent unnecessary worrying.
- Patients < 65 years of age express more affective words to describe pain than those ≥ 65 years of age, and may thus be more emotionally affected by the disease.
- Measuring pain in OA is complex, and pain and emotional well-being may be discordant.
- Qualitative interviews and qualitative pain assessment may complement traditionally used self-administered questionnaires and VAS to better understand the lived experiences of OA and the emotional impact pain has on an individual.
- The use of a stemmed TKA lead to improvement in pain relief and patient satisfaction regardless if it is used primary or as a revision TKA and should be considered when indications exist.

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