The hip journey

An exploration of needs, treatment decision-making and psychosocial predictors of surgical outcomes in patients with hip osteoarthritis

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Preface

I am sometimes asked why I chose to become a nurse, and at a first glance the answer is not self-evident. After upper secondary school, I started studying computer science together with several friends of mine. However, at the end of the second semester, I realized that I wanted to see more of the world and decided to move to Oslo. Besides a general interest in computers and programming, I was also interested in German history and language. My new plan was to study one or two years at the University of Oslo (UiO) and then move to Berlin. Things did not turn out the way I had planned this time either. I was blessed to meet my boyfriend Julian, and a few months later, I had started nursing school.

Thinking back, my interest in healthcare probably started at an earlier stage. As a teenager, I was admitted to the local hospital for two weeks with severe bacterial meningitis. I still can remember how the nurses cared for my family and me during this distressing situation. This experience has undoubtedly affected my young adulthood and choice of career. Early in my studies, I particularly enjoyed the unique opportunity to communicate with patients and learn about their healthcare needs. Furthermore, the combination of practical and theoretical learning suited me well. Reflecting on my past personal experience as a patient, communication was early on identified as a much-needed skill. I had clinical rotations in home nursing care during my second year as a nursing student. Practicing nursing in this context fascinated me. When I completed my studies, I was fortunate to get a full time position in the same municipal district. Julian had started medical school and we bought our first apartment. Life was good!

Three years passed and I eventually felt a need for new perspectives. I was eager to learn more about specialized nursing and further develop my clinical skills. Pain and palliative care were areas of particular interest. In 2009, I was accepted as master's student in clinical nursing science. The first year was demanding, but also very stimulating - both on a personal and professional level. My main subjects were pain management and health counselling, and it was clear to me that I wanted to combine these topics in a project. After one of the lectures, Professor Hilde Eide asked me if I was interested to take part in an ongoing research project called: *"Stimulating self-management in patients with fibromyalgia syndrome through web-based situational feedback".* This was a great opportunity for me to get first-hand insight into a clinical research project. The use of cognitive behavioural therapy as the main therapeutic strategy for pain and health counselling through a smartphone was fascinating.

After finishing my master's degree, I returned to my old job with new perspectives, knowledge and motivation. I really enjoyed coming back and I soon became involved in new exciting projects. One was implementation and testing of a new scoring system aimed to identify patients with subacute symptoms, and the other was related to the implementation of an electronic messaging between home care services and general practitioners (GPs). To my surprise, Hilde Eide contacted me late 2012 with an encouragement to apply for a four-year position as PhD student in Drammen. I was intrigued, but also had mixed feelings. A PhD? Me? In Drammen?

I decided to apply after careful consideration, and was fortunate to get the job. My PhD journey had started. Initially I planned a randomized controlled trial, including the development and testing of a web-based support tool for patients with hip or knee osteoarthritis (OA) undergoing joint replacement surgery. The intervention was supposed to be developed and implemented in the primary care setting. However, I realized that the scope of the project was too comprehensive for a PhD with limited resources. Additionally, it turned out that close collaboration with GPs for research purposes was a challenge. I kept my interest on the development of a web-based tool, and after several discussions, we planned to develop and pilot-test a web-based decision aid for patients with hip OA referred to an orthopaedic surgeon for specialist evaluation.

When interviewing patients with hip OA about their experiences and perception of needs, we explored the possibilities to cooperate with a professional IT company that develop web-based educational technology solutions. They were very much interested in the idea as it represented a new and promising area for them, but unfortunately, the costs exceeded our budget.

At this point, I was stressed and eager to proceed with my research. Fortunately, an ad-hoc possibility was available. My co-supervisor Heidi Kapstad finished her PhD in 2010, and she had parts of a data set that would complement and add value to our investigation about the needs of patients with hip OA. It also provided me the rewarding opportunity to learn more about quantitative methods and statistics.

When reviewing the literature on patient centred care and patient decision aids, shared decision-making (SDM) and patient involvement became central concepts for me. After presenting my PhD project at a workshop, we got in contact with a group in Tromsø developing web-based patient decision aids called “Mine Behandlingsvalg”. Soon after, a collaboration to develop decision aids for patients with hip or knee OA was established.

I believe this story explains a bit of my background and starting point as a PhD student. It also describes some of the challenges that I have faced during my PhD journey. I am very proud to hand in this work, knowing that this journey is about to end, and a new journey is just around the corner.

Acknowledgments

Many people have supported my PhD journey, but I would like to start thanking Lise Gladhus at the Department of Nursing and Health Sciences for providing the necessary resources to complete this PhD work. Many thanks to Katrine Hordvik Wilhelmsen who has accommodated my needs when combining research activities with other duties. I would also like to thank the Department of Behavioural Sciences in Medicine at UiO for accepting me as student at the PhD programme in medicine and health sciences.

Many people have accepted the invitation to participate in the different parts of this project, and I would like to thank each and one of them for their invaluable contributions and for placing trust in me as a researcher.

I am fortunate to have four supervisors, and I would like to start thanking my main supervisor Professor Hilde Eide. My first recollection of Hilde was when I attended a communication skills training as part of my nursing education. She used video recording of the role-plays for peer feedback and I can still remember how this challenged my somewhat shy personality. At a later point, she invited me to write my master thesis as part of an ongoing research project in which she was primary investigator. Now she has acted as my main supervisor in this work for the last 6 years. During all these years, I have learned to know Hilde as a dedicated, knowledgeable, professional, inspiring and inclusive researcher with ambitious goals. In the process, she shares her many creative views and innovative ideas, and guides the way forward. As my main supervisor, she has challenged my opinions and ideas, and at the same time, supported me through challenging periods in a trusting and empathic way. I am especially grateful for the way she has included me in her comprehensive research network and introduced me to the field of health communication research.

My second supervisor is our Dean at the Faculty, Heidi Kapstad. She wrote her PhD on osteoarthritis and her knowledge and expertise in the field has been very helpful for me. I would especially like to thank her for sharing some of the data acquired as part of her PhD work.

Professor Sandra van Dulmen has been a valuable collaborator and supervisor. I know Sandra as a professional and friendly colleague who unselfishly shares her wisdom and research experience. During our dialogues and discussions, she tends to ask questions that

stimulate reflective thinking. In times of frustration or difficulties, she has unique abilities to sort out potential solutions. Sandra's guidance and feedback have been utmost constructive and helpful during all phases of the work.

Professor emeritus Arnstein Finset is my supervisor at UiO. Arnstein has provided valuable 'outside-in perspectives' that have helped me to better understand how this thesis relates to a broader research agenda.

Several people associated with the Department of Emergency and Orthopaedics at the local hospital in Drammen deserve many thanks for providing both resources and expertise. Lukas Månsson has been involved in the planning and adjustments of the research project from the very beginning, and has enabled access to the clinical field for data collection purposes. As co-author of paper 1, he acted as a clinical expert with invaluable advice and perspectives. He has also invited me to present and discuss parts of my project at the hospital and this has given me important feedback in the process.

Several general practitioners and nurses helped me recruit participants and shared their perspectives in relation to my research project. This has been very helpful, and has given me a unique insight into some of the health care challenges that are pertinent in the more remote parts of Norway.

Professor Tom Eide has acted as a kind of mentor for me – supportive, reflective and upfront. I really appreciate his occasional door knock and informal chats. He knows how to challenge settled ideas and to stimulate critical discussions. As co-author of the first paper, he participated in the phases of data-analysis and helped me to stay curious when trying to make sense of the rich qualitative data material.

An exciting and innovative part of my PhD work is related to the development of a web-based patient decision aid. I first met Professor Jürgen Kasper at the OCHER-workshop in 2016 and since then he has willingly shared his knowledge on shared decision-making. As co-author of the third paper in this thesis, he supervised me through the different research processes. Jürgen's commitment to our collaboration has been outstanding. I also would like to thank Mirjam Lauritzen and the other team members of Samvalgssenteret at the University hospital of North Norway for our collaboration.

All of my colleagues at the University of South-Eastern Norway and in the extended research network must be thanked for their continuous interest in my project and progress. None mentioned, none forgotten they say, but I trust that you know how much I appreciate your help and support in this process!

On a more personal level, I would like to express my deepest gratitude to my family and friends. Your continuous backing and encouragement have been very important to me. My boyfriend Julian has inspired and provided me with self-confidence, assurance and motivation to carry out this work. I am forever thankful for all of your love and compassion!

Thesis summary

Background:

Hip osteoarthritis (OA) may significantly reduce patient's quality of life because of loss of physical function and of the ability to engage in valued activities. Pain and stiffness are cardinal symptoms, and no curative treatment is yet available. Patients are encouraged to change behaviour towards a more active and healthy lifestyle, to participate in structural physical training programs and to take pain-relief and anti-inflammatory medication, when needed. A total hip replacement (THR) may be offered when the disease progresses and conservative treatment options show limited effect on pain and physical function. In Norway, slogans such as "Pasientens helsetjeneste [The patient's healthcare service]" frequently permeate policy documents. This entails a shift towards a more patient centered healthcare service built around the needs and experiences of the individual patient. To be able to offer such a service, more insight is needed to understand the journey the patients go through when developing a progressive, long-term disease like hip OA. In light of this, the overall aim of this thesis was to explore changing patients' needs during the continuum of the disease, focusing on information needs, psychosocial support and treatment decision-making. We also planned to develop a web-based patient decision aid (PDA) offered through the official health portal in Norway *helsenorge.no/samvalg*.

Methods:

The present research involves both qualitative and quantitative research methods. In paper 1, individual interviews were used to explore 13 patients' accounts of their healthcare needs. In Paper 2, a quantitative approach was used involving univariate and multiple regression models to determine whether self-reported measures on social support and self-efficacy predicted variability in short time recovery in 223 patients undergoing THR. In paper 3 we observed and audio-recorded 19 routine consultations at an orthopedic outpatient clinic and used thematic analysis to explore how patients are involved in decision-making, and what patient-related barriers and facilitators influence shared decision-making (SDM). The PDA was developed in close collaboration with the University Hospital of North Norway in Tromsø and the Department of Emergency and Orthopaedics at Vestre Viken Hospital Trust in Drammen. The content, including evidence based information and patient narratives, was developed and quality assured through the involvement of patients, healthcare professionals and researchers. The procedure follows an existing development protocol called “DAfactory”.

Findings:

The findings of paper 1 resulted in a model called “The hip osteoarthritis continuum” which illustrates how patients’ information and emotional needs arise and change in line with the symptomatic progression of the disease, the clinical encounters and the decision-making processes. In paper 2, we determined that OA patients’ general self-efficacy and the expectation of others’ tangible assistance predicted short time recovery in our cohort after THR. In paper 3, we found that the patients’ intention towards SDM behaviour appeared influenced by the chronic (non-life-threatening) nature of the disease. The controlled context within the outpatient setting, and the imbalanced power-relationship between the (unexperienced) patient and the (experienced) orthopedic surgeon may hinder realistic opportunities for SDM. Proactive patients with previous experience in making treatment choices, and having a family member present during hospital visits facilitated SDM.

Conclusion:

Patients with hip OA need adequate and tailored information about the disease and treatment options. They need realistic opportunities, support and encouragement from their healthcare professionals and social network to take an active role in the planning and implementation of a personal health plan. Surgical decision-making should not be limited to the orthopedic outpatient setting, but rather be initiated earlier in the continuum of the disease. The PDA we developed will be implemented and tested in a follow-up research project.

Sammendrag (Summary in Norwegian)

Bakgrunn:

Hofteartrose kan begrense en persons livskvalitet betraktelig grunnet tap av fysisk funksjon og evnen til å gjennomføre verdsatte aktiviteter. Smerter og stivhet er kjernesymptomer ved artrose, og ingen kurativ behandling er per i dag tilgjengelig. Generelt oppfordres alle pasienter med hofteartrose livsstilsendring med vektreduksjon og en aktiv og sunn livsstil. Mange har nytte av fysioterapi og noen også smertelindrende og betennelsesdempende medisiner ved behov. Etter hvert som sykdommen og symptomene utvikler seg og konservative behandlingsalternativer viser begrenset effekt på smerte og fysisk funksjon, kan det være aktuelt med protesekirurgi. I Norge benyttes ofte paroler som *«Pasientens helsetjeneste»* i helsepolitiske styringsdokumenter. Dette innebærer kort sagt et skifte mot en mer personorientert helsetjeneste hvor situasjonen og behovene til den enkelte pasient skal ligge til grunn for det endelige behandlingstilbudet som tilbys. For å kunne bygge opp pasientens helsetjeneste er det avgjørende med mer kunnskap for å forstå forløpet pasienter gjennomgår under utvikling av en progressiv, degenerativ og langvarig sykdom som hofteartrose er. I lys av dette er det overordnede målet med denne studien å utforske endrede pasientbehov i et kronisk sykdomsforløp, med fokus på informasjon, psykososial støtte og kliniske beslutningsprosesser. En parallell forsknings- og utviklingsprosess er å produsere et nettbasert samvalgsverktøy som skal publiseres på den offisielle helseportalen *helsenorge.no/samvalg*.

Metoder:

Denne doktorgradsavhandlingen involverer både kvalitative og kvantitative forskningsmetoder. I artikkel 1 ble det benyttet individuelt dybdeintervju med lydopptak for å utforske 13 pasienters erfaringer og oppfatninger om deres helserelaterte behov knyttet til det å leve med symptomatisk hofteartrose over tid. I artikkel 2 ble det brukt en kvantitativ tilnærming med univariate og multiple regresjonsmodeller for å avgjøre om selvrapportert grad av sosial støtte og mestringstro (self-efficacy) kunne predikere endringer i behandlingsresultatet etter unilateral kirurgi med innsetting av total hofteprotese i en kohort bestående av i alt 223 pasienter. I artikkel 3 observerte vi 19 rutinekonsultasjoner ved en ortopedisk poliklinikk og brukte kvalitativ tematisk analyse på transkriberte lydopptak og observasjonsnotater for å studere hvordan pasienter er involvert i beslutningsprosesser, og avgjøre hvilke pasientrelaterte faktorer som enten fremmer eller hemmer samvalg. Samvalgsverktøyet er utviklet i nært samarbeid med Universitetssykehuset Nord-Norge i Tromsø, samt avdeling for ortopedi og akuttmottak ved Vestre Viken helseforetak i Drammen. Innholdet, inkludert evidensbasert informasjon og pasientfortellinger (videobaserte narrativer), ble utviklet og kvalitetssikret gjennom involvering av pasienter, helsepersonell og forskere. Prosedyren følger en utviklingsprotokoll kalt "DAfactory".

Resultater:

Resultatene fra artikkel 1 resulterte i en modell kalt "The hip osteoarthritis continuum" som sammen med en empiribasert fasebeskrivelse illustrerer hvordan pasientenes informasjons og emosjonelle behov oppstår og endres i takt med den symptomatiske utviklingen av sykdommen, oppfølging fra helsevesenet og ulike beslutningsprosesser. Analyser i artikkel 2 viste at økt grad av mestringstro og forventning om reell bistand fra andre i ens sosiale nettverk predikerte resultatet etter kirurgi i den aktuelle kohorten. I artikkel 3 fant vi at pasientenes intensjon om samvalg så ut til å være påvirket av sykdommens kroniske (ikke-livstruende) natur. Den kontrollerte konteksten som den polikliniske settingen representerer, og det ubalanserte maktforholdet mellom en (uerfaren) pasient og (erfaren) ortopedisk kirurg kan hemme realistiske muligheter for samvalg. Proaktive pasienter med tidligere erfaring med å foreta behandlingsvalg, og tilstedeværelse av et familiemedlem under konsultasjonen virket å fremme samvalg.

Konklusjon:

Pasienter med hofteartrose trenger god og tilpasset informasjon om sykdommen og behandlingsalternativene. De trenger realistiske muligheter, støtte og oppmuntring fra helsepersonell og sosialt nettverk for å ta en aktiv rolle i planleggingen og gjennomføringen av en individuell behandlingsplan. Kirurgiske beslutningsprosesser bør ikke begrenses til poliklinikker, men snarere settes i gang tidlig i forløpet av sykdommen. Samvalgsverktøyet vil bli implementert og testet i et senere forskningsprosjekt.

List of papers

1. Brembo, E. A., Kapstad, H., Eide, T., Månsson, L., Van Dulmen, S., & Eide, H. Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study. *BMC Health Services Research*, 2016, 16(1), 1-15. doi:10.1186/s12913-016-1342-5

2. Brembo, E. A., Kapstad, H., Van Dulmen, S., & Eide, H. (2017). Role of self-efficacy and social support in short-term recovery after total hip replacement: a prospective cohort study. *Health and Quality of Life Outcomes*, 2017, 15(1), 68. doi:10.1186/s12955-017-0649-1

3. Brembo, E. A., Eide, H., Lauritzen, M. van Dulmen, S., & Kasper, J. Building ground for didactics in a patient decision aid for hip osteoarthritis. Exploring patient-related barriers and facilitators towards shared decision-making. *Under review, August 2019*.

Abbreviations

ADL:	Activities of daily living
GP:	General practitioner
GSE:	General self-efficacy
GSES:	General self-efficacy scale
HCP:	Healthcare professional
HL:	Health literacy
IPDAS:	International Patient Decision Aid Standards
MMR:	Mixed Methods Research
NICE:	National Institute for Health and Care Excellence
NSAID:	Non steroid anti-inflammatory drug
OA:	Osteoarthritis
OARSI:	Osteoarthritis Research Society International
OPC:	Outpatient clinic
PCC:	Person-centred care
PCR:	Person centred research
PROM:	Patient reported outcome measure
PDA:	Patient decision aid
RA:	Rheumatoid arthritis
SDM:	Shared decision-making
SPS:	Social provisions scale
SPSS:	Statistical Package for the Social Sciences
TA:	Template analysis
TENS:	Transcutaneous electrical nerve stimulation
THR:	Total hip replacement
TKR:	Total knee replacement
TPB:	Theory of planned behaviour
UNN:	University Hospital of North Norway
WHO:	World Health Organization
WOMAC:	Western Ontario and McMaster Universities Osteoarthritis Index
QoL:	Quality of life

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1. Introduction and background

1.1 Introduction

All chronic conditions present with a set of challenges for the person who suffers and his or her family. Some of these challenges are concerned with dealing with symptoms, disability, emotional impacts, complex medication regimens, challenging lifestyle adjustments, and obtaining and accepting helpful care, support and medical treatment. Many people with chronic conditions struggle with the physical, psychological, and social demands of their illness and do not experience much help or support from medical care. Furthermore, the help received, while well intentioned, may fail to afford optimal clinical care or to meet the persons' needs to enable and support effective self-management of their illness [1].

This research focuses on patients with hip osteoarthritis (OA), which is the most common form of arthritis; based on a population survey, the prevalence in Norway has been estimated to be 5.5% [2]. Hip OA usually presents itself around the age of 50, but people can also be affected at a younger age (see section 2.2 for more information on prevalence and incidence). It is a chronic and progressive condition characterized by pain and stiffness without any effective curative treatment. Hence, pain, stiffness and subsequent impaired function is a reality for many affected patients who continuously are trying their best to live a normal life as long as possible. These patients clearly need support and guidance from healthcare professionals (HCPs) to optimise self-management strategies in daily living [3, 4]. However, patients with OA seem to receive little or poor information about management options, especially during early phases of the disease, resulting in a gap between clinical management guidelines and actual practice. Patients and HCPs' attitudes toward OA as a disease has for long been characterised by a view that it is a normal consequence of aging and that there is not much to do to reduce the impact of symptoms [5]. Two Norwegian studies investigating the current quality of hip and knee OA management and the patients' perceived quality of the care in a Norwegian county, found that the patients seem rather satisfied with the OA care received. However, they also found that less than 50% of the recommended care was provided. Referral to weight reduction had the lowest pass rate, whereas referral to and information about physical activity had the highest. These findings indicate that there is significant room for improvement in the quality of care delivered in the primary healthcare context [6, 7]. Apparently, the service provided is not at all patient-centred, i.e. not built around the needs and experiences of the individual patient. To be able to offer such a service, more insight is needed to understand the journey the patients go through when developing a progressive, long-term disease like hip OA.

In this PhD-project, I have used mixed research methods to investigate how patients experience and express their healthcare needs while living with hip OA – their *hip journey,* with an emphasis on information exchange, psychosocial needs and clinical decision-making.

The project has two parallel processes. The first process is a series of empirical studies related to different aspects of the hip journey and patients' needs, which form the main part of the doctoral thesis. The second process has been the development of a web-based patient decision aid (PDA) intended to support patients in their communication with HCPs during critical phases, e.g. when a change in treatment may be required, as part of their hip journey. However, the PDA is yet to be implemented, and an evaluation and broader discussion of the PDA will therefore be fulfilled after the PhD project has been finished. A short description of the development of the PDA is provided in section 3.5 as part of the general background of the empirical studies. However, the empirical findings will have implications for the actual implementation of the PDA. These implications are discussed in section 8.1 of the thesis.

In the following sections, I present the theory and perspectives that constitute important background information of this research.

1.2 Patient perspective

1.2.1 The patients' healthcare service

Patients with chronic diseases may have complex healthcare needs which places high demands on health services [8]. In the Norwegian Health coordination reform, "Proper treatment – at the right place and right time" [9], there is a strong emphasis on how to strengthen and safeguard the individual patients' role within the health system. The primary aim is to achieve better distribution of resources and better healthcare service quality. The healthcare system is undergoing a process of comprehensive change to become more sustainable and better coordinated, to meet the needs of a changing population, and to guarantee patients equal access to good, equitable and balanced health and care services. One of the initiatives is that a larger portion of health services is now provided by the municipal health service so that excessive use of specialized hospital resources is reduced. Good quality of services is supposed to be ensured, among other things, by strengthening employee competence and improved cooperation between health levels. The Office of the Auditor General of Norway evaluated the effect of the coordination reform and submitted a report to the Norwegian Parliament in 2016 [10]. The report points out that the capacity of the municipalities to meet the increasing healthcare needs of patients has not been sufficiently strengthened and the competence of the employees is not adequately improved. Another central point is that the information flow between health levels is insufficient which hampers healthcare quality.

The implementation of digital information and communication technologies (ICT) plays a crucial role in the current and future healthcare system. The Norwegian Directorate for eHealth was established in 2016, and is responsible for the coordination, development and implementation of national ICT solutions (see *ehelse.no/english*). The National eHealth Strategy and Action Plan 2017-2022 describes the proposed strategic direction for the goal of a digitized, integrated healthcare system that is experienced as simpler, better and more comprehensive for the population [11]. A national health platform *helsenorge.no* is central in this respect and includes a range of features that enables the patient to take on an active patient role and participate in the planning of own health. Together with quality ensured health information, it enables access to a range of self-service solutions. The patient can access personal health information, revise the summary care record (Norwegian: Kjernejournal), select/change GP, review prescriptions and check vaccinations. Another feature gives an overview of waiting time for specific treatment or screening options, and guidance on how to choose between hospitals. The portal includes quality ensured and updated information about health, lifestyle, diseases and treatment. A recently added component is a collection of web-based patient decision aids (Norwegian: Samvalgsverktøy), which may help patients to decide between different treatment options.

In The Health and Hospital Plan, The Norwegian Government emphasizes the creation of “the patients’ healthcare service” [12]. This means that patients are given more influence, and that their preferences and needs are given more weight in treatment decision-making, including how treatment should be provided. Patients’ competence (as patient expert) should simply count as equally valuable as HCPs’ competence and expertise. The guiding principle “No decision about me, without me” is emphasized in the white paper entitled Primary Health and Care Services of Tomorrow – Localized and Integrated. [13]. This principle was first introduced in an article from 2001 called “Healthcare in a land called PeoplePower: nothing about me, without me” [14], and later highlighted among the UK Government healthcare strategies in the British white paper “Equity and excellence: Liberating the NHS” [15].

Creating the patients’ healthcare service entails true change in culture, attitudes, organization and administration within the healthcare system [12]. The patient role has changed drastically over the last couple of decades. People increasingly request information about their own health and personal risk factors. They expect high quality care and to be involved as equal partners in the planning of care and treatment. HCPs must acknowledge this shift and develop practices that really put the patients’ first.

1.2.2 Patients’ involvement in healthcare decisions - a collaborative responsibility

In this section, patients’ involvement in decision-making is seen in light of the assumption “No one can make decisions for another, act for them or solve their problems, because these are matters of personal responsibility and choice”. This assumption forms the basis for a client-centred counselling model developed by Carl Rogers in the late 1940s, which has influenced the modern conceptualisation of ‘patient-centred care’ (PCC) [16, 17]. At its’ core, PCC involves perceiving and evaluating healthcare from the patient’s perspective and then adapting care to meet the needs and expectations of patients [18]. Five distinct dimensions that describe PCC are [19]:

1. Adopting the biopsychosocial perspective (as opposed to a perspective that is narrowly biomedical)
2. Understanding the patient as a person in his or her own right, not merely as a body with an illness
3. Sharing power and responsibility between the doctor and the patient

4. Building a therapeutic alliance, a relationship that is both instrumentally and intrinsically valuable
5. Understanding the doctor as a person, not merely as a skilled technician

Patients have by law the right to actively participate in decisions related to personal health [20], commonly known as shared decision-making (SDM). SDM has evolved as an offspring of patient-centred medicine and patient-centred communication [21-24]. There are different views with regard to what constitutes patient involvement and participation in healthcare [25] and several interpretations of what constitutes SDM [23]. Patient involvement in decision-making involves more than the intuitive, common sense meaning. Entwistle and Watt [26] propose that patients can be involved not only because of *what they say and do* to influence a decision, but also by virtue of what they think and feel about their *roles*, *efforts* and *contributions* to decision-making and their relationships with their clinicians. Arguments for patient involvement are based on claims that it matters to patients, it is indicative of (HCPs' respect for) patients' personal autonomy, and it is beneficial for health and well-being [27]. Clearly, the patient-centred paradigm places high demands on HCPs' attitudes towards patient involvement and their communication skills. Insight into the patients' experiences and needs, like sought in the present thesis, helps to bridge the world of the HCP and that of the patient and contribute to succeeding in the effort to centre healthcare around the patient.

2. Osteoarthritis: a chronic musculoskeletal condition affecting daily functioning and quality of life

2.1 Hip OA patients' health needs

WHO defines perceived health needs as "*the need for health services as experienced by the individual and which he/she is prepared to acknowledge*" [28]. OA is primarily a disease that affects older people many of whom also suffer from comorbidities. In a Canadian retrospective cohort study involving 207 610 individuals, 67% of patients with an OA diagnosis had at least one comorbidity. These included hypertension, depression, chronic obstructive pulmonary disease (COPD), and epilepsy [29]. Diabetes mellitus is also relatively common with an estimated prevalence of 14.4% [30]. OA is not an easy condition to treat and self-manage. It is heterogeneous, has an unpredictable natural course, and has variable effects on the individuals' health status. This contributes to the complex picture when older persons seek help for their OA related symptoms and problems. A challenge is that management of OA often begins after the onset of symptoms, by which the disease is well established and significant joint damage has already occurred [31]. Hip OA is primarily treated by HCPs located in primary care. GPs are responsible for diagnostic procedures and symptom assessments, provision of evidence-based information and advice about the disease and treatment alternatives, pharmacological treatment and referral to specialist care. The GP also acts as a medical coordinator for the patient and is responsible to cooperate with other relevant HCPs to secure a well-functioning healthcare team. Physiotherapists have specialist knowledge about OA and evidence-based conservative treatment approaches. They provide physical therapy, education about the role of physical exercise and weight loss in OA care, and tailor self-management strategies based on individual needs.

The complexity of OA and its management may explain the gap that is evident between evidence and practice [32]. Many adults with chronic musculoskeletal pain, such as OA pain of the hip, do not seek help at a regular basis from HCPs. Research findings suggest that disability is a more important determinant for help-seeking behaviour than pain severity [33]. A previously mentioned study investigating 1247 Norwegian OA patients' perceived quality of care, document that there is room for improvement. Measured by the OsteoArthritis Quality Indicator questionnaire [34], developed with input from experts and relevant stakeholders, less than 50% of recommended care was provided according to the study participants [6]. Similar results were confirmed in a systematic review performed by Hagen and colleagues [35], summarizing studies assessing the quality of community care provided to patients with hip or knee OA. Eleven of the fifteen included studies reported overall pass rates below 50%, and on average, the pass rates for first-line non-pharmacological approaches were under 40%.

2.1.1 Information and emotional needs

It is crucial to gain more understanding of some of the reasons for this gap between evidence and practice, and further how to help patients with hip OA to optimize self-management and decision-making throughout the disease continuum, which can last for many years. As we will see later in this chapter, treatment alternatives for all hip OA patients involve conservative treatment options, which for many requires a drastic change in lifestyle and long-lasting adherence to physical activity and exercise, and for some also medical treatment regimens. These patients make every day decisions about if and how to adhere to these recommendations. This necessitates that patients receive adequate and individually tailored education and support. Investigation of the information and emotional needs of patients with hip OA may help researchers and clinicians to develop effective interventions that meet the needs of these patients.

Patients and clinicians call for more proactive care, and improved information, especially for those with early stage OA as measures to give them greater control over their condition and enable them to take responsibility for managing their OA successfully and independently [3]. The need for clear communication of information, the need to obtain information from a variety of sources and the content needs of health information are three areas identified in a systematic scoping review regarding patients' perceived health information needs for OA [36]. The language used by HCPs (i.e. medical jargon) may be misinterpreted by patients and may lead to negative connotations. Difficulties with access to HCPs and insufficient information are frequent concerns perceived by patients. Furthermore, women show more interest in disease management than men, whilst men prioritize work commitments over health concerns, demonstrating demographic differences in the perceived needs among patients with OA. There is also evidence suggesting that people with higher education have more unfulfilled health information expectations and dissatisfaction with the amount and clarification of knowledge relating to management options, the prognosis of OA and preventive strategies [36].

The continuous struggle to cope with pain and physical limitations in daily living has profound impact on patients’ well-being and quality of life (QoL) and may lead to mental health problems, including depression and anxiety. The prevalence of depressive symptoms and anxiety among patients with OA is reported to be 19.9% and 21.3%, respectively [37]. These psychological comorbidities are frequently associated with higher pain and physical limitation, poor outcomes to both conservative and surgical interventions, and increased pharmacotherapy and healthcare utilization [38]. HCPs involved in the care of OA patients must therefore also address the emotional and psychosocial needs of patients and consider the need for multidisciplinary treatment. The current evidence on psychological interventions (e.g., cognitive behavioural therapy, coping skills training, hypnosis/relaxation) for OA patients shows, however, a lack of documented effects on depression and anxiety [39].

A recent systematic scoping review synthesised the evidence regarding patients' perceived healthcare service needs related to OA [4]. Five key findings emerged: (1) Symptom control drives the need for both conventional and complementary services; (2) An individualized relationship is sought with a practitioner knowledgeable in OA care who adopted a holistic approach, whether providing conventional or alternative therapies; (3) Medications are required to obtain symptomatic relief, with use tempered by recognition of potential side effects and financial cost; (4) The need for allied health services is recognised, although patient and system issues such as access and cost are barriers to uptake; (5) Patient's attitudes towards joint replacement, orthoses and physical aids are influenced by their preferences and previous healthcare experiences.

2.2 Epidemiology of hip OA: prevalence, progression and implications

Worldwide, OA is the most common joint condition, affecting an estimated 9.6% of men and 18% of women over 60 years of age. The prevalence of symptomatic hip OA in the Norwegian population is reported to be 5.5% [2]. Since the prevalence of OA increases with age, the prevalence and burden is expected to increase substantially in the near future due to demographic changes. By 2020, OA is estimated as the fourth leading cause of disability worldwide [40]. OA most commonly affects the knees, hips, fingers and spine. The disease generally develops progressively over a number of years before becoming symptomatic, potentially leading to disability, and social isolation. However, the time from the onset of symptoms to more severe states varies at the individual level. The trend toward disability, with all its consequences, the economic burden of OA in European countries is high; per patient average costs are estimated to range from €1330 to €10 452, depending on the country and the methodological approach taken [41, 42]. Pain and loss of function are the main clinical features that lead to treatment, including non-pharmacological, pharmacological, and surgical approaches.

2.3 Characteristic features of osteoarthritis and diagnostic criteria

OA is a disorder of the joints characterized by progressive deterioration of the articular cartilage or of the entire joint, including the articular cartilage, the synovium (joint lining), the ligaments, and the subchondral bone (bone beneath the cartilage) [43]. Osteoarthritis Research Society International (OARSI) defines OA as "*a progressive disease representing the failed repair of joint damage that, in the preponderance of cases, has been triggered by abnormal intraarticular stress"* [44]. A classification system developed by Kellgren and Lawrence [45] includes a series of radiological structures that are considered evidence of OA. It divides the disease into five grades (Table 1):

Table 1: Kellgren-Lawrence classification system of osteoarthritis

0 - None	No OA changes
1 – Doubtful	Doubtful joint space narrowing (JSN) and possible osteophytic lipping
2 – Minimal:	Definite OA and possible JSN
3 – Moderate	Moderate multiple osteophytes, definite JSN, some sclerosis, possible bone end deformity
4 – Severe:	Large osteophytes marked JSN, severe sclerosis, definite deformity of bone ends

OA is either primary (idiopathic, with no identifiable cause) or secondary (caused by an underlying condition). Traditionally, OA is further classified according to the anatomical site of involvement (e.g. hand, hip, knee or spine), and whether it is localized to one particular area, or generalized, with involvement of three or more areas [46]. Figure 1 illustrates a normal and a contralateral OA affected hip joint.

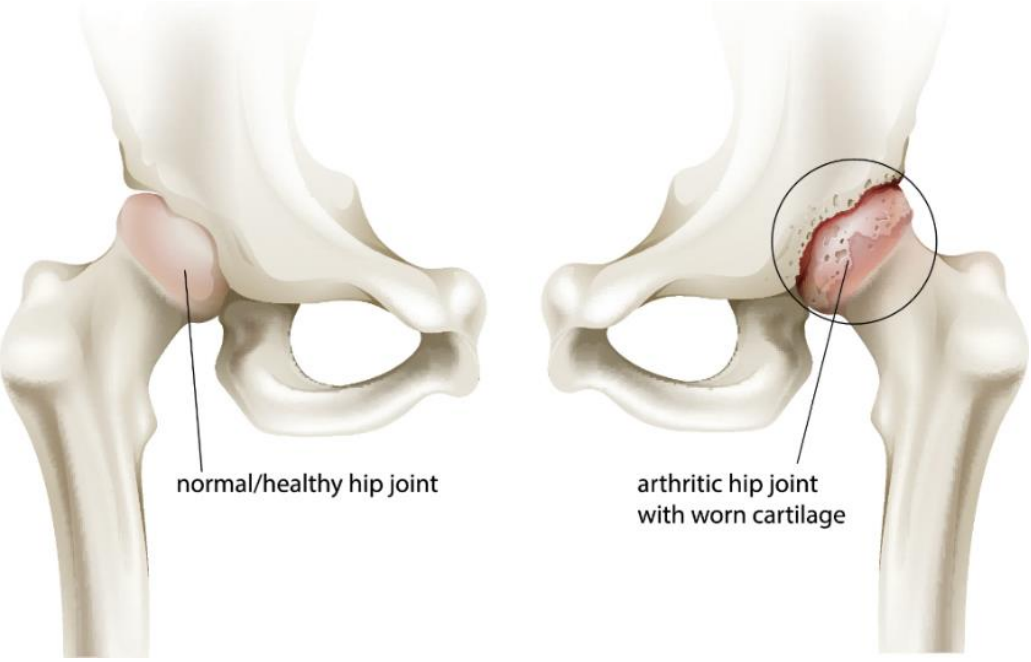


Figure 1: Illustration of a hip joint with worn cartilage. Credit: colourbox.com

The criteria by the American College of Rheumatology (ACR) are commonly used for the diagnosis of hip OA in clinical practice [47]. The criteria are presented in Table 2:

Table 2: ACR criteria for the diagnosis of hip osteoarthritis

Clinical criteria A	**Clinical criteria B**	**Clinical and radiographic criteria**
Hip pain AND	Hip pain AND	Hip pain AND any 2 of the following
Internal hip rotation < 15˚ AND	Pain with internal hip rotation > 15 ˚ AND	ESR <20 mm/h
ESR* ≤ 45 mm/h or hip flexion ≤ 115˚ if ESR unavailable	Morning stiffness of hip ≤60 min AND	Radiographic femoral and/or acetabular osteophytes
	Age > 50 years	Radiographic JSN

**ESR=erythrocyte sedimentation rate*

It is possible to diagnose hip OA without radiographic investigation, but it is commonly used to confirm the diagnosis and to monitor disease progression [31]. Clinically, hip OA must be distinguished from hip pain stemming from facet joint OA, sacroiliitis (inflammation of the sacroiliac joint), trochanteric bursitis and iliotibial band syndrome.

2.4 Symptoms

Hip OA is associated with the classical antalgic gait, and pain symptoms typically develop over months to years rather than acutely. An achy groin pain, which at first is intermittent, worse at the end of the day, and activity related are common descriptions. The pain may radiate to the buttock, trochanteric bursae (frequently associated with bursitis), anterolateral thigh (differential diagnosis with femoral neuralgia) or the knee

[48]. Many patients experience morning stiffness in and around the affected joint, and it lasts typically less than 30 minutes. Pain, stiffness and subsequently muscle weakness and joint instability lead to impaired physical function. If pain persists over time, psychological distress may develop [48, 49]. The Harris Hip Score (HHS) and Oxford Hip Score (OHS) are examples of two outcome measures designed to assess the results of hip surgery [50], but they are also used by HCPs to monitor variation in symptoms and physical limitations.

2.5 Risk factors for hip OA

The World Health Organization (WHO) defines a risk factor as any attribute, characteristic or exposure of an individual that increases the likelihood of developing a disease or injury [51]. According to Murphy, Eyles and Hunter [31], risk factors for hip OA can be split into those at the joint level and those at the person level (Table 3). Importantly, these do not exist independently of one another. Joint level risk factors may be considered the etiological basis for the development of hip OA, whereas person level risk factors contribute to the development of hip OA indirectly, by increasing susceptibility to joint level risk factors.

Table 3: Risk factors for hip osteoarthritis

Joint level risk factors	**Abnormal hip joint morphology**	Can lead to pathological loading patterns that produce shear stresses on the hip joint.
	Hip dysplasia	The femoral head is less stable within the shallow acetabulum, causing the distribution of shear forces that damage the articular cartilage and predispose to labral tears.
	Femoroacetabular impingement (FAI):	The femoral head rubs abnormally or does not permit a normal range of motion in the acetabular socket.
	Muscle weakness	The deep stabilizing muscles of the hip absorbs shock and protects the joint for aberrant movement patterns. Muscular dysfunction plays a role in pathological hip joint biomechanics.
	Acetabular labral tear	Damage to cartilage and tissue in the acetabulum caused by an acute traumatic event, osseous morphology or degenerative changes.
Person level risk factors	**Age**	The prevalence of OA in any joint increases considerably with age, starting at around age 50 – 55 [52]. Several factors contributes, including the senescence of cartilage leading to its fragility [53], the failure of periarticular structures which provide protection against joint damage during weight bearing, including muscle weakness, neurosensory failure, and ligamentous laxity [54].
	Sex	The association between sex and hip OA is unclear. A meta-analysis suggests that females have greater risk for prevalent and incident knee and hand OA and incident hip OA. No significant sex difference in hip OA prevalence or radiographic severity was found [55].
	Weight	High BMI (body mass index) is associated with increased risk of hip OA. However, this relationship seems to be stronger in knee OA. A large systematic review and meta-analysis found that a 5-unit increase in BMI was associated with an 11% increased risk of hip OA – both in men and women [56].
	Genetics	Genes are the strongest risk factors for OA in the general population. Evidence of a genetic influence of OA comes from a number of sources, including studies of family history and family clustering, twin studies, and exploration of rare genetic disorders. Estimates suggest a heritability of OA of 50% or more, indicating that half the variation in susceptibility to disease in the population is explained by genetic factors. Heritability appears to be greater in females [57].
	Ethnicity	The prevalence of OA and patterns of affected joints vary among racial and ethnic groups [58]. The prevalence of OA is higher in Europe and the USA than other parts of the world [40]. Knee OA is more common in African-American women than in white women, but that is not the case for hip OA. European whites are more frequently affected by hip OA than Jamaican blacks, African blacks, or Chinese [43, 58].
	Occupation	Long-term exposure to heavy lifting seems to be significantly associated with developing chronic hip or knee pain. Farmers and men working in the construction industry appear to be at particular risk, and the risk is markedly increased if the worker is obese [59].
	Diet	Several vitamins and minerals have been investigated, but no strong evidence exists to support dietary factors as risk of OA [31].

2.6 Patients' experience of pain and its consequences in daily living

OA is a multifaceted disease, in which the structural evidence of joint damage does not always correlate with the patient's experience of joint pain and disability [60, 61]. Hawker *et al*. [62] conducted focus group interviews with 52 patients with hip OA and 91 patients with knee OA about their experience of pain. Participants described two types of OA related pain – a dull, aching pain that developed into being constant over time, and less frequent, short episodes of more intense, unpredictable, emotionally draining pain. Participants reported that the second type of intense and unpredictable pain particularly interfered with social and recreational activities. As a result, many participants curtailed these activities to avoid triggering intense pain episodes. Poulsen *et al.* [63] aimed to describe pain location and pain distribution in primary care patients with clinically and radiographically confirmed hip OA. Among 108 valid pain drawings, 77% patients had marked the greater trochanter area, 53% the groin area, 42% the anterior/lateral thigh area, 38% the buttock area, 17% the knee and 15% the lower leg area. No patients marked pain exclusively in the areas of the knee, posterior thigh or lower leg. Woolhead *et al.* [64] conducted twenty-six focus group interviews comprising 123 participants to explore the experience of night pain in people with hip or knee OA, sampled in groups to represent mild, moderate and severe pain. The majority (81%) experienced night pain, whereas the remaining 19% were from the moderate or severe groups. The hip and knee participants expressed similar night pain experiences, and notably, night pain was present regardless of the stage of OA. However, the severity of pain increased as the disease progressed. The authors conclude that assessment of night pain should be taken into account as part of the patient narrative, and that night pain does not represent a distinct marker of disease severity [64].

Gignac *et al*. [65] compared the health experiences of middle and older aged adults with moderate OA symptoms with the experiences of healthy individuals. 53 women and 37 men were interviewed about changes in health, the impact of these changes and self-management strategies in focus groups (10 OA and 6 control groups). The participants described OA as part of a normal aging process, requiring acceptance, not treatment. However, younger patients < 55 years of age reported more distress and frustration about management compared to older patients. Patients experienced being at odds with GPs either because GPs made no recommendations to manage symptoms, instead attributing them to the aging process, or because GPs recommended pharmacologic management of pain with little or no discussion of long-term effects and self-management strategies. They were often frustrated and uncertain about where else to seek help. This resulted in low adherence to advice and distrust for some [65].

2.7 Treatment approaches for hip OA

Unfortunately, OA cannot be cured. The goal of treatment is to alleviate pain, increase physical function and improve QoL. According to guidelines provided by the National Institute for Health and Care Excellence (NICE), a holistic approach to OA assessment and management should be adopted [66]. Treatment recommendations include [66-69]:

1. Education and self-management

All patients must be offered accurate verbal and written information to enhance understanding of the condition and its management, ant to counter misconceptions. The information should be an ongoing, integral part of the management plan rather than a single event. Clinicians and patients should agree upon an individualised self-management plan, ensuring that positive behavioural changes such as exercise, weight loss, use of suitable footwear and pacing are appropriately targeted.

2. Non-pharmacological management

Exercise is regarded as core treatment in OA care, irrespective of age, comorbidity, pain severity or disability. Exercise should include local muscle strengthening, general aerobic fitness and range of motion exercises. A physical therapist can provide the patient with instructions and can evaluate the progress together with the patient. Adjuncts to the core treatments include manipulation, stretching and transcutaneous electrical nerve stimulation (TENS). Overweight patients should be offered interventions to lose weight. Appropriate footwear and assistive devices such as a walking stick may reduce pain and improve ambulation. Behavioural changes are difficult to achieve and maintain, and the effect of advice and counselling by clinicians is disappointing. The literature suggests that the following nine factors improve adherence to exercise or physical activity [69]:

- individual exercise
- graded activity
- individualisation according to the person’s exercise goals
- feedback on progress made towards the goals
- iterative problem solving with emphasis on skills that will improve adherence

- reinforcements of maintaining exercise such as additional motivational programmes
- exercise plans and log books
- written, audio- or video- based information
- booster sessions

The largest portion of research on lower-extremity OA is conducted on knee OA. For example, a Cochrane review on the effects of exercise for people with hip OA included only 10 studies [70], while a corresponding review on knee OA included 54 studies [71]. Of the 10 studies in the hip OA review, only five recruited solely participants with symptomatic hip OA, while the other five studies recruited participants with either hip OA or knee OA, or both. The review concludes that there is high-level evidence that land-based exercise reduces hip pain, and improves physical function among people with symptomatic hip OA.

3. Pharmacological management

Paracetamol has traditionally been a core treatment recommendation [72]. However, recent high quality evidence concludes that paracetamol only offers a small, but not clinically important benefit for pain and disability reduction in patients with hip or knee OA. The authors argue that these results support the reconsideration of recommendations to use paracetamol for patients with hip or knee OA in clinical practice guidelines [73]. NSAIDs such as diclofenac, etoricoxib, ibuprofen, naproxen and celecoxib are fundamental agents in the pharmacological management of OA. A recent network meta-analysis assessed the effectiveness of different preparations and doses of NSAIDs on OA pain and physical function, considering randomized trials comparing NSAIDs, paracetamol or placebo. Diclofenac 150 mg/day was found to be most effective in terms of pain and physical function, and superior to the maximum doses of frequently used NSAIDs, including ibuprofen, naproxen, and celecoxib. Etoricoxib at the maximum dose of 60 mg/day was found to be as effective as diclofenac 150 mg/day for treatment of pain, but its effect estimates on physical disability were imprecise. Type and dose of NSAIDs should be chosen based on the analgesic effectiveness in light of the associated risks of gastrointestinal and cardiovascular complications. Patients should be prescribed intermittent short-term use of NSAIDs in moderate to maximum doses as required, rather than long-term fixed doses [74]. Intra-articular injections may be considered for the acute relief of pain not responding to oral analgesia, to treat acute inflammation, or as means to confirm a diagnosis of hip OA [48, 67]. Opioids may be used in special situations, such as for short-term treatment of later stage OA awaiting surgery. However, the substantial risks and only small benefits of opioid treatment and therapeutic alternatives must be considered [75].

4. Referral for consideration of joint surgery

Total hip replacement remains one of the most commonly performed and successful operations in the world [76]. However, there is no clear evidence on when to refer for surgery, and existing guidelines are based only on expert consensus [67]. A general recommendation is to refer a patient for surgical evaluation if symptoms have a substantial impact on QoL, and with poor response to conservative treatment. The decision to undergo surgery remains unique, where individual risk-benefit ratio based on symptom severity, general health, expectations and treatment effectiveness should be carefully evaluated.

5. Follow-up and review

All patients with symptomatic hip OA should be offered regular reviews. The purpose of an agreed follow-up plan is to monitor symptoms, the long-term course of the condition, to discuss the individual’s knowledge, address concerns, personal preferences and ability to access healthcare services.

As described, no treatment cures OA, but fortunately, there is substantial ongoing research that investigates new and innovative treatment approaches, such as stem cell therapy. Present studies report promising results in terms of symptom reduction and the potential to halt cartilage damage, but there is inconclusive evidence about its benefit due to limited high quality evidence and long-term follow-up [77]. The treatment alternatives for OA are shown in Figure 3, modified from Roos and Juhl [78].

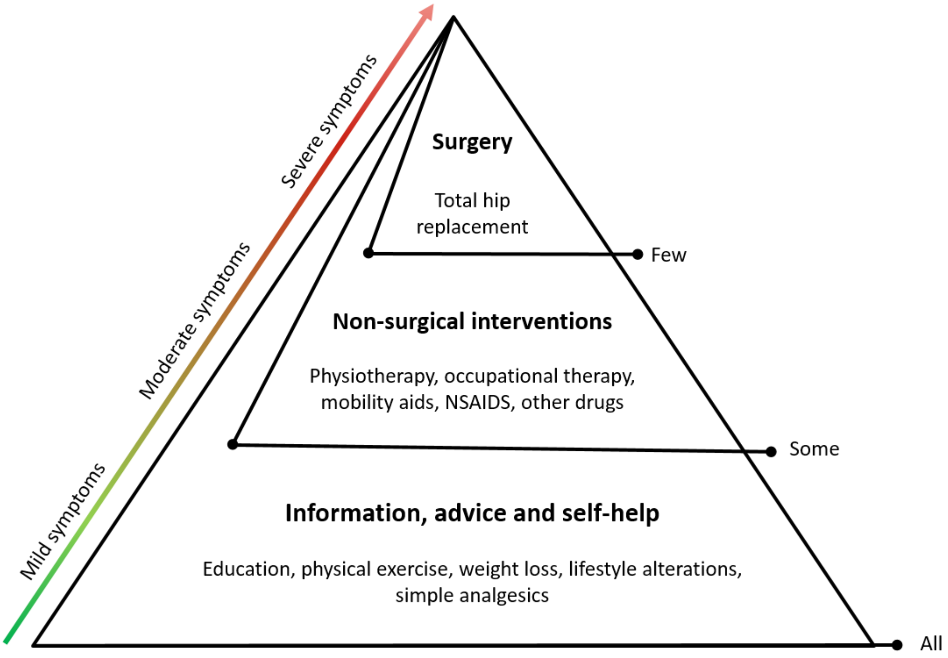


Figure 2: Pyramid illustrating available treatment alternatives for patients with OA

There are several international, Nordic and national initiatives to improve the quality of care and increase the uptake of evidence-based recommendations concerning early prevention and conservative treatment of OA. Three similar Scandinavian projects - BOA *(boa.registercentrum.se/)* in Sweden, GLA;D *(glaid.dk/)* in Denmark, and AktivA (*aktivmedartrose.no/)* in Norway - all aim to increase physiotherapists' competence in OA, secure uptake of evidence-based treatment guidelines, and through structured conservative treatment increase patient's self-management skills and QoL. They also produce large amounts of prospective data, which enable research projects on Master's and PhD levels. For example, the BOA registry in Sweden contained data on 96 000 patients as of April 2018. In addition to this, many patients and their families are provided with information and support by the national patient organization.

2.8 Patient involvement in decisions regarding total hip replacement

Total hip replacement (THR) is usually considered for patients with significant pain and decreased ADL function and with non-adequate response to pharmacological and other non-surgical treatment strategies [66, 67, 79]. However, the selection based on individual factors to help determine appropriateness for surgery is by far a clear-cut procedure. Realizing that the process of greater patient involvement in decision-making is more than choosing options from a menu [26], the process of decision-making in orthopaedic surgery is described in metaphors as “the moving target” [80] and “the final straw” [81]. The moving-target captures the constantly shifting threshold at which the trade-offs can tilt in favour of willingness to consider THR, whereas the final straw characterizes those patients who have reached a point where THR seems to be the last standing option.

The patients need to establish their goals and expectations, examine their values and preferences, and how they relate to their ability to cope with their condition, their need for pain relief, QoL restoration, and the goals and expectations of undergoing THR or not. They might also need to acknowledge fears surrounding the procedure and any previous experiences. Physician’s opinion of surgery, the social impact of others, and knowledge and concerns about recovery can also impact patients’ decisions regarding surgery [82]. As outlined above, patients are very heterogeneous in terms of individual needs and experiences. Patients considering having a THR have multiple questions and concerns, reflecting the need for appropriate information, including core information to all and education tailored to individual needs [83]. Studies demonstrate that patients make decisions for THR without raising all their concerns during clinical consultations. A study of 59 patients with hip or knee OA considering surgery identified a total of 164 expressed concerns by using telephone interviews, but found that the patients raised only half of their concerns during planned audio-recorded orthopaedic consultations [84]. Patients’ decisions have been reported to be affected by the increasing severity of limitations - affecting their quality of daily living, relationships and psychological well-being [81].

It can be argued that THR is an acute intervention in the context of a chronic disease, and that decision-making should take into account these experiences as a whole, in the context of patient’ preferences, needs and values [85]. With this perspective, it is evident that patients would benefit from a person-centred approach to decision-making. This implicates a holistic approach that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care [86]. This level of involvement can be achieved through the SDM model as described earlier in this chapter.

3. Theoretical and practical perspectives

The studies performed as part of this PhD thesis are built on different underlying theories that together have provided a firm scientific framework. Is this chapter these theories will be described for their relevance for the different studies.

3.1 Self-efficacy

As human beings we continuously make decisions about what courses of action to pursue and how long to continue to undertake these actions. Social learning theory posits that the initiation and regulation of transactions with the environment are partly governed by judgments of self-efficacy. Self-efficacy refers to a person's perceived expectations to successfully execute and accomplish a specific task [87]. Self-efficacy is not a perception of whether one will perform these tasks or whether one will necessarily achieve the desired outcomes, but an evaluation of whether one can perform the necessary tasks (confidence in one's own abilities). Self-efficacy has been proven as a crucial psychological factor in health behaviour research. Persons who are diagnosed with a chronic disease, such as hip OA, are usually expected to learn and adapt to a range of self-management strategies. The persistent and pervasive nature of chronic pain requires patients to make constant adjustments to learn to live with their disease. Thus, many non-pharmacologic treatments target self-efficacy as an important process variable [88]. Anyone who has tried to lose weight or starting exercising have probably experienced a range of factors that might influence success - such as motivation, realistic goals, relevant knowledge, prioritizing time, help seeking behaviour and communication skills, self-confidence, and accessible social support. Patients with a chronic disease such as OA are faced with such challenges on a daily basis, which is very stressful. The required self-deliberation process takes place within a context of being in pain, feeling sick, not free to move and dependence on others.

People with high self-efficacy are more likely to achieve their desired goals compared to people with low self-efficacy. Their mastery expectations affect how they complete specific tasks, i.e. how much effort they make and how long they persist in executing them. People with high self-efficacy choose to perform more challenging tasks, set higher goals and stick to them. Furthermore, when goals are not achieved, they recover more quickly and remain committed to their goals. However, persons with low efficacy expectations may experience incentives to learn more about an unfamiliar subject and therefore prepare better for a task than persons with high expectations. Efficacy expectations represent an era of expectations that differ in a pursued goal. An outcome expectancy is defined as a person's estimate that a given behaviour will lead to certain outcomes. An efficacy expectation is the conviction that one can successfully execute the behaviour required to produce the outcomes. Outcome and efficacy expectations must be differentiated (as shown in Figure 4), because individuals can believe that a particular course of action will produce certain outcomes, but if they have serious doubts about whether they can perform the necessary activities, such information does not influence their behaviour [87].

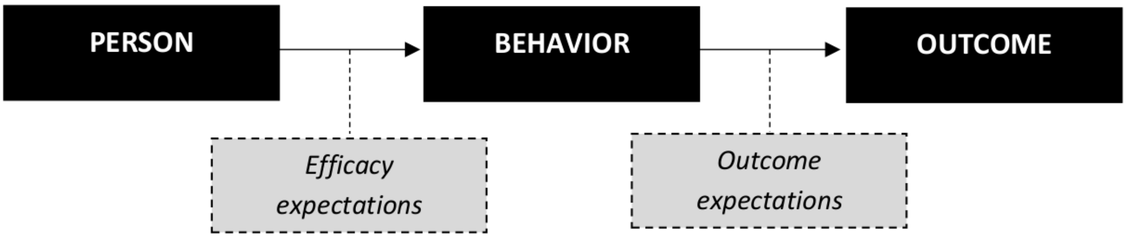


Figure 3: Diagram showing the difference between efficacy expectations and outcome expectations

Expectations of personal efficacy stem from four main sources of information: *Performance* accomplishments provide the most influential efficacy information because it is based on personal mastery experiences. The three other sources of information include *vicarious experiences* of observing others succeed through their efforts, *verbal persuasion* that one possesses the capabilities to cope successfully, and *states of physiological arousal* from which people judge their level of anxiety and vulnerability to stress [87].

Self-efficacy is most commonly understood as being task or domain specific, but it is also identified as important at a more general level of functioning. General self-efficacy (GSE) is conceptualized as "*a global confidence in one's coping ability across a wide range of demanding or novel situations*" [89]. GSE aims at a broad and stable sense of personal competence to deal effectively with a variety of demanding situations. This personal competence is constantly evolving relative to the levels and amount of exposure to new and challenging situations, and based on this, each person's perceived competence to deal with them influences whether or not he or she succeeds with the desired goals.

Schultz *et al.* [90] examined the influence of GSE on pain intensity and pain-related disability in multi-morbid primary care patients with OA and chronic pain aged 65 and older. Controlling for age and number of diseases, they found little evidence that GSE partially mediated the relation between pain intensity and pain-related disability among the 1028 patients recruited from 158 primary care practices in eight different German regions. The authors called for further research to prove the effects [90]. In the studies carried out in the PhD thesis, self-efficacy is a recurrent concept relating to perceived treatment coping skills, as a predictor of variability in short term recovery following THR, and as a factor affecting capacity to engage actively in treatment decision-making.

3.2 Social support

According to Lazarus and Folkman's stress and coping model [91], the impact of stress due to chronic diseases on psychological wellbeing is influenced by social support and personal coping resources. A meta-analytic review investigating the extent to which social relationships influence risk for mortality indicates that individuals with adequate social relationships have a 50% greater likelihood of survival compared to those with poor or insufficient social relationships. This finding was consistent across age, sex, initial health status, cause of death, and follow-up period [92].

Theories and evidence suggest that social support is a heterogeneous concept that may influence mental and physical health through multiple pathways. Two models are proposed to explain how social support operates. The buffering model suggests that when individuals are exposed to stressors, strong social support reduces adverse health consequences. However – if stressors are not present, social support is not associated with health status [93]. The additive or main-effect model suggests that strong social support is beneficial regardless of stressors. Accordingly, social support is regarded as protective and can prevent the occurrence of stress or related stimuli that may compromise health [94]. The literature has shown that both of these models contribute to understanding the relation between social support and health [95].

The influence of social relationships has been conceptualized and measured in several ways in the research literature, but a common categorization includes two types. One examines the *structure* and the other examines the *functions* of social relationships [96]. Structural aspects refer to the extent to which individuals are integrated into social networks, which describes the connections between individuals and their relationships or network ties. Typical measures of social networks include the density, size or number of social contacts. Social integration describes the extent of an individual's participation in a broad range of social relationships, including active engagement in a variety of social activities or relationships and a sense of communality and identification with one's social roles. Marital status, living alone or with others, social isolation are other common structural measures used to assess social relationships [96].

Functional measures of social support focus on the specific functions served by relationships - the actual (received) or perceived availability of support, aid, or resources from these relationships. Three components of social relationships are evaluated: 1. The degree of integration in social networks; 2. Social interactions that are intended to be supportive (e.g., received social support); and 3. Beliefs and perceptions about support availability held by individuals (e.g., perceived social support) [96]. Individuals perceived as supportive make available or provide what can be termed emotional support (e.g., expressions of caring), informational support (e.g., information that might be used to deal with problems or stress), tangible support (e.g., direct material aid, also referred to as instrumental, practical, or financial support), and belonging support (e.g., having others to engage with in social activities) [97]. Perceived support – the expectation that others will provide support if needed, and received support – the actual provision of support by another, are only moderately correlated, and thus are considered distinct constructs.

A study Penninx *et al*. [98] investigated the direct and buffer effect of social support among patients with arthritis (Rheumatoid Arthritis [RA] and/or OA). They found that the effects of structural support measures were present irrespective of a stressor, whereas functional support exchanges were especially effective in the presence of a stressor. From this finding, they concluded that the direct and buffering effects of social support on psychological functioning might occur simultaneously, depending on the type of the measure of support.

In the present study, social relationships and functional social support are examined by interviewing patients about their management strategies when living with hip OA, determining whether social support contributes to explain the variability in short term recovery after THR, and analysing its role in communication about treatment options during busy outpatient consultations.

3.3 The biopsychosocial model as theoretical framework for needs assessment related to pain and disability in hip OA

3.3.1 Pain

Under normal circumstances, pain is a warning sign of potential or actual tissue damage; pain from touching a hot stove, having a finger cut while chopping unions, or chest pain due to heart ischemia. In these instances, pain plays a protective role, signalling to the individual to withdraw from the threat, rest to allow tissue healing, or seek help. However, once its warning role is over, persistence or continued pain, i.e. chronic pain (usually defined as such when the pain lasts at least six months), is considered maladaptive [99]. The International Association for the Study of Pain (IASP) defines pain as "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*" [100]. Each person learns the application of the word related to injury experienced in early life. Biologists recognize that those stimuli that cause pain are liable to tissue damage. Accordingly, pain is that *experience we associate with actual or potential tissue damage*. It is clearly a sensation in one or more parts of the body, but it is also always *unpleasant* and therefore also an emotional experience. Notably, many people report pain in the absence of tissue damage, or any likely pathophysiological cause and this happens usually for psychological reasons. It is generally not possible to distinguish their experience from that due to tissue damage – if they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain. This aligns well with an alternative pain definition offered by Margo McCaffery in 1968: "*Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does*".

3.3.2 Biopsychosocial understanding of pain

The recognition of pain as a complex and subjective phenomenon has led to an understanding that the total pain experience is influenced by biological, psychological and social factors. A traditional biomedical model of illness would assume a direct relationship between nociception and pain. Under this theory, one would cure the pain once the discrete nociceptive stimulus has been identified and appropriately addressed. Thus, this model is characterized by a reductionist approach that attributes pain to a single cause located within the body and that considers psychological and social processes as separate and unrelated. In contrast, the *biopsychosocial model* emphasizes the limited correlation between nociception and pain, and acknowledges the complex influences of biological, psychological, cultural and social variables on individual's experience of pain [101-105]. The late American psychologist and internist George Engel proposed the biopsychosocial model back in 1977. He argued that to understand the determinants of disease and arrive at rational treatments and patterns of healthcare, a medical model must take into account the patient, the social context in which he lives, the physician role and the healthcare system [101]. This theory is frequently used as an approach to understand both pain and disability in a variety of health conditions. In 2001, The International Classification of Functioning, Disability, and Health (ICF) was published and adhered to a biopsychosocial understanding of health [106]. Accordingly, the biopsychosocial model of arthritis pain and disability (Figure 2) emphasises that arthritis-related pain and disability are not only affected by underlying biological factors, but also by psychological and social factors, which require multidimensional approaches involving both biomedical and psychosocial interventions [103, 105].

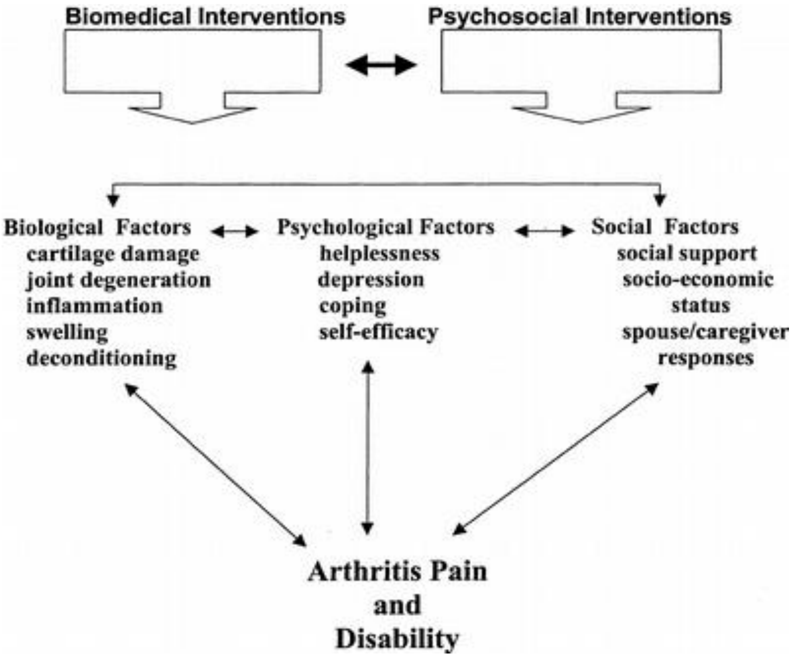


Figure 4: The biopsychosocial model of arthritis pain and disability [103]

In this thesis, this line of thinking is incorporated by attending specifically to the individual burden of disease and aspects of needs experienced and reported by patients with symptomatic hip OA; more specifically related to information and emotional needs, psychosocial factors and treatment decision-making.

3.4 Shared decision-making and underlying theory

3.4.1 Shared decision-making

Shared decision-making (SDM) is one among several treatment decision-making models discussed in the literature. The approach is often positioned between the paternalistic model, where the physicians make the decisions, and the informed model where patients make the decisions [107]. In contrast to the informed model, the essential characteristic of the shared model is its interactional nature in that the doctor and patient share all stages of the decision-making process simultaneously [21, 108]. SDM is a model for communication where patients are encouraged to be actively involved in the decision-making process. The goal is a mutualistic patient-clinician relationship characterized by a balance in power and symbolic resources. The agenda is negotiated, the patient’s values are explored and the clinician takes an advisory role regarding the patient’s treatment goals and decisions [109]. SDM may involve negotiation and compromise, but at its core lies the recognition that clinicians and patients bring different, but equally important forms of expertise to the decision-making process. The clinician’s expertise is based on knowledge of the diagnosis, likely prognosis, treatment and support options and the range of possible outcomes associated with the available options. Importantly, these treatment options may have uncertain evidence profiles concerning expected outcomes and associated risks. This situation is termed clinical equipoise requiring the HCP to state explicitly that a decision will ultimately depend on the patients’ preferences. The patient has first-hand knowledge about how the condition affects their daily life, and what their personal attitude is to risk, values and preferences. The patient’s knowledge and preferences are taken into account alongside the clinician’s expertise, and the decisions they reach together are informed by research evidence on effective treatment, care or support strategies [110]. Makoul and Clayman [23] systematically reviewed the literature to determine the range of conceptual definitions of SDM. Based on 161 articles they found no common definition of SDM. They propose nine essential elements (Table 4) that must be present for patients and HCPs to engage in the process of SDM:

Table 4: Essential SDM elements [23]

1	Define/explain problem	Patients and HPs must first define and/or explain the problem that needs to be addressed.
2	Present options	HPs should review options, if options exist, and patients should raise options of which they may be aware.

3	Discuss pros/cons (benefits/risks/costs)	HPs and patients should discuss the pros and cons of options raised, particularly because they may have different perspectives on the relative importance of benefits, risks, and costs.
4	Patient values/preferences	Explication of patients' ideas, concerns and outcome expectations.
5	Discuss patient ability/ self-efficacy	Discussion of patients' perceived ability or self-efficacy to follow through with a plan.
6	Doctor knowledge/ recommendations	HPs knowledge and recommendations in the context of the decision at hand.
7	Check/clarify understanding	Throughout the process, both parties should periodically check understanding of facts and perspectives, providing further clarification as needed.
8	Make or explicitly defer decision	Decisions are not always ''made'' when problems are first discussed; they may be explicitly deferred for a later time.
9	Arrange follow-up	Arrange follow-up to track the outcome of decisions that have been made, or reach resolution on those that have not.

A status report about the implementation of SDM and PDAs in Norway was recently published [111]. The authors conclude that recent dynamics driven by the patient's voice, legislation and honest political will have initiated a broad national movement towards implementation of SDM. However, there are still several challenges ahead in order to succeed with full implementation. Primary healthcare has not yet become sufficiently included and involved in this notion as compared to specialist healthcare. Postgraduate training in SDM is a requirement and must be systematically implemented in order to succeed. Klar$_{for}$Samvalg (Eng: Ready to SDM) is one such initiative, which is a meta-curriculum for teaching and training health personnel in SDM communication [112]. It is now included into the newly revised specialist medical training [111].

3.4.2 Theory of planned behaviour underlying our research into SDM

The behaviour to engage actively in decision-making may be influenced by several individual, social and contextual factors. The Theory of Planned Behaviour (TPB) provides a systematic method for understanding and predicting human behaviour. We applied the TPB in paper 3 as theoretical underpinning as means to qualitatively explore patient-related barriers and facilitators towards SDM. TPB has been used in several studies to investigate or assess factors influencing SDM behaviour; in emergency physicians [113], orthopedic surgeons and residents [114], patients and providers in HIV care [115], seniors with dementia, their caregivers, and healthcare providers [116], HCPs' intention to use a decision aid for down syndrome screening [117], contraceptive decision making in U.S. Latinas' [118], dieticians' and patients' adoption of SDM behaviours in dietetic consultations [119], SDM implementation related to antibiotics use for acute respiratory infections [120], primary care consultation on cardiovascular risk prevention [121] and multiple sclerosis patients' decisions on disease modifying therapy [122].

According to the TPB, intentions (and behaviours) are a function of three basic determinants. One personal in nature, one reflecting social influence, and a third dealing with issues of control [123]. The TPB is an extension to the Theory of Reasoned Action (TRA), which was concerned with the casual antecedents of intentions to perform behaviours over which people have sufficient control [123]. Both theories assume intention as the best predictor of behaviour, which is determined by attitudes toward and social normative perceptions regarding the behaviour [124]. Intention is the sum of the motivational factors that influence a behaviour, i.e. they indicate the effort people are planning to exert in order to perform the behaviour [125]. Attitude refers to the individual’s positive or negative evaluation of performing the particular behaviour of interest. Attitude is determined by individuals’ beliefs about outcomes or attributes of performing the behaviour, weighted by evaluations of those outcomes or attributes. Strong beliefs that positively valued outcomes will result from performing the behaviour in question will result in positive attitude toward the behaviour. Subjective norm is the person’s perception of social pressure to perform or not perform the behaviour under consideration. A person’s subjective norm is determined by his or her normative beliefs. This refers to whether important referent individuals approve or disapprove of performing the behaviour, weighted by the person’s motivation to comply with those referents. A person who believes that the referents think that he or she should not perform the behaviour will have a negative subjective norm. A person who is less motivated to comply with those referents will have a relatively neutral subjective norm. The TPB addresses the possibility of incomplete volitional control by incorporating the additional construct of perceived behaviour control (see figure 5) [126]. This concept of perceived behavioral control over specific behaviours is similar to Bandura's self-efficacy concept [127]. Perceived behaviour control refers to the person’s beliefs as to how easy or difficult performing the behaviour is likely to be. It is assumed to reflect external factors (e.g. availability of time or money, social support) as well as internal factors (e.g. ability, skill, knowledge) [128]. Perceived behavioral control is determined by control beliefs concerning the presence or absence of facilitators and barriers to behavioral performance, weighted by their perceived power.

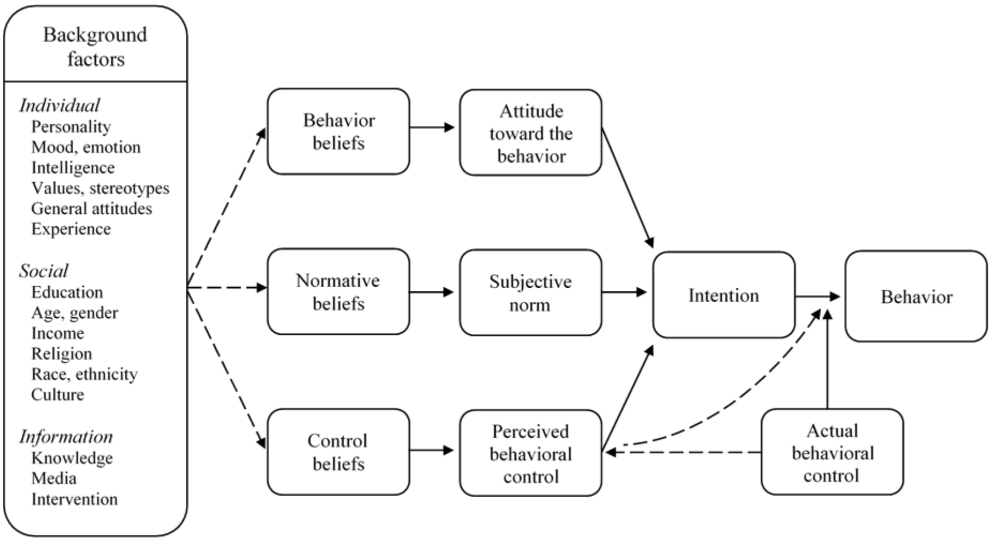


Figure 5: The Theory of Planned Behaviour [129]

There are several fundamental assumptions implicit in this model:

1. Intention is the immediate antecedent of actual behaviour
2. Intention, in turn, is determined by attitude toward the behaviour, subjective norm, and perceived behavioral control.
3. These determinants are themselves a function, respectively, of underlying behavioral, normative, and control beliefs.
4. Behavioral, normative, and control beliefs can vary as a function of a wide range of background factors.

The solid arrow pointing from actual control to the intention-behaviour link indicates that volitional control is expected to moderate the intention-behaviour relation such that the effect of intention on behaviour is stronger when actual control is high rather than low. The dotted arrows that connect actual control to perceived control and perceived control to the intention-behaviour link indicate that perceived behavioral control can serve as a proxy for actual control and used to improve prediction of behaviour [129].

3.5 Patient decision aids

3.5.1 PDA and IPDAS

PDAs are developed and implemented in clinical practice to support both the patient and clinician in SDM. The International Patient Decision Aid Standards Collaboration (IPDAS) provides an evidence-based standard for the development of PDAs [130]. PDAs may be administered with the use of various media, such as decision boards, interactive videodiscs, personal computers, audio-recordings, pamphlets and group presentations. They are meant to prepare patients to participate in making deliberated, personalized choices about specific heath care options. PDAs provide tailored evidence-based (non-directive) information and help patients to prepare for consultations by explaining options, quantifying risks and benefits, helping patients to clarify their values, and providing structured guidance in deliberation and communication. Importantly, they do not advise the users to choose one option over another, nor are they meant to replace practitioner consultation. Instead, they aim to prepare patients to make informed values-based decisions. The features of options that patients value may include the health states that might be affected by the decision, their attitudes towards the chances associated with relevant options, their willingness to make trade-offs over time and other issues relevant to the decision, including beliefs about the acceptability of particular healthcare procedures [109]. Research findings support the use of PDAs in clinical practice. A Cochrane Review [131] shows that when people use decision aids, they improve their knowledge of the options and feel better informed and more clear about what matters most to them. It increases the degree in which people and their clinicians talk about the decision. Further, PDAs may lead to more accurate expectations of benefits and harms of options and increase patients' involvement in decision-making. Decisions tend to be more consistent with patient's values, although evidence is ambiguous [131].

3.5.2 Mine behandlingsvalg

Mine behandlingsvalg (Eng: My treatment choices) is the result of an initiative to develop web-based PDAs for a broad range of medical conditions. They are developed and published by the SDM development group at University Hospital of North Norway (UNN). The first series of five PDAs was launched at *minebehandlingsvalg.no* in autumn

2015 for patients with pancreatic cyst, inoperable pancreatic cancer, prostate cancer (low and moderate/high risk), and obesity. The Norwegian Directorate of Health considered the model as suitable as a prototype for the national health portal *helsenorge.no* and the SDM group at UNN was encouraged by the recommendation of the national health and hospital plan to produce more patient decision aids [12, 132]. The first PDAs on *helsenorge.no/samvalg* were adapted and launched in autumn 2016 and six more have later been transferred. Several more PDAs are in production. A PDA for hip OA (Appendix 1a-e) is the result of a collaboration between The Science Centre Health and Technology at the University of South-Eastern Norway, Mine Behandlingsvalg at The University Hospital of North Norway in Tromsø and the Department of Emergency and Orthopaedics at Vestre Viken Hospital Trust in Drammen. Mine Behandlingsvalg changed its name to 'Samvalgssenteret' late autumn 2018, but I use the former term in this thesis. The PDAs consist of four main sections (Table 5).

Table 5: Summary of content in Mine behandlingsvalg

Main heading	**Descriptions of content**	**Text**	**Video**		
			HCP	Pt	Ani
1. My choice (Appendix 1a)	1.1 Why is it necessary to make a decision?	X	X	X	X
	1.2 What is my health situation?	X	X		
	1.3 What is the choice about?	X	X	X	
	1.4 Why should I be involved in decision-making	X	X	X	
2. My options (Appendix 1b & 1c)	2.1 Carrying out the treatment option	X	X		
	2.2 Evidence of efficiency	X	X		
	2.3 Does the treatment work?	X	X		
	2.4 Side effects and complications	X	X		
3. Summary (Appendix 1d)	Treatment options are summarized to enable comparisons	X			
4. My reflections (Appendix 1e)	State readiness for decision-making and take notes about concerns or questions related to decision-making. Prioritize personal preferences and indicate what treatment option is most acceptable.	X			X

HCP=Healthcare professional, Pt=Patient, Ani=animation

Importantly, the patient may also log in (using a secure electronic ID) to save the results of the reflections and prioritization, make notes and print a summary.

3.5.3 Description of the development of a PDA for patients with hip OA

The content, including evidence-based written information and video-recorded narratives, was developed by involving patients, HCPs and researchers through all steps. The procedure followed a generic development protocol called the DAfactory. A description of the procedure and available resources are published at *unn.no/fag-og-forskning/utvikling-av-samvalgsverktoy*. The DAfactory is described as a virtual production site with generic procedures complying with international concepts of quality relevant for this purpose: in particular IPDAS [133] and the Knowledge-to-Action Framework [134, 135]. In addition, the DAfactory provides structural guidance on how to explore user specific barriers towards SDM and how to tailor PDAs to meet specific needs accordingly. Recommended methods to identify and organize such barriers as well as didactics used to tailor the motivation process refer to TPB [125].

The written information presented in the PDA was developed through several iterative steps to ensure its relevance, quality and readability. All content was developed in collaboration with clinical experts (one orthopaedic surgeon and one physiotherapist) and further improved to make it as informative and concise as possible. A crucial step was to review the current evidence-base on the effects of relevant treatment options for hip OA. This information was based on a report produced by the Norwegian Institute of Public Health for this particular purpose [136].

A central didactic feature of the PDA is the provision of patient narratives mediated through short videos that aims to help patients to overcome barriers to involvement in decision-making (as assessed in the third paper of this thesis). The videos were developed together with a professional film-production company. Four types of videos are presented [137]:

1. Information videos with health personnel
2. Information videos with patients providing their experience and points of view
3. Motivation videos with HPCs encouraging patient involvement in decision-making
4. Motivation videos showing patients reflecting on challenges related to making treatment decisions

The use of patient narratives as didactic approach within PDAs is common [138]. However, it has been questioned to bias individuals' decision-making, which may result in lower-quality decisions [139]. Concerns suggest that narrative information have a stronger influence on treatment decision-making than statistical information. This implies that patients would base their final decisions on the experiences of few while ignoring data from many [140]. These include, for example: social matching/mismatching between the individuals in the stories and the individuals viewing the decision aid; inadvertent story-induced misrepresentations, such as over/under-weighting of risks/benefits, and hidden story-induced framing biases [140-142]. There is a lack of consensus around the effectiveness of including patient narratives in PDAs [143]. It is hypothesized that the conflicting findings about the effects of patient narratives are the result of an insufficient and vague operational definition of patient narratives [140]. Attempting to reduce the risk of such bias, the DAfactory framework emphasizes that the purpose of the videos are not to expose users with personal or individual reasons for making specific decisions, but rather balanced narratives that shed light on some common issues that may arise in the process of treatment decision-making. More precisely, patients are stimulated to share their reflections about decision-making and participation in choices related to their own health, but not their experience of different treatments. Accordingly, the HCPs are instructed to provide balanced information about the different treatment options, as opposed to favoring one treatment over others. In this project, we recruited one orthopaedic surgeon, two physiotherapists and three experienced patients to share their expertise and experience on video. A workshop was arranged in good time prior to the filming-sessions. It was introduced with information about SDM and PDAs, including examples of common factors that may facilitate or hinder participation in decision-making. Thereafter, the participants were invited into a collaborative discussion about participation in treatment decision-making to stimulate their own reflections. Trial interviews were performed to make the participants familiar with the setting.

The final videos presented in the PDA are meant to stimulate reflection for the individual user and thus start the process of deliberation about how the different treatment alternatives relate to own health situation, values and expectations. HCPs provide short and comprehensible explanations and information related to the specific content. This is meant to supplement the textual content in educating the patient about the disease and treatment options. Moreover, it aims to stimulate considerations of each option in light of personal values and preferences. Each option is presented in a fixed structure, and in a separate section, all options are summarized allowing for a simple overview and comparison.

The meaning and rationale of SDM and patient involvement may be difficult for the patient to understand. An animated video is provided to explain this in a simple way. There is also another animated video under “My reflections” that informs about three questions to ask the doctor: (1) What are my options; (2) What are the possible benefits and harms of those options; and (3) Do you understand what is most important for me. These short questions are evidence-based and may help the patients to reflect upon important factors relevant for the decision-making process. At the end of the PDA, a value deliberation tool is provided where patients arrange statements according to how important they are perceived. This tool explicitly aims to facilitate the process of reflection, but not stimulate specific choices. A remaining process relates to pilot testing of the final PDA with potential users. This is an important step to get feedback on the usability of the tool and constitutes as a final quality check before online publication.

4. Aim and research questions

In light of OA being a chronic and progressive joint disease affecting a large number of people in the elderly population, the overall aim of the research project was to explore patients' needs in relation to self-management and how these needs vary within the OA disease trajectory. Three papers address different aspects relating to patients' needs: (1) information and emotional needs, (2) psychosocial factors affecting short-term recovery after joint replacement surgery, and (3) knowledge about patient related barriers and facilitators towards SDM. A parallel process involved the development of a patient decision aid designed to support patients with hip OA in treatment decision-making. This is reported below, before the presentation and discussion of the three papers.

Paper 1:

Aim: To examine the perceived informational and emotional needs in patients with primary hip OA.

Research questions:

1. What information and emotional needs do patients living with hip OA have?
2. How do patients' needs change over time as the disease progresses?
3. How does decision-making in relation to total hip replacement take place?

Paper 2:

Aim: To determine whether perceived social support and general self-efficacy contribute to the variability in short-term postoperative recovery in a sample of OA patients who have undergone THR.

Research questions:

4. Do low self-efficacy and low social support predict poor short-term recovery after total hip replacement?
5. Do patients' social support, general self-efficacy and short-term recovery vary according to sex, age group and number of comorbidities?

Paper 3:

Aim: To explore barriers and facilitators influencing hip OA patients' capacity and opportunities to engage actively in SDM. A secondary aim was to determine if the observation method provided by the DAfactory was useful in this particular context.

Research questions:

6. How are patients involved in decisions related to treatment of hip OA?
7. Which patient-related factors facilitate or impede SDM in hip OA?

5. Material and Methods

5.1 Design

The design of this PhD project involves a combination of qualitative and quantitative research methods. It is framed within a pragmatic world view which is characterized by the flexibility to choose the methods, techniques, and procedures of research that best address the aim and purpose of the study [144]. Figure 6 shows a timeline of the research activities related to each of the three papers (bold font) and procedures related to the development of the PDA (italic and grey font). As it has been necessary to limit the scope of this PhD, the particular process of developing the PDA is not included as part of the research design. It is, however, described as an important part of the context in which the research is conducted.

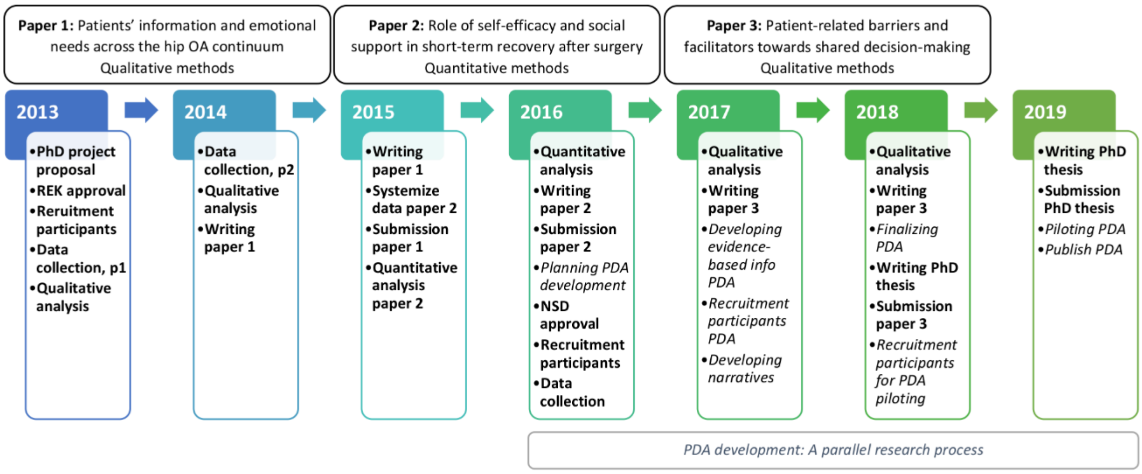


Figure 6: Timeline showing an overview of the different research processes

Paper 1 has an explorative qualitative design. Individual semi-structured interview was considered the most appropriate method to examine the perceived informational and emotional needs in patients with primary hip OA. This approach made it possible for the participants to freely express their viewpoints and choose what they wanted to disclose. Furthermore, this allowed the interviewer to prompt follow-up questions relevant for the research questions. The study was planned to generate important knowledge for the development of a web-based support tool.

Paper 2 is a prospective cohort study, comprising secondary analysis of unutilized longitudinal data from a PhD project conducted from 2003-2010 by Heidi Kapstad (co-supervisor). The data were collected through six different questionnaires in addition to demographic information between June 2003 and June 2004. Kapstad explored possible changes in pain and health status among patients with hip or knee OA who underwent joint replacement, and used three of the questionnaires in her final PhD study [145-148].

Paper 1 revealed that social support and self-efficacy were central components of perceived patient needs, and accordingly, we wanted to utilize the opportunity to explore the possible role of these psychosocial constructs in a relatively large and readily available cohort of patients who had undergone THR. The pragmatic and clinically relevant idea was that if higher self-reported measures of social support and self-efficacy appeared to improve postoperative recovery, these are both proven possible to strengthen preoperatively by appropriate interventions in primary care.

Paper 3 has a qualitative observational design allowing for theory-driven in-depth investigation of real OA decision-making processes happening in the orthopedic outpatient clinic. The chosen method was considered suitable to gain direct insight into the ongoing communication taking place in this particular context. A guiding principle was to get as close and direct insight into the ongoing consultation as possible, without affecting it by potentially invasive presence.

5.2 Sample

5.2.1 Paper I

A purposive sample of patients with hip OA was included from two settings: (1) the hospital setting prior to scheduled surgery, and (2) the GP setting. Seven participants were recruited from an orthopedic outpatient clinic at a local hospital in the Southeastern part of Norway. The letter of invitation and consent form for participation were sent together with the notice of a scheduled surgical appointment. The second group of six participants was recruited from a general practitioner’s office situated at a remote municipality in the Northern part of Norway. A take-home letter of invitation was given to eligible patients by their general practitioners during a planned consultation. Having read the information, interested participants were asked to contact the researcher to schedule an interview. The inclusion criteria were that the participants had a confirmed diagnosis of primary hip OA, were able to communicate in Norwegian and were cognitively capable of participating in an individual in-depth interview of approximately one hour in duration. Furthermore, participants of both sexes and different age groups were included. The recruitment procedures at both settings continued until data saturation was considered reached; the point at which new data stopped generating any substantial new ideas [149].

5.2.2 Paper II

Nurses or administrative staff members at six different study hospitals identified potential participants. The inclusion criteria in the original study were as follows:

- > 18 years of age
- Being placed on the waiting list for primary hip or knee joint replacement surgery
- Sufficiently proficient in the Norwegian language to be able to complete the questionnaires

In this study, we only included patients with hip OA who had undergone THR.

5.2.3 Paper III

A purposive sample of patients with primary hip OA referred to an orthopedic outpatient clinic for specialist evaluation and surgical decision-making were invited to participate in the study. In cooperation with the Head of Department, two study days at the clinic were arranged, with the aim to recruit a total of about 20 patients. We included patients with primary hip OA referred to an orthopedic surgeon for treatment decision-making (i.e. excluding follow-ups), having more than one option to consider, and being principally capable to actively participate in the decision-making process (i.e. no severe cognitive impairments). A secretary attached information about the study and an invitation to participate together with the scheduled appointment letter.

5.3 Data collection

5.3.1 Paper I

The research questions were explored using individual interviews with a sample of patients who were most likely to be able to share lived experiences that illuminate important insights related to the aim of the study. Interviewing can be defined as a ‘professional conversation’, having the objective of getting a participant to talk about their experiences and perspectives and to capture their language and concepts in relation to a topic that the interviewer has determined [149, 150].

The first group of participants was individually interviewed in private rooms at the hospital hotel one day prior to elective total hip replacement surgery. It was proposed that these patients could provide valuable perspectives regarding their experiences throughout a relatively long history with hip pain; including how and why they came to the decision to undergo hip surgery. The interviews were planned and performed in the evening to that the doctors and nurses had finished their routine work with admissions. It was discussed with the participants whether it was appropriate to conduct the interviews the day before their elective surgery, and they were offered alternative options, but all informants found the suggested time to be convenient. The second group of informants was interviewed at the local health center where the GP office was situated. The reason for recruiting these participants was to reach out to persons who manage the disease in a primary care context, and to learn from the experiences they had along the OA treatment and care continuum.

The interviews were audio-recorded and conducted in the manner of a conversation, although a semi-structured interview guide was prepared (See Appendix 3). This explorative approach gave the participants an opportunity to freely disclose and discuss issues that were important to them, rather than respond to specific pre-selected questions. A typical interview was initiated by highlighting essential information about the study and its purpose, and then letting the participant talk freely about his or her hip journey, prompted by an open question like “can you start by telling about yourself and how your life is affected by your hip OA?” Recurrent follow-up questions were “can you describe in words how your pain feels?”, “what strategies help you cope with your hip pain?”, “what/how have you learned about osteoarthritis?”, “does your pain have any consequences for your social life?” and “can you tell me (if) how and why you have decided to undergo hip replacement?” When the interview was presumed to be finished, the audio-recorder was stopped. The participant was then given some time to settle, whereupon some participants disclosed additional thoughts and perspectives that had not been discussed previously. The audio-recorder was then re-started by the interviewer, but the participant was explicitly made aware of the opportunity and right to delete this part of the interview.

After each interview, the researcher made notes in order to preserve immediate reflections and important features of the conversation. The participants completed a self-reported questionnaire of basic demographic data, duration of OA symptoms, help-seeking behaviour and self-reported comorbidities (See Appendix 4). This information was collected to acquire relevant data on the characteristics of the participants.

5.3.2 Paper II

In the original study, patients responded to the questionnaires at four time points: At baseline (T1), two weeks prior to surgery (T2), 3 months after surgery (T3) and 1 year after surgery (T4). To investigate the research question in this study, we isolated data collected by three of the six questionnaires at baseline (T1) and three months after surgery (T3).

356 patients with primary hip OA were invited to participate, of which 250 patients consented and completed the baseline questionnaire (70.2% response rate). 223 patients underwent THR and completed questionnaires at the 3-month follow-up (89.2% response rate). According to power calculations conducted by Kapstad in the original study [145], this sample size would detect clinically significant changes in health status (Clinically relevant change (Δ) = 10%, significance level (α) = 0.05, standard deviation (σ) = 20 and statistical power = 90). Figure 7 displays a flow chart of the recruitment process.

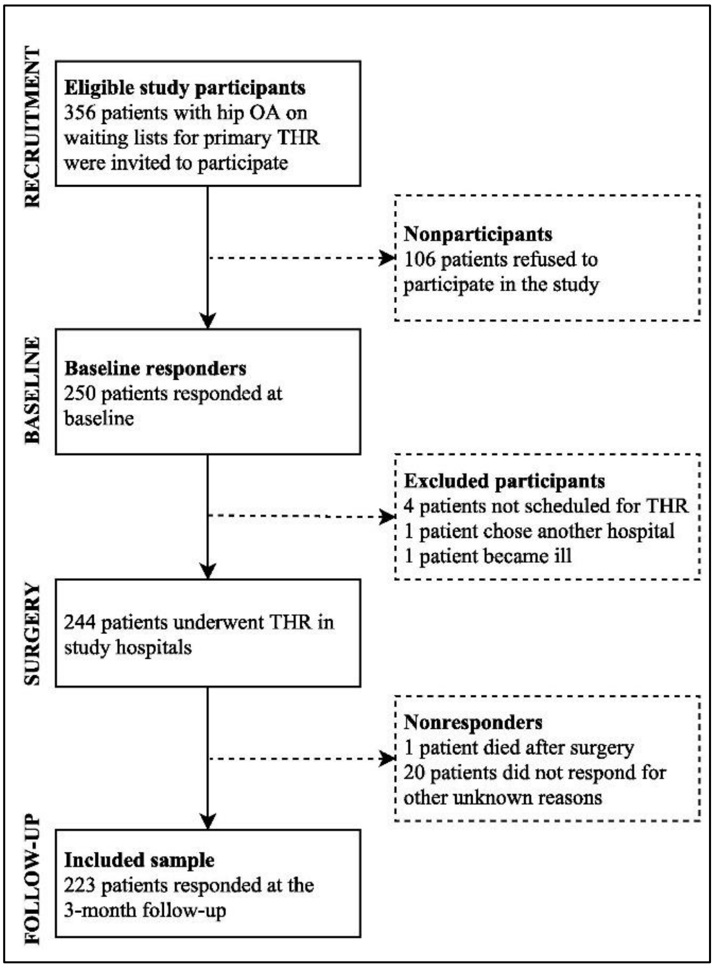


Figure 7: Flow chart illustrating the recruitment process

Patients completed a package of questionnaires that obtained sample characteristics, including sex, age, marital status, cohabitation, number of children, educational level, employment status, comorbidity, and number of years with hip pain and reduced mobility (before the decision to undergo THR). At baseline and at 3 months after surgery, they also reported overall satisfaction with life on a 7-point Likert scale, and pain and mobility levels on a 5-point Likert scale. Three patient reported outcome measures (PROMS) measured health status, social support and self-efficacy: the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC), The Social Provisions Scale (SPS) and The General Perceived Self-Efficacy Scale (GSES).

Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC)

WOMAC (see Appendix 5) is a widely used disease-specific questionnaire developed to study health status in patients with hip or knee OA. It has a multidimensional scale comprising 24 items grouped into three dimensions: pain (five items), stiffness (two items), and physical function (17 items). The 3.0 Likert version has five response categories for each item representing different degrees of intensity (none, mild, moderate, severe, or extreme) and is scored from 0 to 4 [151]. The total WOMAC score was chosen as an appropriate outcome measure of recovery after THR and was calculated by adding the aggregate scores for pain, stiffness, and physical function. The data were standardized to scales with values from 0 to 100, where 0 represents the best health status and 100 the worst health status. Missing data were handled according to the user's manual [151]. Previous research has shown WOMAC to be reliable, valid, and sensitive to changes in the health status of patients with hip or knee OA. It has adequate internal consistency demonstrated by Cronbach's alpha coefficients of 0.81 – 0.96, acceptable test-retest reliability with Intra-class correlation coefficients between 0.43 – 0.96, Spearman's rank correlation coefficient of 0.87, construct validity estimates of 0.43 – 0.59, and adequate responsiveness with effect sizes of 1.0 – 4.8 for THR [152-155].

The Social Provisions Scale (SPS)

Perceived social support was assessed using the revised SPS scale [156]. This 24-item instrument is based on Robert Weiss model of social provisions, and (see Appendix 6) asks respondents to rate the degree to which their social relationships currently are supplying each of six relational provisions [157]. According to Weiss, all six provisions are needed for individuals to feel adequately supported and to avoid loneliness. However, different provisions may be most crucial in certain circumstances or at different times in life. Each of the provisions is most often obtained from a particular kind of relationship, but multiple provisions may be obtained from the same person. These social provisions may be divided conceptually into two broad categories (*A* and *B*) [156]:

A: Assistance-related: directly relevant to problem-solving in the context of stress.

1. **Guidance**: advice or information

2. **Reliable alliance**: the assurance that others can be counted upon for tangible assistance

B: Non-assistance-related: not directly associated with problem solving. Considered to have beneficial effects through mediation of self-efficacy under both high and low stress conditions.

3. **Reassurance of worth**: recognition of one's competence, skills, and value by others

4. **Attachment**: emotional closeness from which one derives a sense of security

5. **Social integration**: a sense of belonging to a group that shares similar interests, concerns, and recreational activities

6. **Opportunity for nurturance**: the sense that others rely upon one for their well-being

Each provision is assessed by four items: two describing the presence and two the absence of the provision. Respondents indicate on 4-point scales the extent to which each statement describes their current social relationships. For scoring purposes, the negative items are reversed and summed together with the positive items to form a score for each social provision, which gives a minimum score of 4 and a maximum score of 16. An aggregated social support score is also calculated with a minimum score of 24 points and a maximum score of 96. A high score indicates a high degree of perceived social support. Internal consistency (alpha coefficient) for the SPS has been reported to range from 0.85 to 0.92 across a variety of populations and from 0.64 to 0.76 for the individual subscales [158]. Evidence supports the reliability and validity of the SPS. Internal consistency reliability for the SPS is relatively high, ranging from 0.85 – 0.92 across varying populations. A six-factor structure corresponding to the six social provisions has been confirmed through factor analysis. Alpha coefficients for the individual subscales range from 0.64 to 0.76. Several studies support its construct validity [156, 159].

The General Perceived Self-Efficacy Scale (GSES)

Self-efficacy was measured using the GSES with 10 items developed by Jerusalem and Schwarzer [160]. The GSES (see Appendix 7) is widely used, reliable, homogeneous, and unidimensional [161-163]. The GSES assesses the strength of a person's belief in his or her ability to respond to novel or difficult situations and to deal with any associated obstacles or setbacks. All items have the following response format: 1 = not at all true, 2 = hardly true, 3 = moderately true, and 4 = exactly true. The total GSES score is calculated by summing the item scores, and ranges between 10 (lowest GSES) and 40 (highest GSES). We calculated the sum score in this study for subjects with no more than three items missing [164].

5.3.3 Paper III

Data were obtained through direct observation and listening to the audio-recordings of orthopedic outpatient consultations scheduled to make a treatment decision for hip OA. The purpose of audio recording was to enable a comprehensive and reproducible analysis of the ongoing verbal communication, and to allow for analysis by a second researcher. Direct observation made understanding of structural features as well as non-verbal events possible. Figure 8 illustrates the setting. The orthopedic surgeon (S) sat on a swivel chair behind the computer desk. This allowed him to change positions during the conversation – facing the patient and the computer interchangeably. The patient sat on a chair beside the computer desk as shown (see figure 8). Parts of the consultation happened during the physical examination, and the patient moved over to the examination bench. The observer/researcher (O) sat in the back of the room, having adequate view of the ongoing conversation. The audio-recorder was started when the patient had confirmed his consent, and stopped when the consultation ended. An observation guide provided structure to identify key verbal, non-verbal and contextual events (see Appendix 9).

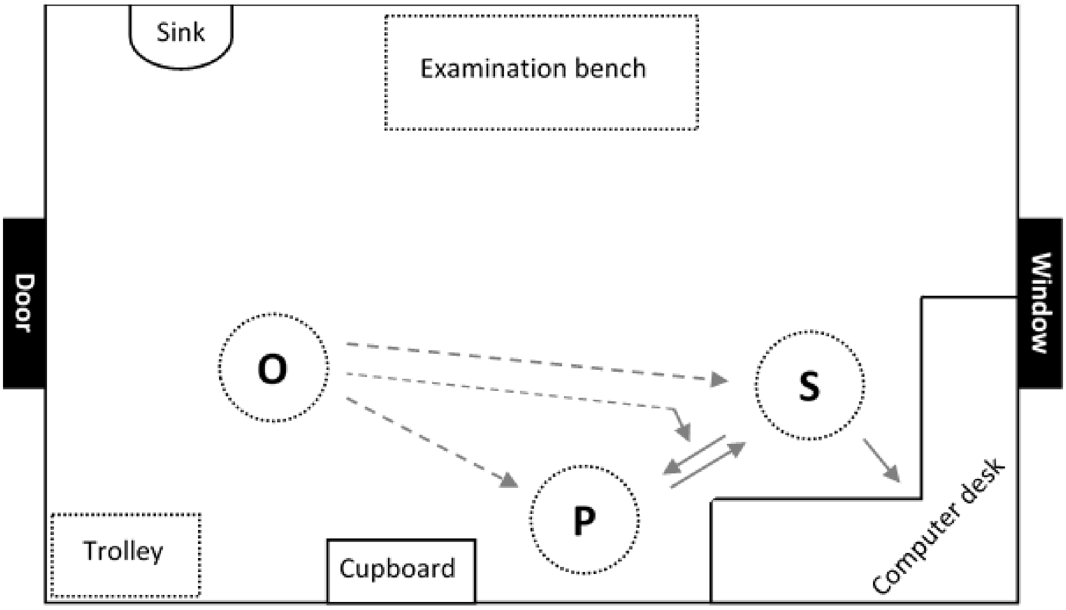


Figure 8: Illustration of the observation setting

The observation guide included instructions on how to actively listen and process the ongoing consultation to identify events relevant with regard to the research questions. Following this method, the observer produced data by perceiving the immediate occurring events (orientation to novel stimuli), and subsequently processed by a following interpretation. Each observation session is guided rigorously by using imagination of an ideal SDM process as a sensory corridor. Recognition of relevant events is meant to result from continuous comparison of the ideal with the actual process and identifying either divergence or accordance. Events are utterances or any other kind of communicative behaviours including lack of behaviour, where it would have been appropriate. Raw data are seen as thoughts, ideas or hypotheses on the observer's side, while the communication, taking place between the doctor and the patient, works as a generator of stimuli. In a psychological understanding, the observer seeks identification with the patient role, and uses projections occurring from this state as data material for further analysis. Documentation of the latter could appear as single notes, quotes, short descriptions of behaviour, or hypothetic utterances, which were created by the observer in accordance with his projection. Information about patients' age and sex was collected as well as doctors' extent of previous communication training in SDM.

5.4 Analysis

5.4.1 Paper I

Each audio recording was transcribed verbatim in word processing software by the first author, aided by a basic notation system and transcription kit. The transcripts were imported into NVivo (Version 10), a software program that allows systematic coding and retrieval of qualitative data [165]. Inspired by Braun and Clarke, we used an indicative approach to thematic analysis guided by a six-phased analytical process [149, 150]. Braun and Clarke vouch for the rigorous, independent and flexible qualities of this process and explain it as "*a method for identifying, analyzing and reporting patterns (themes) within data"* [150]. A theme is defined as *"an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole"* [166]. Each step is further described in Table 6.

Table 6: Steps in thematic analysis

Step	Purpose:	Process:
1	Familiarizing yourself with your data	Transcribing data, reading and re-reading the data, noting down initial ideas
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3	Searching for codes	Collating codes into potential themes, gathering all data relevant to each potential theme
4	Reviewing themes	Checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map

5	Defining and naming themes	Ongoing analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme
6	Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a report of the analysis.

At the initial coding stage, two researchers independently read and coded two interview transcripts. This collaborative coding process sought to ‘calibrate’ the analytic approach by facilitating structured discussions of possible interpretations. The coded extracts were carefully compared and modified, and preliminary themes were defined. The inductive analytic approach proceeded with iterative and comprehensive coding across the remaining dataset. During this process, each of the coded transcripts was re-checked against the audio-recordings to make sure that the themes bridged the essence of the transcripts with the research questions in focus. When the results had been summarized through major themes, we conducted discussions with nurses and orthopedic surgeons to ascertain their ‘common sense’ opinions of the accounts, based on their experiences from working on a daily basis with hip OA patients.

5.4.2 Paper II

We used IBM SPSS Statistics for Windows version 23.0 [167] to organize and analyze the data. Descriptive statistics were used to estimate the data for sample characteristics. We compared groups of responders and non-responders using Pearson’s chi-squared test, independent samples *t* test, or Mann–Whitney *U* test, where applicable. Preoperative and postoperative WOMAC total and dimension scores were compared using nonparametric related-samples (Wilcoxon) tests. The Mann–Whitney *U* test was used to compare scores between sex and age groups. We assessed internal consistency reliability of the questionnaires using Cronbach’s coefficient alpha. Pearson and Spearman rank correlation coefficients were used to identify the variables for inclusion in the regression analyses based on associations between selected predictor variables and the primary measure of recovery at 3 months after THR, as appropriate. We included predictors based on the availability of data and on our theoretical hypothesis about possible relationships relating to the aim of the study: age, sex, cohabitation, number of children, education level, work status, number of comorbidities, years with hip pain, years with mobility problems, overall satisfaction with life and baseline scores (including WOMAC, SPS, and GSES). Linear regression models were used to study the associations between the predictors and the recovery variable WOMAC total. We applied the following steps after a thorough evaluation of the theoretical assumptions relevant to linear regression.

1. Predictor variables that correlated with the recovery variable ($\alpha = 0.10$) were included into a univariate linear regression model. This step identified how well each variable predicted recovery after THR without controlling for any confounding factors.

2. The next step was to proceed with a multiple linear regression model. We included all predictors with a significant association with the recovery variable ($\alpha = 0.05$) in the initial model. Residual plots were controlled.

3. To identify the best predictive model of recovery after THR, we used a backward elimination procedure. For each step in this stepwise procedure, we evaluated each β value and its 95% confidence interval. Non-significant predictors were omitted sequentially from the model until all remaining variables were statistically significant in explaining the variance in post-THR recovery.

5.4.3 Paper III

The audio recordings were transcribed verbatim and analyzed together with field notes inspired by a thematic approach called Template Analysis (TA) [168]. TA emphasizes the use of hierarchical coding, but balances a relatively high degree of structure in the process of analyzing textual data with the flexibility to adapt it to the needs of a particular study. TA allows for the definition of ‘a priori’ codes in advance of the analysis process, which are aspects of the phenomena under investigation that are of particular interest. Central to the process of analysis involves the development of a coding *template*, usually based on theoretical assumptions or a subset of data, which is then applied to further data, revised and refined [168, 169]. Those a priori codes that do not prove useful in representing and capturing key messages are redefined or discarded as the template is modified in the process of data analysis. New themes, emerging through analytic engagement with the data are defined and added to the template structure.

Consistent with this approach, we started out with a generic taxonomy of a priori categories representing common patient-related barriers towards SDM. This classification is based on corresponding observation sessions in other clinical contexts (obesity, pancreatic cancer and prostate cancer). The taxonomy is structured according to three TPB constructs, proposed to determine an individual's intention (i.e., an indication of a person's readiness) to perform a particular behaviour. Figure 9 displays a modified TPB-model which illustrates the eight main categories of the taxonomy and how it is classified according to the TPB constructs.

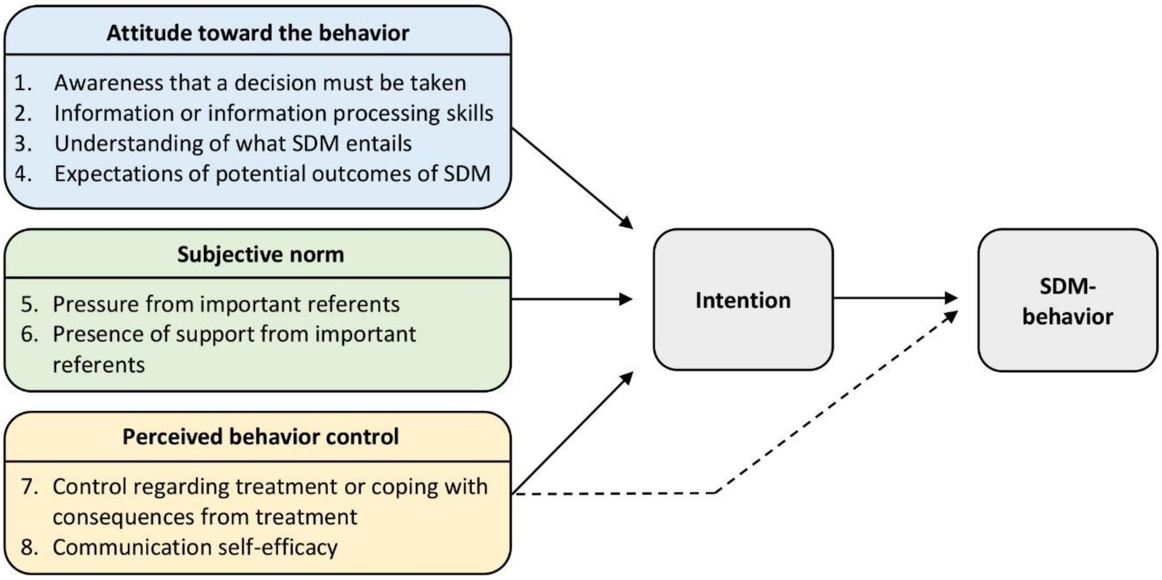


Figure 9: Modified Theory of Planned Behaviour model

The full taxonomy is organized on three abstraction levels: the level of the three TPB theoretical constructs, the level of subcategories providing abstracted groups of beliefs and the level of condensed empirical descriptions.

TA purposed refinement of the taxonomy. Specific target-group factors, identified as potential moderators of the patients' active engagement in negotiating and making own decisions, were categorized with regard to the given theory and generic taxonomy. An analytical goal was to determine which elements of the taxonomy were applicable to OA patients, and how these elements would turn out in the particular context (level of empirical descriptions). In addition, we intended to determine whether new types of barriers appear, suggesting new elements on the subcategory level. NVivo11 qualitative data analysis software was used for data management [170]. The analysis process is described in the following three steps:

Step 1: Based on immediate recall of the overall observations and the field notes, the generic taxonomy underwent an initial refinement to correspond with the particular context. As part of the approach to contextualize and relate the observations through the patients' perspective, the consultations were also described according to typical structural features.

Step 2: The audio-recordings were transcribed verbatim and analyzed deductively. Specific target-group factors (events), considered as potential moderators of hip OA patients' intentions for active engagement in negotiating and making own decisions were thematically labeled according to the main and subcategory level of the generic taxonomy.

Step 3: An inductive approach proceeded to determine which elements of the taxonomy were applicable to hip OA patients, and how these elements would turn out in the particular context (level of empirical descriptions). Furthermore, we intended to determine new types of barriers, suggesting context specific factors at the subcategory and empirical level. A final procedure purposed refinement and completion of a modified and context-specific taxonomy.

5.5 Research ethics

The Regional Committee for Medical and Health Research Ethics (REK) evaluated and approved the execution of the first study (See appendix 2). REK and the Norwegian Centre for Research Data (NSD) approved the original study in which the data set of the second study originated. Further, ethical approvals relating to this study was not necessary to obtain, as all data were anonymized. NSD assessed the third study and found it to be subject to notification according to current legislations (See appendix 8). All studies complied to the principles stated in the Helsinki declaration [171]. All participants of each study were given written information about the rationale of the studies, aims and purposes, and possible implications of participation. Patients who agreed to participate provided written informed consent, explicitly informed about their right to withdraw at any time within the study periods.

6. Summary of results

This chapter presents a summary of the research findings presented in the three papers.

6.1 Paper I

Brembo, E. A., Kapstad, H., Eide, T., Månsson, L., Van Dulmen, S., & Eide, H. (2016). Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study. *BMC Health Services Research*, 16(1), 1-15.

In this paper, we aimed to examine the perceived informational and emotional needs in patients with primary hip OA. Seven patients were recruited from the hospital setting and six patients from the GP setting. Both sexes were evenly represented with a wide age distribution, the youngest at 59 years old, and the oldest 88.

6.1.1 Patients' descriptions of perceived healthcare needs in light of a fluctuating disease progression

This study provides empirical evidence of information and support needs among patients with hip OA throughout the whole disease continuum. Several decisions are being made at different times and in different contexts, relating to symptoms, help seeking behaviour, self-efficacy and treatment response. The thematic analysis resulted in a list of questions as condensed representations of both stated and unstated needs expressed by the patients during the interviews. A temporal organization of these questions assigned them into six different phases along with typical quotes that provided empirical grounding of the findings.

Participants in our sample described a pattern of not receiving enough information about OA and management options, but at the same time not expecting such information to be provided by the GP or physiotherapist. A few patients sought information from the Internet or other sources, but the majority did not. This passive behaviour towards OA and management resulted in a struggle to find effective pain-management strategies in daily living, often resulting in avoidance of meaningful activities and decreased QoL. Some patients said that they did not know what to ask the GP. Perception of limited time during consultations was a recurrent theme that influenced the possibilities for information exchange. OA was by some seen as an inevitable part of the aging process, and that HCPs did not offer effective alternatives to pain medication. Most patient stated reluctance to take painkillers or other drugs to alleviate the pain, and some said that they did not use them at all by principle. Experiences with exercise and physiotherapy leading to pain exacerbation led to discontinuation.

6.1.2 The hip osteoarthritis continuum

The hip osteoarthritis continuum is a care pathway model which illustrates a patient's typical hip journey (Figure 10). The model is divided into the six phases, designed to demonstrate the information and emotional needs of patients with hip OA, and how these needs may change over time related to the development of the disease, the clinical encounters within the healthcare services, and the subsequent decision-making processes.

1) The first phase represents the early hip OA-stage where the first symptoms emerge, diagnosis is set and an initial treatment plan is discussed.

2) The second phase represents the moderate hip OA-stage. This phase indicates a deterioration of symptoms, where the patient seeks and tries out more treatment options that might alleviate the situation.

3) The third phase represents the severe hip OA-stage, where the symptoms are perceived as severe and more or less refractory to conservative treatment, leading up to a referral for orthopedic evaluation.

4) The fourth phase represents the surgical decision-making phase with three possible outcomes where the patient and the orthopedic surgeon discuss whether the patient will benefit from hip replacement surgery.

A) Patients who are accepted for surgery are placed on the waiting list. These patients are advised to undergo pre-surgical muscle strengthening exercises and prepare for the postoperative recovery period at home, by procuring necessary aids for ADL.

B) Patients who are rejected or choose to await surgery are advised to continue conservative treatment until a renewed orthopedic evaluation is warranted. If patients are unhappy about the final decision, they have a legal right to a second evaluation by another surgeon.

C) This route represents an alternative route for patients who are not medically suitable for, or for some reason do not prefer to undergo surgery. This route might be taken at any point throughout the continuum, and it includes all treatment recommendations, in addition to surgery as a final option. These patients need to come to an acceptance of the situation, while optimizing the available non-surgical treatment options in order to live a meaningful life despite pain and its accompanying limitations.

5) The fifth phase represents the perioperative phase when patients follow a standardized hip-replacement program. Patients receive interdisciplinary pre- and postoperative care, guided instructions and training concerning movement restrictions and general take-home physical exercises that stimulate optimal joint function.

6) The sixth phase represents the postoperative recovery period. A minority of patients who at some point experience post-operative complications may be re-admitted to the orthopedic clinic for revision surgery, whereas the majority can enjoy a functional hip, although requiring a substantial rehabilitation period until fully recovered.

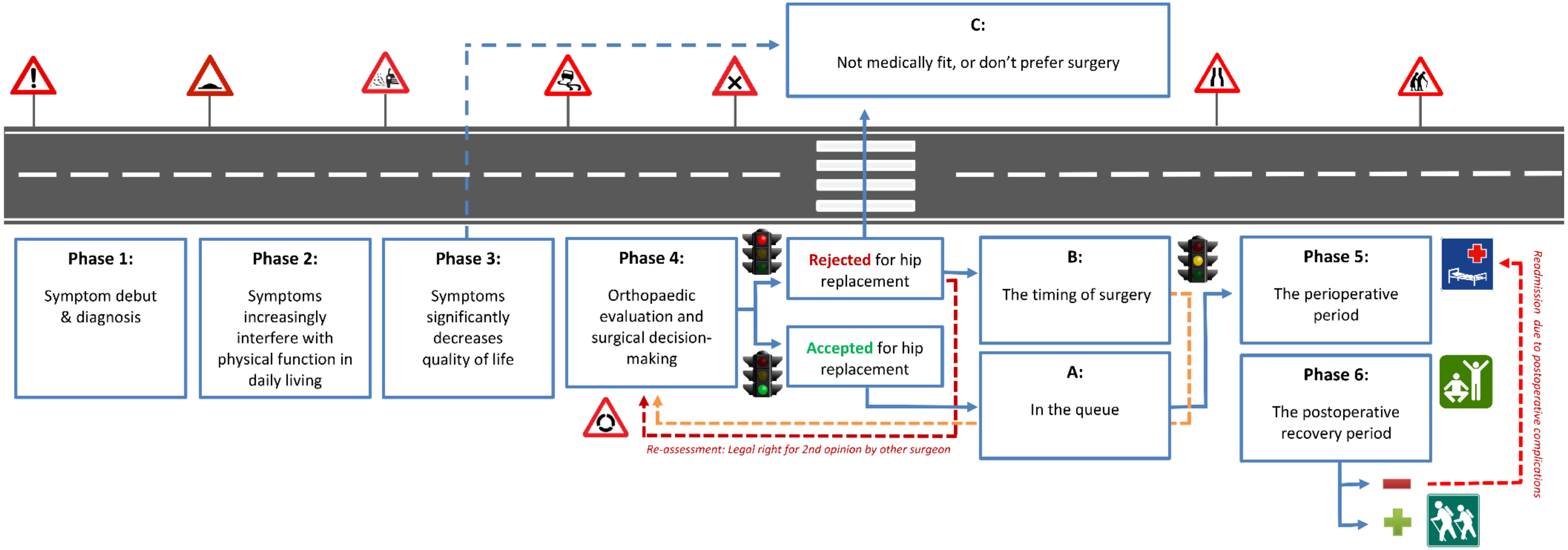


Figure 10: The hip osteoarthritis continuum

6.1.3 Patients’ experiences of surgical decision-making

Pain was the main reason for considering THR. Another central theme was social influence in relation to decision-making. It seemed important for the participants to discuss experiences with others who had undergone THR for reassurance and advice. Some had previous experiences of discussions with their GP or an orthopaedic surgeon about THR, where factors such as low age and limited radiographic evidence of OA had led to a decision to postpone surgery. The phase of surgical decision-making is a complex process. It appears to start before the actual meeting with the orthopaedic surgeon, either based on advice from HCPs or after observing other’s experiences from undergoing THR. The patients know that this is a final and effective option, but the issue of timing is very challenging for both the patient and the orthopaedic surgeon.

6.2 Paper II

Brembo, E. A., Kapstad, H., Van Dulmen, S., & Eide, H. (2017). Role of self-efficacy and social support in short-term recovery after total hip replacement: a prospective cohort study. *Health and quality of life outcomes*, 15(1), 68

In this paper, we aimed to determine whether perceived social support and general self-efficacy contribute to the variability in short-term postoperative recovery in a sample of OA patients who have undergone THR. We statistically analysed self-reported questionnaire data provided pre- and postoperatively by 223 patients undergoing elective THR.

6.2.1 Self-efficacy and social support as predictors of short-term recovery after THR

In the present sample, higher preoperative levels of GSE and reliable alliances tended to independently predict better short-term recovery from THR. This was evident even after adjusting for age, number of comorbidities, and preoperative WOMAC score in the multiple regression model. We anticipated that sex would play a role, but because of a very small and statistically non-significant β coefficient, we omitted it. Neither social support nor GSE seemed to change as a consequence of undergoing THR. Health status measured preoperatively by the total WOMAC score was the most substantial independent predictor of short-term recovery.

6.2.2 Subgroup analysis: Variation according to age, sex and comorbidity

Age: Patients older than 70 years of age reported significantly worse short-time recovery compared to younger patients. Patients younger than 70 years reported significantly higher levels of social support and GSE at baseline. This pattern was also evident for all SPS subscales except for reliable alliance and reassurance of worth.

Sex: Females reported significantly worse short-time recovery compared to men. No significant sex differences for perceived social support were found, however women reported having significantly lower GSE than men did.

Comorbidity: Patients with less than two comorbidities reported significantly better short-time recovery compared to those reporting two or more comorbidities. We found no significant difference in social support or GSE when comparing these two groups.

6.3 Paper III

Brembo, E. A., Eide, H., Lauritzen, M. van Dulmen, S., &. Kasper, J. Building ground for didactics in a patient decision aid for hip osteoarthritis. Exploring patient-related barriers and facilitators towards shared decision-making. *Under review, August 2019.*

In this paper, we conducted direct observation and audio recording of routine orthopaedic outpatient consultations as means to explore and describe the ongoing communication from a theoretical perspective based on SDM principles and socio-cognitive theory.

6.3.1 How patients are involved in decisions related to treatment of hip osteoarthritis

The observations and subsequent qualitative analysis revealed that decision-making in this particular orthopedic outpatient setting involved two parallel processes (Figure 11). One explicit “surgeon-driven” process primarily concerned with diagnostic procedures aimed to determine medical indication for surgery, and the other, a more implicit treatment decision-making process involved the consideration of which treatment is optimal. We identified three temporal phases. Phase one predominantly involved confirmation of an OA diagnosis, and discussion of its individual manifestation regarding ADL and QoL. This was carried out by the surgeon’s thorough consideration of available information in the referral document, review of recent X-rays, medical history and structured clinical assessment using the Harris Hip Score.

Phase two involved information and negotiation of available treatments. The surgical option was given priority. Dependent on individual features and characteristics, engagement and arguments from both parties varied. In case of suspicion of other possible reasons for the troublesome symptoms, the doctors challenged the patient’s wish for surgery by spending more emphasis on explanation of the associated risks. If the medical indication seemed clear, the doctors prioritized encouragement of the patient by emphasizing possible benefit. Mutual engagement in critical negotiation of pros and cons seemed also influenced by varying attitudes on the patients’ side.

In phase three, the patients’ subjective experience and concerns were exhaustively discussed and medical decisions for or against THR or about additional diagnostic tests were made clearly. In addition, the consultations included follow-up plans, and sometimes instructions about further evaluation of the decision. Both parties engaged in communicative activities to reassure mutual understanding in this process.

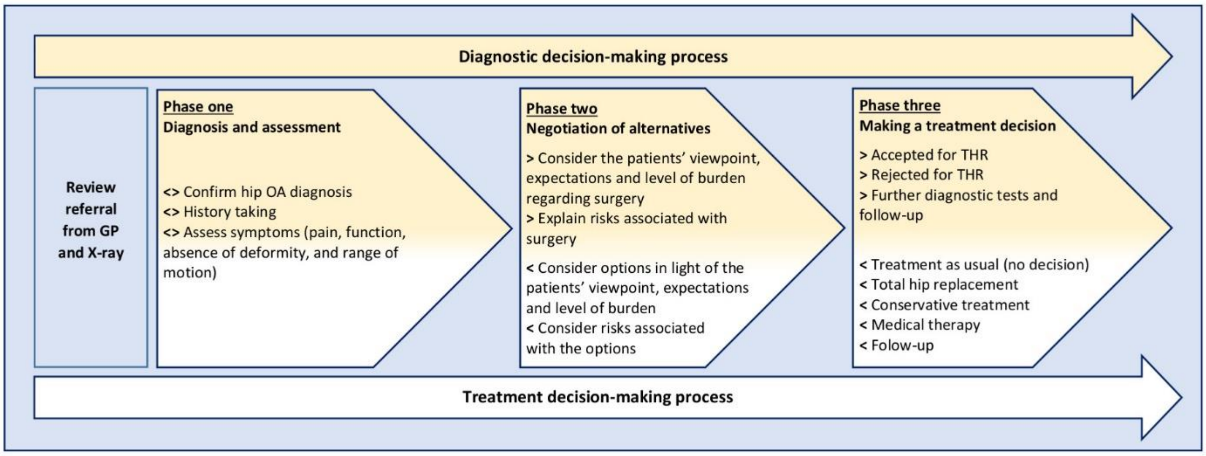


Figure 11: Overview of the typical course of an orthopaedic outpatient consultation on hip OA, demonstrating two overlapping but also different communication processes.

6.3.2 Patient-related factors facilitating or impeding patient involvement in decision-making for hip OA

A revised taxonomy of patient-related barriers towards SDM is shown in Table 7. Each barrier is structured according to the three TPB constructs. We identified 25 barriers that could be classified by the original taxonomy, and provided condensed empirical examples fitted to this particular patient group. In addition, we added one barrier that represented patients' feeling of being disempowered in changing the agenda. Fourteen barriers were classified as attitudes, six as social norms, and six as perceived behavioural control.

Table 7: Revised DAfactory taxonomy of generic patient-related barriers to SDM

Level 1: Main categories	Level 2: Subcategories of abstracted groups of beliefs	Level 3: Condensed empirical examples
1. Awareness that a decision must be made	Being aware of available treatment options	*My only concern is to receive treatment for my pain*
	Expecting that the decision is already made by the doctor	*Nothing I mean or say can influence whether or not I receive hip replacement*
	Expecting that my predetermined decision will be final	*I am convinced that the only solution for my problem is to replace my hip*
	Future-oriented focus (avoid any personal uncertainties that might arise in the decision-making process)	*My focus is what I can expect after undergoing total hip replacement*
	^{X} Unreadiness to make a decision (including to defer treatment decision) or avoiding negotiations of a decision	
2. Information and information processing skills	Being uninformed and/or lacking necessary knowledge	*I don't know much about osteoarthritis or which treatment alternatives exist*
	Having difficulties to understand the information (ex. medical jargon)	*It is sometimes difficult to understand what the surgeon means when he talks so quickly*
	Having difficulties to perceive the information (ex. present emotions are blocking)	*I am so excited about whether or not I receive the operation that I do not perceive what the doctor says*
	Having difficulties to evaluate the information (ex. too much information)	*It is difficult to concentrate when the surgeon both talks and asks questions while doing physical examinations*
3. Understanding of what SDM entails in practice	Expectation of a passive role in the decision-making process	*My contribution into the decision-making process is to answer questions.*
	Expectation of a traditional doctor-patient relationship: the patient disclose personal information and the doctor makes the decision	*I am here because I want an operation – I want to move on with my life. However, I do not have the authority to make this decision. It is the doctor's responsibility*
	^{X} Understanding of the doctor as specialist, but patient makes the decision	
4. Expectations of potential outcomes of SDM	Relying heavily on the opinions of the doctor over own preferences and values	*Ultimately, I don't think my views matter when it comes to deciding which treatment is best*
	Frustration about others expectations of being actively involved in the decision-making process	*I just want my doctor to decide what I should do*
	Strong conviction with regards to prognosis	*I do whatever it takes to get rid of this pain*
	^{X} Having concern of being self-responsible for any negative treatment outcomes	
	^{X} Assuming that all treatment options are equally effective	
	Expectation of not being entitled of control over own health-situation	*I am anxious and I need the surgeon to tell me what to do*

5. Pressure from important referents	Having excessive trust on others opinions/advice	*I believe that the surgeon can decide what is best for me*
	Feeling of responsibility for significant others	*My employer expects me to return to work in April. I need an operation before that*
	^{X} Avoiding conflicts or other social consequences	
	Being unfamiliar or uncomfortable with taking an active role in the decision-making process	*My doctor tells me what to do, and I usually agree with his decisions*
	Assuming that the doctor take one's personal needs into account and makes the optimal decision	*I believe that the surgeon knows what it most important for me*
6. Presence of support from important referents	Lacking social support in the decision-making process (impacts motivation/self-efficacy)	*It would help to bring someone to the consultation so that I would remember what to ask the surgeon*
	^{X} Lacking communication with important referents about to the forthcoming decision	
	Experiencing conflicting opinions among health professionals	*I have been to several doctors and they all have different opinions about what treatment I should receive*
7. Control regarding treatment or coping with consequences from treatment	Being uncertain around possible challenges or demands of treatment options	*I do not believe that I can stop smoking or lose enough weight*
	Being uncertain around possible challenges or demands of the consequences of treatment	*I am afraid what it actually entails to put a prosthesis into my body*
8. Communication self-efficacy	Feeling of shame (self-image, lack of knowledge)	*I know that I should have done more to lose weight*
	Having low self-confidence	*I don't think my concerns are important enough to discuss with the orthopedic surgeon*
	Belief whether the outpatient consultation is an arena to discuss/disclose personal feelings and concerns	*The surgeon does not have time to listen to my concerns, so I keep them for myself*
	^{Y} Feeling of being disempowered in changing the agenda	*My main concern is that I want to discuss which of the available treatment options fits best to me in my current situation*

Empirical examples in the third column are context specific. ^{X}: Element not identified in this context. ^{Y}: New element of the generic taxonomy

7. Discussion

In this chapter, I will first discuss methodological aspects that are important to consider before I proceed with discussing the principle findings in this thesis and its implications for practice and future research.

7.1 Study design and methodological considerations

7.1.1 Design

The research design of a study provides a framework for the collection and analysis of data. The choice reflects decisions about the priority being given to a range of dimensions of the research process, an may be attached to expressing causal connections, generalizing to larger groups, understanding behaviour in specific social context or temporal appreciation of social phenomena and their interconnections [172]. Each of the papers within this thesis address different perspectives related to the needs of patients with hip OA; information and emotional needs, psychosocial needs and needs related to active involvement in decision-making. The research questions have been investigated by using a combination of qualitative and quantitative research methods. The methods have been chosen primarily based on the research questions at hand. Furthermore, I have used different types of qualitative methods – in-depth interviews and direct observations. I have also used various approaches to qualitative analysis, one being more inductively oriented, and the other more deductive.

When planning for paper 2, I was fortunate to gain access to a large data material based on a longitudinal prospective study. However, this somewhat restricted what I could plan for as the questionnaires were chosen by another researcher. When seeing the different papers in relation to each other, this mix of methods has proven to serve the aim of the PhD project well. Furthermore, as a researcher in training, this has given me the opportunity to learn different research methods. Despite it being rewarding, it has also at times been challenging to acquire new skills and to work with three very different types of empirical data. For example, it requires different knowledge and skills to analyse data based on qualitative interviews compared to data based on observation notes and audio-recordings of outpatient consultations. A strength of this work is that I have conducted the data collection, transcription and analysis of the two qualitative studies. This has made me well acquainted with the participants and the data material, which helped me to "re-contextualise" different parts of the analysis back to the actual setting. The combination of audio-recordings and observation notes helped me in this respect to remember the participants as persons – i.e. how they appeared in the specific setting or how they non-verbally reacted to questions or situations. These important features will never be captured on audio-recordings alone, and this has proven to be important in the overall analysis process. There is however a risk that my immediate impressions or interpretations of others' behaviour, without possibility for member checking, are inaccurate or at worst completely wrong. If this type of conceptions were used uncritically, it may have posed a threat to the trustworthiness of the results. I have therefore spent much effort to reflect upon different functions of such interpretations, and discussed perspectives with supervisors. An important feature of qualitative research is the active role of the researcher in the whole process of collecting and analysing data and it is therefore important that I reflect upon how this might have affected the trustworthiness of the results presented in this thesis. This refers to the concept of reflexivity.

7.1.2 Reflexivity

Reflexivity is concerned with a critical reflection on the research, both as process and as practice, on one's own role as researcher, and on one's relation to knowledge. Reflexive research is that which acknowledges the role of the researcher in the research process [149]. Malterud defines reflexivity as: *An attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process"* [173]. When I started working on this topic in 2013, I had limited formal knowledge about OA and SDM. However, during my clinical experience as a nurse in home care settings, I provided care for patients suffering from severe pain and reduced physical function in relation to different diagnoses including OA. This experience, alongside a general and professional interest in chronic pain management and health communication (optional subjects in my clinical master's degree) motivated me to study this particular patient group. I believe that I started this research process without having strong and potentially biased preconceptions about OA patients' situation and perception of needs, and that this starting point has been a great advantage. This enabled me to stay curious and ask open – and sometimes naïve questions. Although I had prepared a semi-structured interview guide, I typically used it as a reminder of topics in case of difficulties in maintaining a meaningful dialogue, or alternatively if the content of the dialogue shifted towards topics not considered relevant for the research questions. Participants were generally very willing to share their experiences, so the first issue was usually not a problem. Some participants claimed that this was the first time someone had asked them about their experiences and feelings relating to living with hip OA. If the latter happened, in which it did several times, I strived to be patient without interrupting and instead actively listen to what was being said. However, there was sometimes a need to guide the participants "back on track" when they tended to speak about other matters that was triggered by the setting. This balance of providing space and openness in the conversation, and at the same time keeping some structure and control, was undoubtedly a challenging task. This was a new setting for me as a PhD student, and in retrospect, I realize that I could have been even more open-ended in my interviewing-technique (e.g., paraphrasing and mirroring) which could have stimulated more in-depth reflections about important aspects. Paraphrasing may also act as a strategy to verify that own understanding of key utterances concur with the intended meaning of the participants.

Throughout a PhD period lasting several years, it is a difficult task to conceptualize how my relation to knowledge has developed and how various scientific positioning's have shaped me as a researcher, and more specifically this research process. I am sure that the wide range of activities related to my role as a PhD student has transformed my knowledge, understanding and my way of perceiving current practice. In other words – I am not quite the same person that I was six years ago. Inevitably, this has shaped my overall understanding about central topics in this project. I acknowledge that this continuous intellectual and academic development is normal and essential in a PhD journey. I believe it is of great value to reflect upon the potential implications of any research process, indicating that it should be a lifelong endeavor and not limited to a PhD project. It helps me stay critical towards my own understanding, and provides a source for self-confidence, stamina and motivation in the process of working with complex and sometimes very difficult tasks.

The significant role of reflexivity was perhaps most apparent for me while working with paper 3. My theoretical understanding of SDM and my conception of how it might look like in clinical practice has been evolving since the very start of the project. The same applies for my understanding of the theory of planned behaviour. The chosen method for collecting and analysis the data was very much determined by how this knowledge and experience had evolved on a personal level. During these years, I have attended several conferences and workshops, read a fair amount of relevant research literature, discussed the theoretical and ethical implications of SDM at PhD courses and seminars with fellow PhD students and with senior researchers. As part of becoming familiar and confident with the particular method for collecting and analyzing data, I have collaborated closely with a senior researcher (Professor Jürgen Kasper) who has previous experience with SDM research and has developed the particular methodology as part of the DAfactory. This ongoing personal development of my understanding of theory and practice was put to test continuously throughout the whole process of completing the study – from planning to submission. As my knowledge has expanded, I have realized the complexity of these theories and how vulnerable this kind of qualitative study is to personal biases – i.e. the ultimate findings and conclusions are somewhat limited by my theoretical and practical understanding of SDM and TPB, and also the fixed boundaries of which the particular observation method operates.

7.1.3 Sample

Qualitative research usually has smaller sample sizes than quantitative research. A sample size of between 15 and 30 individual interviews tends to be common in research aiming to identify patterns across data. The judgment on how many participants are needed for a particular study may be affected by what you want to know, the purpose of the study, what is at stake, what will be useful, what will have credibility and what can be done with available time and resources. Other factors affecting the sample size are the quality of data, the scope of the study, the nature of the topic, the amount of useful information obtained from each particular participant, the number of interviews per participant and the qualitative method and study design used [149]. Hence, there are multiple considerations when planning a qualitative study. Recruitment for the two qualitative studies in this thesis involved a purposive sampling approach. This implies that participants were sampled in a strategic way in order to be relevant to the research questions under study. A general goal is to achieve a variety in the resulting sample so that the participants differ from each other in terms of key characteristics [172]. In both qualitative studies, we obtained a good age and sex balance. In the paper 1 we achieved variety in education level, work status, time with hip-pain and comorbidity. None of the participants was representing any other ethnic group than Norwegians, which is a limitation of our sampling. Immigrants and the children of immigrants constituted around 17% of the population of Norway in 2017, a total of around 920 000 people [174]. Evidence suggests that there are several ethnic disparities among patients with OA, and some are related to pain perception [175], management [176], engagement in physical exercise [177] and joint replacement utilization [178]. This diminishes the generalization of the findings presented in this thesis.

The decision to end the process of recruitment in the qualitative studies was related to a judgment of saturation, or “data adequacy”, which refers to the point when additional data fails to generate new information [179]. Although the themes of the studies were quite broad (i.e. patient needs, and shared decision-making), we defined quite narrow focuses (i.e. information and emotional needs, and patient-related barriers towards SDM). This affected how many interviews and consultations that were considered needed for this particular study. This judgment was not a straightforward decision to make, and as seen retrospectively, it could have improved the data if we would have been able to recruit more patients in primary care. This would have allowed us to expand the exploration of the patients’ perceived needs as experienced earlier in the disease continuum, and also the needs arising after surgery. In paper 3, we chose to focus on the orthopedic outpatient setting to investigate patient-related factors that influenced SDM. We ended up with 19 patients and it is difficult to determine if more patients could have provided new information. Furthermore, as only two orthopedic surgeons performed the consultations, there is a need to interpret the results with caution.

Paper 3 was based on a previous dataset of patients undergoing THR enrolled in a longitudinal study. The participants were consecutively recruited over a 1 year period at six different hospitals. This was a strength and may have ensured a representative sample. The mean age of the responders was 69 years of whom 71% were female. A comparison of the sample in this study (N = 223) with the population of Norwegian patients who underwent THR in 2017 (N = 9097) reveals similar age and sex distributions (mean age 69 years and 67% females) [180]. Power calculations were conducted based on the assumption that a 10% change in health status would be clinically significant [181]. As these data were already collected, it was not possible to increase the number of participants. However, the total number of 223 patients and the low rate of missing data (less than seven patients failed to complete the preoperative or postoperative questionnaires) maintained the statistical power, and thus was considered sufficient for group and sub-group analysis. To check for response bias, we analyzed if the included participants (responders) differed with regards to demographic variables compared to non-responders. No statistically significant differences were detected on age, sex, marital status, education level, employment or number of comorbidities.

7.1.4 Data collection and validity

Validity refers most basically to whether research actually shows what it claims to show. There are different forms of validity, with *ecological* validity being the most commonly used in qualitative research. Ecological validity is about whether or not research captures meaning in a way closely related to real life situations. Qualitative research is generally considered more ecologically valid than quantitative research because it tends to gather data in ways that are less far removed from the real world [149]. In this thesis, two studies were qualitative and the methods used to collect data included individual interviews of patients with OA who were allocated at specific phases of the continuum of the disease, and direct observation of orthopedic outpatient consultations. Figure 12 illustrates the allocation and focus of the three papers within the hip OA continuum model.

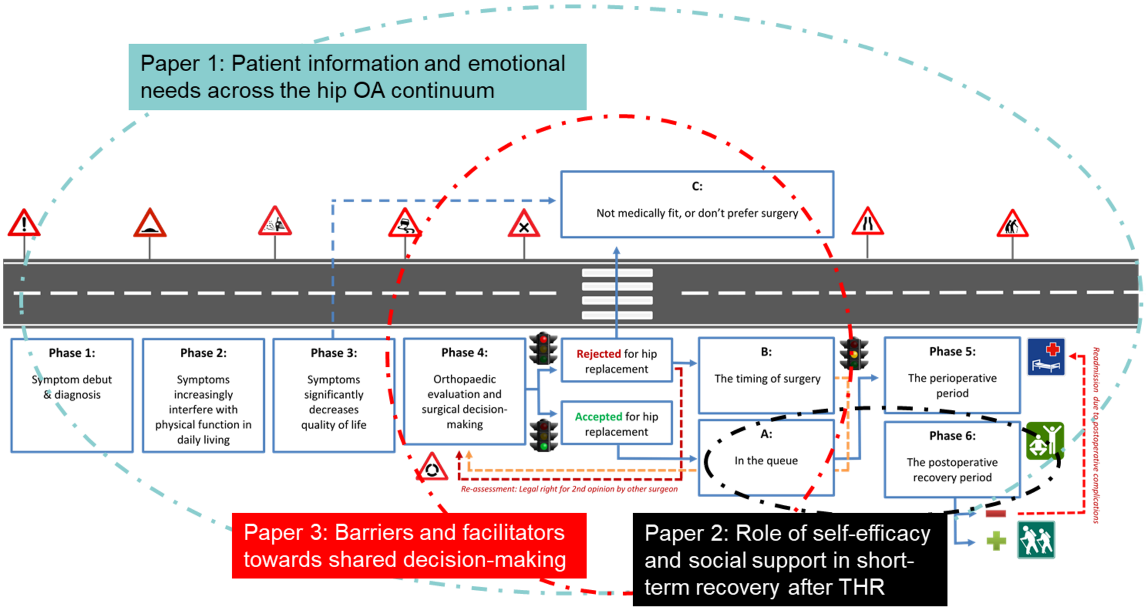


Figure 12: Allocation and focus of the three papers within the hip OA continuum

In paper 1, we ensured to include patients from both primary and specialist care. In paper 3, the chosen setting allowed for in depth investigation of ongoing communication happening during real-life consultations. The reason to recruit patients in primary care was to reach out to those who had either mild or moderate OA, or those who had previously undergone contralateral THR. The second recruitment strategy allowed us to reach out for patients who were referred to THR, thus representing individuals with severe OA. Following this procedure, we were able to adapt the interview approach to fit with the individuals' real-life situation. For example – patients with newly diagnosed hip OA had no knowledge about the later stages of the disease and the continuum of care, but could explain in detail how they ended up with an OA diagnosis. Patients allocated later in the disease continuum could explain their present experience in detail, and also reflect retrospectively upon previous stages. This sample composition thus improved ecological validity. However, the low number of participants allocated at each of the different phases calls on the need for a larger study to confirm the findings of these two studies and to provide further details of the needs of hip OA patients related to information, emotional support and decision-making.

Other methodological strategies can play a role in improving the overall validity. After data collection and analysis are completed, some researchers choose to reengage the participants, with the objective of strengthening the trustworthiness, accuracy, and validity of the findings. Two types of strategies are discussed here: 1) Follow-up interviews meant to examine the authenticity of emerging insights and verification of participants intended meanings, and 2) member checking carried out individually or in a group setting to enable discussions of the results and conclusions of the study. These strategies may, however have implications and consequences for the research, including a commitment to revise the research findings because of participant reservations or because of the researcher's fear of negative participant reactions. Participants may also find it difficult to confront the researchers' analysis. Furthermore, from an ethical point of view, participants might be recognized through the personal vignettes included in the research report or through the member-checking process, and thus a threat to anonymity may be posed [182]. We considered to invite participants to partake in individual follow-up interviews to discuss the findings and conclusions in both of the qualitative studies, and it was also included in the information and consent letter. An important reason that explains why we ended up not to pursue this idea is primarily related to time constraints within the framework of a PhD. This strategy would entail renewed contact with the participants, including arranging new meetings after careful planning how to involve the participants in this stage of the analysis and not least to determine how to make use of the results of this process. In qualitative research and based on my experience from working with this empirical data, there is a risk of inaccurate interpretations and generalization in the presentation and discussion of results. I expect that follow-up interviews would give even more detailed findings in relation to areas that appeared important and also that our interpretations could become more nuanced and more accurately in line with intended meanings of the participants.

In paper 2, quantitative methods were used based on questionnaire data, in which the patient responded at fixed points in time (pre- and postoperatively) and in direct connection with an upcoming event (undergoing THR). This resembled some relevant features of a real-life situation. However, these questionnaires only mapped predefined topics captured in the questionnaires chosen by the researchers and did not allow participants to provide additional information. For example, some patients who completed the SPS questionnaire may have wanted to provide other information relating to social support not covered in the questionnaire. Given the limitations of using questionnaires to investigate complex psychosocial concepts, the empirical data and our results do not allow us to draw conclusive conclusions in the sense that they only measure specific pre-defined domains of social support and self-efficacy. A mixed methods approach involving both quantitative and qualitative methods could have provided a broader understanding of the role of social support and self-efficacy in relation to postoperative recovery after hip prosthetic surgery. However, it would not have been possible to recruit the same participants, as paper 2 was a retrospective study based on data collected in 2003-2004. Therefore, a sample of other participants with similar characteristics had to be recruited for a secondary qualitative study.

In quantitative research, it is common to distinguish between construct, internal and external validity. Construct validity is concerned with whether a questionnaire measures what it intends to measure. It also refers to whether the results from a measure can be generalized to the wider construct. Internal validity is concerned with whether the effects identified are in fact being caused by the variable(s) under study, rather than some other, confounding factor. External validity refers to whether the results from the study can be generalized from the sample to the wider population [149].

As described in the methods section, all of the questionnaires used in this study are widely used in health research and have been validated in different settings through psychometric testing. There are, however, important considerations to be made when interpreting the validity of the results. As previously described, we considered that the available sample was appropriate to reflect characteristics of the population under study. The fact that the data were collected over 10 years prior to the analysis and publication of the results is an obvious factor that may be questioned. Comparing our sample with data published by the Norwegian Arthroplasty Register in 2018, we can see that the samples have comparable age and sex distributions [180]. In addition, the patient care pathways can be claimed to have not changed to any appreciable extent. We do, however, not know in detail how the current population may differ from the one 16 years ago when the data were collected. We know that patients in general become more knowledgeable and this can influence a person’s perceptions of self-efficacy and social support. Furthermore, apart from the WOMAC questionnaire, no other studies were found using the GSES or SPS questionnaires in relation to postoperative recovery after THR in patients with OA. It is therefore difficult to compare the results from this study with other similar studies which have used disease- or domain-specific questionnaires to measure the predictive value of self-efficacy on postoperative outcomes following joint replacement; The Self-Efficacy for Rehabilitation Outcome Scale [183], The Pain Self-Efficacy Scale [184], and the Arthritis Self-Efficacy Scale [185] are three examples. Furthermore, there is a range of different social support questionnaires being used to investigate the effect of psychosocial variables on outcomes following joint replacement; The ENRICHD Social Support Instrument [186], the Medical Outcomes Study Social Support Scale [185], and the F-SozU [187] are examples. When it comes to measuring health status in patients with hip OA, there are also several questionnaires other than the WOMAC that are being used. Examples are Harris Hip Score, Hip Disability and Osteoarthritis Outcome Score (HOOS), Oxford Hip Score, Lequesne Index of Severity for Osteoarthritis of the Hip (LISOH) and American Academy of Orthopedic Surgeons (AAOS) Hip and Knee Questionnaire [50].

There is evidence suggesting that the WOMAC may lack discriminant validity [188], and that the content and structure of the scale minimize the ability of the largest 17-item domain (physical function) to detect change [189]. The huge variety of questionnaires and the different theoretical conceptualizations, in which these questionnaires are based on, complicate our ability to make firm conclusions on the predictive power of self-efficacy and social support on health status after THR. We can, however, make conclusions about how this sample responded on the GSES and SPS questionnaires, and how the variables contributed to explain the variability in short term recovery after THR as measured by the total WOMAC score. We also provide valuable data that can be used as basis for comparison in future studies.

7.2 General discussion of the results

As the title of this thesis reflects, we describe living with hip OA by a journey metaphor. The participants who willingly shared their experiences describe this particular journey as an unpleasant adventure that inevitably defines their everyday lives. Although individual experiences of this journey varied, some patterns were distinct and common for most patients. We were hence able to describe a typical hip OA continuum reflecting the different phases related to disease progression, the changing needs and decision-making points.

This research explores the patients' needs at different phases of the OA disease continuum. The model, which is presented in paper 1, has proved to be a useful outline for the different parts of this research. Paper 1 explores informational and emotional needs across the whole disease continuum (phases 1-6). Paper 2 investigates the role of social support and general self-efficacy in relation to hip surgery (phases 4a – 6). Paper 2 explores ongoing outpatient communication in the context of SDM (phase 4). The three different perspectives on patient needs are discussed below in the context of self-management of hip OA.

7.2.1 Perceived information and emotional needs in patients with hip OA

The patients' informational and emotional needs identified in paper 1 are condensed into key questions representing the main concerns of the patients at the respective phases along the continuum. These findings seem to align with other studies and add the evidence base with valuable and in-depth insight into the perception of needs experienced by patients across the disease continuum. A recent scoping review [4] synthesised the evidence regarding patients' perceived health service needs related to OA, and seven areas of need were identified and relate to: medical care, pharmacologic therapy and pain management, physiotherapy and exercise therapy, complementary alternative medicine, joint replacement surgery, access to healthcare services and needs related to orthoses and physical aids. Another systematic scoping review reports the evidence about OA patients' perceived health information needs based on 30 studies. Patients perceive need for clearer communication and explanations, information from various reliable sources, and more information about diagnosis, management, prognosis, and prevention [36].

The very nature of hip OA, being a disease that is not life threatening, and existing beliefs held by both patients and HCPs that OA is a natural part of the aging process, with limited treatment alternatives, seemed to result in cycles of delayed treatment and dysfunctional coping strategies. This pattern is well documented in the literature and it remains a challenge to implement high quality OA treatment and care. Patients want help and support to self-manage, but do not receive the full range of core treatments. Short-term changes in behaviour that benefit patients with OA are often not maintained in the long term [190]. Patients arguably need a structured and personalized treatment plan that is appropriately evaluated by the GP and patient on a regular basis. Exercise is considered as one of the cornerstones in the treatment of hip OA, and there is a dose-response relationship, meaning that the effectiveness of exercise on pain and physical functioning depends on how well a patient complies with evidence-based recommendations [191]. Thus, exercise adherence seems to be an important predictor of the long-term effectiveness of exercise therapy. Evidence from a prospective observational study showed that adherence was significantly associated with better outcomes of pain, physical function, and self-perceived effect in 150 patients with hip or knee OA [192]. A review shows that booster sessions with a physiotherapist and behavioural graded exercise improve adherence [193]. The ability to incorporate the exercise intervention into everyday life, perception of symptom burden, and of intervention effectiveness are factors affecting patients' decisions to comply with treatment [194]. It is therefore important to consider various factors that influence the individual patients' day-to-day decisions about physical exercise. Evidence suggests that symptom relief and mobility, positive exercise experiences and beliefs, knowledge, enjoying exercise, a 'keep going' attitude, adjusting and prioritising physical exercise and having professional and social support are factors that facilitate physical exercise in patients with hip and knee OA. [195]. These findings show that each patient needs individual tailoring of treatment and continuous support from both HCPs and social network. From a biopsychosocial perspective on pain, it is necessary to target the numerous facets (both positive and negative) that comprise the pain experience. HCPs should approach OA patient care with this in mind and encourage communication across all pain management specialties [196].

Pain is a hallmark symptom in OA and it is important to understand how this pain affects the patients' self-management strategies. Based on the findings of the present research, symptoms were generally characterized as intermittent, unpredictable and difficult to manage. An aspect, which may contribute to understand the patients' behaviour towards OA management, is how they prioritize OA-related symptoms and subsequent physical limitations among other comorbid conditions. A study suggests that patients either may prioritize OA over other conditions, not prioritize OA at any point, or as most participants described, have time-specific (shifting) priorities [197]. Clinicians must therefore be aware of the dynamic nature of OA itself and its interplay with comorbidities. The authors argue that each consultation should include a biopsychosocial assessment of the patient experience at that specific point in time to ensure that clinicians understand patient priorities, and that this approach would facilitate improved communication and concordance in decision-making [197]. A biopsychosocial approach entails that biological, psychological and social factors are all considered in the effort to understand pain mechanisms and disability. As discussed by Keefe *et al.* [103] the biopsychosocial model provides a systems perspective on arthritis in the sense that changes in one part of the system produces changes in another part. For example, sudden pain exacerbation can lead to increases in anxiety and depression, and decreases in the ability to work or perform household chores, both of which, in turn, can increase pain and disability [103]. Alternatively, targeting patients' psychological resources by increasing self-efficacy in controlling OA symptoms can lead to enhanced compliance with medications or increased interaction with supportive friends and family, both of which can reduce pain and disability. To be able to provide accurate descriptions with the clinician, patients could benefit from learning and having access to new ways to self-monitor biological and psychological symptoms, helpful social resources, and apply helpful management strategies in daily life over time and to keep track of the relative effects of the chosen strategies. This could stimulate awareness of which issues to prioritize during up-coming consultations. It would also help the clinician to gain better insight into how the symptoms vary and into, treatment adherence, and serve as a basis for person-centred communication and shared decision-making. Web-based interventions may provide innovative and personalized means to improve physical activity behaviour in patients with OA [198, 199]. However, factors such as lack of personal guidance, insufficient motivation, presence of physical problems and bad mood influence the usage of such technologies. Older patients with comorbidities may need a more personal (face-to-face) approach [200], or blended care interventions combining face-to-face interactions with digital solutions [201]. Application of a participatory research design where patients and relevant stakeholders are invited to innovate and develop technologies together with developers and researchers seems to be important to meet individual patients' needs and overcome motivational barriers [202, 203].

Participants in the qualitative studies described that maintenance of an active lifestyle was difficult to achieve because of the pain that tended to increase while trying to perform physical exercise. They also expressed worry that the symptoms would deteriorate and cause even more problems. The literature shows that increased pain during physical exercise may cause fear and the lack of appropriate knowledge about pain mechanisms in OA may cause non-adherence. Patients' beliefs about chronic pain shape their attitudes and behaviours about how to manage their pain. Patients with OA are confused about the cause of their pain, and bewildered by its variability and randomness. Without adequate information and advice from HPCs, they do not know what they should and should not do, and may therefore avoid activities in fear of causing harm [204]. Fordyce *et al.* [205] has described how pain behaviour may result from avoidance learning. Avoidance refers to *"the performance of a behaviour which postpones or averts the presentation of an aversive event"* [206]. Fear of movement has been studied in diverse patient populations and has been associated with increased pain, physical disability, and psychological disability [207]. A Swedish study [208] investigated the prevalence of fear among individuals with OA that their joints would be harmed as a consequence of performing physical activity, and whether an education intervention would reduce this fear. More than a quarter of the participants reported fear and the intervention appeared promising as means to reduce the fear. A Dutch cross-sectional study comprising 254 patients with OA found that pain-related fear was significantly associated with functional limitations [209].

Catastrophizing, the tendency to ruminate about and magnify pain, is also a critically important variable in understanding the experience of pain in rheumatologic disorders as well as other chronic pain conditions. There appear to be multiple mechanisms by which catastrophizing exerts its harmful effects, from maladaptive influences on the social environment to direct amplification of the central nervous system's processing of pain [210]. Cognitive behavioral therapy, multimodal treatment, and Acceptance and Commitment Therapy (ACT) are approaches that has been shown to produce modifying effects on pain catastrophizing in adults with chronic non-cancer pain [211].

There are several studies that demonstrate these psychological mechanisms, and seen in light with other more common barriers related to behaviour change, it is not difficult to imagine that an older patient who suffers from unpredictable OA, and sometimes unbearable pain in the hips, has major challenges in the effort to successfully adhere to a prescribed treatment plan. This leads us to an important point in this thesis. Patients need tailored and frequently delivered information throughout the continuum of the disease, and most importantly, care pathways must secure that this educational intervention starts immediately after a diagnosis is received. This would increase the chance that patients start with preventive physical exercise at an early stage of the disease.

Research on patient-surgeon communication shows that surgeons spend the majority of their time educating patients and helping them to make choices, and that they are generally thorough in providing details about surgical conditions and treatments. However, the emotions or concerns of patients seem poorly addressed by the surgeon [212]. Levinson *et al.* [213] assessed how patients present clues and how physicians respond to these clues in routine primary care and surgical settings. They found that patients offer clues that present opportunities for physicians to express empathy and understand patients’ lives. Because these clues were often expressed in subtle ways embedded in the context of a discussion about a health problem, physicians who are busy attending to the biomedical details of diagnosis and management may easily miss them. In both settings, physicians tended to bypass these clues, and thus missed potential important information and opportunities to strengthen the patient-physician relationship [213]. Relationship-building skills include listening, expressing concern for patient’s emotions, expressing empathy, and understanding the impact of the disease on patients’ lives. These skills are essential in effective clinical communication, and as seen from the patients' perspective, inappropriate responses to important concerns may lead to dissatisfaction [212]. Patients are more satisfied when physicians explore illness in the context of the patient's life, understanding the broad concerns of the patient, not just the patient's disease [214]. This is particularly important in the context of chronic disease management. As previously discussed, older patients with hip OA may have comorbidities that affect how they prioritize their OA among other conditions. Ensuring that clinicians understand patient priorities will facilitate improved communication and concordance in decision-making within the limited time of consultations, which may translate into improved outcomes [215]. In the context of orthopedic outpatient care, it is relevant to discuss the relative roles and responsibilities of the GP and the orthopedic surgeon. The GP functions as a gatekeeper to specialist healthcare services, but also as the primary care provider who knows the patient best. A Norwegian study shows that patients have the same GP for 5.9 years [216]. According to Statistics Norway, patients aged 67 – 79 years visit their GP four times a year on average [217]. The patient and the orthopedic, however, are most likely strangers to each other. Patients who visit an orthopedic surgeon are typically referred because the GP and the patient consider that conservative treatment options are insufficient to relieve pain and improve physical function. Evidently, this important factor affects the communication and decision-making process for both parties.

7.2.2 Shared decision-making in patients with hip OA

The research-body on shared decision-making and other elements relating to the concept of patient-centeredness is rapidly growing. There are still ongoing discussions about how to understand SDM at a conceptual level and not least why and how to implement it in clinical practice. An integrative model of patient-centeredness is proposed to secure that different stakeholders speak the same language, and as a foundation for creating better measures and interventions [218]. A goal of SDM is to ensure that patients are well informed and reach treatment decisions concurrent with personal preferences. Informed, patient-centered decisions are associated with better health outcomes in orthopedics. Patients who are well informed and receive their preferred treatment have better overall and disease-specific QoL, report less regret and more satisfaction with symptoms and treatment [219]. A survey study among 64 Dutch orthopedic surgeons and 71 residents found that physicians are willing to perform SDM and consider SDM as favorable in the orthopedic clinic. To implement SDM in the hip OA continuum, it is vital to gain more in-depth knowledge about how patients and doctors actually communicate about treatment choices and to identify potential factors that affect the decision-making process.

In paper 3, we explored from the patients' point of view, ongoing communication and decision-making within the context of orthopedic outpatient consultations. The direct observation of routine outpatient consultations and the application of a generic TPB-based taxonomy of SDM barriers in the analytical phase enabled identification of a pool of influencing factors relevant for this particular setting. A prominent finding was the apparent overlapping decision-making processes, one being concerned with diagnostics and determination of surgical indication, and the other with reaching the optimal treatment option. The strong focus on surgical indication seemed to blur the fundamental message that an informed and shared treatment decision-making is achieved through careful negotiation of all available treatment options and that the patients' opinion is important [220]. Concerning the latter point, our findings revealed that the clarification of patients' role during these processes was somewhat unclear, which seemed to evoke passive patient behaviour – or missed initiative to put forward own questions, concerns or perspectives.

At the core of SDM is an assumption that the doctor-patient relationship is based on mutual respect and joint interest to achieve beneficial outcomes where decisions and responsibility are shared. This entails sharing of information, recognizing patients' expertise from an insider's point of view, understanding patients' attitudes, values and preferences, and acknowledging doctors' expertise in diagnostic procedures, disease etiology, prognosis, treatment options and preventive strategies [221]. One strategy to clarify the importance of patients' opinions is to explain the concept of clinical equipoise [222] and state that the best way to deal with the problem will ultimately depend on the patient's preferences. Couët *et al.* systematically reviewed studies that used the OPTION instrument to observe the extent to which patients are involved in decision-making across a range of clinical contexts and showed that equipoise was explained in only five out of 16 studies [223].

Diagnostic procedures are important features of medical consultations. A correct diagnosis and systematic assessment of past and current health status are fundamental requirements in order to determine if surgery is medically indicated. However, patients might be unfamiliar with the overall purpose of these procedures unless the orthopedic surgeon informs the patients well about how it relates to the different steps and phases of an outpatient consultation. Furthermore, patients should be informed about how vital their involvement is during both of these processes. The potential benefits of involving others from the social network in the decision-making process, and bringing someone who can contribute with important information and perspectives should be emphasized. Because some patients have limited or no understanding that they can participate in decision-making with HCPs, patients and their social support networks should be educated on what engagement is and what the different levels of engagement are [224]. These strategies would potentially stimulate awareness of own role through better knowledge and understanding, increased social support in decision-making and self-efficacy in communication. Ultimately, it's up to the patients to decide how much they want to participate in healthcare decision-making, but they should be encouraged by HPCs and supported by the system to do so [224].

Adequate health literacy (HL) is essential for patient involvement in their healthcare and decision-making [225, 226]. WHO defines HL as *"The cognitive and social skills which determine the motivation and ability of individuals to gain access and to understand and use information in ways which promote and maintain good health"* [227]. Sørensen *et al.* [228] reviewed the HL literature and identified 17 definitions. Based on these definitions and conceptual frameworks, they propose the following and more comprehensive definition: *Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course [228]*. The development of HL skills in patients with a long-term health condition is an ongoing process that develops over time through a range of health experiences and encounters within different health contexts [229]. We did not assess HL in any of the studies of this PhD thesis, but do acknowledge HL as an important asset that should be considered at all stages of development of interventions aimed at patient involvement in health care processes and improved self-management [229, 230].

Gulbrandsen *et al.* [231] discuss uncertainty, vulnerability, dependency, autonomy, power, trust and responsibility as core concepts of SDM. They argue that uncertainty and vulnerability caused by illness expose existential aspects of being, and may lead to dependency on the HCP, which underscores that autonomy is not just an individual status, but also a varying capacity, relational of nature. Montori *et al.* [232] argue that treatment decisions in the chronic care setting are likely to require a more active patient role in carrying out the decision and to offer a longer window of opportunity to make decisions and to revisit and reverse them without important loss than acute care decisions. They further highlight the importance of establishing partnership in chronic care management. A well-functional and ongoing partnership may foster trust and mutual respect that creates an environment conducive to successful patient self-management. It is essential that patients are given the opportunity to acknowledge failures and shortcomings in the process of adapting to new and challenging treatment strategies without fear of disappointing the clinician or damaging the relationship. The environment should also allow patients to point out if the clinician fails to understand the perceived factors that affects capability to succeed [232]. As discussed by Gignac [65] patients with OA may lose trust in their physician as a consequence of a lack of specific treatment recommendations to manage symptoms or being given pharmacological treatment recommendations with little or no discussion of long-term effects. This lack of trust may partly explain why several participants in paper 1 described uncertainty about what treatment to pursue. Patients may feel vulnerable and dependent on the good will of their physicians, as they know that they will need to return at later points in time. This may affect the behaviour of patients and how they perceive their capacity and opportunity to engage actively in decision-making processes. The literature suggests that patients' fear of being categorized as "difficult" by the physician may prevent patients from participating. Furthermore, physicians might not be aware of the need to create a safe environment for open communication to facilitate SDM [233].

7.2.3 The role of social support and self-efficacy in patients with hip OA undergoing hip replacement surgery

Social support was evidently an important factor for the participants in this study. Learning from others with OA affected their knowledge and understanding of OA as something treatable, and it clearly affected their expectations about treatment options. Without any specific reference, it was an overall impression that many of the participants placed great trust in others' experiences and opinions. Participants in both study one and three referred to other persons in the context of their arguments for or against specific treatment options. This could for example be persuasion from a colleague who had undergone successful THR, or clear advice from a friend to avoid surgery due to suboptimal outcomes. A recurrent statement was that people in their social network, on the Internet or other media, had shared their experience with the mini invasive procedure offered at the local hospital. This seemed to motivate these participants to seek more information about this particular surgical procedure, and for some this was decisive for their decision to be referred to this particular hospital.

Having someone present during consultations with an orthopaedic surgeon seemed in the observations conducted in study three to facilitate more patient-centred communication – e.g., that important values were raised and preferences discussed. This finding is confirmed by the literature to facilitate patient involvement in communication and decision-making [234]. Several factors may explain why patients may benefit from having a patient advocate present. Patients may feel insecure in the consultation setting and not dare to ask questions, and they may forget what they planned to ask before entering the room. The use of advocates may help to overcome practical barriers (e.g. access, forgetfulness) and to support active involvement during the consultation (e.g. asking questions) [235].

The findings from paper 2 show that patients with better preoperative health status reported better short time recovery after total hip replacement. This is well documented in the literature [186, 236-239], and is illustrated in Figure 13. It is important to notice that patients with more severe radiological OA and lower function preoperatively appear to experience greater improvements, but they do not reach the same postoperative levels in functioning as patients with less severe OA or higher baseline function scores [240]. These findings may be used as basis to educate patients about the important and beneficial role of physical exercise. It can also help clarifying patients’ expectations, and in determination of the optimal timing of THR for the individual patient [240].

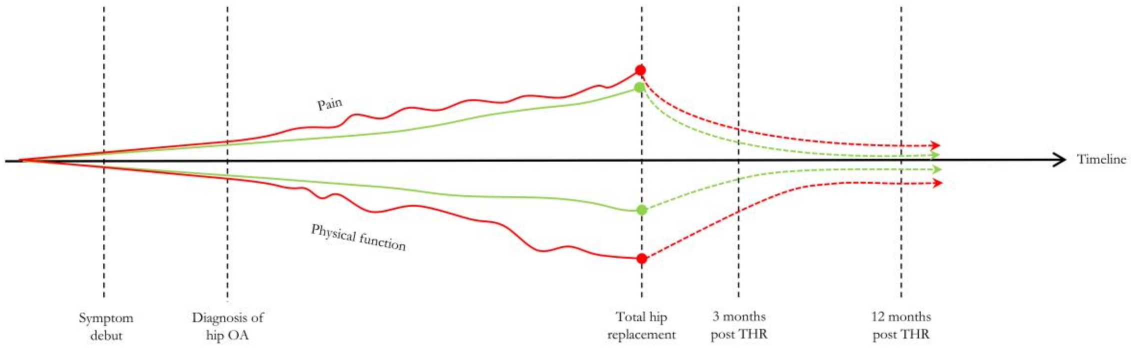


Figure 13: Impact of preoperative health status on recovery after THR

Unfit patients might be advised to postpone surgery to optimize preoperative functional status, whereas other patients might benefit from undergoing surgery earlier in the course of functional decline [238]. Optimizing preoperative health status in the form of pre-habilitation programs (exercise and education) improves function, pain and hospital length of stay [241]. Furthermore, self-efficacy and social support are important psychosocial determinants of physical activity among older adults [242]. It appears to be a synergic effect between social support and self-efficacy. A study found that people with low self-efficacy were less likely to be active in spite of having social support. People with low support were less likely to be active even if they were high in self-efficacy. Social support from friends was more effective for frequent exercise when older adults had strong self-beliefs in being capable of exercising [243]. Adopting new behaviours are dependent on several factors, as modelled in the I-Change Model by de Vries *et al.* [244, 245]. This model assumes that behaviour is the result of behavioural intentions and abilities, and it distinguishes between three phases of motivational change (pre-motivational, motivational, and post-motivational) and their corresponding determinants. According to van Stralen *et al.* [242], interventions should be tailored according to the participants' needs and characteristics for either *initiation* or *maintenance* of physical activity. To stimulate initiation, interventions should enhance the individuals' self-efficacy, intention, outcome expectations, perceived physical activity benefits and mood status, and should stimulate positive social and environmental influences. Further, stimulating the formation of goals, plans and action control by increasing self-monitoring and self-regulatory efforts could increase initiation. To maintain physical activity, interventions should focus on the satisfaction with one's accomplishments, enhance self-efficacy to maintain physical activity, mood status and intentions, remove barriers and positively increase environmental influences. Further, stimulating the formation of coping plans should enhance physical activity maintenance among older adults [242]. This demonstrates that the initiation and maintenance of physical activity in older adults entail a range of biopsychosocial mechanisms that require a person-centred approach where each individual’s resources and challenges towards behaviour change are adequately targeted.

In our study, we found that general self-efficacy and the expectation of others’ tangible assistance, measured pre-operatively, predicted better recovery. Magklara *et al.* [246] conducted a systematic review to investigate the role of self-efficacy in functional recovery and well-being outcomes in OA patients undergoing hip or knee replacement surgery. From this review, it appears that self-efficacy measured postoperatively is more consistently associated with recovery outcomes than preoperative self-efficacy. The authors argue that self-efficacy beliefs prior to surgery may reflect less realistic expectations than later beliefs because patients have yet to experience the actual changes that emerge after surgery. They highlight the need for appropriate timing of interventions aimed at improving functional outcomes in patients undergoing joint replacement [246]. Bletterman *et al*. [247] systematically evaluated the predictive value of seven preoperative psychosocial factors up to 12 months after total joint replacement. Their results suggest no overall longitudinal association between preoperative psychosocial factors and perceived or observed patient’s postoperative functional recovery after total joint arthroplasty. However, the high proportion of high-risk studies (22 of 26) confines generalizability.

It appears from the literature that both self-efficacy and social support have an important role in self-management of hip OA, but the predictive role of these constructs on postoperative recovery are inconclusive due to different ways of conceptualizing and measuring self-efficacy and social support and the use of different outcome variables.

8. Practice implications and future research

As already discussed, this study does not provide a complete picture of patients' needs throughout the trajectory of the disease. In a future study, it could be helpful to use the hip OA continuum as a tool to systematically recruit and allocate study participants according to each of the six phases. This may produce deeper understanding of needs that again can be targeted in interventions designed for both patients and HCPs.

The role of social support in clinical encounters between patients with hip OA and HCPs where treatment options are discussed should be further investigated. In the care of patients with hip OA who are planning to undergo surgery, there is much focus on the significance of optimizing physical health status to increase the likelihood of a positive outcome. With this as a context, there is a need for studies that investigate the relationship between GSE and preoperative health status, and the potential association between social support and efficacy expectations. A hypothesis could be that patients reporting good physical health despite having symptomatic OA have high levels of GSE and social support. It is important to understand facilitating factors of successful OA self-management and further investigate how these factors can be enhanced for individual patients with different outsets. There is a lack of studies investigating the potential negative effects of social support. Patients may put too much trust in others' experiences or opinions that are potentially harming or impairing health promoting behaviour and decision-making.

The DAfactory methodology used in this study to explore patient-related barriers towards SDM in particular settings is promising, but also difficult to standardize and validate. The findings produced by direct observation are highly dependent on the observer (i.e. theoretical knowledge, familiarity of the clinical setting and listening skills), and the qualitative analysis of audio-recordings is comprehensive. A future and more thorough study could involve two present observers and subsequent interviews with both patients and HCPs to increase validity and transferability of the results.

8.1 Implementation of the PDA into the hip OA continuum

An important and practice-oriented part of this PhD has been to develop a web-based PDA. As previously described, this work forms a parallel process within this PhD project. As a whole and seen in light of the current evidence described in this thesis, this study confirms that patients with hip OA are in great need of accessible and tailored information. This proves that a PDA is required with the potential to help patients, their families and HCPs at the different decision-making points throughout the disease continuum. Each of the three papers has contributed with important knowledge about the specific needs of patients with hip OA and has informed the different phases of the development process. Findings from paper 1 provide condensed key questions representing the main concerns of the patients at the respective phases along the hip OA continuum. Thus, it was possible to address these questions through relevant information in a PDA. For example, the question “Something is wrong, what is this hip pain?” demonstrates that patients with undiagnosed hip OA need information about the disease and how to receive a diagnosis. The question “My hip really bothers me, what can I do?” reflects a need for further knowledge about the benefits and harms associated with treatment options and support with choosing appropriate self-management strategies aligned with own preferences and life-situation.

Paper 2 shows that general self-efficacy and the expectation of others’ tangible assistance influence short time recovery after THR. As seen from a biopsychosocial perspective, these findings aligns with the overall evidence that social and psychological factors are important to address when planning and implementing interventions aimed to motivate patients with hip OA to become actively engaged in their own health situation. A PDA is no psychological intervention in itself, but it can stimulate patients to reflect upon and to identify matters that are important to them. This can be done in a safe environment, at home together with significant others, while the PDA provides a source of high quality information. Potential users of PDAs are encouraged to involve significant others in the treatment decision-making process and a central goal is to increase the patients’ perceived self-efficacy in treatment decision-making.

Paper 3 relates to this goal and provides knowledge about factors that influence hip OA patients’ capacity and opportunities to engage actively in SDM. Referring to the constructs of TPB, perceived behaviour control has great impact on intentions to perform behaviours, such as engaging in SDM. Evidence also suggest that social norm is a strong predictor of SDM behaviour. As described earlier, based on the TPB, we were able to analyse and present the barriers and facilitators towards SDM behaviour according to the three constructs. These findings were used to inform the development of video-based patient narratives that are presented in the PDA as means to stimulate reflection and awareness of patients' own role in the decision-making process.

We believe that better prepared and well-informed patients lead to better decisions, but we acknowledge that providing access to a web-based PDA is not enough to achieve this goal. It remains substantial work to implement the PDA in clinical practice. The PDA has no value if it is not used. A systematic and user-focused implementation process within the hip OA continuum would increase the likelihood that the PDA actually improves the decision-making process, where the users are actively participating at every step. Figure 14 illustrates a possible scenario, where the PDA is implemented in both primary and specialist care services. During the early phases of OA, patients are typically followed by their GP and physiotherapist. This period can last for months and years, and a fully functioning PDA could support the multiple decision-making processes involved. When patients with more severe hip OA are referred to an orthopaedic surgeon to consider surgery, the PDA should be a familiar tool for the patients, and it would help them to prepare better for the upcoming consultation and thus empowering them for active participation in treatment decision-making. An action research project, using a participatory design would enable a systematic and research-based implementation process [248, 249]. This would also provide valuable input in the ongoing process of updating and improving the PDA.

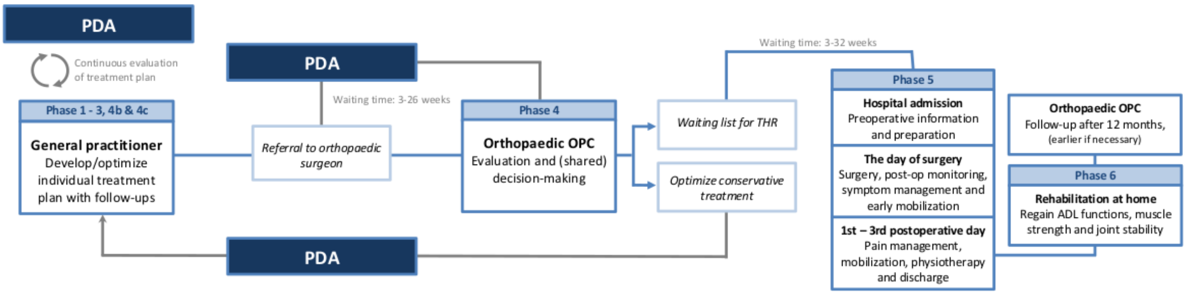


Figure 14: Implementing Mine Behandlingsvalg into the hip OA continuum

Full-scale implementation of SDM in the particular setting of orthopedic decision-making requires that communication skills training is made available for the involved orthopedic surgeons preforming the outpatient consultations. The findings in this study suggest that there is a mix of different and overlapping diagnostic and decision-making relevant elements happening in the orthopedic outpatient consultations. As part of an SDM communication skills training program, orthopedic surgeons could be made aware of this and stimulated to reflect about its possible consequences for the overall decision-making process. Figure 15 illustrates an alternative model for the orthopedic outpatient consultations, which separates the diagnostic decision-making process and the treatment decision-making process. In this model, the orthopedic surgeon starts the consultations with performing all necessary medical assessments with regards to determining a correct diagnosis. After history taking, symptom assessment and physical examination, a systematic treatment decision-making process based on SDM principles may proceed. The three phases shown in the figure is informed by the three steps described in the three-talk model [250].

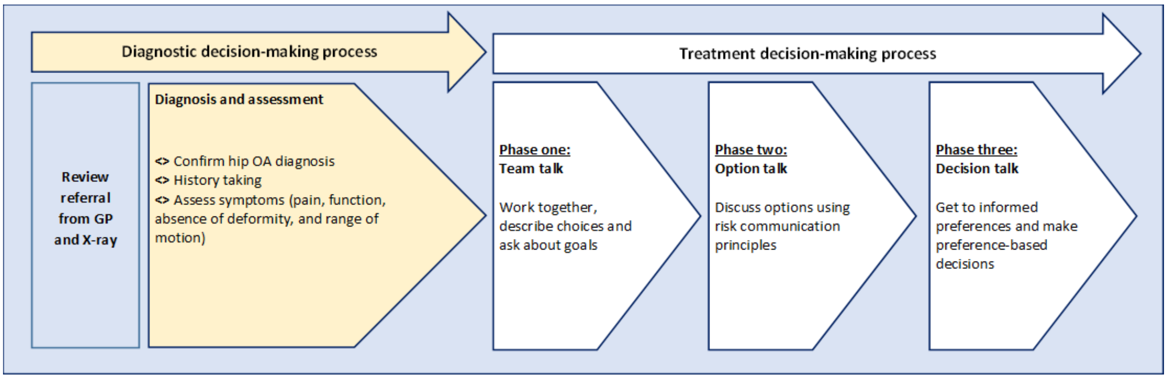


Figure 15: Proposed consultation model illustrating two separate decision-making processes.

9. Conclusions

This PhD project has provided important knowledge that elucidates different perspectives related to the needs of patients living with hip OA. Our findings support a general impression that many patients with hip OA do not receive the high quality and tailored information that is needed in order to know, choose and adhere to appropriate treatment strategies. The constant struggle to cope with troublesome symptoms seems a lonesome experience which evidently leads to insecurity, distress and decreased QoL. Patients need provision of resources to build up a knowledge base about the chronic nature of hip OA and to learn how the manifestation of symptoms affects daily life at the individual level. In this process, they need continuous and clear guidance from HCPs to adapt evidence-based self-management strategies. Many elderly patients have additional health problems, and hip OA should be appropriately prioritized within a holistic approach to prevention and treatment.

Readily access of social support and development of self-efficacy are psychosocial resources that should be targeted within self-management interventions. If provided early in the disease continuum, this might improve adherence to treatment, but also recovery outcomes after total hip replacement. Our findings showed that self-reported general self-efficacy and reliable alliance measured pre-operatively predicted improved postoperative recovery. The goal of optimized health status at all phases of the disease entails great effort by the individual patient, but also reveals great responsibility for the GP and other HCPs who are responsible for conservative treatment. This means that passivity must be replaced with active, timely right and individually tailored approaches.

Undergoing total hip replacement is a major decision to make. Our findings seem to indicate that patients are introduced to the surgical decision-making process too late in the disease trajectory. This may lead to unrealistic expectations about outcomes, but also influence their capacity to be involved in treatment decision-making. Patients face challenging tasks when expected to bring forward own concerns, values and preferences during busy outpatient consultations. This psychological skill of behavioral control towards SDM behaviour is something that could be strengthened through systematic implementation of a PDA. This can help patients understand and appreciate the importance of their contribution into the decision-making process. The hip osteoarthritis continuum should be known as a person centered care pathway where patients are well informed, supported and actively invited to participate in all treatment decisions.

References

1. Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A: Improving chronic illness care: translating evidence into action. *Health Aff (Millwood)* 2001, 20(6):64-78.

2. Grotle M, Hagen KB, Natvig B, Dahl FA, Kvien TK: Prevalence and burden of osteoarthritis: results from a population survey in Norway. *J Rheumatol* 2008, 35(4):677-684.

3. Mann C, Gooberman-Hill R: Health care provision for osteoarthritis: concordance between what patients would like and what health professionals think they should have. *Arthritis Care Res* 2011, 63(7):963-972. doi:10.1002/acr.20459

4. Papandony MC, Chou L, Seneviwickrama M, Cicuttini FM, Lasserre K, Teichtahl AJ, Wang Y, Briggs AM, Wluka AE: Patients' perceived health service needs for osteoarthritis (OA) care: a scoping systematic review. *Osteoarthritis Cartilage* 2017, 25(7):1010-1025. doi:https://doi.org/10.1016/j.joca.2017.02.799

5. Paskins Z, Sanders T, Hassell AB: Comparison of patient experiences of the osteoarthritis consultation with GP attitudes and beliefs to OA: a narrative review. *BMC Family Practice* 2014, 15(1). doi:10.1186/1471-2296-15-46

6. Gronhaug G, Hagfors J, Borch I, Osteras N, Hagen KB: Perceived quality of health care services among people with osteoarthritis - results from a nationwide survey. *Patient Prefer Adherence* 2015, 9:1255-1261. doi:10.2147/PPA.S82441

7. Gronhaug G, Osteras N, Hagen KB: Quality of hip and knee osteoarthritis management in primary health care in a Norwegian county: a cross-sectional survey. *BMC Health Serv Res* 2014, 14:598. doi:10.1186/s12913-014-0598-x

8. McPhail SM: Multimorbidity in chronic disease: impact on health care resources and costs. *Risk Manag Healthc Policy* 2016, 9:143-156. doi:10.2147/RMHP.S97248

9. Helse- og omsorgsdepartementet: St.meld. nr. 47 (2008-2009). A new health sector reform. The Coordination Reform. 2009.

10. Riksrevisjonen: Riksrevisjonens undersøkelse av ressursutnyttelse og kvalitet i helsetjenesten etter innføringen av samhandlingsreformen. 2016.

11. Direktoratet for eHelse: Nasjonal e-helsestrategi og mål 2017-2022. 2017.

12. Helse- og omsorgsdepartementet. Nasjonal helse- og sykehusplan (2016-2019). (Meld. St. 11 2015-2016). 2015. https://www.regjeringen.no/no/dokumenter/meld.-st.-11-20152016/id2462047/.

13. Helse- og omsorgsdepartementet: Fremtidens primærhelsetjeneste - nærhet og helhet (Meld. St. 26). 201526(2014-2015).

14. Delbanco T, Berwick DM, Boufford JI, Edgman-Levitan S, Ollenschlager G, Plamping D, Rockefeller RG: Healthcare in a land called PeoplePower: nothing about me without me. *Health Expect* 2001, 4(3):144-150.

15. Department of Health: Equity and excellence : liberating the NHS. London: The Stationery Office; 2010.

16. Dow B, Haralambous B, Bremner F, Fearn M: What is person-centred health care? A literature review. In: *Report to the Department of Human Services (Victoria).* Melbourne: National Aging Reserach Institute; 2006.

17. Lane L: Client-Centred Practice: Is it Compatible with Early Discharge Hospital-at-Home Policies? *The British Journal of Occupational Therapy* 2000, 63(7):310-315. doi:10.1177/030802260006300703

18. Beach MC, Saha S, Cooper LA: The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality. In.: The Commonwealth Fund, October 2006; 2006.

19. Mead N, Bower P: Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000, 51(7):1087-1110. doi:10.1016/S0277-9536(00)00098-8

20. Pasient- og brukerrettighetsloven: Lov om pasient- og brukerrettigheter (pasient- og brukerrettighetsloven). 1999. https://lovdata.no/lov/1999-07-02-63.

21. Charles C, Gafni A, Whelan T: Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997, 44(5):681-692. doi:10.1016/S0277-9536(96)00221-3

22. Stiggelbout AM, Weijden TVd, Wit MPTD, Frosch D, Legare F, Montori VM, Trevena L, Elwyn G: Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012, 344(jan27 1):e256-e256. doi:10.1136/bmj.e256

23. Makoul G, Clayman ML: An integrative model of shared decision making in medical encounters. *Patient education and counseling* 2006, 60(3):301-312. doi:10.1016/j.pec.2005.06.010

24. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, Cording E, Tomson D, Dodd C, Rollnick S *et al*: Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012, 27(10):1361-1367. doi:10.1007/s11606-012-2077-6

25. Thompson AGH: The meaning of patient involvement and participation in health care consultations: A taxonomy. *Soc Sci Med* 2007, 64(6):1297-1310. doi:10.1016/j.socscimed.2006.11.002

26. Entwistle VA, Watt IS: Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling* 2006, 63(3):268-278. doi:10.1016/j.pec.2006.05.002

27. Entwistle V: Patient involvement in decision-making: The importance of a broad conceptualization. In: *Shared decision-making in health care: Achieving evidence-based patient choice.* edn. Edited by Edwards A, Elwyn G. Oxford: Oxford University Press; 2009: 17-22.

28. WHO. Health Systems Strengthening. Glossary. 2019. https://www.who.int/healthsystems/hss_glossary/en/index5.html Accessed 2501 2019.

29. Birtwhistle R, Morkem R, Peat G, Williamson T, Green ME, Khan S, Jordan KP: Prevalence and management of osteoarthritis in primary care: an epidemiologic cohort study from the Canadian Primary Care Sentinel Surveillance Network. *CMAJ Open* 2015, 3(3):E270-275. doi:10.9778/cmajo.20150018

30. Louati K, Vidal C, Berenbaum F, Sellam J: Association between diabetes mellitus and osteoarthritis: systematic literature review and meta-analysis. *RMD Open* 2015, 1(1):e000077. doi:10.1136/rmdopen-2015-000077

31. Murphy NJ, Eyles JP, Hunter DJ: Hip Osteoarthritis: Etiopathogenesis and Implications for Management. *Adv Ther* 2016. doi:10.1007/s12325-016-0409-3

32. Dieppe P, Doherty M: Contextualizing Osteoarthritis Care and the Reasons for the Gap Between Evidence and Practice. *Clinics in Geriatric Medicine* 2010, 26(3):419-431. doi:10.1016/j.cger.2010.03.004

33. Thorstensson CA, Gooberman-Hill R, Adamson J, Williams S, Dieppe P: Help-seeking behaviour among people living with chronic hip or knee pain in the community. *BMC Musculoskelet Disord* 2009, 10(1). doi:10.1186/1471-2474-10-153

34. Osteras N, Garratt A, Grotle M, Natvig B, Kjeken I, Kvien TK, Hagen KB: Patient-reported quality of care for osteoarthritis: development and testing of the osteoarthritis quality indicator questionnaire. *Arthritis Care Res (Hoboken)* 2013, 65(7):1043-1051. doi:10.1002/acr.21976

35. Hagen KB, Smedslund G, Osteras N, Jamtvedt G: Quality of Community-Based Osteoarthritis Care: A Systematic Review and Meta-Analysis. *Arthritis Care Res (Hoboken)* 2016, 68(10):1443-1452. doi:10.1002/acr.22891

36. Chou L, Ellis L, Papandony M, Seneviwickrama K, Cicuttini FM, Sullivan K, Teichtahl AJ, Wang Y, Briggs AM, Wluka AE: Patients' perceived needs of osteoarthritis health information: A systematic scoping review. *PLoS One* 2018, 13(4):e0195489. doi:10.1371/journal.pone.0195489

37. Stubbs B, Aluko Y, Myint PK, Smith TO: Prevalence of depressive symptoms and anxiety in osteoarthritis: a systematic review and meta-analysis. *Age Ageing* 2016, 45(2):228-235. doi:10.1093/ageing/afw001

38. Sharma A, Kudesia P, Shi Q, Gandhi R: Anxiety and depression in patients with osteoarthritis: impact and management challenges. *Open Access Rheumatol* 2016, 8:103-113. doi:10.2147/OARRR.S93516

39. Zhang L, Fu T, Zhang Q, Yin R, Zhu L, He Y, Fu W, Shen B: Effects of psychological interventions for patients with osteoarthritis: a systematic review and meta-analysis. *Psychol Health Med* 2018, 23(1):1-17. doi:10.1080/13548506.2017.1282160

40. Woolf A, Pfleger B: Burden of major musculoskeletal conditions. *Bull World Health Organ* 2003, 81(9):646 - 656.

41. Hiligsmann M, Cooper C, Arden N, Boers M, Branco JC, Luisa Brandi M, Bruyere O, Guillemin F, Hochberg MC, Hunter DJ *et al*: Health economics in the field of osteoarthritis: an expert's consensus paper from the European Society for Clinical and Economic Aspects of Osteoporosis and Osteoarthritis (ESCEO). *Semin Arthritis Rheum* 2013, 43(3):303-313. doi:10.1016/j.semarthrit.2013.07.003

42. Hiligsmann M, Reginster JY: The economic weight of osteoarthritis in Europe. *Medicographia* 2013, 35:197-202.

43. Arden N, Blanco F, Cooper C, Guermazi A, Hayashi D, Hunter D, Javaid MK, Rannou F, Roemer F, Reginster J-Y: Atlas of Osteoarthritis. Tarporley: Springer Healthcare Ltd.: Tarporley; 2014.

44. Lane NE, Brandt K, Hawker G, Peeva E, Schreyer E, Tsuji W, Hochberg MC: OARSI-FDA initiative: defining the disease state of osteoarthritis. *Osteoarthritis Cartilage* 2011, 19(5):478-482. doi:10.1016/j.joca.2010.09.013

45. Kellgren JH, Lawrence JS: Radiological assessment of osteo-arthrosis. *Ann Rheum Dis* 1957, 16(4):494-502.

46. Dowell S, Hochberg MC: Definition, classification and risk factors. In: *Addressing Unmet Needs in Osteoarthritis.* edn.: Future Medicine Ltd; 2013: 6-19.

47. Altman R, Alarcon G, Appelrouth D, Bloch D, Borenstein D, Brandt K, Brown C, Cooke TD, Daniel W, Feldman D *et al*: The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hip. *Arthritis Rheum* 1991, 34(5):505-514.

48. Aresti N, Kassam J, Nicholas N, Achan P: Hip osteoarthritis. *BMJ* 2016, 354:i3405. doi:10.1136/bmj.i3405

49. Hunter DJ, McDougall JJ, Keefe FJ: The symptoms of osteoarthritis and the genesis of pain. *Rheum Dis Clin North Am* 2008, 34(3):623-643. doi:10.1016/j.rdc.2008.05.004

50. Nilsdotter A, Bremander A: Measures of hip function and symptoms: Harris Hip Score (HHS), Hip Disability and Osteoarthritis Outcome Score (HOOS), Oxford Hip Score (OHS), Lequesne Index of Severity for Osteoarthritis of the Hip (LISOH), and American Academy of Orthopedic Surgeons (AAOS) Hip and Knee Questionnaire. *Arthritis Care Res* 2011, 63 Suppl 11:S200-207. doi:10.1002/acr.20549

51. WHO. Health topics: Risk factors. 2017. http://www.who.int/topics/risk_factors/en/ Accessed 07.08 2019.

52. Felson DT, Lawrence RC, Dieppe PA, Hirsch R, Helmick CG, Jordan JM, Kington RS, Lane NE, Nevitt MC, Zhang Y *et al*: Osteoarthritis: new insights. Part 1: the disease and its risk factors. *Annals of Internal Medicine* 2000, 133(8):635-646.

53. Loeser RF: Aging and osteoarthritis: the role of chondrocyte senescence and aging changes in the cartilage matrix. *Osteoarthritis Cartilage* 2009, 17(8):971-979. doi:10.1016/j.joca.2009.03.002

54. Felson DT, Hodgson R: Identifying and treating preclinical and early osteoarthritis. *Rheum Dis Clin North Am* 2014, 40(4):699-710. doi:10.1016/j.rdc.2014.07.012

55. Srikanth VK, Fryer JL, Zhai G, Winzenberg TM, Hosmer D, Jones G: A meta-analysis of sex differences prevalence, incidence and severity of osteoarthritis. *Osteoarthritis Cartilage* 2005, 13(9):769-781. doi:https://doi.org/10.1016/j.joca.2005.04.014

56. Jiang L, Rong J, Wang Y, Hu F, Bao C, Li X, Zhao Y: The relationship between body mass index and hip osteoarthritis: a systematic review and meta-analysis. *Joint Bone Spine* 2011, 78(2):150-155. doi:10.1016/j.jbspin.2010.04.011

57. Spector TD, MacGregor AJ: Risk factors for osteoarthritis: genetics *Osteoarthritis Cartilage* 2004, 12:39-44. doi:10.1016/j.joca.2003.09.005

58. Neogi T, Zhang Y: Epidemiology of Osteoarthritis. *Rheumatic Disease Clinics of North America* 2013, 39(1):1-19. doi:http://dx.doi.org/10.1016/j.rdc.2012.10.004

59. Fransen M, Agaliotis M, Bridgett L, Mackey MG: Hip and knee pain: Role of occupational factors. *Best Practice & Research Clinical Rheumatology* 2011, 25(1):81-101. doi:https://doi.org/10.1016/j.berh.2011.01.012

60. Kidd B: Mechanisms of Pain in Osteoarthritis. *HSS J* 2012, 8(1):26-28. doi:10.1007/s11420-011-9263-7

61. Gwilym SE, Pollard TCB, Carr AJ: Understanding pain in osteoarthritis. *Bone & Joint Journal* 2008, 90-B(3):280-287. doi:10.1302/0301-620x.90b3.20167

62. Hawker GA, Stewart L, French MR, Cibere J, Jordan JM, March L, Suarez-Almazor M, Gooberman-Hill R: Understanding the pain experience in hip and knee osteoarthritis – an OARSI/OMERACT initiative. *Osteoarthritis Cartilage* 2008, 16(4):415-422. doi:10.1016/j.joca.2007.12.017

63. Poulsen E, Hartvigsen J, Overgaard S, Christensen HW, Vestergaard JT: Pain distribution in primary care patients with hip osteoarthritis. *Fam Pract* 2016, 33(6):601-606. doi:10.1093/fampra/cmw071

64. Woolhead G, Gooberman-Hill R, Dieppe P, Hawker G: Night pain in hip and knee osteoarthritis: A focus group study. *Arthritis Care Res* 2010, 62(7):944-949. doi:10.1002/acr.20164

65. Gignac MAM, Davis AM, Hawker G, Wright JG, Mahomed N, Fortin PR, Badley EM: "What do you expect? You're just getting older": A comparison of perceived

osteoarthritis-related and aging-related health experiences in middle- and older-age adults. *Arthritis Rheum* 2006, 55(6):905-912. doi:10.1002/art.22338

66. NICE. Osteoarthritis: Care and management in adults. Clinical guideline [CG177]. 2014. https://www.nice.org.uk/guidance/cg177 Accessed 15.May 2018.

67. Zhang W, Moskowitz RW, Nuki G, Abramson S, Altman RD, Arden N, Bierma-Zeinstra S, Brandt KD, Croft P, Doherty M *et al*: OARSI recommendations for the management of hip and knee osteoarthritis, Part II: OARSI evidence-based, expert consensus guidelines. *Osteoarthritis Cartilage* 2008, 16(2):137-162. doi:10.1016/j.joca.2007.12.013

68. Stoffer MA, Smolen JS, Woolf A, Ambrozic A, Berghea F, Boonen A, Bosworth A, Carmona L, Dougados M, de Wit M *et al*: Development of patient-centred standards of care for osteoarthritis in Europe: the eumusc.net-project. *Ann Rheum Dis* 2014. doi:10.1136/annrheumdis-2014-206176

69. Fernandes L, Hagen KB, Bijlsma JWJ, Andreassen O, Christensen P, Conaghan PG, Doherty M, Geenen R, Hammond A, Kjeken I *et al*: EULAR recommendations for the non-pharmacological core management of hip and knee osteoarthritis. *Ann Rheum Dis* 2013, 72(7):1125-1135. doi:10.1136/annrheumdis-2012-202745

70. Fransen M, McConnell S, Hernandez-Molina G, Reichenbach S: Exercise for osteoarthritis of the hip. *Cochrane Database Syst Rev* 2014(4):CD007912. doi:10.1002/14651858.CD007912.pub2

71. Fransen M, McConnell S, Harmer AR, Van der Esch M, Simic M, Bennell KL: Exercise for osteoarthritis of the knee. *Cochrane Database Syst Rev* 2015, 1:CD004376. doi:10.1002/14651858.CD004376.pub3

72. Zhang W, Moskowitz RW, Nuki G, Abramson S, Altman RD, Arden N, Bierma-Zeinstra S, Brandt KD, Croft P, Doherty M *et al*: OARSI recommendations for the management of hip and knee osteoarthritis, part I: critical appraisal of existing treatment guidelines and systematic review of current research evidence. *Osteoarthritis Cartilage* 2007, 15(9):981-1000. doi:10.1016/j.joca.2007.06.014

73. Machado GC, Maher CG, Ferreira PH, Pinheiro MB, Lin CW, Day RO, McLachlan AJ, Ferreira ML: Efficacy and safety of paracetamol for spinal pain and osteoarthritis: systematic review and meta-analysis of randomised placebo controlled trials. *BMJ* 2015, 350:h1225. doi:10.1136/bmj.h1225

74. da Costa BR, Reichenbach S, Keller N, Nartey L, Wandel S, Jüni P, Trelle S: Effectiveness of non-steroidal anti-inflammatory drugs for the treatment of pain in knee and hip osteoarthritis: a network meta-analysis. *Lancet* 2016. doi:10.1016/S0140-6736(16)30002-2

75. da Costa BR, Nuesch E, Kasteler R, Husni E, Welch V, Rutjes AW, Juni P: Oral or transdermal opioids for osteoarthritis of the knee or hip. *Cochrane Database Syst Rev* 2014, 9:CD003115. doi:10.1002/14651858.CD003115.pub4

76. Chang RW, Pellissier JM, Hazen GB: A cost-effectiveness analysis of total hip arthroplasty for osteoarthritis of the hip. *JAMA* 1996, 275(11):858-865. doi:10.1001/jama.1996.03530350040032

77. Jevotovsky DS, Alfonso AR, Einhorn TA, Chiu ES: Osteoarthritis and stem cell therapy in humans: a systematic review. *Osteoarthritis Cartilage* 2018, 26(6):711-729. doi:10.1016/j.joca.2018.02.906

78. Roos EM, Juhl CB: Osteoarthritis 2012 year in review: rehabilitation and outcomes. *Osteoarthritis Cartilage* 2012, 20(12):1477-1483. doi:https://doi.org/10.1016/j.joca.2012.08.028

79. Helsedirektoratet. Prioriteringsveileder - ortopedi. Hofteleddsartrose. 2015. https://helsedirektoratet.no/retningslinjer/ortopedi/seksjon?Tittel=hofteartrose-9584.

80. Clark JP, Hudak PL, Hawker GA, Coyte PC, Mahomed NN, Kreder HJ, Wright JG: The moving target: a qualitative study of elderly patients' decision-making regarding total joint replacement surgery. *J Bone Joint Surg Am* 2004, 86-A(7):1366-1374.

81. Dosanjh S, Matta JM, Bhandari M: The final straw: a qualitative study to explore patient decisions to undergo total hip arthroplasty. *Arch Orthop Trauma Surg* 2009, 129(6):719-727. doi:10.1007/s00402-008-0671-1

82. Slover J, Shue J, Koenig K: Shared Decision-making in Orthopaedic Surgery. *Clin Orthop Relat Res* 2012, 470(4):1046-1053. doi:10.1007/s11999-011-2156-8

83. Macario A, Schilling P, Rubio R, Bhalla A, Goodman S: What questions do patients undergoing lower extremity joint replacement surgery have? *BMC Health Serv Res* 2003, 3(1):11. doi:10.1186/1472-6963-3-11

84. Hudak PL, Armstrong K, Braddock C, Frankel RM, Levinson W: Older Patients' Unexpressed Concerns About Orthopaedic Surgery. *J Bone Joint Surg Am* 2008, 90(7):1427-1435. doi:10.2106/JBJS.G.01077

85. Webster F, Perruccio AV, Jenkinson R, Jaglal S, Schemitsch E, Waddell JP, Bremner S, Mobilio MH, Venkataramanan V, Davis AM: Where is the patient in models of patient-centred care: a grounded theory study of total joint replacement patients. *BMC Health Services Research* 2013, 13(1). doi:10.1186/1472-6963-13-531

86. Morgan S, Yoder LH: A Concept Analysis of Person-Centered Care. *Journal of Holistic Nursing* 2012, 30(1):6-15. doi:10.1177/0898010111412189

87. Bandura A: Self-efficacy: Toward a unifying theory of behavioral change. *Psychological Review* 1977, 84(2):191-215. doi:10.1037/0033-295X.84.2.191

88. Edwards RR, Dworkin RH, Sullivan MD, Turk DC, Wasan AD: The Role of Psychosocial Processes in the Development and Maintenance of Chronic Pain. *J Pain* 2016, 17(9 Suppl):T70-92. doi:10.1016/j.jpain.2016.01.001

89. Jerusalem M, Schwarzer R: Self-efficacy as a resource factor in stress appraisal processes. In: *Self-efficacy: thought control of action.* edn. Edited by Schwarzer R. Washington: Hemisphere Publishing Corporation; 1992: 195-213.

90. Schulz S, Brenk-Franz K, Kratz A, Petersen JJ, Riedel-Heller SG, Schafer I, Weyerer S, Wiese B, Fuchs A, Maier W *et al*: Self-efficacy in multimorbid elderly patients with osteoarthritis in primary care--influence on pain-related disability. *Clin Rheumatol* 2015, 34(10):1761-1767. doi:10.1007/s10067-014-2766-0

91. Lazarus RS, Folkman S: Stress, appraisal, and coping. New York: Springer; 1984.

92. Holt-Lunstad J, Smith TB, Layton JB: Social relationships and mortality risk: a meta-analytic review. *PLoS Med* 2010, 7(7):e1000316. doi:10.1371/journal.pmed.1000316

93. Dean A, Lin N: The stress-buffering role of social support. Problems and prospects for systematic investigation. *J Nerv Ment Dis* 1977, 165(6):403-417.

94. Norris FH, Murrell SA: Protective Function of Resources Related to Life Events, Global Stress, and Depression in Older Adults. *J Health Soc Behav* 1984, 25(4):424-437. doi:10.2307/2136380

95. Cohen S, Wills TA: Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985, 98(2):310-357.

96. Holt-Lunstad J, Uchino BN: Social support and health. In: *Health behavior: Theory, research, and practice, 5th ed.* edn. San Francisco, CA, US: Jossey-Bass; 2015: 183-204.

97. Cutrona CE, Russell DW: Type of social support and specific stress: Toward a theory of optimal matching. In: *Social support: An interactional view.* edn. Oxford, England: John Wiley & Sons; 1990: 319-366.

98. Penninx BWJH, Van Tilburg T, Deeg DJH, Kriegsman DMW, Boeke AJP, Van Eijk JTM: Direct and buffer effects of social support and personal coping resources in individuals with arthritis. *Soc Sci Med* 1997, 44(3):393-402. doi:10.1016/S0277-9536(96)00156-6

99. Neogi T: The epidemiology and impact of pain in osteoarthritis. *Osteoarthritis Cartilage* 2013, 21(9):1145-1153. doi:http://dx.doi.org/10.1016/j.joca.2013.03.018

100. IASP. IASP taxonomy: Pain. 220512 2012. https://www.iasp-pain.org/Taxonomy?navItemNumber=576#Pain Accessed 0506 2017.

101. Engel GL: The need for a new medical model: a challenge for biomedicine. *Science* 1977, 196(4286):129-136.

102. Vranceanu AM, Barsky A, Ring D: Psychosocial aspects of disabling musculoskeletal pain. *J Bone Joint Surg Am* 2009, 91(8):2014-2018. doi:10.2106/JBJS.H.01512

103. Keefe FJ, Smith SJ, Buffington AL, Gibson J, Studts JL, Caldwell DS: Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. *J Consult Clin Psychol* 2002, 70(3):640-655.

104. Keefe FJ, Kashikar-Zuck S, Opiteck J, Hage E, Dalrymple L, Blumenthal JA: Pain in Arthritis and Musculoskeletal Disorders: The Role of Coping Skills Training and Exercise Interventions. *J Orthop Sports Phys Ther* 1996, 24(4):279-290. doi:10.2519/jospt.1996.24.4.279

105. Keefe FJ, Bonk V: PSYCHOSOCIAL ASSESSMENT OF PAIN IN PATIENTS HAVING RHEUMATIC DISEASES. *Rheumatic Disease Clinics of North America* 1999, 25(1):81-103. doi:http://dx.doi.org/10.1016/S0889-857X(05)70056-9

106. World Health O: International classification of functioning, disability and health : ICF. In. Geneva: World Health Organization; 2001.

107. Charles C, Whelan T, Gafni A: What do we mean by partnership in making decisions about treatment?, vol. 319; 1999.

108. Charles C, Gafni A, Whelan T: Decision-making in the physician–patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med* 1999, 49(5):651-661. doi:10.1016/S0277-9536(99)00145-8

109. Edwards A, Elwyn G: Shared decision-making in health care: Achieving evidence-based patient choice. In: *Shared decision-making in health care: Achieving evidence-based patient choice.* 2nd ed edn. Edited by Edwards A, Elwyn G. Oxford: Oxford University Press; 2009.

110. Coulter A, Collins A: Making shared decision-making a reality : no decision about me, without me. London: King's Fund; 2011.

111. Kasper J, Lager AR, Rumpsfeld M, Kienlin S, Smestad KH, Bråthen T, Ankell H, Knutsen T, Kløvtveit R, Gulbrandsen P *et al*: Status report from Norway: Implementation of patient involvement in Norwegian health care. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* 2017, 123–124:75-80. doi:10.1016/j.zefq.2017.05.015

112. Kienlin S, Nytrøen K, Geiger F, Liethmann K, Kasper J: Ready to SDM - Modelling and pretesting a training module in shared decision-making addressing health professionals. In: *The 9th International Shared Decision Making conference: 2017; Lyon, France*; 2017.

113. Schoenfeld EM, Goff SL, Elia TR, Khordipour ER, Poronsky KE, Nault KA, Lindenauer PK, Mazor KM: Physician-identified barriers to and facilitators of shared decision-making in the Emergency Department: an exploratory analysis. *Emerg Med J* 2019. doi:10.1136/emermed-2018-208242

114. Bossen JKJ, van der Weijden T, Driessen EW, Heyligers IC: Experienced barriers in shared decision-making behaviour of orthopaedic surgery residents compared with orthopaedic surgeons. *Musculoskeletal Care* 2019. doi:10.1002/msc.1390

115. Taylor BS, Fornos L, Tarbutton J, Munoz J, Saber JA, Bullock D, Villarreal R, Nijhawan AE: Improving HIV Care Engagement in the South from the Patient and Provider Perspective: The Role of Stigma, Social Support, and Shared Decision-Making. *AIDS Patient Care STDS* 2018, 32(9):368-378. doi:10.1089/apc.2018.0039

116. Giguere AMC, Lawani MA, Fortier-Brochu E, Carmichael PH, Legare F, Kroger E, Witteman HO, Voyer P, Caron D, Rodriguez C: Tailoring and evaluating an intervention to improve shared decision-making among seniors with dementia, their caregivers, and healthcare providers: study protocol for a randomized controlled trial. *Trials* 2018, 19(1):332. doi:10.1186/s13063-018-2697-1

117. Abbasgholizadeh Rahimi S, Lepine J, Croteau J, Robitaille H, Giguere AM, Wilson BJ, Rousseau F, Levesque I, Legare F: Psychosocial Factors of Health Professionals' Intention to Use a Decision Aid for Down Syndrome Screening: Cross-Sectional Quantitative Study. *J Med Internet Res* 2018, 20(4):e114. doi:10.2196/jmir.9036

118. Carvajal DN, Gioia D, Mudafort ER, Brown PB, Barnet B: How can Primary Care Physicians Best Support Contraceptive Decision Making? A Qualitative Study Exploring the Perspectives of Baltimore Latinas. *Womens Health Issues* 2017, 27(2):158-166. doi:10.1016/j.whi.2016.09.015

119. Vaillancourt H, Legare F, Gagnon MP, Lapointe A, Deschenes SM, Desroches S: Exploration of shared decision-making processes among dieticians and patients during a consultation for the nutritional treatment of dyslipidaemia. *Health Expect* 2015, 18(6):2764-2775. doi:10.1111/hex.12250

120. Legare F, Guerrier M, Nadeau C, Rheaume C, Turcotte S, Labrecque M: Impact of DECISION + 2 on patient and physician assessment of shared decision making implementation in the context of antibiotics use for acute respiratory infections. *Implement Sci* 2013, 8:144. doi:10.1186/1748-5908-8-144

121. Krones T, Keller H, Becker A, Sonnichsen A, Baum E, Donner-Banzhoff N: The theory of planned behaviour in a randomized trial of a decision aid on cardiovascular risk prevention. *Patient Educ Couns* 2010, 78(2):169-176. doi:10.1016/j.pec.2009.06.010

122. Kasper J, Kopke S, Fischer K, Schaffler N, Backhus I, Solari A, Heesen C: Applying the theory of planned behaviour to multiple sclerosis patients' decisions on disease modifying therapy--questionnaire concept and validation. *BMC Med Inform Decis Mak* 2012, 12:60. doi:10.1186/1472-6947-12-60

123. Ajzen I: Attitudes, Personality and Behavior, 2nd ed. edn. Maidenhead: McGraw-Hill Education; 2007.

124. Montaño DE, Kasprzyk D: Theory of Reasoned Action, Theory of Planned Behavior, and the Integrated Behavioral Model. In: *Health behavior : theory, research, and practice.* 5th edn. Edited by Glanz K, Rimer BK, Viswanath K. San Francisco: Jossey-Bass; 2015: 95-124.

125. Ajzen I: The theory of planned behavior. *Organ Behav Hum Decis Process* 1991, 50. doi:10.1016/0749-5978(91)90020-t

126. Ajzen I: From Intentions to Actions: A Theory of Planned Behavior. In: *Action Control: From Cognition to Behavior.* edn. Edited by Kuhl J, Beckmann J. Berlin, Heidelberg: Springer Berlin Heidelberg; 1985: 11-39.

127. Bandura A: Self-efficacy mechanism in human agency. *American Psychologist* 1982, 37(2):122-147. doi:10.1037/0003-066X.37.2.122

128. Ajzen I, Timko C: Correspondence Between Health Attitudes and Behavior. *Basic Appl Soc Psych* 1986, 7(4):259-276. doi:10.1207/s15324834basp0704_2

129. Ajzen I, Fishbein M: The Influence of Attitudes on Behavior. In: *The Handbook of attitudes.* edn. Edited by Albarracín D, Johnson BT, Zanna MP. Mahwah, N.J: Lawrence Erlbaum Associates; 2005.

130. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, van der Weijden T: A systematic development process for patient decision aids. *BMC Med Inform Decis Mak* 2013, 13(Suppl 2). doi:10.1186/1472-6947-13-S2-S2

131. Stacey D, Légaré F, Lewis K, Barry MJ, Bennett CL, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thomson R *et al*: Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2017(4). doi:10.1002/14651858.CD001431.pub5

132. UNN. Nasjonalt prosjekt. 2018. https://unn.no/samvalg/nasjonalt-prosjekt Accessed 23.02 2019.

133. International Patient Decision Aids Standards (IPDAS) Collaboration. 2013. http://ipdas.ohri.ca/ Accessed 15. May 2018.

134. Straus SE, Tetroe J, Graham ID: Knowledge translation: What it is and what it isn't. In: *Knowledge translation in health care : moving from evidence to practice.* Edited by Straus SE, Tetroe J, Graham ID, 2nd ed. edn. Chichester, West Sussex: John Wiley & Sons; 2013: 3-13.

135. Graham ID, Logan J, Harrison MB, Straus SE, Tetroe J, Caswell W, Robinson N: Lost in knowledge translation: time for a map? *J Contin Educ Health Prof* 2006, 26(1):13-24. doi:10.1002/chp.47

136. Dalsbø T, Fønhus M, Laurtizen M, Brembo E: Nytteverdien av behandling for hofteartrose: dokumentasjonsgrunnlag for samvalgsverktøy. [Effectiveness of treatment for hip osteoarthritis: evidence base for shared decision making]. 2018.

137. Decision Aid Factory. http://dafactory.helsekompetanse.no/en Accessed 0203 2019.

138. Feldman-Stewart D, Brennenstuhl S, McIssac K, Austoker J, Charvet A, Hewitson P, Sepucha KR, Whelan T: A systematic review of information in decision aids. *Health Expect* 2007, 10(1):46-61. doi:10.1111/j.1369-7625.2006.00420.x

139. Winterbottom A, Bekker HL, Conner M, Mooney A: Does narrative information bias individual's decision making? A systematic review. *Soc Sci Med* 2008, 67(12):2079-2088. doi:10.1016/j.socscimed.2008.09.037

140. Shaffer VA, Zikmund-Fisher BJ: All stories are not alike: a purpose-, content-, and valence-based taxonomy of patient narratives in decision aids. *Med Decis Making* 2013, 33(1):4-13. doi:10.1177/0272989X12463266

141. Ubel PA, Jepson C, Baron J: The inclusion of patient testimonials in decision aids: effects on treatment choices. *Med Decis Making* 2001, 21(1):60-68.

142. Zikmund-Fisher BJ, Windschitl PD, Exe N, Ubel PA: 'I'll do what they did": social norm information and cancer treatment decisions. *Patient Educ Couns* 2011, 85(2):225-229. doi:10.1016/j.pec.2011.01.031

143. Bekker HL, Winterbottom AE, Butow P, Dillard AJ, Feldman-Stewart D, Fowler FJ, Jibaja-Weiss ML, Shaffer VA, Volk RJ: Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Med Inform Decis Mak* 2013, 13(2):S9. doi:10.1186/1472-6947-13-s2-s9

144. Creswell JW: Research design : qualitative, quantitative, and mixed methods approaches, 3rd ed. International student ed. edn. Los Angeles, Calif: SAGE; 2009.

145. Kapstad H: Pain and health status in patients with osteoarthritis of the hip or knee undergoing joint replacement surgery: measurement issues and outcomes. *PhD thesis.* Bergen: University of Bergen; 2010.

146. Kapstad H, Rustøen T, Hanestad BR, Moum T, Langeland N, Stavem K: Changes in pain, stiffness and physical function in patients with osteoarthritis waiting for hip or knee joint replacement surgery. *Osteoarthritis Cartilage* 2007, 15(7):837-843. doi:http://dx.doi.org/10.1016/j.joca.2007.01.015

147. Kapstad H, Hanestad BR, Langeland N, Rustøen T, Stavem K: Cutpoints for mild, moderate and severe pain in patients with osteoarthritis of the hip or knee ready for joint replacement surgery. *BMC Musculoskelet Disord* 2008, 9:55-55. doi:10.1186/1471-2474-9-55

148. Kapstad H, Rokne B, Stavem K: Psychometric properties of the Brief Pain Inventory among patients with osteoarthritis undergoing total hip replacement surgery. *Health Qual Life Outcomes* 2010, 8. doi:10.1186/1477-7525-8-148

149. Braun V, Clarke V: Successful qualitative research : a practical guide for beginners. Los Angeles, Calif.: Sage; 2013.

150. Braun V, Clarke V: Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006, 3(2):77-101. doi:10.1191/1478088706qp063oa

151. Bellamy N: WOMAC Osteoarthritis Index User Guide. Version V. Brisbane, Australia; 2002.

152. Bellamy N, Buchanan W, Goldsmith C, Campbell J, Stitt L: Validation study of WOMAC: a health status instrument for measuring clinically important patient

relevant outcomes to antirheumatic drug therapy in patients with osteoarthritis of the hip or knee. *J Rheumatol* 1988, 15(12):1833-1840.

153. Söderman P, Malchau H: Validity and reliability of Swedish WOMAC osteoarthritis index: a self-administered disease-specific questionnaire (WOMAC) versus generic instruments (SF-36 and NHP). *Acta Orthop Scand* 2000, 71(1):39-46. doi:10.1080/000164700052943874

154. McConnell S, Kolopack P, Davis AM: The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC): a review of its utility and measurement properties. *Arthritis Care Res* 2001, 45(5):453-461. doi:10.1002/1529-0131(200110)45:5<453::AID-ART365>3.0.CO;2-W

155. Stucki G, Sangha O, Stucki S, Michel BA, Tyndall A, Dick W, Theiler R: Comparison of the WOMAC (Western Ontario and McMaster Universities) osteoarthritis index and a self-report format of the self-administered Lequesne-Algofunctional index in patients with knee and hip osteoarthritis. *Osteoarthritis Cartilage* 1998, 6(2):79-86. doi:10.1053/joca.1997.0097

156. Cutrona CE, Russell DW: The provisions of social relationships and adaptation to stress. In: *Advances in personal relationships. Volume 1*, edn. Edited by Jones WH, Perlman D. Greenwich, CT: JAI Press; 1987: 37-67.

157. Weiss RS: The provisions of social relationships. In: *Doing unto others: Joining, molding, conforming, helping, loving.* edn. Edited by Rubin Z. Englewood Cliffs, N.J.: Prentice-Hall; 1974: 17-26.

158. Cutrona C, Russell D, Rose J: Social support and adaptation to stress by the elderly. *Psychol Aging* 1986, 1(1):47-54.

159. Cutrona CE: Objective determinants of perceived social support. *J Pers Soc Psychol* 1986, 50(2):349-355.

160. Schwarzer R, Jerusalem M: Generalized Self-Efficacy Scale. In: *Measures in health psychology: a user´s portfolio Causal and control beliefs.* edn. Edited by Johnston M, Wright SC, Weinman J. Windsor, UK: NFER-NELSON; 1995: 35-37.

161. Scholz U, Doña BG, Sud S, Schwarzer R: Is general self-efficacy a universal construct? Psychometric findings from 25 countries. *Eur J Psychol Assess* 2002, 18(3):242-251. doi:10.1027//1015-5759.18.3.242

162. Røysamb E, Schwarzer R, Jerusalem M. Norwegian version of the general perceived self-efficacy scale. 1998. http://userpage.fu-berlin.de/~health/norway.htm Accessed 12 Oct 2015.

163. Barlow JH, Williams B, Wright C: The generalized self-efficacy scale in people with arthritis. *Arthritis Rheum* 1996, 9(3):189-196. doi:10.1002/1529-0131(199606)9:3<189::AID-ANR1790090307>3.0.CO;2-#

164. Schwarzer R. Everything you wanted to know about the General Self-Efficacy Scale but were afraid to ask. 2014. http://userpage.fu-berlin.de/~health/faq_gse.pdf Accessed 26 May 2016.

165. QSR International: NVivo qualitative data analysis Software, Version 10. In. Melbourne, Australia: QSR International Pty Ltd.; 2012.

166. DeSantis L, Ugarriza DN: The concept of theme as used in qualitative nursing research. *Western journal of nursing research* 2000, 22(3):351-372.

167. IBM Corp: Released 2015. IBM SPSS Statistics for Windows, Version 23.0. In. Armonk, NY: IBM Corp.

168. Crabtree BF, Miller WL: Using Codes and Code Manuals. A Template Organizing Style of Interpration. In: *Doing qualitative research.* edn. Edited by Crabtree BF, Miller WL. Thousand Oaks, California: Sage Publications; 1999: 163-177.

169. Brooks J, McCluskey S, Turley E, King N: The Utility of Template Analysis in Qualitative Psychology Research. *Qual Res Psychol* 2015, 12(2):202-222. doi:10.1080/14780887.2014.955224

170. NVivo qualitative data analysis software: QSR International Pty Ltd. Version 11. In.; 2015.

171. World Medical Association: World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2013, 310(20):2191-2194. doi:10.1001/jama.2013.281053

172. Bryman A: Social research methods, 4th ed. edn. Oxford: Oxford University Press; 2012.

173. Malterud K: Qualitative research: standards, challenges, and guidelines. *Lancet* 2001, 358(9280):483-488. doi:10.1016/S0140-6736(01)05627-6

174. Norwegian Institute of Public Health: Public Health Report: Health Status in Norway 2018. Oslo: Norwegian Institute of Public Health, 2018.

175. Cruz-Almeida Y, Sibille KT, Goodin BR, Petrov ME, Bartley EJ, Riley JL, 3rd, King CD, Glover TL, Sotolongo A, Herbert MS *et al*: Racial and ethnic differences in older adults with knee osteoarthritis. *Arthritis Rheumatol* 2014, 66(7):1800-1810. doi:10.1002/art.38620

176. Mossey JM: Defining racial and ethnic disparities in pain management. *Clin Orthop Relat Res* 2011, 469(7):1859-1870. doi:10.1007/s11999-011-1770-9

177. Stubbs B, Hurley M, Smith T: What are the factors that influence physical activity participation in adults with knee and hip osteoarthritis? A systematic review of physical activity correlates. *Clin Rehabil* 2015, 29(1):80-94. doi:10.1177/0269215514538069

178. Blum MA, Ibrahim SA: Race/Ethnicity and Use of Elective Joint Replacement in the Management of End-Stage Knee/Hip Osteoarthritis: A Review of the Literature. *Clinics in Geriatric Medicine* 2012, 28(3):521-532. doi:https://doi.org/10.1016/j.cger.2012.05.002

179. Morse JM: The Significance of Saturation. *Qualitative Health Research* 1995, 5(2):147-149. doi:10.1177/104973239500500201

180. NRL. The Norwegian Arthroplasty Register, Report 2018. 2018. http://nrlweb.ihelse.net/Rapporter/Rapport2018.pdf Accessed 28 June 2019.

181. Ehrich EW, Davies GM, Watson DJ, Bolognese JA, Seidenberg BC, Bellamy N: Minimal perceptible clinical improvement with the Western Ontario and McMaster Universities osteoarthritis index questionnaire and global assessments in patients with osteoarthritis. *J Rheumatol* 2000, 27(11):2635-2641.

182. Karnieli-Miller O, Strier R, Pessach L: Power relations in qualitative research. *Qual Health Res* 2009, 19(2):279-289. doi:10.1177/1049732308329306

183. van den Akker-Scheek I, Stevens M, Groothoff JW, Bulstra SK, Zijlstra W: Preoperative or postoperative self-efficacy: which is a better predictor of outcome after total hip or knee arthroplasty? *Patient Educ Couns* 2007, 66(1):92-99. doi:10.1016/j.pec.2006.10.012

184. Wylde V, Dixon S, Blom AW: The Role of Preoperative Self-Efficacy in Predicting Outcome after Total Knee Replacement. *Musculoskeletal Care* 2012, 10(2):110-118. doi:10.1002/msc.1008

185. Lopez-Olivo MA, Landon GC, Siff SJ, Edelstein D, Pak C, Kallen MA, Stanley M, Zhang H, Robinson KC, Suarez-Almazor ME: Psychosocial determinants of outcomes in knee replacement. *Ann Rheum Dis* 2011, 70(10):1775-1781. doi:10.1136/ard.2010.146423

186. McHugh GA, Campbell M, Luker KA: Predictors of outcomes of recovery following total hip replacement surgery: A prospective study. *Bone Joint Res* 2013, 2(11):248-254. doi:10.1302/2046-3758.211.2000206

187. Lindner M, Nosseir O, Keller-Pliessnig A, Teigelack P, Teufel M, Tagay S: Psychosocial predictors for outcome after total joint arthroplasty: a prospective comparison of hip and knee arthroplasty. *BMC Musculoskelet Disord* 2018, 19(1):159. doi:10.1186/s12891-018-2058-y

188. Pua YH, Cowan SM, Wrigley TV, Bennell KL: Discriminant validity of the Western Ontario and McMaster Universities Osteoarthritis index physical functioning subscale in community samples with hip osteoarthritis. *Arch Phys Med Rehabil* 2009, 90(10):1772-1777. doi:10.1016/j.apmr.2009.04.011

189. Stratford PW, Kennedy DM: Does parallel item content on WOMAC's pain and function subscales limit its ability to detect change in functional status? *BMC Musculoskelet Disord* 2004, 5:17. doi:10.1186/1471-2474-5-17

190. Hay E, Dziedzic K, Foster N, Peat G, van der Windt D, Bartlam B, Blagojevic-Bucknall M, Edwards J, Healey E, Holden M *et al*: Optimal primary care management of clinical osteoarthritis and joint pain in older people: a mixed-methods programme of systematic reviews, observational and qualitative studies, and randomised controlled trials. Southampton (UK), 2018.

191. Moseng T, Dagfinrud H, Smedslund G, Osteras N: The importance of dose in land-based supervised exercise for people with hip osteoarthritis. A systematic review and meta-analysis. *Osteoarthritis Cartilage* 2017, 25(10):1563-1576. doi:10.1016/j.joca.2017.06.004

192. Pisters MF, Veenhof C, Schellevis FG, Twisk JW, Dekker J, De Bakker DH: Exercise adherence improving long-term patient outcome in patients with osteoarthritis of the hip and/or knee. *Arthritis Care Res (Hoboken)* 2010, 62(8):1087-1094. doi:10.1002/acr.20182

193. Nicolson PJA, Bennell KL, Dobson FL, Van Ginckel A, Holden MA, Hinman RS: Interventions to increase adherence to therapeutic exercise in older adults with low back pain and/or hip/knee osteoarthritis: a systematic review and meta-analysis. *Br J Sports Med* 2017, 51(10):791-799. doi:10.1136/bjsports-2016-096458

194. Campbell R, Evans M, Tucker M, Quilty B, Dieppe P, Donovan JL: Why don't patients do their exercises? Understanding non-compliance with physiotherapy in patients with osteoarthritis of the knee. *Journal of Epidemiology and Community Health* 2001, 55(2):132-138. doi:10.1136/jech.55.2.132

195. Kanavaki AM, Rushton A, Efstathiou N, Alrushud A, Klocke R, Abhishek A, Duda JL: Barriers and facilitators of physical activity in knee and hip osteoarthritis: a systematic review of qualitative evidence. *BMJ Open* 2017, 7(12):e017042. doi:10.1136/bmjopen-2017-017042

196. Bartley EJ, Palit S, Staud R: Predictors of Osteoarthritis Pain: the Importance of Resilience. *Curr Rheumatol Rep* 2017, 19(9):57. doi:10.1007/s11926-017-0683-3

197. Cheraghi-Sohi S, Bower P, Kennedy A, Morden A, Rogers A, Richardson J, Sanders T, Stevenson F, Ong BN: Patient Priorities in Osteoarthritis and Comorbid Conditions: A Secondary Analysis of Qualitative Data. *Arthritis Care Res* 2013, 65(6):920-927. doi:10.1002/acr.21897

198. Bossen D, Veenhof C, Van Beek KEC, Spreeuwenberg PMM, Dekker J, De Bakker DH: Effectiveness of a Web-Based Physical Activity Intervention in Patients With Knee and/or Hip Osteoarthritis: Randomized Controlled Trial. *Journal of Medical Internet Research* 2013, 15(11):e257. doi:10.2196/jmir.2662

199. Bossen D, Veenhof C, Dekker J, de Bakker D: The usability and preliminary effectiveness of a web-based physical activity intervention in patients with knee and/or hip osteoarthritis. *BMC Med Inform Decis Mak* 2013, 13:61-61. doi:10.1186/1472-6947-13-61

200. Bossen D, Buskermolen M, Veenhof C, de Bakker D, Dekker J: Adherence to a Web-Based Physical Activity Intervention for Patients With Knee and/or Hip Osteoarthritis: A Mixed Method Study. *Journal of Medical Internet Research* 2013, 15(10):e223. doi:10.2196/jmir.2742

201. Kloek C, Bossen D, de Bakker DH, Veenhof C, Dekker J: Blended Interventions to Change Behavior in Patients With Chronic Somatic Disorders: Systematic Review. *J Med Internet Res* 2017, 19(12):e418. doi:10.2196/jmir.8108

202. Danbjorg DB, Villadsen A, Gill E, Rothmann MJ, Clemensen J: Usage of an Exercise App in the Care for People With Osteoarthritis: User-Driven Exploratory Study. *JMIR Mhealth Uhealth* 2018, 6(1):e11. doi:10.2196/mhealth.7734

203. van Bruinessen IR, van Weel-Baumgarten EM, Snippe HW, Gouw H, Zijlstra JM, van Dulmen S: Active Patient Participation in the Development of an Online Intervention. *JMIR Research Protocols* 2014, 3(4):e59. doi:10.2196/resprot.3695

204. Hurley M, Dickson K, Hallett R, Grant R, Hauari H, Walsh N, Stansfield C, Oliver S: Exercise interventions and patient beliefs for people with hip, knee or hip and knee osteoarthritis: a mixed methods review. *Cochrane Database Syst Rev* 2018, 4:CD010842. doi:10.1002/14651858.CD010842.pub2

205. Fordyce WE, Shelton JL, Dundore DE: The modification of avoidance learning pain behaviors. *J Behav Med* 1982, 5(4):405-414. doi:10.1007/BF00845370

206. Vlaeyen JWS, Kole-Snijders AMJ, Rotteveel AM, Ruesink R, Heuts PHTG: The role of fear of movement/(re)injury in pain disability. *Journal of Occupational Rehabilitation* 1995, 5(4):235-252. doi:10.1007/BF02109988

207. Vlaeyen JW, Linton SJ: Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. *Pain* 2000, 85(3):317-332.

208. Sjögren Forss K, Stjernberg L, Ekvall Hansson E: Osteoarthritis and fear of physical activity—The effect of patient education. *Cogent Medicine* 2017, 4(1). doi:10.1080/2331205X.2017.1328820

209. Heuts PH, Vlaeyen JW, Roelofs J, de Bie RA, Aretz K, van Weel C, van Schayck OC: Pain-related fear and daily functioning in patients with osteoarthritis. *Pain* 2004, 110(1-2):228-235. doi:10.1016/j.pain.2004.03.035

210. Edwards RR, Bingham CO, 3rd, Bathon J, Haythornthwaite JA: Catastrophizing and pain in arthritis, fibromyalgia, and other rheumatic diseases. *Arthritis Rheum* 2006, 55(2):325-332. doi:10.1002/art.21865

211. Schütze R, Rees C, Smith A, Slater H, Campbell JM, O'Sullivan P: How Can We Best Reduce Pain Catastrophizing in Adults With Chronic Noncancer Pain? A Systematic Review and Meta-Analysis. *The Journal of Pain* 2018, 19(3):233-256. doi:10.1016/j.jpain.2017.09.010

212. Levinson W, Hudak P, Tricco AC: A systematic review of surgeon–patient communication: Strengths and opportunities for improvement. *Patient Education and Counseling* 2013, 93(1):3-17. doi:10.1016/j.pec.2013.03.023

213. Levinson W, Gorawara-Bhat R, Lamb J: A study of patient clues and physician responses in primary care and surgical settings. *JAMA* 2000, 284(8):1021-1027.

214. Levinson W, Chaumeton N: Communication between surgeons and patients in routine office visits. *Surgery* 1999, 125(2):127-134. doi:https://doi.org/10.1016/S0039-6060(99)70255-2

215. Cheraghi-Sohi S, Bower P, Kennedy A, Morden A, Rogers A, Richardson J, Sanders T, Stevenson F, Ong BN: Patient priorities in osteoarthritis and comorbid conditions: a secondary analysis of qualitative data. *Arthritis Care Res (Hoboken)* 2013, 65(6):920-927. doi:10.1002/acr.21897

216. Abelsen B, Gaski M, Brandstorp H: Duration of general practitioner contracts. *Tidsskr Nor Laegeforen* 2015, 135(22):2045-2049. doi:10.4045/tidsskr.15.0003

217. Statistics Norway. Allmennlegetjenesten. 12.06 2018. https://www.ssb.no/helse/statistikker/fastlegetj Accessed 10.03 2019.

218. Scholl I, Zill JM, Härter M, Dirmaier J: An Integrative Model of Patient-Centeredness – A Systematic Review and Concept Analysis. *PLoS ONE* 2014, 9(9). doi:10.1371/journal.pone.0107828

219. Sepucha KR, Atlas SJ, Chang Y, Freiberg A, Malchau H, Mangla M, Rubash H, Simmons LH, Cha T: Informed, Patient-Centered Decisions Associated with Better Health Outcomes in Orthopedics: Prospective Cohort Study. *Med Decis Making* 2018, 38(8):1018-1026. doi:10.1177/0272989X18801308

220. Stiggelbout AM, Pieterse AH, De Haes JC: Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns* 2015, 98(10):1172-1179. doi:10.1016/j.pec.2015.06.022

221. Karnieli-Miller O, Eisikovits Z: Physician as partner or salesman? Shared decision-making in real-time encounters. *Soc Sci Med* 2009, 69(1):1-8. doi:10.1016/j.socscimed.2009.04.030

222. Elwyn G, Edwards A, Kinnersley P, Grol R: Shared decision making and the concept of equipoise: the competences of involving patients in healthcare choices. *The British Journal of General Practice* 2000, 50(460):892-899.

223. Couet N, Desroches S, Robitaille H, Vaillancourt H, Leblanc A, Turcotte S, Elwyn G, Legare F: Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expect* 2015, 18(4):542-561. doi:10.1111/hex.12054

224. Elliott J, McNeil H, Ashbourne J, Huson K, Boscart V, Stolee P: Engaging Older Adults in Health Care Decision-Making: A Realist Synthesis. *The Patient - Patient-Centered Outcomes Research* 2016, 9(5):383-393. doi:10.1007/s40271-016-0168-x

225. Protheroe J, Nutbeam D, Rowlands G: Health literacy: a necessity for increasing participation in health care. *Br J Gen Pract* 2009, 59(567):721-723. doi:10.3399/bjgp09X472584

226. Coulter A: Engaging patients in healthcare. Berkshire, England; New York: Open University Press; 2011.

227. Nutbeam D: Health promotion glossary. *Health Promot Int* 1998, 13(4):349-364. doi:10.1093/heapro/13.4.349

228. Sorensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, Brand H, Consortium Health Literacy Project E: Health literacy and public health: a systematic review and integration of definitions and models. *BMC Public Health* 2012, 12:80. doi:10.1186/1471-2458-12-80

229. Edwards M, Wood F, Davies M, Edwards A: The development of health literacy in patients with a long-term health condition: the health literacy pathway model. *BMC Public Health* 2012, 12. doi:10.1186/1471-2458-12-130

230. McCaffery KJ, Holmes-Rovner M, Smith SK, Rovner D, Nutbeam D, Clayman ML, Kelly-Blake K, Wolf MS, Sheridan SL: Addressing health literacy in patient decision aids. *BMC Med Inform Decis Mak* 2013, 13 Suppl 2:S10. doi:10.1186/1472-6947-13-S2-S10

231. Gulbrandsen P, Clayman ML, Beach MC, Han PK, Boss EF, Ofstad EH, Elwyn G: Shared decision-making as an existential journey: Aiming for restored autonomous capacity. *Patient Education and Counseling* 2016, 99(9):1505-1510. doi:https://doi.org/10.1016/j.pec.2016.07.014

232. Montori VM, Gafni A, Charles C: A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expect* 2006, 9(1):25-36. doi:10.1111/j.1369-7625.2006.00359.x

233. Frosch DL, May SG, Rendle KA, Tietbohl C, Elwyn G: Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making. *Health Aff (Millwood)* 2012, 31(5):1030-1038. doi:10.1377/hlthaff.2011.0576

234. Joseph-Williams N, Elwyn G, Edwards A: Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling* 2014, 94(3):291-309. doi:10.1016/j.pec.2013.10.031

235. Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R: Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling* 2007, 68(1):33-42. doi:https://doi.org/10.1016/j.pec.2007.03.025

236. Nilsdotter AK, Petersson IF, Roos EM, Lohmander LS: Predictors of patient relevant outcome after total hip replacement for osteoarthritis: a prospective study. *Ann Rheum Dis* 2003, 62(10):923-930. doi:10.1136/ard.62.10.923

237. Fortin PR, Clarke AE, Joseph L, Liang MH, Tanzer M, Ferland D, Phillips C, Partridge AJ, Bélisle P, Fossel AH *et al*: Outcomes of total hip and knee replacement: preoperative functional status predicts outcomes at six months after surgery. *Arthritis Rheum* 1999, 42(8):1722-1728. doi:10.1002/1529-0131(199908)42:8<1722::AID-ANR22>3.0.CO;2-R

238. Fortin PR, Penrod JR, Clarke AE, St Pierre Y, Joseph L, Belisle P, Liang MH, Ferland D, Phillips CB, Mahomed N *et al*: Timing of total joint replacement affects

clinical outcomes among patients with osteoarthritis of the hip or knee. *Arthritis Rheum* 2002, 46. doi:10.1002/art.10631

239. Montin L, Leino-Kilpi H, Suominen T, Lepisto J: A systematic review of empirical studies between 1966 and 2005 of patient outcomes of total hip arthroplasty and related factors. *J Clin Nurs* 2008, 17(1):40-45. doi:10.1111/j.1365-2702.2007.01944.x

240. Hofstede SN, Gademan MGJ, Vliet Vlieland TPM, Nelissen RGHH, Marang-van de Mheen PJ: Preoperative predictors for outcomes after total hip replacement in patients with osteoarthritis: a systematic review. *BMC Musculoskelet Disord* 2016, 17(1):1-11. doi:10.1186/s12891-016-1070-3

241. Moyer R, Ikert K, Long K, Marsh J: The Value of Preoperative Exercise and Education for Patients Undergoing Total Hip and Knee Arthroplasty: A Systematic Review and Meta-Analysis. *JBJS Rev* 2017, 5(12):e2. doi:10.2106/JBJS.RVW.17.00015

242. van Stralen MM, De Vries H, Mudde AN, Bolman C, Lechner L: Determinants of initiation and maintenance of physical activity among older adults: a literature review. *Health Psychol Rev* 2009, 3(2):147-207. doi:10.1080/17437190903229462

243. Warner LM, Ziegelmann JP, Schuz B, Wurm S, Schwarzer R: Synergistic effect of social support and self-efficacy on physical exercise in older adults. *J Aging Phys Act* 2011, 19(3):249-261.

244. de Vries H, Kremers SP, Smeets T, Brug J, Eijmael K: The effectiveness of tailored feedback and action plans in an intervention addressing multiple health behaviors. *Am J Health Promot* 2008, 22(6):417-425. doi:10.4278/ajhp.22.6.417

245. de Vries H, Mudde A, Leijs I, Charlton A, Vartiainen E, Buijs G, Clemente MP, Storm H, Gonzalez Navarro A, Nebot M *et al*: The European Smoking Prevention Framework Approach (EFSA): an example of integral prevention. *Health Educ Res* 2003, 18(5):611-626.

246. Magklara E, Burton CR, Morrison V: Does self-efficacy influence recovery and well-being in osteoarthritis patients undergoing joint replacement? A systematic review. *Clin Rehabil* 2014, 28(9):835-846. doi:10.1177/0269215514527843

247. Bletterman AN, de Geest-Vrolijk ME, Vriezekolk JE, Nijhuis-van der Sanden MW, van Meeteren NL, Hoogeboom TJ: Preoperative psychosocial factors predicting patient's functional recovery after total knee or total hip arthroplasty: a systematic review. *Clin Rehabil* 2018, 32(4):512-525. doi:10.1177/0269215517730669

248. Clemensen J, Rothmann MJ, Smith AC, Caffery LJ, Danbjorg DB: Participatory design methods in telemedicine research. *J Telemed Telecare* 2017, 23(9):780-785. doi:10.1177/1357633X16686747

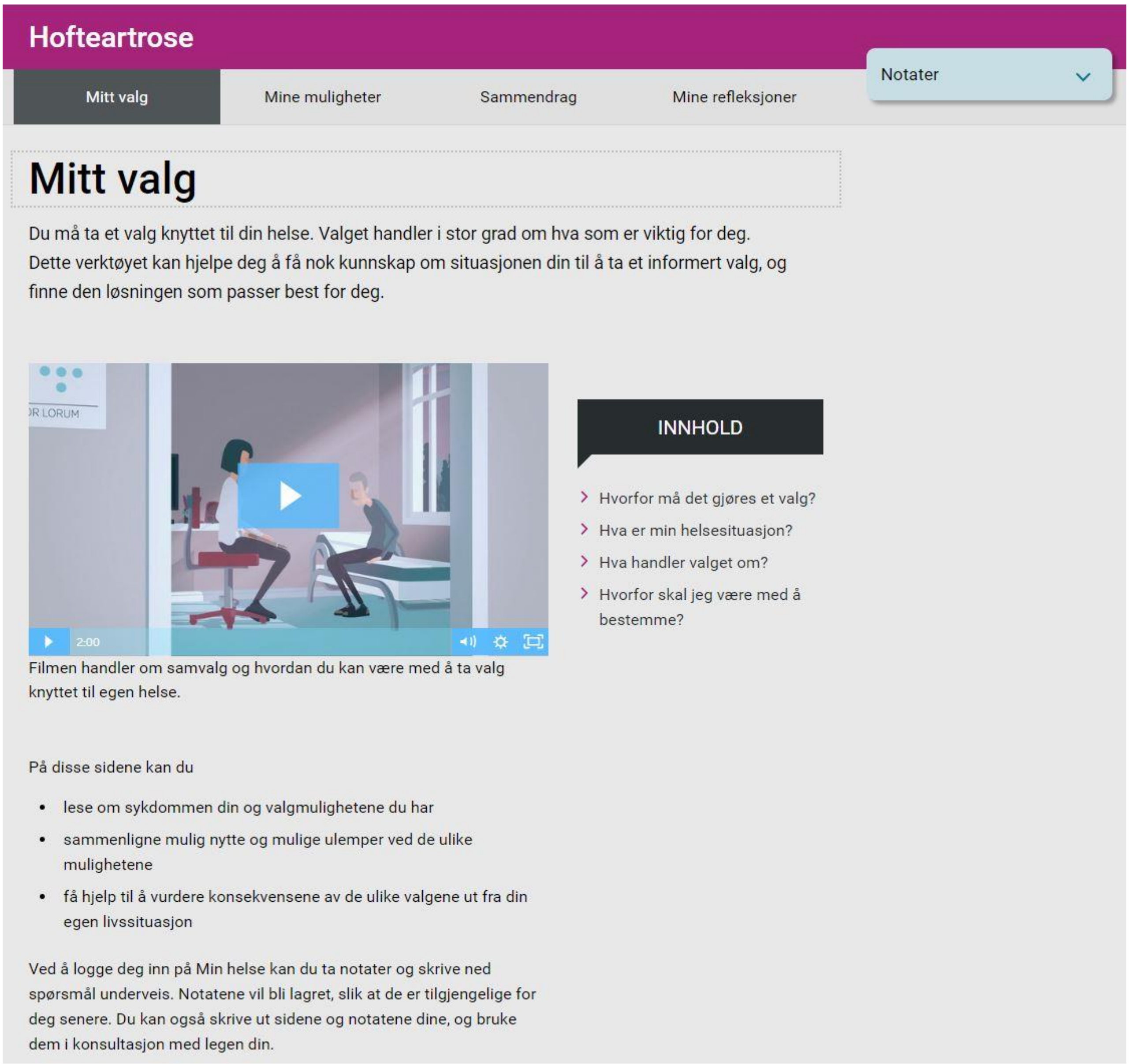
249. Robertson T, Simonsen J: Routledge International Handbook of Participatory Design. New York: Routledge; 2013.

250. Elwyn G, Durand MA, Song J, Aarts J, Barr PJ, Berger Z, Cochran N, Frosch D, Galasinski D, Gulbrandsen P *et al*: A three-talk model for shared decision making: multistage consultation process. *BMJ* 2017, 359:j4891. doi:10.1136/bmj.j4891

Appendix

Appendix 1 (a-d): Screenshots of the PDA for hip OA

1a – My choice



Mitt valg

Du må ta et valg knyttet til din helse. Valget handler i stor grad om hva som er viktig for deg. Dette verktøyet kan hjelpe deg å få nok kunnskap om situasjonen din til å ta et informert valg, og finne den løsningen som passer best for deg.

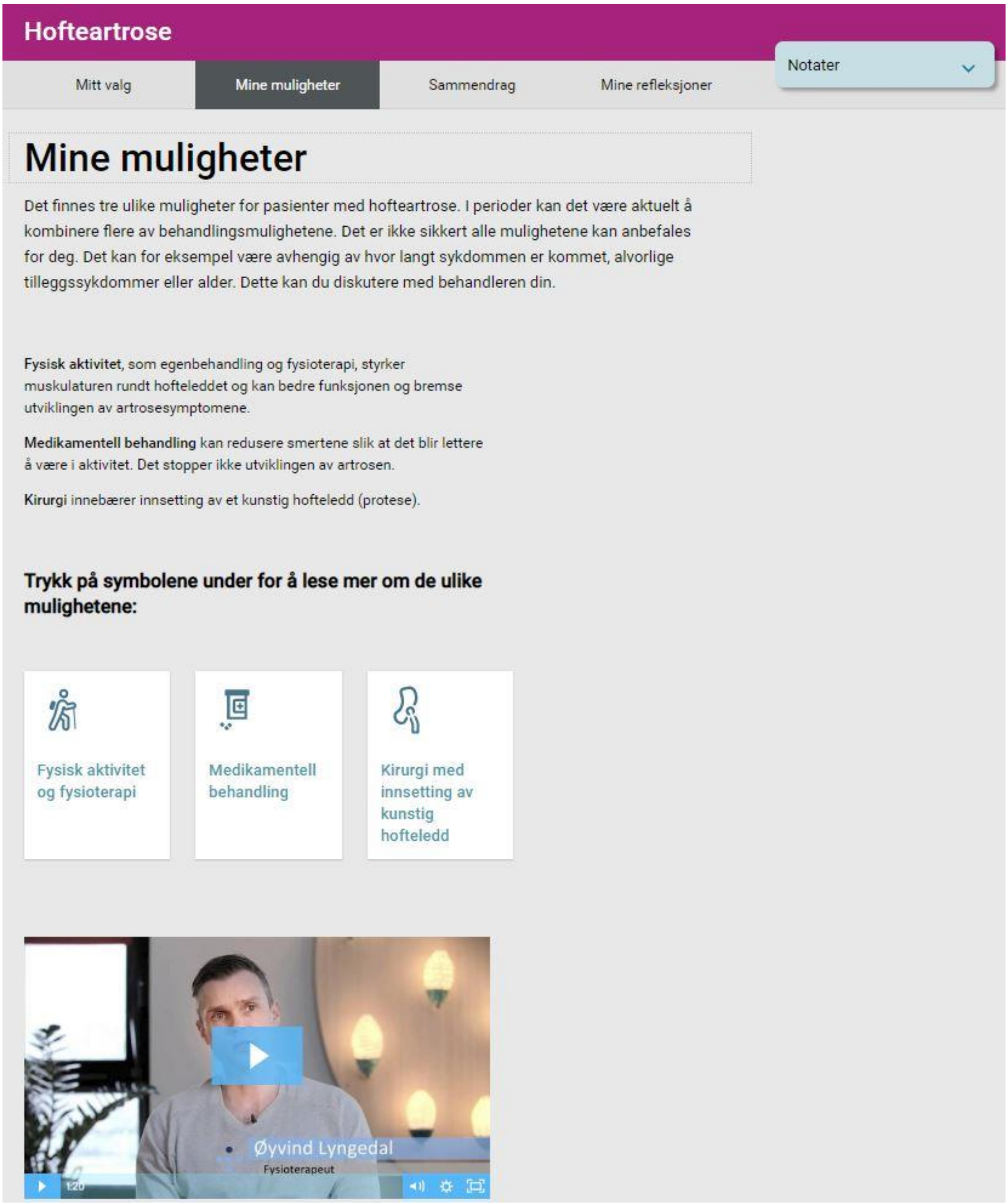
Filmen handler om samvalg og hvordan du kan være med å ta valg knyttet til egen helse.

På disse sidene kan du

- lese om sykdommen din og valgmulighetene du har
- sammenligne mulig nytte og mulige ulemper ved de ulike mulighetene
- få hjelp til å vurdere konsekvensene av de ulike valgene ut fra din egen livssituasjon

Ved å logge deg inn på Min helse kan du ta notater og skrive ned spørsmål underveis. Notatene vil bli lagret, slik at de er tilgjengelige for deg senere. Du kan også skrive ut sidene og notatene dine, og bruke dem i konsultasjon med legen din.

1b – Overview of available treatment options



Mine muligheter

Det finnes tre ulike muligheter for pasienter med hofteartrose. I perioder kan det være aktuelt å kombinere flere av behandlingsmulighetene. Det er ikke sikkert alle mulighetene kan anbefales for deg. Det kan for eksempel være avhengig av hvor langt sykdommen er kommet, alvorlige tilleggssykdommer eller alder. Dette kan du diskutere med behandleren din.

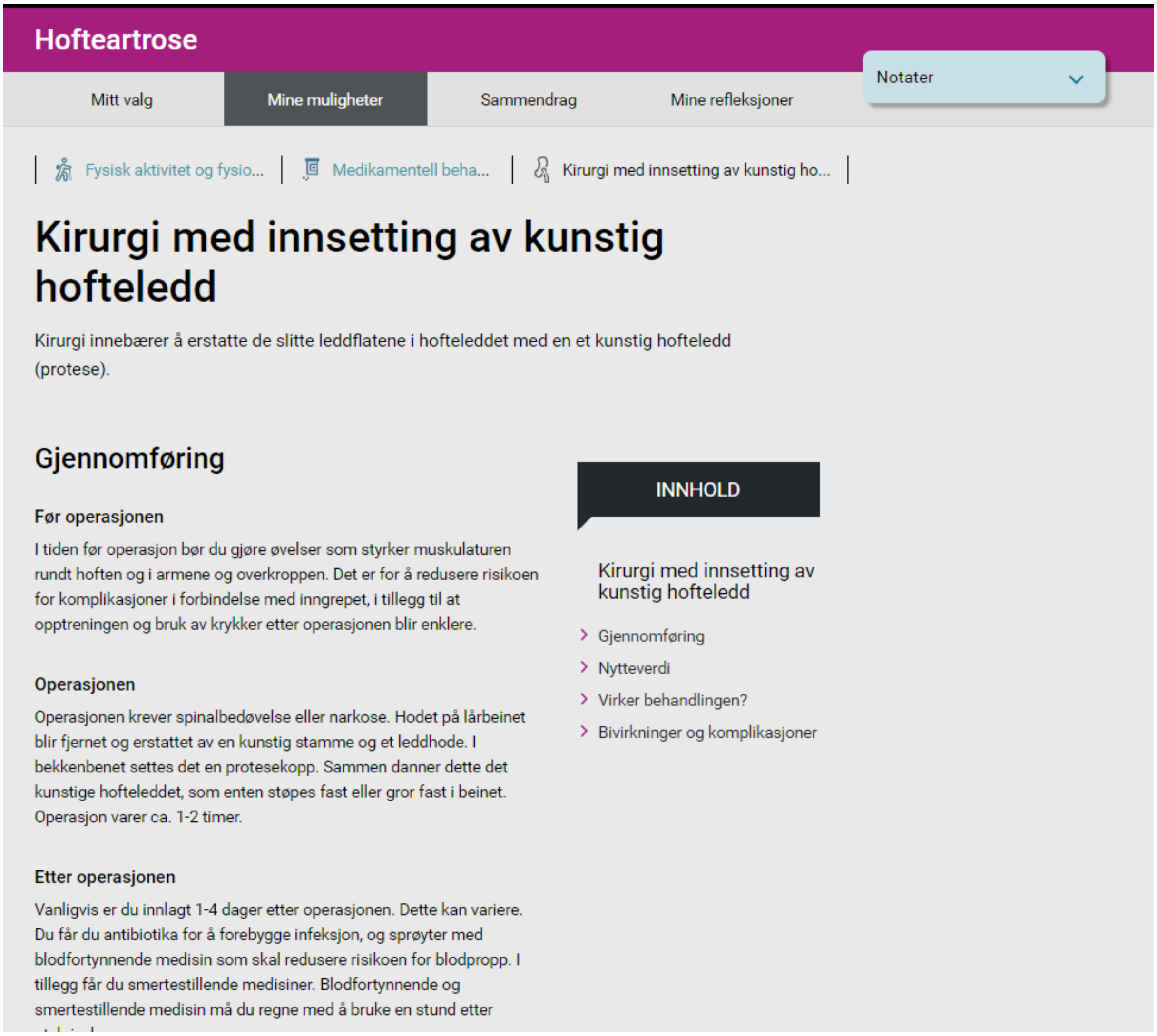
Fysisk aktivitet, som egenbehandling og fysioterapi, styrker muskulaturen rundt hofteleddet og kan bedre funksjonen og bremse utviklingen av artrosesymptomene.

Medikamentell behandling kan redusere smertene slik at det blir lettere å være i aktivitet. Det stopper ikke utviklingen av artrosen.

Kirurgi innebærer innsetting av et kunstig hofteledd (protese).

Trykk på symbolene under for å lese mer om de ulike mulighetene:

1c – Presentation of surgical option



Kirurgi med innsetting av kunstig hofteledd

Kirurgi innebærer å erstatte de slitte leddflatene i hofteleddet med en et kunstig hofteledd (protese).

Gjennomføring

Før operasjonen

I tiden før operasjon bør du gjøre øvelser som styrker muskulaturen rundt hoften og i armene og overkroppen. Det er for å redusere risikoen for komplikasjoner i forbindelse med inngrepet, i tillegg til at opptreningen og bruk av krykker etter operasjonen blir enklere.

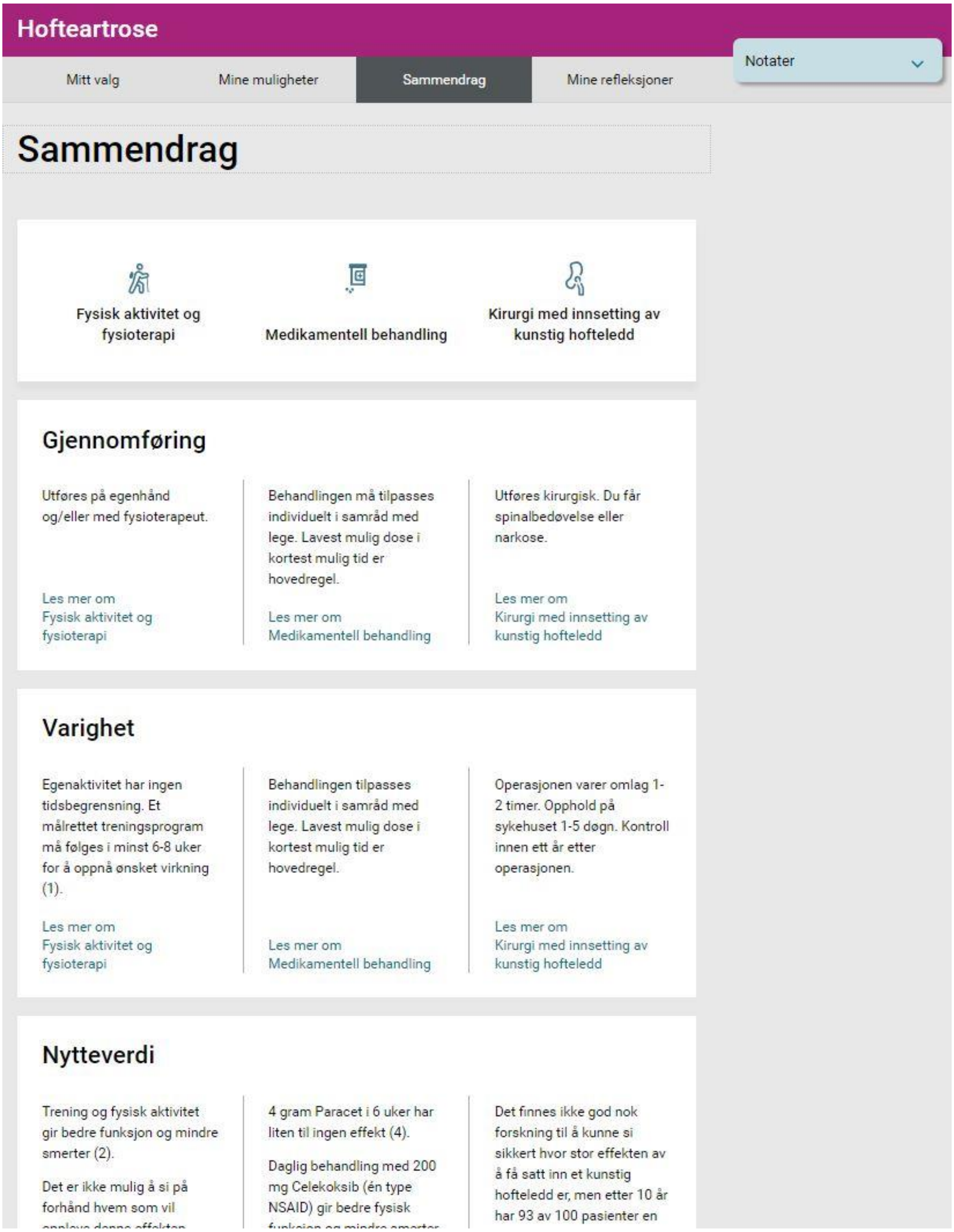
Operasjonen

Operasjonen krever spinalbedøvelse eller narkose. Hodet på lårbeinet blir fjernet og erstattet av en kunstig stamme og et leddhode. I bekkenbenet settes det en protesekopp. Sammen danner dette det kunstige hofteleddet, som enten støpes fast eller gror fast i beinet. Operasjon varer ca. 1-2 timer.

Etter operasjonen

Vanligvis er du innlagt 1-4 dager etter operasjonen. Dette kan variere. Du får du antibiotika for å forebygge infeksjon, og sprøyter med blodfortynnende medisin som skal redusere risikoen for blodpropp. I tillegg får du smertestillende medisiner. Blodfortynnende og smertestillende medisin må du regne med å bruke en stund etter

1d - Summary



Sammendrag

Fysisk aktivitet og fysioterapi	Medikamentell behandling	Kirurgi med innsetting av kunstig hofteledd

Gjennomføring

Utføres på egenhånd og/eller med fysioterapeut.	Behandlingen må tilpasses individuelt i samråd med lege. Lavest mulig dose i kortest mulig tid er hovedregel.	Utføres kirurgisk. Du får spinalbedøvelse eller narkose.
Les mer om Fysisk aktivitet og fysioterapi	Les mer om Medikamentell behandling	Les mer om Kirurgi med innsetting av kunstig hofteledd

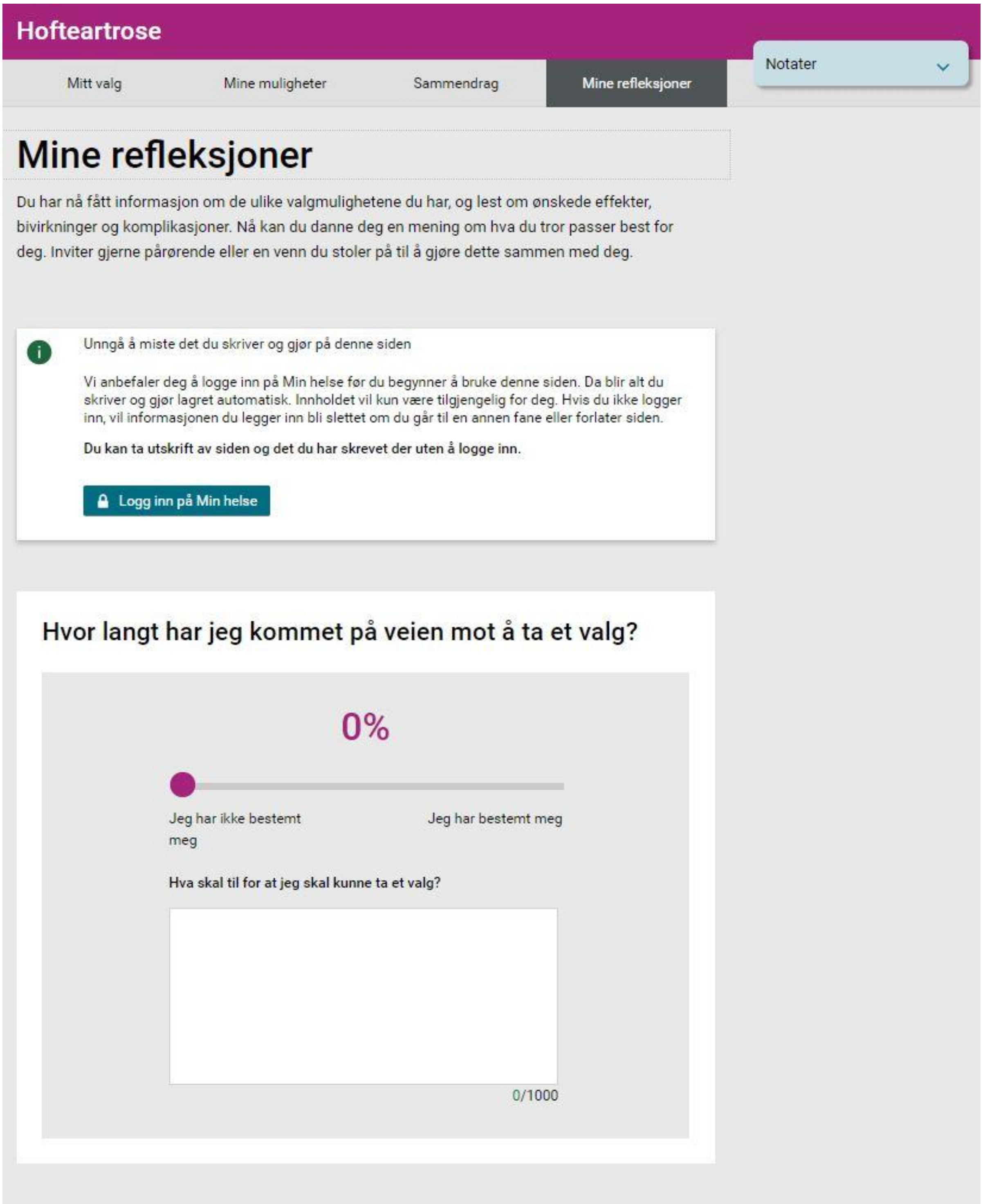
Varighet

Egenaktivitet har ingen tidsbegrensning. Et målrettet treningsprogram må følges i minst 6-8 uker for å oppnå ønsket virkning (1).	Behandlingen tilpasses individuelt i samråd med lege. Lavest mulig dose i kortest mulig tid er hovedregel.	Operasjonen varer omlag 1-2 timer. Opphold på sykehuset 1-5 døgn. Kontroll innen ett år etter operasjonen.
Les mer om Fysisk aktivitet og fysioterapi	Les mer om Medikamentell behandling	Les mer om Kirurgi med innsetting av kunstig hofteledd

Nytteverdi

Trening og fysisk aktivitet gir bedre funksjon og mindre smerter (2). Det er ikke mulig å si på forhånd hvem som vil	4 gram Paracet i 6 uker har liten til ingen effekt (4). Daglig behandling med 200 mg Celekoksib (én type NSAID) gir bedre fysisk	Det finnes ikke god nok forskning til å kunne si sikkert hvor stor effekten av å få satt inn et kunstig hofteledd er, men etter 10 år har 93 av 100 pasienter en

1e – My reflections



Mine refleksjoner

Du har nå fått informasjon om de ulike valgmulighetene du har, og lest om ønskede effekter, bivirkninger og komplikasjoner. Nå kan du danne deg en mening om hva du tror passer best for deg. Inviter gjerne pårørende eller en venn du stoler på til å gjøre dette sammen med deg.

Unngå å miste det du skriver og gjør på denne siden

Vi anbefaler deg å logge inn på Min helse før du begynner å bruke denne siden. Da blir alt du skriver og gjør lagret automatisk. Innholdet vil kun være tilgjengelig for deg. Hvis du ikke logger inn, vil informasjonen du legger inn bli slettet om du går til en annen fane eller forlater siden.

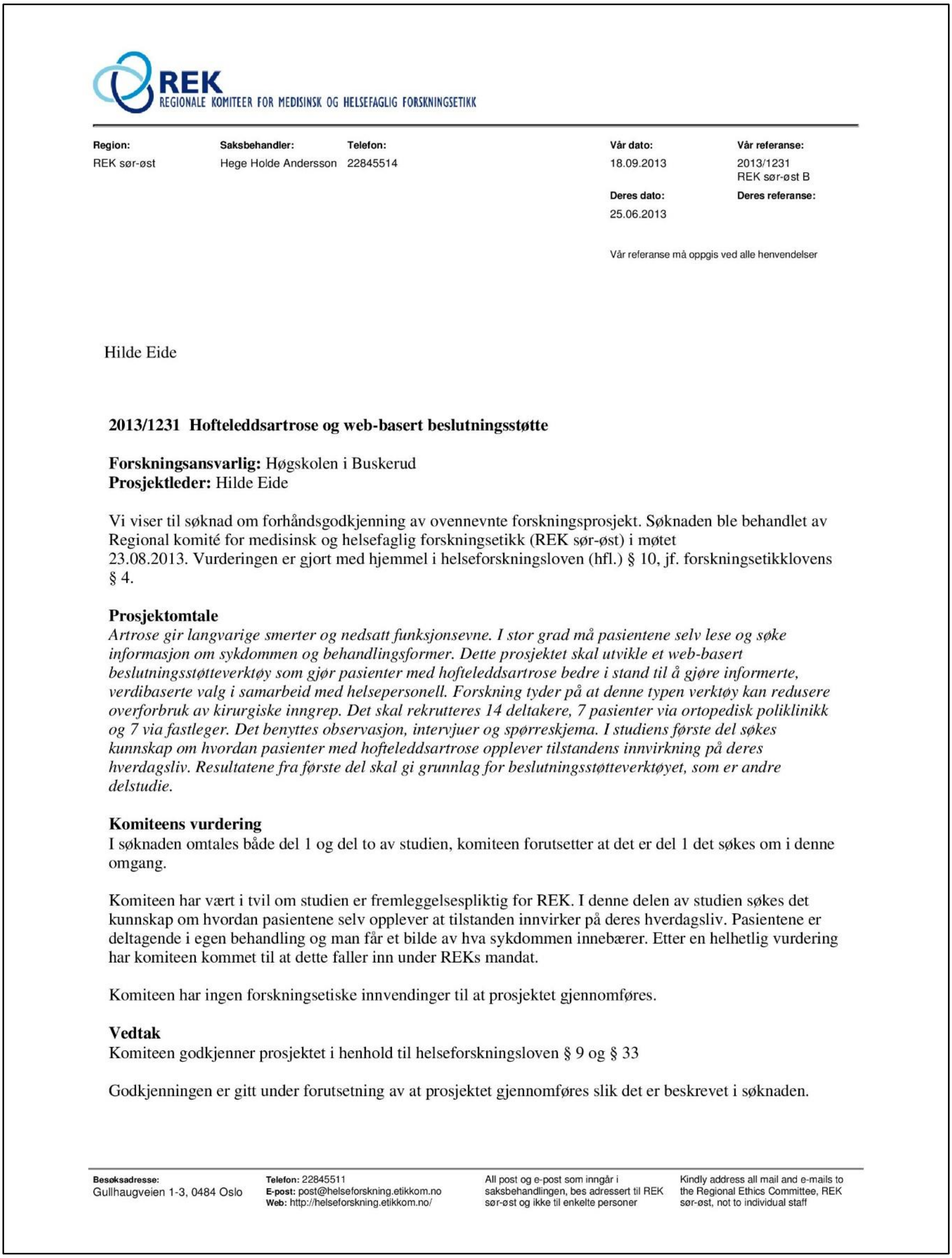
Du kan ta utskrift av siden og det du har skrevet der uten å logge inn.

Hvor langt har jeg kommet på veien mot å ta et valg?

0%

Hva skal til for at jeg skal kunne ta et valg?

Appendix 2: Decision letter Regional Committee for Medical and Health Research Ethics, REK (Paper 1)



REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	**Saksbehandler:**	**Telefon:**	**Vår dato:**	**Vår referanse:**
REK sør-øst	Hege Holde Andersson	22845514	18.09.2013	2013/1231 REK sør-øst B
			Deres dato:	**Deres referanse:**
			25.06.2013	

Vår referanse må oppgis ved alle henvendelser

Hilde Eide

2013/1231 Hofteleddsartrose og web-basert beslutningsstøtte

Forskningsansvarlig: Høgskolen i Buskerud
Prosjektleder: Hilde Eide

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk (REK sør-øst) i møtet 23.08.2013. Vurderingen er gjort med hjemmel i helseforskningsloven (hfl.) § 10, jf. forskningsetikklovens § 4.

Prosjektomtale

Artrose gir langvarige smerter og nedsatt funksjonsevne. I stor grad må pasientene selv lese og søke informasjon om sykdommen og behandlingsformer. Dette prosjektet skal utvikle et web-basert beslutningsstøtteverktøy som gjør pasienter med hofteleddsartrose bedre i stand til å gjøre informerte, verdibaserte valg i samarbeid med helsepersonell. Forskning tyder på at denne typen verktøy kan redusere overforbruk av kirurgiske inngrep. Det skal rekrutteres 14 deltakere, 7 pasienter via ortopedisk poliklinikk og 7 via fastleger. Det benyttes observasjon, intervjuer og spørreskjema. I studiens første del søkes kunnskap om hvordan pasienter med hofteleddsartrose opplever tilstandens innvirkning på deres hverdagsliv. Resultatene fra første del skal gi grunnlag for beslutningsstøtteverktøyet, som er andre delstudie.

Komiteens vurdering

I søknaden omtales både del 1 og del to av studien, komiteen forutsetter at det er del 1 det søkes om i denne omgang.

Komiteen har vært i tvil om studien er fremleggelsespliktig for REK. I denne delen av studien søkes det kunnskap om hvordan pasientene selv opplever at tilstanden innvirker på deres hverdagsliv. Pasientene er deltagende i egen behandling og man får et bilde av hva sykdommen innebærer. Etter en helhetlig vurdering har komiteen kommet til at dette faller inn under REKs mandat.

Komiteen har ingen forskningsetiske innvendinger til at prosjektet gjennomføres.

Vedtak

Komiteen godkjenner prosjektet i henhold til helseforskningsloven § 9 og § 33

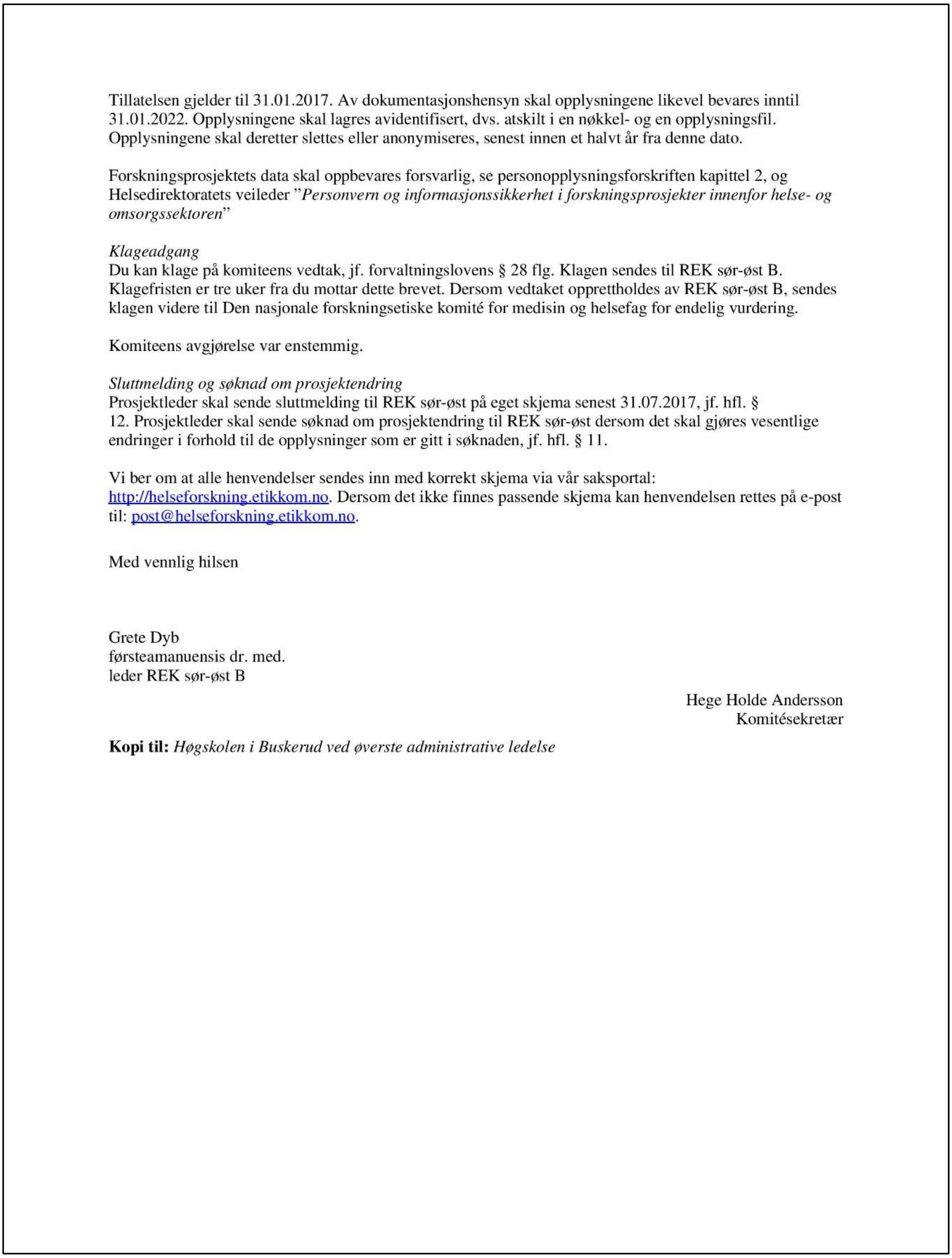
Godkjenningen er gitt under forutsetning av at prosjektet gjennomføres slik det er beskrevet i søknaden.

Besøksadresse:
Gullhaugveien 1-3, 0484 Oslo

Telefon: 22845511
E-post: post@helseforskning.etikkom.no
Web: http://helseforskning.etikkom.no/

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff



Tillatelsen gjelder til 31.01.2017. Av dokumentasjonshensyn skal opplysningene likevel bevares inntil 31.01.2022. Opplysningene skal lagres avidentifisert, dvs. atskilt i en nøkkel- og en opplysningsfil. Opplysningene skal deretter slettes eller anonymiseres, senest innen et halvt år fra denne dato.

Forskningsprosjektets data skal oppbevares forsvarlig, se personopplysningsforskriften kapittel 2, og Helsedirektoratets veileder "*Personvern og informasjonssikkerhet i forskningsprosjekter innenfor helse- og omsorgssektoren*"

Klageadgang
Du kan klage på komiteens vedtak, jf. forvaltningslovens § 28 flg. Klagen sendes til REK sør-øst B. Klagefristen er tre uker fra du mottar dette brevet. Dersom vedtaket opprettholdes av REK sør-øst B, sendes klagen videre til Den nasjonale forskningsetiske komité for medisin og helsefag for endelig vurdering.

Komiteens avgjørelse var enstemmig.

Sluttmelding og søknad om prosjektendring
Prosjektleder skal sende sluttmelding til REK sør-øst på eget skjema senest 31.07.2017, jf. hfl. § 12. Prosjektleder skal sende søknad om prosjektendring til REK sør-øst dersom det skal gjøres vesentlige endringer i forhold til de opplysninger som er gitt i søknaden, jf. hfl. § 11.

Vi ber om at alle henvendelser sendes inn med korrekt skjema via vår saksportal: http://helseforskning.etikkom.no. Dersom det ikke finnes passende skjema kan henvendelsen rettes på e-post til: post@helseforskning.etikkom.no.

Med vennlig hilsen

Grete Dyb
førsteamanuensis dr. med.
leder REK sør-øst B

Hege Holde Andersson
Komitésekretær

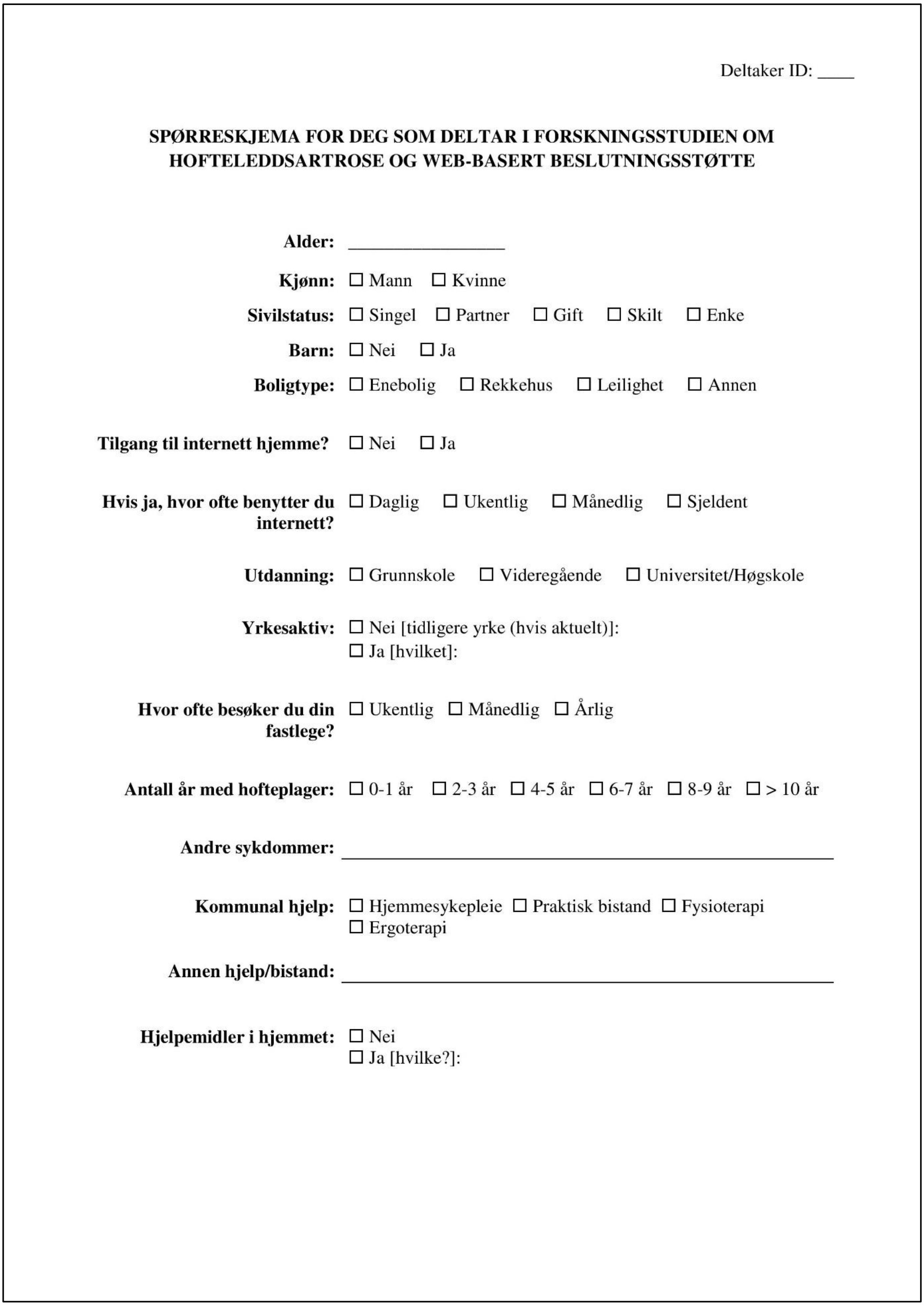
Kopi til: *Høgskolen i Buskerud ved øverste administrative ledelse*

Appendix 3: Interview guide (Paper 1)

Intervjuguide pasienter med hofteartrose

Tema	**Spørsmål**
Innledning	Kan du fortelle litt om deg selv?
Artrose	Kan du beskrive hvordan hofteplagene dine innvirker på dagliglivet og livskvalitet?
	Hva har du gjort til nå for å leve best mulig med dine hofteplager?
Informasjon	Hvilke erfaringer har du i forhold til å forstå den informasjonen som blir gitt av helsepersonell?
- Egenskaper	Hvilke egenskaper mener du er avgjørende å ha for å søke, forstå og anvende helseinformasjon relevant for dine behov?
- Tilpasning	Hvordan føler du informasjonen du får fra helsepersonell eller fra andre kilder er tilpasset DINE behov og forutsetninger?
- Når	Kan du fortelle litt om når du oppsøker informasjon om dine helseplager?
- Hvor	Hvor har du fått informasjon som har vært viktig for deg i forhold til dine hofteplager?
- Nytte	Hvordan har du opplevd denne informasjonen med tanke på nytte?
- Internett	Hvilke erfaringer har du i forhold til å søke helseinformasjon på internett?
Medvirkning	Har du noen tanker om hva som menes med pasientmedvirkning?
- Rolle	Hva er viktig for deg i valg av ulike behandlingsalternativer eller valg som medfører endringer?
	Hvem/hva har innvirket i beslutningen om henvisning til vurdering for operasjon*?(spesialisthelsetjenesten).*
- Informert valg	I hvilken grad føler du at valgene du har tatt så lang har vært informerte valg?
Sosial påvirkning	Hvilken rolle har venner/familie hatt i forhold til din søken om informasjon om hofteleddsartrose og hvordan du best kan håndtere plagene i hverdagen?
Kommunikasjon	Hvordan opplever du dine muligheter eller evner til å uttrykke dine bekymringer og behov i møtet med helsepersonell?
- Verdier	Hvordan opplever du at DINE verdier eller anliggender blir ivaretatt i konsultasjoner med fastlegen din?
Følelser/emosjoner	Kan du fortelle noe om hvordan situasjonen din påvirker dine følelser? [f.eks.sinne/frustrasjon/angst/depresjon]
Avslutning	Er det noe avslutningsvis du ønsker å fortelle?

Appendix 4: Demographics questionnaire (Paper 1)



Deltaker ID: ____

SPØRRESKJEMA FOR DEG SOM DELTAR I FORSKNINGSSTUDIEN OM HOFTELEDDSARTROSE OG WEB-BASERT BESLUTNINGSSTØTTE

Alder: ________________

Kjønn: ☐ Mann ☐ Kvinne

Sivilstatus: ☐ Singel ☐ Partner ☐ Gift ☐ Skilt ☐ Enke

Barn: ☐ Nei ☐ Ja

Boligtype: ☐ Enebolig ☐ Rekkehus ☐ Leilighet ☐ Annen

Tilgang til internett hjemme? ☐ Nei ☐ Ja

Hvis ja, hvor ofte benytter du internett? ☐ Daglig ☐ Ukentlig ☐ Månedlig ☐ Sjeldent

Utdanning: ☐ Grunnskole ☐ Videregående ☐ Universitet/Høgskole

Yrkesaktiv: ☐ Nei [tidligere yrke (hvis aktuelt)]:
☐ Ja [hvilket]:

Hvor ofte besøker du din fastlege? ☐ Ukentlig ☐ Månedlig ☐ Årlig

Antall år med hofteplager: ☐ 0-1 år ☐ 2-3 år ☐ 4-5 år ☐ 6-7 år ☐ 8-9 år ☐ > 10 år

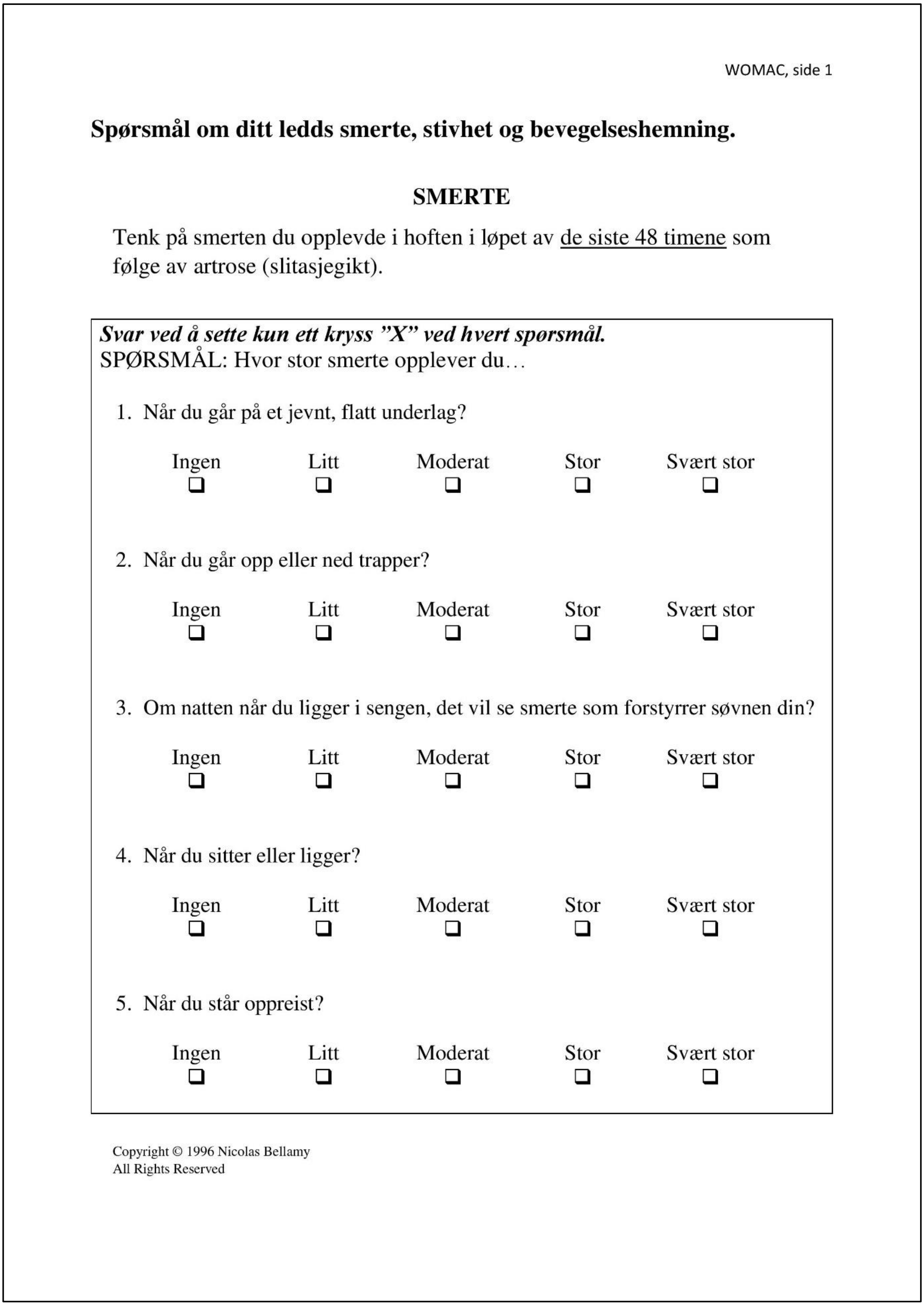
Andre sykdommer: ____

Kommunal hjelp: ☐ Hjemmesykepleie ☐ Praktisk bistand ☐ Fysioterapi
☐ Ergoterapi

Annen hjelp/bistand: ____

Hjelpemidler i hjemmet: ☐ Nei
☐ Ja [hvilke?]:

Appendix 5: Western Ontario and McMaster Universities Osteoarthritis Index, WOMAC (Norwegian version, paper 2)



WOMAC, side 1

Spørsmål om ditt ledds smerte, stivhet og bevegelseshemning.

SMERTE

Tenk på smerten du opplevde i hoften i løpet av <u>de siste 48 timene</u> som følge av artrose (slitasjegikt).

Svar ved å sette kun ett kryss "X" ved hvert spørsmål.
SPØRSMÅL: Hvor stor smerte opplever du…

1. Når du går på et jevnt, flatt underlag?

Ingen	Litt	Moderat	Stor	Svært stor
☐	☐	☐	☐	☐

2. Når du går opp eller ned trapper?

Ingen	Litt	Moderat	Stor	Svært stor
☐	☐	☐	☐	☐

3. Om natten når du ligger i sengen, det vil se smerte som forstyrrer søvnen din?

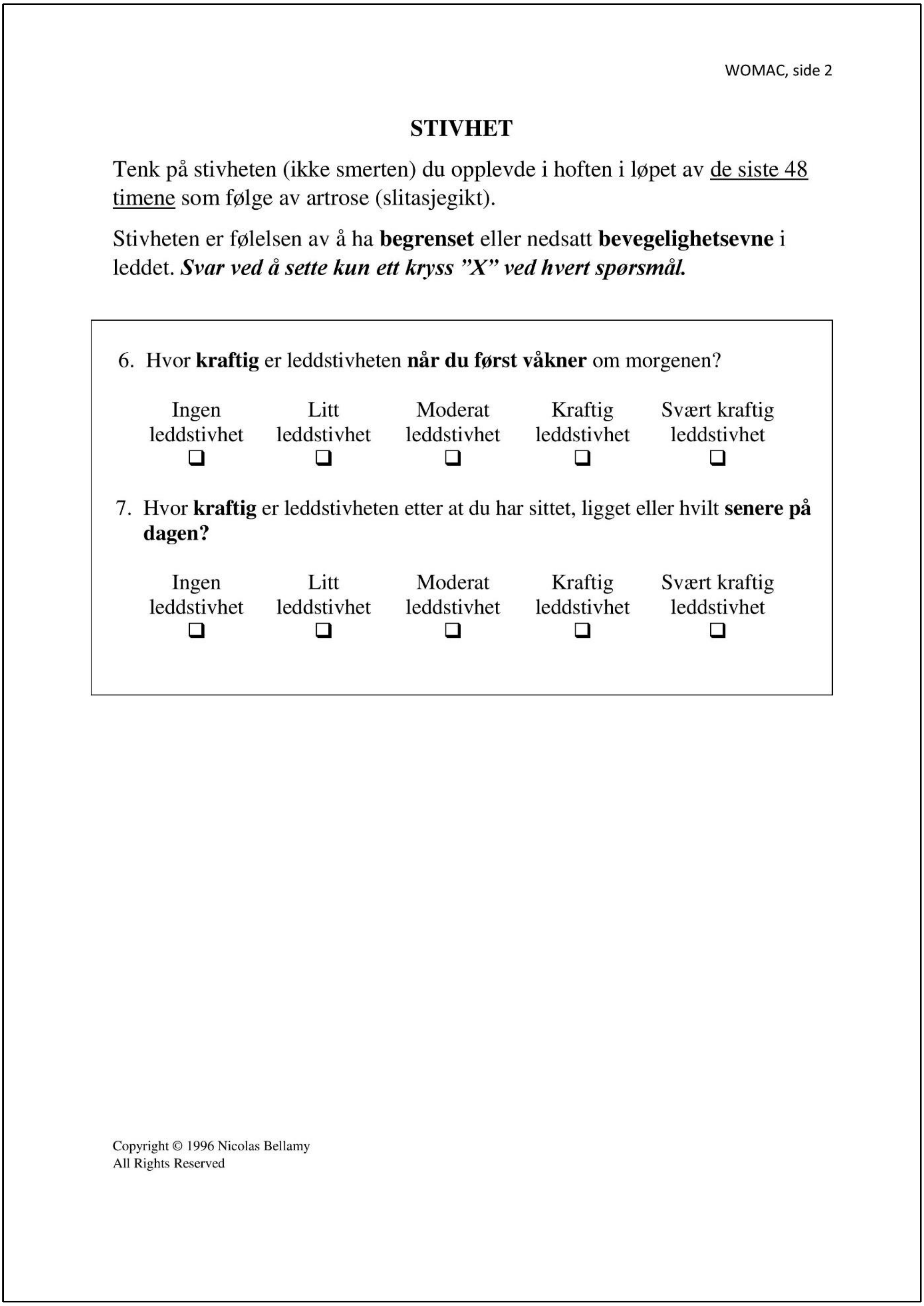
Ingen	Litt	Moderat	Stor	Svært stor
☐	☐	☐	☐	☐

4. Når du sitter eller ligger?

Ingen	Litt	Moderat	Stor	Svært stor
☐	☐	☐	☐	☐

5. Når du står oppreist?

Ingen	Litt	Moderat	Stor	Svært stor
☐	☐	☐	☐	☐



STIVHET

Tenk på stivheten (ikke smerten) du opplevde i hoften i løpet av de siste 48 timene som følge av artrose (slitasjegikt).

Stivheten er følelsen av å ha **begrenset** eller nedsatt **bevegelighetsevne** i leddet. ***Svar ved å sette kun ett kryss "X" ved hvert spørsmål.***

6. Hvor **kraftig** er leddstivheten **når du først våkner** om morgenen?

Ingen leddstivhet	Litt leddstivhet	Moderat leddstivhet	Kraftig leddstivhet	Svært kraftig leddstivhet
☐	☐	☐	☐	☐

7. Hvor **kraftig** er leddstivheten etter at du har sittet, ligget eller hvilt **senere på dagen?**

Ingen leddstivhet	Litt leddstivhet	Moderat leddstivhet	Kraftig leddstivhet	Svært kraftig leddstivhet
☐	☐	☐	☐	☐

VANSKELIGHETER VED UTFØRELSE AV DAGLIGE AKTIVITETER

Tenk på hvor vanskelig det har vært å utføre følgende daglige fysiske aktiviteter i løpet av de siste 48 timene, som følge av artrose (slitasjegikt) i hoften.
Med dette mener vi din bevegelsesevne og evne til å klare deg selv.
Svar ved å sette kun ett kryss ”X” ved hvert spørsmål.

SPØRSMÅL: Hvor vanskelig har det vært å…

8. Gå ned trapper?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

9. Gå opp trapper?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

10. Reise deg etter å ha sittet?

Ingen	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

11. Stå oppreist?

Ingen	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

12. Bøye deg ned mot gulvet?

Ingen	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

13. Gå på et jevnt, flatt underlag?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

SPØRSMÅL: Hvor vanskelig har det vært å…

Svar ved å sette kun ett kryss "X" ved hvert spørsmål.

14. Stige inn/ut av en bil eller av/på en buss?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

15. Gå på handletur?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

16. Ta på deg sokker/strømper?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

17. Stå opp av sengen?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

18. Ta av deg sokker/strømper?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

19. Ligge i sengen?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

20. Gå ned i/opp av badekaret?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

SPØRSMÅL: Hvor vanskelig har det vært å…

Svar ved å sette kun ett kryss "X" ved hvert spørsmål.

21.Sitte?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

22. Sette deg på/reise deg fra toalettet?

Ikke	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

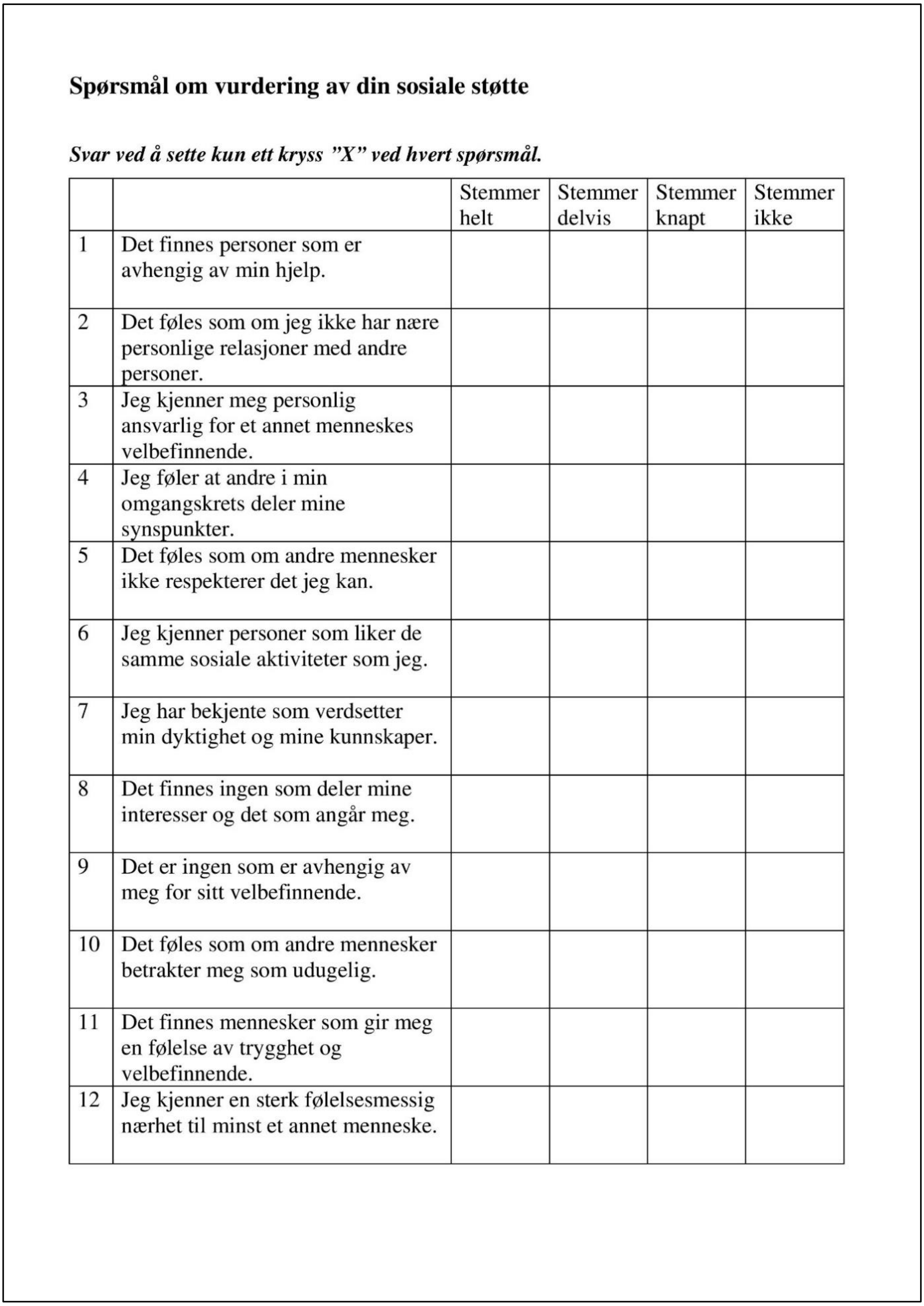
23. Utføre tungt husarbeid?

Ingen	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

24. Utføre lett husarbeid?

Ingen	Litt	Moderat	Svært	Ekstremt
☐	☐	☐	☐	☐

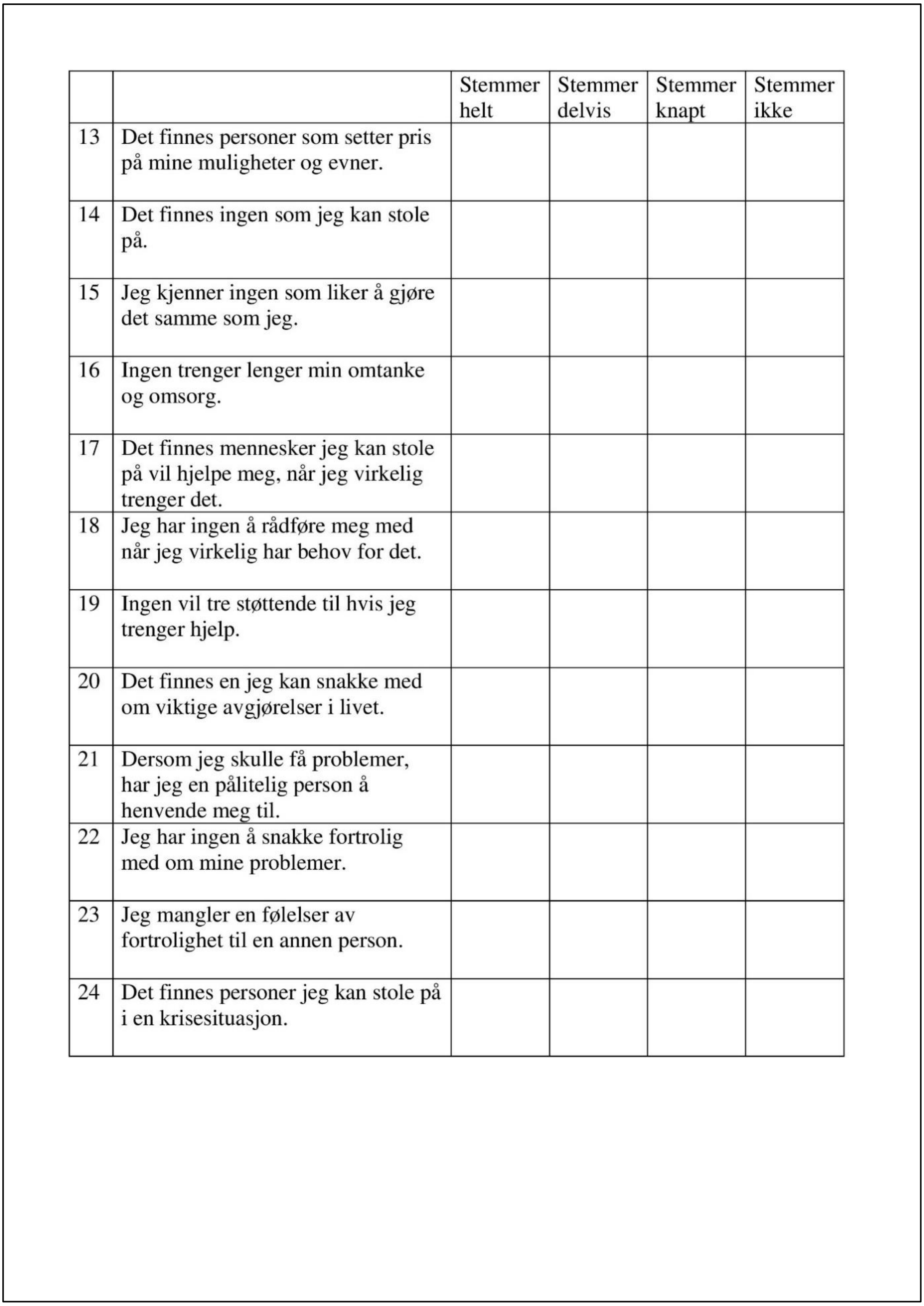
Appendix 6: Social provision scale (Norwegian version, paper 2)



Spørsmål om vurdering av din sosiale støtte

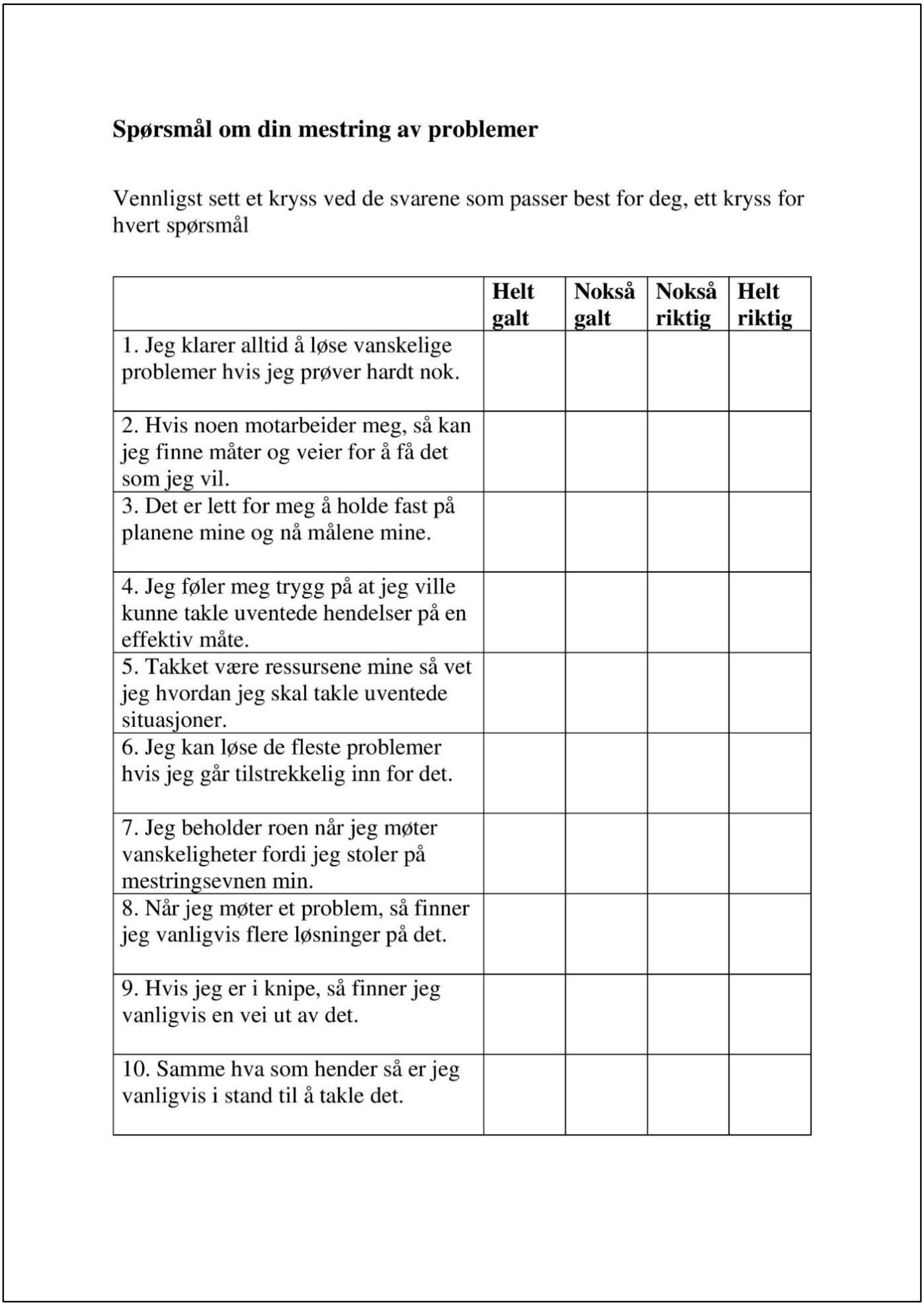
Svar ved å sette kun ett kryss "X" ved hvert spørsmål.

		Stemmer helt	Stemmer delvis	Stemmer knapt	Stemmer ikke
1	Det finnes personer som er avhengig av min hjelp.				
2	Det føles som om jeg ikke har nære personlige relasjoner med andre personer.				
3	Jeg kjenner meg personlig ansvarlig for et annet menneskes velbefinnende.				
4	Jeg føler at andre i min omgangskrets deler mine synspunkter.				
5	Det føles som om andre mennesker ikke respekterer det jeg kan.				
6	Jeg kjenner personer som liker de samme sosiale aktiviteter som jeg.				
7	Jeg har bekjente som verdsetter min dyktighet og mine kunnskaper.				
8	Det finnes ingen som deler mine interesser og det som angår meg.				
9	Det er ingen som er avhengig av meg for sitt velbefinnende.				
10	Det føles som om andre mennesker betrakter meg som udugelig.				
11	Det finnes mennesker som gir meg en følelse av trygghet og velbefinnende.				
12	Jeg kjenner en sterk følelsesmessig nærhet til minst et annet menneske.				



		Stemmer helt	Stemmer delvis	Stemmer knapt	Stemmer ikke
13	Det finnes personer som setter pris på mine muligheter og evner.				
14	Det finnes ingen som jeg kan stole på.				
15	Jeg kjenner ingen som liker å gjøre det samme som jeg.				
16	Ingen trenger lenger min omtanke og omsorg.				
17	Det finnes mennesker jeg kan stole på vil hjelpe meg, når jeg virkelig trenger det.				
18	Jeg har ingen å rådføre meg med når jeg virkelig har behov for det.				
19	Ingen vil tre støttende til hvis jeg trenger hjelp.				
20	Det finnes en jeg kan snakke med om viktige avgjørelser i livet.				
21	Dersom jeg skulle få problemer, har jeg en pålitelig person å henvende meg til.				
22	Jeg har ingen å snakke fortrolig med om mine problemer.				
23	Jeg mangler en følelser av fortrolighet til en annen person.				
24	Det finnes personer jeg kan stole på i en krisesituasjon.				

Appendix 7: The general self-efficacy scale (Norwegian version, paper 2)

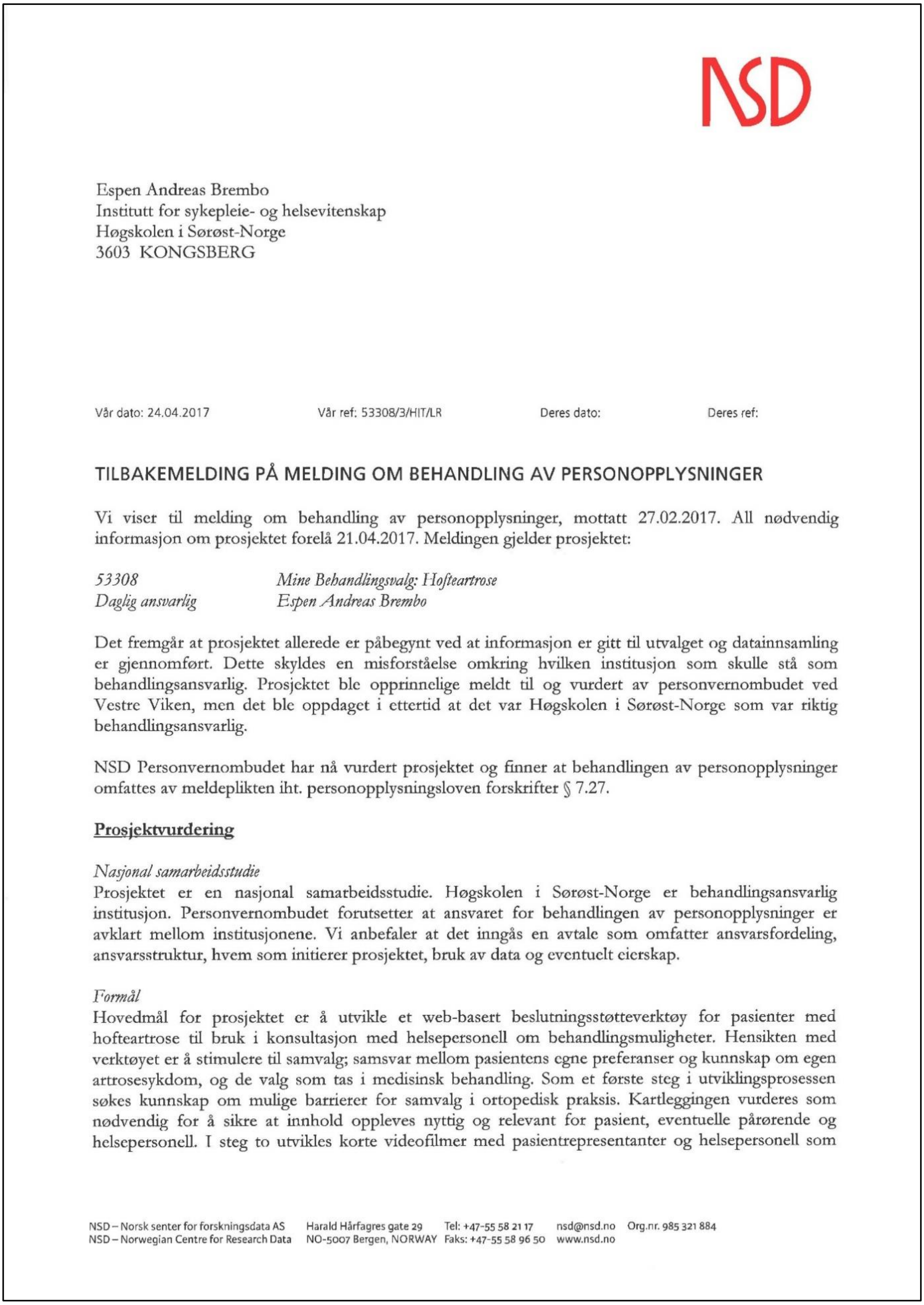


Spørsmål om din mestring av problemer

Vennligst sett et kryss ved de svarene som passer best for deg, ett kryss for hvert spørsmål

	Helt galt	**Nokså galt**	**Nokså riktig**	**Helt riktig**
1. Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok.				
2. Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil.				
3. Det er lett for meg å holde fast på planene mine og nå målene mine.				
4. Jeg føler meg trygg på at jeg ville kunne takle uventede hendelser på en effektiv måte.				
5. Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner.				
6. Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det.				
7. Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsevnen min.				
8. Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det.				
9. Hvis jeg er i knipe, så finner jeg vanligvis en vei ut av det.				
10. Samme hva som hender så er jeg vanligvis i stand til å takle det.				

Appendix 8: Decision letter Norwegian Centre for Research Data, NSD (Paper 3)



Espen Andreas Brembo
Institutt for sykepleie- og helsevitenskap
Høgskolen i Sørøst-Norge
3603 KONGSBERG

Vår dato: 24.04.2017	Vår ref: 53308/3/HIT/LR	Deres dato:	Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 27.02.2017. All nødvendig informasjon om prosjektet forelå 21.04.2017. Meldingen gjelder prosjektet:

53308	*Mine Behandlingsvalg: Hofteartrose*
Daglig ansvarlig	*Espen Andreas Brembo*

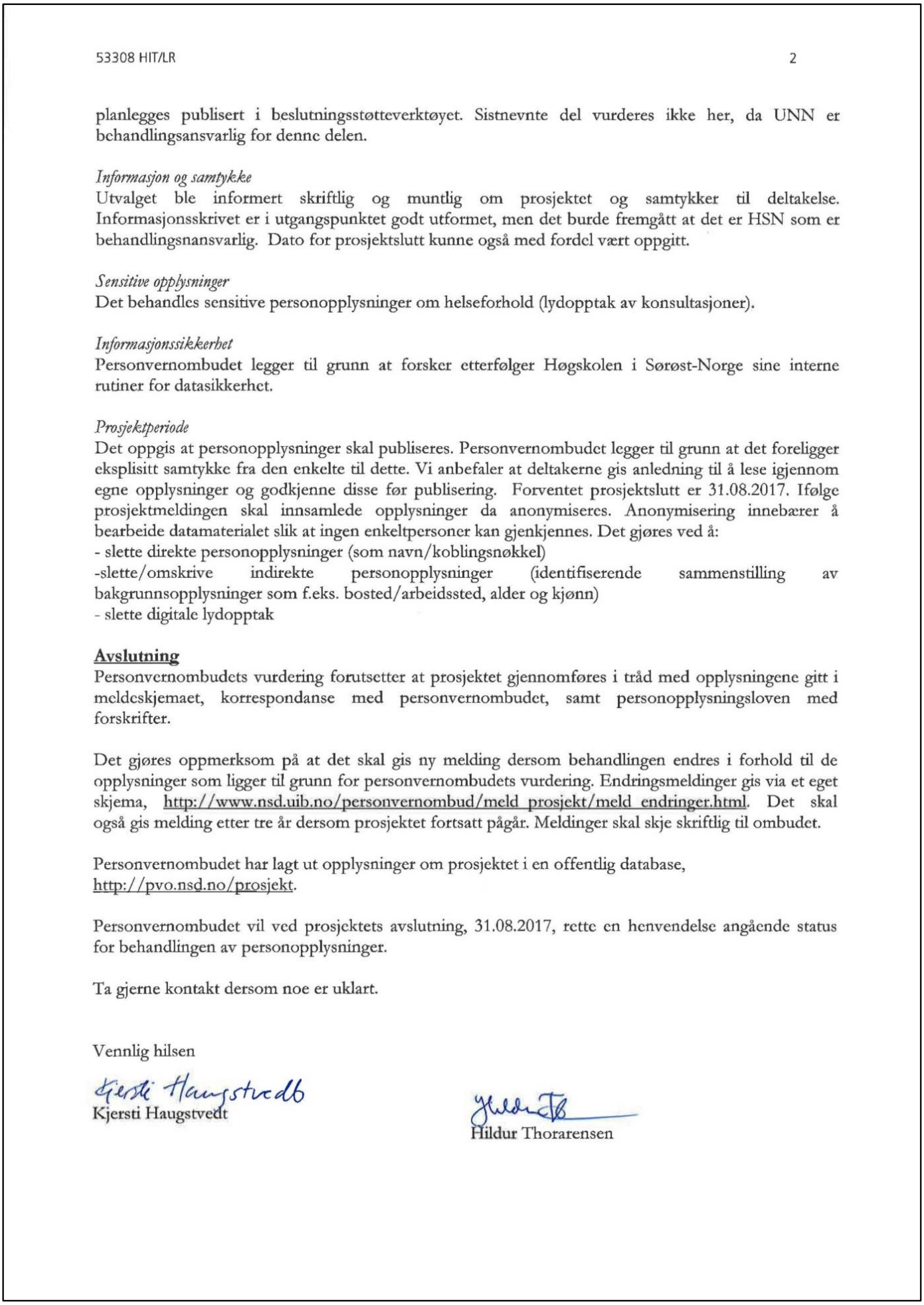
Det fremgår at prosjektet allerede er påbegynt ved at informasjon er gitt til utvalget og datainnsamling er gjennomført. Dette skyldes en misforståelse omkring hvilken institusjon som skulle stå som behandlingsansvarlig. Prosjektet ble opprinnelige meldt til og vurdert av personvernombudet ved Vestre Viken, men det ble oppdaget i ettertid at det var Høgskolen i Sørøst-Norge som var riktig behandlingsansvarlig.

NSD Personvernombudet har nå vurdert prosjektet og finner at behandlingen av personopplysninger omfattes av meldeplikten iht. personopplysningsloven forskrifter § 7.27.

Prosjektvurdering

Nasjonal samarbeidsstudie
Prosjektet er en nasjonal samarbeidsstudie. Høgskolen i Sørøst-Norge er behandlingsansvarlig institusjon. Personvernombudet forutsetter at ansvaret for behandlingen av personopplysninger er avklart mellom institusjonene. Vi anbefaler at det inngås en avtale som omfatter ansvarsfordeling, ansvarsstruktur, hvem som initierer prosjektet, bruk av data og eventuelt eierskap.

Formål
Hovedmål for prosjektet er å utvikle et web-basert beslutningsstøtteverktøy for pasienter med hofteartrose til bruk i konsultasjon med helsepersonell om behandlingsmuligheter. Hensikten med verktøyet er å stimulere til samvalg; samsvar mellom pasientens egne preferanser og kunnskap om egen artrosesykdom, og de valg som tas i medisinsk behandling. Som et første steg i utviklingsprosessen søkes kunnskap om mulige barrierer for samvalg i ortopedisk praksis. Kartleggingen vurderes som nødvendig for å sikre at innhold oppleves nyttig og relevant for pasient, eventuelle pårørende og helsepersonell. I steg to utvikles korte videofilmer med pasientrepresentanter og helsepersonell som



planlegges publisert i beslutningsstøtteverktøyet. Sistnevnte del vurderes ikke her, da UNN er behandlingsansvarlig for denne delen.

Informasjon og samtykke
Utvalget ble informert skriftlig og muntlig om prosjektet og samtykker til deltakelse. Informasjonsskrivet er i utgangspunktet godt utformet, men det burde fremgått at det er HSN som er behandlingsnansvarlig. Dato for prosjektslutt kunne også med fordel vært oppgitt.

Sensitive opplysninger
Det behandles sensitive personopplysninger om helseforhold (lydopptak av konsultasjoner).

Informasjonssikkerhet
Personvernombudet legger til grunn at forsker etterfølger Høgskolen i Sørøst-Norge sine interne rutiner for datasikkerhet.

Prosjektperiode
Det oppgis at personopplysninger skal publiseres. Personvernombudet legger til grunn at det foreligger eksplisitt samtykke fra den enkelte til dette. Vi anbefaler at deltakerne gis anledning til å lese igjennom egne opplysninger og godkjenne disse før publisering. Forventet prosjektslutt er 31.08.2017. Ifølge prosjektmeldingen skal innsamlede opplysninger da anonymiseres. Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan gjenkjennes. Det gjøres ved å:
- slette direkte personopplysninger (som navn/koblingsnøkkel)
-slette/omskrive indirekte personopplysninger (identifiserende sammenstilling av bakgrunnsopplysninger som f.eks. bosted/arbeidssted, alder og kjønn)
- slette digitale lydopptak

Avslutning
Personvernombudets vurdering forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med personvernombudet, samt personopplysningsloven med forskrifter.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvernombud/meld_prosjekt/meld_endringer.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://pvo.nsd.no/prosjekt.

Personvernombudet vil ved prosjektets avslutning, 31.08.2017, rette en henvendelse angående status for behandlingen av personopplysninger.

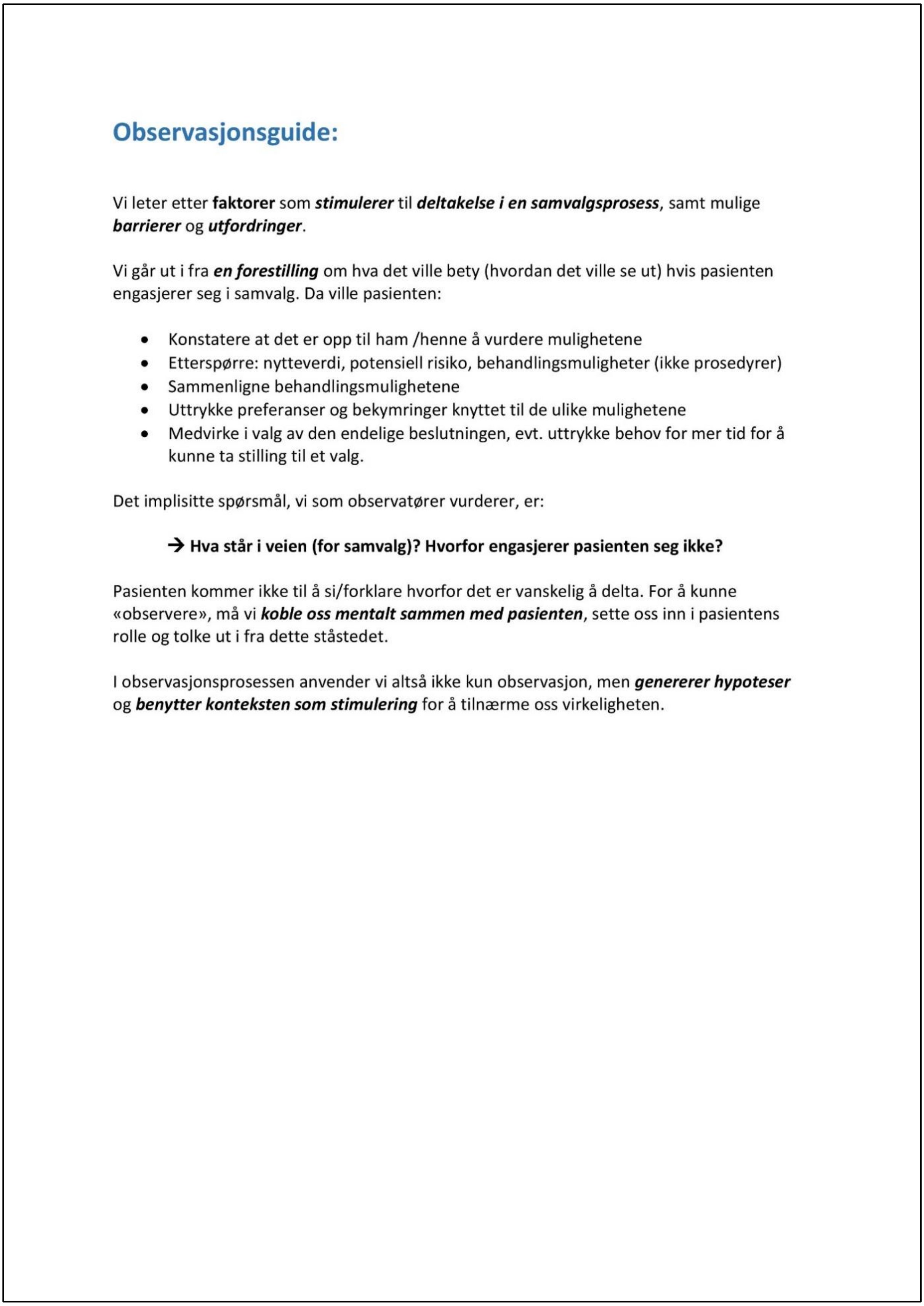
Ta gjerne kontakt dersom noe er uklart.

Vennlig hilsen

Kjersti Haugstvedt
Kjersti Haugstvedt

Hildur Thorarensen

Appendix 9: Observation guide (Paper 3)



Observasjonsguide:

Vi leter etter **faktorer** som ***stimulerer*** til ***deltakelse i en samvalgsprosess***, samt mulige ***barrierer*** og ***utfordringer***.

Vi går ut i fra ***en forestilling*** om hva det ville bety (hvordan det ville se ut) hvis pasienten engasjerer seg i samvalg. Da ville pasienten:

- Konstatere at det er opp til ham /henne å vurdere mulighetene
- Etterspørre: nytteverdi, potensiell risiko, behandlingsmuligheter (ikke prosedyrer)
- Sammenligne behandlingsmulighetene
- Uttrykke preferanser og bekymringer knyttet til de ulike mulighetene
- Medvirke i valg av den endelige beslutningen, evt. uttrykke behov for mer tid for å kunne ta stilling til et valg.

Det implisitte spørsmål, vi som observatører vurderer, er:

→ Hva står i veien (for samvalg)? Hvorfor engasjerer pasienten seg ikke?

Pasienten kommer ikke til å si/forklare hvorfor det er vanskelig å delta. For å kunne «observere», må vi ***koble oss mentalt sammen med pasienten***, sette oss inn i pasientens rolle og tolke ut i fra dette ståstedet.

I observasjonsprosessen anvender vi altså ikke kun observasjon, men ***genererer hypoteser*** og ***benytter konteksten som stimulering*** for å tilnærme oss virkeligheten.

Paper 1-3

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BMC Health Services Research

RESEARCH ARTICLE Open Access

Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study

Espen Andreas Brembo[1,2*], Heidi Kapstad[1], Tom Eide[1], Lukas Månsson[3], Sandra Van Dulmen[1,4,5] and Hilde Eide[1]

Abstract

Background: Osteoarthritis (OA) is the most common form of arthritis worldwide, affecting a growing number of people in the ageing populations. Currently, it affects about 50 % of all people over 65 years of age. There are no disease-modifying treatments for OA; hence preference-sensitive treatment options include symptom reduction, self-management and surgical joint replacement for suitable individuals. People have both ethical and legal rights to be informed about treatment choices and to actively participate in decision-making. Individuals have different needs; they differ in their ability to understand and make use of the provided information and to sustain behaviour change-dependent treatments over time.

Methods: As a part of a larger research project that aims to develop and test a web-based support tool for patients with hip OA, this paper is a qualitative in-depth study to investigate patients' need for information and their personal emotional needs. We invited 13 patients to participate in individual interviews, which were audiotaped. The audio-tapes were transcribed verbatim and analysed using an inductive thematic analysis approach.

Results: The thematic analysis revealed a pattern of patients' information and emotional needs, captured in several key questions relevant to the different stages of the disease experience. Based on these results and research literature, we developed a model illustrating the patients' disease experience and treatment continuum. Six phases with accompanying key questions were identified, displaying how patients information and emotional needs arise and change in line with the progression of the disease experience, the clinical encounters and the decision-making process. We also identified and included in the model an alternative route that bypasses the surgical treatment option.

Conclusion: Patients with hip OA are in great need of information both at the time of diagnosis and further throughout the disease development and care continuum. Lack of information may result in unnecessary and dysfunctional misconceptions, underuse of potentially helpful treatment options and uninformed decisions. Patients need continuous support from health professionals and their families in order to find and consider effective treatment strategies.

Keywords: Osteoarthritis, Needs assessment, Professional-patient relations, Decision-making

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Background

Osteoarthritis (OA) is the most common form of arthritis and a leading cause of disability among older adults [1]. While OA is uncommon in people under the age of 45 years, nearly 60 % of all people over the age of 75 are affected by it. In an American prevalence study of hip OA 36 % reported hip symptoms, 28 % had radiographic hip OA, 10 % had symptomatic hip OA, and 2.5 % had moderate/severe radiographic hip OA [2]. The prevalence of symptomatic hip OA in the Norwegian population is reported to be 5.5 % [3]. Overall, women over 50 years of age face up to 50 % higher risk of OA than men. This gender difference, however, is less significant in hip OA than in knee OA [4].

OA is characterized by pain and stiffness, causing subsequent loss of functional capability and independence, with limitations in daily living activities and impaired quality of life [5, 6]. As a result, OA is described as affecting the patient's sense of self and well-being, particularly because of changes in their ability to participate in valued roles and relationships [7]. Given that there is currently no cure for OA, the main goals of treatment are to relieve pain and to preserve physical function. Conservative management strategies typically include education, advice, exercise, weight control, walking aid provision, physiotherapy, activity modification, and pain medication [8]. A Dutch study showed that hip OA patients were under the care of general practitioners for seven years, on average, before they were referred to orthopaedic evaluation for hip replacement. This demonstrates that there is a significant time frame in which to apply and optimize conservative treatment options [9].

Patients' with hip OA experience their condition as painful, chronic, and incurable but susceptible to control through one or more of the aspects of treatment recommended by their health care provider. The more serious and symptomatic the patients experience the condition, the less positive they feel about the management strategies used to control it [10]. Exercise therapy is a central component of the treatment pathway for OA and has strong evidence [11], but adherence problems are evident [12, 13]. The aim of exercise therapy is to improve muscle strength and joint mobility, often requiring considerable patient commitment over long periods of time.

Turner and colleagues explored the beliefs about the causes of OA among primary care patients [14]. Patients believed that OA and painful joints are an inevitable aspect of ageing rather than an indication of disease. The patients struggled constantly to make minimal use of drugs and maximum use of other management strategies such as resting and avoiding activities. The reluctance to use drugs was prompted by fears of dependency, side effects, and effectiveness waning with long-term use. What worries patients about exercise as treatment, and negatively affects adherence, is the belief that exercise increases the wear and tear of the joint. This indicates the urgent need for information in an early phase of OA. One other study found that adherence to pain medication differed from adherence to other prescribed medications. Perceptions of and attitudes toward pain played an integral role in participants' adherence. In general, participants minimized their pain and claimed to have a high pain tolerance. This made them reluctant to take pain medication and when they did so, they took a lower dose of medication or took it less frequently than prescribed [15]. Alami and colleagues [16] identified the views of patients and care providers regarding the management of knee OA. The participants felt that their GPs did not take their complaints seriously. They also felt that practitioners are technically focused, paying more attention to the knee than to the individual, and they feel that not enough time is being spent on education and counselling. The care providers emphasized the difficulty in elaborating treatment strategies and the need for a tool to help in decision-making. This may also be the case for persons with hip OA. According to the NICE guidelines, patients who are refractory to conservative treatment and experience symptoms that have a substantial impact on their quality of life should be referred for consideration of hip replacement surgery [17]. Total hip replacement (THR) is a well-established, cost-effective surgical procedure with overall excellent short and long-term results [18, 19], and declining complication rates [20]. Norwegian surgeons performed about 6320 total hip replacements for OA patients in 2014 [21]. Patients undergoing THR experience reduced pain levels and improved function and quality of life [22], and most patients are satisfied [23, 24]. A recent report from the Nordic Arthroplasty Register Association demonstrates that 86 of 100 patients have a functional replaced hip joint without the need for revision after 15 years [25].

The optimal timing for surgery is not known [26, 27], but may be more important than previously acknowledged. Patients with poor pre-operative function are more likely to have postoperative pain and low postoperative physical function [28, 29]. In a prospective study of 165 patients undergoing hip or knee replacement, Fortin and colleagues postulate that performing surgery earlier in the course of functional decline leads to better outcomes in terms of pain and physical function [30]. Because many of the patients with hip OA are older, they may suffer from multi-morbidity and pain in multiple joints. It can be argued that THR is an acute intervention in the context of a chronic disease, and that decision-making should take into account these experiences as a whole, in the context of patient' preferences, needs and values [31]. With this perspective, it is evident that patient care would benefit from insight into patients' needs.

Aim of the study

To our knowledge, there are no studies exploring patents' emotional and informational needs across the whole care continuum, the studies focussed either on the process related to surgical decision-making or to early phases and self-management support. In the Norwegian Health coordination reform, *Proper treatment – at the right place and right time* [32], there is a strong emphasis on how to strengthen and safeguard the individual patients' role within the health system. The system is currently undergoing a process of comprehensive change to become better coordinated, to meet the needs of a changing population, and to guarantee patients equal access to good, equitable and balanced health and care services. In this process, successful implementation of structures and systems for more cohesive care pathways is regarded as one important step. This pathway approach is used because it is regarded as helpful in orienting all involved systems and services toward assisting the individual to cope with life or to restore functioning [32]. This is also in line with the recent political ambition in Norway to enhance the person-centeredness of the system and create "the patient's health service" [33].

In this qualitative study, we examine, across the disease continuum, the (changing) informational and emotional needs in patients with hip osteoarthritis. Based on these perspectives, we developed a model to describe a typical care pathway based on the patient's experiences and needs illustrated by introspective questions that reflect patients' needs at different stages throughout the disease. The key research questions in this study are: 1) What information and emotional needs do patients living with hip OA have? 2) How do patients' needs change over time as the disease progresses? 3) How does decision-making about total hip replacement take place?

Methods

Study design

The study has an explorative qualitative design. The individual semi-structured interview was considered to be the most appropriate method for collecting data so that participants were given an opportunity to speak openly about their personal "hip OA journey". Interviewing can be defined as a 'professional conversation', having the objective of getting a participant to talk about their experiences and perspectives and to capture their language and concepts in relation to a topic that the interviewer has determined [34, 35].

Sample

A purposive sample of patients with hip OA were included from two settings; the hospital setting prior to scheduled surgery and the GP setting. Seven participants were recruited from an orthopaedic outpatient clinic at a local hospital in the South-eastern part of Norway. The letter of invitation and consent form for participation were sent together with the notice of a scheduled surgical appointment. The second group of six participants was recruited from a general practitioner's office situated at a remote municipality in the Northern part of Norway. A take-home letter of invitation was given to eligible patients by their general practitioners during a planned consultation. Having read the information, interested participants were asked to contact the researcher to schedule an interview. The inclusion criteria were that the participants had a confirmed diagnosis of primary hip OA, were able to communicate in Norwegian and were cognitively capable of participating in an individual in-depth interview of approximately one hour in duration. Furthermore, participants of both genders and different age groups were included. The recruitment procedures at both settings continued until data saturation was considered reached; the point at which new data stopped generating any substantial new ideas [34].

Data collection

The research questions were explored using individual interviews with a sample of patients who were most likely to be able to share lived experiences that illuminate important insights related to the aim of the study. The first group of participants were individually interviewed in private rooms at the hospital hotel one day prior to elective total hip replacement surgery. It was proposed that these patients could provide valuable perspectives regarding their experiences throughout a relatively long history with hip pain, including how and why they came to the decision to undergo hip surgery. The interviews were planned and performed in the evening to that the doctors and nurses had finished their routine work with admissions. It was discussed with the participants whether it was appropriate to conduct the interviews the day before their elective surgery, and they were offered alternative option, but all informants found the suggested time to be convenient. The second group of informants were interviewed at the local health centre where the GP office was situated. The reason for recruiting these participants was to reach out to persons who manage the disease in a primary care context, and to learn from the experiences they had along the OA treatment and care continuum.

The interviews were audiotaped and conducted in the manner of a conversation, although a semi-structured interview guide was prepared. This explorative approach gave the participants an opportunity to freely disclose and discuss issues that were important to them, rather than respond to specific pre-selected questions. A typical interview was initiated by highlighting essential information about the study and its purpose, and then letting the participant talk freely about his or her "hip journey", prompted by an open question like "can you start by telling about yourself and how your life is affected by your hip OA?". Recurrent follow-up questions were *"can you describe in words how your pain feels?", "what strategies help you cope with your hip pain?", "what/how have you learned about osteoarthritis?", "does your pain have any consequences for your social life?"* and *"can you tell me (if) how and why you have decided to undergo hip replacement?"* When the interview was presumed to be finished, the audio-recorder was stopped. The participant was then given some time to settle, whereupon some participants disclosed additional thoughts and perspectives that hadn't been discussed previously. The audio-recorder was then re-started by the interviewer, but the participant was explicitly made aware of the opportunity and right to delete this part of the interview.

After each interview, the researcher made notes in order to preserve immediate reflections and important features of the conversation. The participants completed a self-reported questionnaire of basic demographic data, duration of OA symptoms, help-seeking behaviour and self-reported comorbidities. This information was collected to acquire relevant data on the characteristics of the participants.

Research ethics

The study is approved by the Regional Committee for Medical and Health Research Ethics (Ref.: 2013/1231) [36] and complies with the ethical principles stated in the Helsinki declaration [37]. All participants were informed of the goals and design of the study and were assured of confidentiality before they provided written informed consent to participate. At the time of the interview, participants were re-informed and given time to ask any questions they might have.

Qualitative analysis

Each audio recording was transcribed verbatim in word processing software by the first author, aided by a basic notation system and transcription kit. The transcripts were imported into NVivo (Version 10), a software program that allows systematic coding and retrieval of qualitative data. Inspired by Braun and Clarke, we used an indicative approach to thematic analysis guided by a six-phased analytical process [34, 35]. Braun and Clarke vouch for the rigorous, independent and flexible qualities of this process and explain it as "*a method for identifying, analysing and reporting patterns (themes) within data"* [35]. A theme is defined as *"an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole"* [38].

At the initial coding stage, two researchers (EB and TE) independently read and coded two interview transcripts. This collaborative coding process sought to 'calibrate' the analytic approach by facilitating structured discussions of possible interpretations. The coded extracts were carefully compared and modified, and preliminary themes were defined. The inductive analytic approach proceeded with iterative and comprehensive coding across the remaining dataset. During this process, each of the coded transcripts was re-checked against the audio-tapes to make sure that the themes bridged the essence of the transcripts with the research questions in focus. When the results had been summarized through major themes, we conducted discussions with nurses and orthopaedic surgeons with the purpose to ascertain their 'common sense' opinions of the accounts, based on their experiences from working on a daily basis with hip OA patients. This contributed with a sense of reassurance that the main results and discussions points were realistically presented, as seen from their clinical experience. The first author also spent time observing out-patient consultations and had informal conversations about the research questions and preliminary results with in-patients and their care providers at the ward. The ecological validity of the study was by this strategy strengthened [34].

Results

Sample

Nine of the 13 participants had experienced hip symptoms for more than six years, and a subset of five patients for more than ten years. Four of the participants were still working, but were partly on sick leave. Both genders are evenly represented with a wide age distribution, the youngest at 59 years old, and the oldest 88. All seven participants in Group One underwent elective hip replacement the day after the interviews. One participant in group two was accepted for surgery, while two participants were referred and were awaiting orthopaedic evaluation. One participant had previously undergone hip replacement for OA in the contralateral hip. One participant had recently undergone revision surgery due to postoperative femur fracture. A majority had other health problems in addition to their hip OA, such as fibromyalgia, rheumatoid arthritis (RA) and diabetes. Most had access to the Internet and used it at on a regular basis, but only a few used it to seek health information. The interviews had a mean duration of approximately 69 min. All participants in Group One were treated with an anterior total hip replacement technique. The characteristics of the participants are summarized in Table 1.

The hip osteoarthritis continuum

As a result of the qualitative analysis presented in the following sections and from reviewing the literature, we developed a care pathway model, *The hip OA continuum*, which illustrates a patients' typical "hip journey" (Fig. 1).

Table 1 Characteristics of participants in Group One (ID 1–7) and Group Two (ID 8–13)

ID	Age	Gender	Marital status	Children	Internet access	Internet usage	Education level	Work status	Time with hip-pain	Self-reported comorbidity	Interview duration (min)
1	85–89	Female	Married	Yes	Yes	Never	Junior high school	Retired	6–7 years	Acute back-pain (recent injury)	133
2	80–84	Female	Widow	Yes	No	N/A	High school	Retired	2–3 years	Diabetes	68
3	60–64	Male	Married	Yes	Yes	Weekly	High school	Mechanic	8–9 years	Hemochromatosis	68
4	70–74	Female	Widow	Yes	Yes	Daily	High school	Retired	6–7 years	RA	65
5	75–79	Male	Married	Yes	Yes	Daily	High school	Retired	4–5 years	Bilateral Hip OA	61
6	70–74	Female	Single	No	Yes	Weekly	High school	Retired	>10 years	RA, shoulder OA	69
7	65–69	Male	Single	No	Yes	Daily	University	Retired	4–5 years	None	80
8	65–69	Female	Married	Yes	Yes	Weekly	University	Retired	4–5 years	Fibromyalgia	60
9	55–59	Female	Married	Yes	Yes	Daily	Junior high school	Shop assistant	>10 years	Knee OA	70
10	65–69	Male	Married	Yes	Yes	Daily	University	Teacher	>10 years	Bilateral Hip OA	58
11	65–69	Female	Married	Yes	Yes	Daily	University	Teacher	>10 years	Fibromyalgia, hand OA	67
12	70–74	Male	Married	Yes	Yes	Rarely	Junior high school	Retired	6–7 years	Bilateral Hip OA	46
13	65–69	Male	Married	Yes	Yes	Monthly	High school	Retired	>10 years	None	51

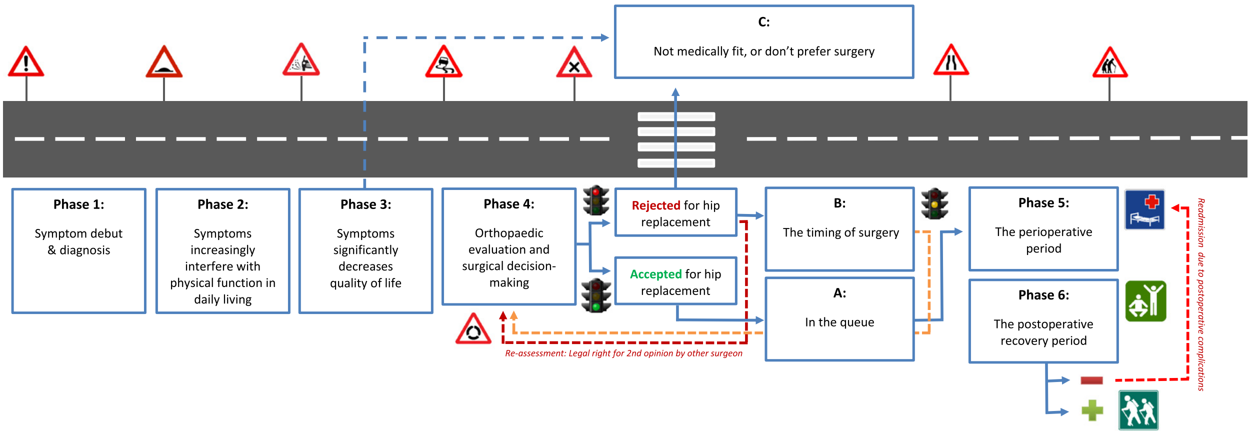

Fig. 1 The hip OA continuum. Needs and help-seeking behaviour change over time dependent on disease severity, treatment response and decision-making processes

The model is divided into six phases, designed to demonstrate the informational and emotional needs of patients with hip OA, and how these needs may change over time related to the development of the disease, the clinical encounters within the health care services, and the subsequent decision-making processes. The patients' needs' are analysed and condensed into key questions representing the main concerns of the patients at the respective phases along the continuum. Thus, this approach has a distinct person-centred focus.

1) The first phase represents the early hip OA-stage where the first symptoms emerge, diagnosis is set and an initial treatment plan is discussed.
2) The second phase represents the moderate hip OA-stage. This phase indicate a deterioration of symptoms, leading the patient to seek and try out more treatment options that might help the situation.
3) The third phase represents the severe hip OA-stage, where the symptoms are perceived as severe and more or less refractory to conservative treatment, leading up to a need of referral for orthopaedic evaluation.
4) The fourth phase represents the surgical decision-making phase with three possible options where the patient and the orthopaedic surgeon discuss whether or not the patient will benefit from hip replacement surgery. A) Patients who are accepted for surgery are placed in the waiting queue. These patients are advised to undergo pre-surgical muscle strengthening exercises and prepare for the postoperative recovery period at home, by procuring necessary ADL-aids. B) Patients who are rejected or choose to await surgery, are advised to continue conservative treatment until a renewed orthopaedic evaluation is warranted. If patients are unhappy about the final decision, they have a legal right to a second evaluation by another surgeon. C) This route represents an alternative route for patients who are not medically suitable for, or for some reason do not prefer to undergo surgery. This route might be taken at any point through the continuum, and it includes all treatment recommendations, in addition to surgery as a final option. These patients need to come to an acceptance of the situation, while optimizing the available non-surgical treatment options in order to live a meaningful life despite pain and its accompanying limitations.
5) The fifth phase represents the perioperative phase when patients follow a standardized hip-replacement programme. The patients receive interdisciplinary pre- and postoperative care, guided instructions and training concerning movement restrictions and general take-home physical exercises that stimulate optimal joint function.
6) The sixth phase represents the postoperative recovery period. The minority of patients who at some point experience post-operative complications may be re-admitted to the orthopaedic clinic for revision surgery, whereas the majority can enjoy a functional hip, although requiring a substantial rehabilitation period until fully recovered.

It is important to point out that for some patients this hip-journey may last for several years, but only months for others, reflecting individual differences in patients' disease development, health seeking behaviour and access to appropriate health care services.

Patients´ key questions through the hip OA continuum

An overview of the patients' questions along with a selected empirical example are given in Table 2. A thick description of the participants' experiences follows, structured under each phase of the continuum. We include a comprehensive presentation of verbatim quotations in order to give the participants a voice and to display more of the empirical grounding for the six-phased model and the condensation of meaning into key questions. At the end of the description of each phase, the patients' experiences are summarized.

Phase 1: The early stage of hip OA - symptom debut and diagnosis

In the early hip OA stage, some participants experienced the hip pain as vague or generalized, characterized by intermittent pain and stiffness. Many participants also described concurrent pain experiences in other joints than the hip. Depending on the participants' health care seeking behaviour and the perceived severity of pain and its interference with daily functioning, they visited their GP to get an explanation of what it was.

> *About 10 years ago, I noticed something wrong with my ankle, and then it spread upwards... I then started to get problems with my hip, when I sat down – when I got up and things like that... It felt like something was creaking in there, and I surely hoped it was muscular. I don't remember how long it is since I had my first X-ray, but I was permitted one, and they confirmed wear in the joint.... it wasn't that bad in the beginning, but pretty soon afterwards, it took a turn for the worse (P10, male 65).*

Some participants clearly had waited some time before seeking help from their GP, demonstrating individual differences in health care seeking behaviour.

> *I had hip pain for a longer period of time. I mentioned it to my GP that I had a lot of pain in my hip. I would describe it as intermittent, but with some constant levels of pain. And then I was referred to... yes, for an X-ray maybe? I can't remember if it was an X-ray or MRI, but nevertheless– one evening the GP called me at home and said that it was not unusual that I had this pain, because the hip joint was totally worn out... and that is quite a few years ago, at least seven years (P3, male 60).*

Some participants had a tendency to trivialize their experiences or play down their concerns by referring to possible natural causes, like getting older, pain conditions running in the family, or by comparing their problems with others.

> *I think that as you get older, you expect such things to occur... things you might have to accept [...] I have to admit that now, as a 65 year old – my father was 63 when he died – I think that I am so lucky to still being able to work and be active, and you see so many others that are incapable of that... you know? They*

Table 2 Phases and questions throughout the hip-OA continuum

Phase	Key questions	Typical quotes
1. Symptom debut & diagnosis	Something is wrong, what is this hip pain?	I had noticed this pain in my hips that persisted over a period of time. Then I told my GP about this pain, and he referred me for an X-ray (P3).
2. Symptoms increasingly interfere with physical functioning	My hip really bothers me, what can I do?	I haven't taken any painkillers. I don't want to […] I believe that if you take painkillers you'll become worse and get more pain in the end (P5)
3. Symptoms significantly decreases quality of life	I can´t stand the pain, is it time for surgery?	I have to crawl up the stairs using the arms to push myself upwards (P8)
4. Orthopaedic evaluation and surgical decision-making	Will a hip replacement help me with my problems?	I have long been aware that I would need to replace the hip at some point, but I wanted to wait as long as possible (P3).
4a. The timing of surgery	The doctor tells me that the timing is not right for me, what now?	The doctor said that it (the joint) was worn out, but not enough to allow surgery. Then I just had to wait until it was bad enough (P6).
4b. In the queue	I am waiting for surgery, what should I do?	I have done exercises three times a week the last 3–4 months to prepare for the operation. It is important to strengthen the muscles to become best prepared for the period after surgery (P4)
4c. Not medically fit, or don't prefer surgery	What are my options if I am not receiving surgery?	I have come to a point to wonder whether surgery is a wise thing to do - I'm not so happy about that either you know (P9)
5. The perioperative period	What will happen at the hospital?	They were very good at informing me about what to expect during the hospital stay- it was excellent information! (P10).
6. The recovery period	What can I expect after having surgery?	I was told that the prosthesis isn't worth anything without the muscles- it must be rebuilt… I therefore chose to take part of all available training at the rehab centre (P12).

> *suffer from far more serous conditions – everything is worse than this… It's not serious in a way – nothing really to talk about (P11, female 65)…*

Some also indicated a feeling of shame attached with talking about their emergent hip pain or OA diagnosis, and felt that their hip disease was lower in the hierarchy than other diagnoses, such as cancer and diabetes type 2.

> *It's like…… almost a bit embarrassing to talk about…… it's something that you kind of need to expect when you are so lucky to get old… […] I believe there is a hierarchy – a status related to different diseases among…. in the health care system, yeah? When I got cancer, I was sort of at the top of the pyramid (P11, female 65).*

Some participants clearly stated that they did not exclusively visit their GP to discuss their hip problems, but that it was brought up as an implicit concern at the end of the consultation.

> *I have diabetes and I have typically discussed my hip problems when I have been to my doctor to check my blood glucose (P2, female 84).*

A common finding across the data was that the participants had not received general information about OA and pain management from their GP. Most of the participants did not actively seek information during consultations. This was explained partly by the fact that they did not know what to ask specifically and because the GP was not perceived to have the necessary expertise about OA.

> *GPs aren't specialists in osteoarthritis, so they…. they do what they can to refer me within the health care system, so I can't say that I have anything to complain about in that respect… I get help for things I ask about, but I don't really expect to receive any particular kind of information (P9, female 59).*

One participant explained that she had chosen to replace her GP.

> *I decided to replace this GP immediately, because I thought… I was a bit mad at him - I had lived and struggled with this for so many years without anything being done. They must dedicate more time to each patient, right? (P1, female 88).*

One participant expressed great satisfaction with her GP, however, demonstrating the value of having an attentive GP.

> *I can tell you that I have the world's best GP! She is 67 years old and dreads that she must retire at 70. She is so strict! She gives me all the information I need and instructs me what to do. - You should do this kind of exercises and you'll have an X-ray and you should do this – she arranges the whole show. Everything comes into my mailbox and I check it regularly (P4, female 70).*

Some found it difficult to appropriately disclose their concerns to their GP.

> *You know, when you visit the doctor you do it because of the pain… but .you don't know what causes it…. it's therefore a bit difficult to know what to ask about (P9, female 59).*

Many discussed available time as a barrier.

> *The GP is just keen to get you out in order to let the next patient in… He listens to what you say, but haven't taken it seriously enough (P3, male 60).*

The common experience patients have at this initial stage may be summarized in the question: "Something is wrong, what is this hip pain?" The patients' experiences an unfamiliar hip-related pain sensation that may require a visit to the GP. The GP acquires the medical history, performs relevant examinations (e.g. Harris hip score) and refers the patient to X-ray examination to set the diagnosis OA of the hip. The patient receives basic and variable information about OA and available treatment options depending on the severity of the symptoms and the GP's and other health professional's competence and communication skills.

Phase 2: The moderate pain stage of hip OA – symptom deterioration and decreased physical function

As the hip problems evolved, the participants experienced increased pain, causing difficulties in performing regular and self-care activities.

> *When I have taken a shower, I have troubles drying my feet. I can't reach down, and I can hardly manage to put my socks on. I can't care for my toenails - cutting them for example - that is really difficult on this leg. Then I have to wear long trousers - grab the trouser leg and force the left leg on top of the right one. When I do that I get a lot of pain…. I somehow manage to complete the task, but it's no solution to continuously cross the pain threshold – I have done that increasingly often lately (P4, female 70)…*

Most of the participants had several x-rays, hoping that it would provide some answers.

> *When results of the X-ray came, the radiologist had told the doctor that nothing was wrong with me – they didn't find anything.... Ok, it thought, then there was nothing I could do about it… But with time it became worse, and I was....... I managed to visit the doctor a few times, and eventually they advised me to try those needles (acupuncture)....... (P1, female 88).*

Most participants had clear objections about taking pain killers on a daily basis, although the doctor had prescribed it. They felt there were too many pills to consume with potential troublesome side effects. A recurrent description was not being comfortable with taking pills in general, with statements such as "I'm not a pill-person".

> *It's not ok to carry on like that....... But they....... they just prescribe pills- and I'm not a pill person....... I said to them that pills only relieve the pain, it doesn't....... you're hip will only get worse, and it doesn't cure you....... You know, when you have taken pills over a period of time you'll eventually need even stronger ones (P1, female 88).*

One participant explained that he did not take painkillers because he believed that it might make the situation worse in the long run.

> *No, I don't believe in that. I think that if you take pain killers, it will eventually lead to even more pain and worsening of the joints....... you won't feel the pain and then the situation gets worse - I believe so anyway....... I would rather choose to rest – when you have had some rest, the pain isn't so bad (P5, male 75).*

Despite the general picture of non-adherence to pain medication, some felt that taking painkillers on a regular basis helped them when they tried to cope with the situation.

> *The point is to try to manage it as long as possible. I have taken....... what have helped me so far is that I have taken a slow release tablet- one Ketoprofen every morning for breakfast....... By doing that I actually have managed to live with the pain. That is in fact the reason why I have been able to cope for so long (P3, male 60).*

Some participants described alternative strategies to cope with the pain.

> *I try to concentrate on other things than sickness and pain....... Yeah- simply re-focus. That my focus should be on other things, and I also try to stay positive! (P4, female 70).*

Most of the participants in this study did not attend physiotherapy on a regular basis. Some explained that they felt it was unnecessary because they had other ways of staying physically active.

> *I don't think there is any point in attending physiotherapy .... I don't think they make a difference. The one I had didn't anyway, and I felt kind of cheated. The only thing I did was ride a bike, that's all (P5, male 75).*

Experiences attributed to the moderate hip OA stage can be summarized in the question: *My hip really bothers me, what can I do?* The patients experience that the hip problems continue to evolve, causing decreased physical function due to increased and more persistent pain levels throughout the day. They have various ways of adapting and coping, and some try alternative treatment options. Most continue to live as before, but using activity modification as a strategy to cope with pain and avoid pain exacerbation. Patients become more dependent on help from others for physically challenging household chores. Most have tried physiotherapy, but with various results. Some take pain medication in order to stay active, but most do not because of misconceptions or fears of possible side effects.

Phase 3: The severe pain stage of hip OA– the emerging need for an orthopaedic evaluation

When the symptoms significantly restricted abilities to do desired activities in daily living, some participants expressed that they had explicitly requested referral to an orthopaedic surgeon.

> *It is very unpleasant. I'm pretty active these days - have a lot to do and I want to make the most out of my days. So, it bothers me a lot....... that is why I went to the doctor and said that we need to fix my hip. I can't live with this – its impossible (P5, male 75).*

A decision for surgery may be driven by the hope for a better life.

> *When I hear and see that people get a significantly improved life after surgery....... then, yes....... that makes me think about it as well. I have independently come to the conclusion that if it can help me to live a better life, I'm opting for surgery (P8, female 65).......*

Work responsibilities can influence a decision or desire to undergo hip replacement.

> *I had plans to do this last year, but I received a job offer that......... I have to do this kind of work during*

> *the winter season, so that I don't make things worse for myself, huh? So, it's about planning... And then, yet another year has passed. If so much time elapses, then another year goes by. That is how I have thought about it for many years really (P3, male 60).*

One participant wanted surgery in order to be able to work, but was advised to wait.

> *What has annoyed me the most is that they won't do a joint replacement... If only for the knee, so that I might perform better at work– during the time I have left... They say that as long as I manage as it is now, it's not worth doing surgery, due to the fact that they can't give any guarantees that it will turn out for the best (P9, female 59).*

Most participants explained that their social network of friends, neighbours and family was an important source for information and advice relating to decision-making about total hip replacement.

> *I have a pretty wide social network, and many of them have in fact undergone hip replacement. That makes us talk about these things. It becomes a topic for discussion, and we give each other advice (P4, female 70).*

Learning from others' experiences provided hope for a better future.

> *When you have suffered long enough you'll try almost anything... learning from the experiences of others I have talked to, who have had a successful hip replacement– it makes me see possibilities for myself as well (P13, male 65).*

Undergoing hip replacement was perceived as a common procedure with excellent outcomes.

> *You know, everyone has heard about someone who has replaced hips, and with such good outcomes– the surgeons now have such effective techniques with excellent outcomes (P3, male 60).*

Topics concerning possible risks for pre- and postoperative complications seemed to be of little importance in deliberation about undergoing THR. One stated that there are no guarantees in life.

> *He said (the orthopaedic surgeon) that you never know how it turns out... But I'm ready to take that chance– no one have absolute guarantees for anything in life, yeah? (P1, female 88).*

Others relied heavily on the experience and competence of the orthopaedic surgeon.

> *I consider the probability of that occurring very small, because I have always had confidence in specialists, and I trust them to deal with it... I won't enter the operating theatre being scared! (P13, male 65)*

One participant brought up personal experiences with surgery performed earlier as grounds for deliberation about possible risks.

> *Of course there is a chance, but with the two other operations that I've had, the gall bladder in 1999 and this (other hip) last year– it went just fine! I didn't experience any problems with those... (P6, female 73)*

The common experience patients have at the advanced stage may lead up to the question: *"I can't stand the pain, is it time for surgery?".* As the disease progresses and interferes with the patient's physical function and well-being, the GP prescribes pain medication, refers the patients to a physiotherapist and gives some advice on how the patient should adapt and self-manage. While some patients find satisfactory ways to cope at this stage, some do not respond effectively and experience that the disease continues to progress, leading to significantly decreased physical function and quality of life. The pain levels increase and the sleep quality decreases as a consequence of frequent pain incidents during the night. These patients may be considered for a specialist evaluation to decide whether hip replacement is appropriate.

Phase 4: Orthopaedic evaluation and surgical decision-making

Participants stated that pain was the main reason for considering hip replacement surgery.

> *The reason was to get help and pain relief. It is... it's just that. Yes, I don't exactly know why I asked to be referred, but I have had such terrible pain and currently have terrible pain. I kind of consider my future prospects as dark if I have to live like this the rest of my time! If anything can be done... but I don't know, maybe I can do more– exercise more, or?... (P8, female 65).*

A common finding was that it seemed important for the participants to discuss experiences with others who had undergone hip replacement.

> *It's something you really need to embrace... it's a mental... you kind of surrender one part of the body... voluntarily, you know? I therefore found it helpful to*

> *listen to their story about the time before and after surgery. I found it very important to learn from their experiences… (P10, male 65).*

Participants who were denied hip replacement were told by their GP or orthopaedic surgeon that the features of the X-ray did not show significant changes that would allow for a hip replacement, or they were categorized as too young and therefore advised to postpone the procedure as long as possible.

> *The X-ray showed very little radiographic changes, and they kind of laughed at me and… I asked them if any help is available for this… No! Come and see us in three years they said – that was it… (P8, female 65).*

This phase represents the process of surgical decision-making and can be summarized by the question: "Will a hip replacement help me with my problems?". This illustrates a complex process that is regarded as "the point of no return", as one participant explained. After having updated hip x-rays, the orthopaedic surgeon and the patient review the current situation together. Many participants said that reaching this phase was a relief - something they knew existed as a final option and that might help the situation significantly. Decision-making for THR seems to start before the actual meeting with the orthopaedic surgeon, either as a result of advice from health professionals or after observing others' experiences from undergoing THR. The patients know that this is a final and effective option, but the issue of timing depends on several factors. The question "The doctor tells me that the timing is not right for me, what now?" illustrates rejection as a possible outcome of surgical decision-making. In Norway, these patients have a legal right to a renewed evaluation and may opt for this if they disagree with the decision. Otherwise, these patients continue at their best with conservative treatment, but may be referred for a second orthopaedic evaluation at a later point in time. The question "I am waiting for surgery, what should I do?" reflects the outcome where patients are accepted for hip replacement and placed on the waiting list.

Phase 5: Perioperative period

Most participants who were due for THR had been advised to do joint muscle-strengthening exercises prior to hospital admission.

> *I was told that it is smart to strengthen the muscles… I therefore started intensive training, but it was far too late… I started 14 days prior to surgery with intensive training, but I realize that I should have started much earlier. Clearly! (P10, male 65).*

However, one participant had been informed that muscle strengthening was contraindicated in the preoperative period.

> *We were told that there was no use in doing that… It was no benefits doing surgery on hard muscles… The soft muscles however, the ones that were little trained was better –– they healed more quickly and you would have a shorter recovery period (P12, male 72).*

Elective patients receive standardized information prior to admission that explains what to expect and what they should do to prepare for the recovery period.

> *I think that the information I received here at the hospital – the letters about where to meet, when and what tests to take – generally, the whole course of the operation. I think it was fantastic! (P4, female 70).*

Most of the participants in this study expressed satisfaction about the information provided by the hospital staff.

> *The health providers here are very informative and good at telling what to do and what to expect. It makes you gain confidence in the staff… Yeah, I think it has been very satisfying! (P5, male 75).*

After hospital admission, patients follow a standardized treatment and rehabilitation program. Most patients are discharged during the first or second postoperative day, but with an expectancy of a 6–12 month recovery period to regain full physical strength and energy. This phase is reflected by the question: "What will happen at the hospital?". It represents a range of possible concerns and expectations that the patients might have during this period of the continuum. They are in need of professional guidance on how to adapt to a life with a prosthesis, and they learn ways to optimize its function and minimize the likelihood of complications.

Phase six: Postoperative recovery

Patients are normally not offered in-house rehabilitation following THR in Norway. Most of the participants in Group One who had surgery the next day expected to return to their homes after discharge from the hospital. However, one of participants in Group Two who had previously undergone THR explained the value of admission to a rehabilitation unit.

> *I spent four weeks, that is the maximum time allowed… there you can get all the training you need. Cycling, gymnastics of all kinds, training with weights on your feet, and climbing up and down the steps on a*

> *ladder… yes– overall, to get into shape… I don't question that this is what has helped me improve this much (P12, male 72).*

The question; "what can I expect after having surgery?" reflects the needs of patients who have undergone hip replacement. They are pre-informed before surgery and have completed preparations for this period, but are in need of support and information about ways to prevent postoperative complications. All patients are expected to stay physically active in order to optimize stability and function in the hip joint.

The alternative route: The non-surgery option

Patients who are not considered medically appropriate for surgery, or for some reason do not prefer the procedure, seem to have a need to accept the situation, while optimizing the available non-surgical treatment options in order to live a meaningful life despite pain and its accompanying limitations. One of the participants had ambivalent thoughts regarding surgery.

> *I honestly don't know… you hear what I'm saying – I have come to a point to wonder whether surgery is a wise thing to do. I'm not so happy about that either, you know (P9, female 59).*

One participant said that it was essential to accept the situation, but this did not mean one should let go of the hope that help could be obtained.

> *I do feel that I accept it, I really do… I have to! I must accept it, but I am still thinking about whether there might be something that can help. I always do (P8, female 65).*

This alternative route is reflected through the question: "*What are my options if I'm not receiving surgery?*". This route is included as a possible outcome from surgical decision-making, as some patients may be ineligible for THR and others are cautioned because they have a greater than average risk of post-surgical complications (i.e. Osteoporosis, obesity, diabetes mellitus or heart disease). Some patients may also choose not to receive surgery due to personal reasons (i.e. concerns, previous experiences with surgery, advice from others).

Discussion

The qualitative approach used in this study revealed findings that capture several aspects of the complex nature of how hip OA patients experience the development of their illness, including the encounters with the health care system and the clinical decision-making processes. The model presented with the accompanying key questions give an overview of the OA hip-journey, based on the participants' experiences and research literature. We believe that it provides a simplified, but realistic map of how patients with hip OA navigate and interact with health professionals throughout the continuum. The identified questions are condensed representations of a range of related questions that patients have across the continuum. These questions need to be appropriately addressed in order to increase the patients' possibilities for effective self-management and informed decision-making.

Patient needs

The majority of the participants did not seem to receive information relevant to self-management and surgical decision-making, but at the same time they didn't expect to be given this kind of information from their GP. Most of the participants did not adhere to a prescribed pain medication plan. Furthermore, most did not experience benefits from individual training with a physiotherapist. As a result, they struggle to find effective pain-management strategies in daily living, often including avoidance of activity resulting in increased pain and decline in physical function. Similar and other barriers to utilization of recommended treatments have been reported in several studies [12, 15, 39, 40]. Sanders et al. [41] identified barriers related to three stages: first, some were reluctant to present themselves for treatment because of their perceptions that arthritis was part of normal ageing and that there was little that could be offered to them; second, while many had consulted GPs, their experiences were mostly negative, with GPs appearing to confirm the lack of effective treatment and rarely offering referral to secondary care; and third, waiting lists and rationing were perceived to be a barrier to getting treatment in secondary care and sometimes surgery appeared to be denied because they were considered 'too young' or not sufficiently disabled.

These barriers may partly be explained by a gap in essential knowledge about OA and available treatment alternatives [16, 42, 43]. Dissemination of key information about OA is one approach that could increase patients' knowledge and abilities to make informed decisions. Key messages are the important information a patient needs to know about a disease, its causes, its diagnosis, and its management. A total of 21 key messages have been identified and prioritised through a multistage consensus process involving both OA experts and patients [44].

Decision-making for total hip replacement

The general picture in this study is that patients are not appropriately informed about possible complications associated with THR. This is problematic. Although THR have low complication rates, patients should be realistically informed about possible pre- and postoperative complications. Only a few of the participants expressed explicit concerns about undergoing surgery, and none stated that they had discussed the associated risks with an orthopaedic surgeon or GP. It seemed that they generally put their trust in the orthopaedic surgeons' professional skills and that risks, according to them, hadn't been appropriately addressed when they decided to undergo THR. When asked about the type of information that was perceived as important during orthopaedic consultations, most male participants explained a need to understand how the prosthesis is designed, and that the orthopaedist had drawn pictures and used models to demonstrate how it is fitted into the hip joint. Other aspects were related to an expectation of pain relief and restored physical function, and the abilities to return to work. These expectations have been reported as the most important pre-operative expectations that influence a decision for undergoing surgery [45]. Although few of the patients discussed concerns explicitly during the interviews, it is appropriate to assume that the setting (at the hospital) and timing of the interview (one day prior to surgery) might have affected their desires to talk about concerns that might cause additional anxiety or feelings of uncertainty. Nevertheless, studies demonstrate that patients make decisions for THR without raising all their concerns during clinical consultations. A study of 59 patients with hip or knee OA considering surgery identified a total of 164 expressed concerns by using telephone interviews, but found that the patients raised only half their concerns during planned audiotaped orthopaedic consultations. The identified concerns pertained to the surgery (anticipated quality of life after the surgery, the care facility, the timing of the operation, and the patient's capacity to meet the demands of the surgery) and the surgeons (their competency, communication, and professional practices). Patients were highly selective about the concerns they raised; concerns about logistical aspects of surgery (about the care facility and the timing of the operation) and the anticipated quality of life after the surgery were often expressed, while concerns about their capacity to meet the pre- and postoperative demands of surgery were raised less often, and concerns about surgeons were rarely raised [46].

The process of decision-making for THR should ideally be initiated by the GP during the early phases of the continuum in order to provide time and opportunities for careful deliberation and to identify the optimal timing for referral to an orthopaedic surgeon. The patients need to establish their goals and expectations, examine their values and preferences and how they relate to their ability to cope with their condition, their need for pain relief, quality of life restoration, and the goals and expectations of having THR or not. They might need to acknowledge fears surrounding the procedure and any previous experiences. Physician opinion, the social impact of others, and knowledge and concerns about recovery are also factors that may impact patients' decisions regarding surgery [47]. Shared decision-making (SDM) is increasingly advocated as an ideal model of treatment decision-making in the medical encounter [48]. This includes an evolution from the paternalistic model, in which the physician tells the patient what the treatment will be, to a more patient-centred approach [49]. The SDM model allows both the physician and the patient to actively contribute towards the medical decision. Physicians educate the patient about the treatment options available for their condition, whereas patients indicate how their preferences and values relate to these options. The patient and physician then work together in order to reach a consensus in a two-way exchange of information that enhances the potential outcome for the patient [47].

Strengths of the study

We were able to recruit a relatively broad sample of participants in terms of age, gender and distribution within the hip OA continuum. By conducting in-depth interviews, we produced a rich source of qualitative data which contributes to the understanding of how patients might experience living and coping with hip OA within the Norwegian health care system. It is one of few studies that focuses on the whole hip OA continuum of care, as seen from a person-centred perspective. The proposed model and questions can act as a guide to help patients and their families to visualise the complexity of the disease, what to expect and their role as active participants in communication and decision-making.

Limitations

In this study we have made an effort to illustrate a typical hip OA continuum and further describe accounts that represent patients' informational and emotional needs expressed explicitly or implicitly by the participants. It is clear that all patients entering this OA continuum are heterogeneous human beings with individual needs that are impossible to fully account for through methods used in this study. A relatively small sample of patients were included, thus we expect that other important aspects related to patients' information and emotional needs are missing from this presentation. A majority of the patients included in the study had developed severe hip OA, and were due for or contemplated surgery. It is therefore likely that patients at early stages of hip OA are underrepresented in the sample and their experiences and questions less clearly explored. A future study could use the hip OA model as basis to recruit and allocate participants to each phase, and to assess specific needs expressed by both patients and their care providers.

Conclusions

This study reveals that patients with hip OA are in great need of information and emotional support throughout the whole hip OA continuum. Patients' needs, concerns and expectations must be appropriately understood and met by health providers caring for hip OA patients. The knowledge and model developed through this study will be used as a basis in the development of a web-based tool for hip OA patients, their families and involved health providers designed to increase patients' knowledge and support communication during the process of preparing individualized care plans in clinical settings.

Competing interests

All authors declare to have no competing interest.

Authors' contributions

EAB was responsible for collection and preparation of the data and was the primary author of the manuscript. HE acted as EAB's main supervisor and provided feedback and support continuously during the phases of data collection, analysis and preparation of the manuscript. TE and SvD assisted the qualitative analysis and provided critical comments and suggestions for revisions. SvD, HK and LM contributed in discussions regarding the background and purpose of the study, as well as providing feedback on the manuscript. All authors read and approved the final manuscript.

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References

1. Neogi T, Zhang Y. Epidemiology of osteoarthritis. Rheum Dis Clin N Am. 2013;39(1):1–19.
2. Jordan JM, Helmick CG, Renner JB, Luta G, Dragomir AD, Woodard J, Fang F, Schwartz TA, Nelson AE, Abbate LM et al: Prevalence of hip symptoms and radiographic and symptomatic hip osteoarthritis in African Americans and Caucasians: the Johnston County Osteoarthritis Project. J Rheumatol. 2009; 36(4):809–15.
3. Grotle M, Hagen KB, Natvig B, Dahl FA, Kvien TK. Prevalence and burden of osteoarthritis: results from a population survey in Norway. J Rheumatol. 2008;35(4):677–84.
4. Busija L, Bridgett L, Williams SRM, Osborne RH, Buchbinder R, March L, Fransen M. Osteoarthritis. Best Pract Res Clin Rheumatol. 2010;24(6):757–68.
5. Smith TO, Purdy R, Lister S, Salter C, Fleetcroft R, Conaghan P. Living with osteoarthritis: a systematic review and meta-ethnography. Scandinavian Journal of Rheumatology 2014;43(6):441-52.
6. Neogi T. The epidemiology and impact of pain in osteoarthritis. Osteoarthr Cartil. 2013;21(9):1145–53.
7. Ballantyne PJ, Gignac MAM, Hawker GA. A patient-centered perspective on surgery avoidance for hip or knee arthritis: Lessons for the future. Arthritis Rheum. 2007;57(1):27–34.
8. Zhang W, Moskowitz RW, Nuki G, Abramson S, Altman RD, Arden N, Bierma-Zeinstra S, Brandt KD, Croft P, Doherty M et al: OARSI recommendations for the management of hip and knee osteoarthritis, Part II: OARSI evidence-based, expert consensus guidelines. Osteoarthr Cartil. 2008;16(2):137–62.
9. Paans N, van der Veen WJ, van der Meer K, Bulstra SK, van den Akker-Scheek I, Stevens M. Time spent in primary care for hip osteoarthritis patients once the diagnosis is set: a prospective observational study. BMC Fam Pract. 2011;12:48.
10. Hampson SE, Glasgow RE, Zeiss AM. Personal models of osteoarthritis and their relation to self-management activities and quality of life. J Behav Med. 1994;17(2):143–58.
11. Golightly YM, Allen KD, Caine DJ. A comprehensive review of the effectiveness of different exercise programs for patients with osteoarthritis. Phys Sportsmed. 2012;40(4):52–65.
12. Campbell R, Evans M, Tucker M, Quilty B, Dieppe P, Donovan JL. Why don't patients do their exercises? Understanding non-compliance with physiotherapy in patients with osteoarthritis of the knee. J Epidemiol Community Health. 2001; 55(2):132–8.
13. Austin S, Qu H, Shewchuk R. Association between adherence to physical activity guidelines and health-related quality of life among individuals with physician-diagnosed arthritis. Qual Life Res. 2012;21(8):1347–57.
14. Turner AP, Barlow JH, Buszewicz M, Atkinson A, Rait G. Beliefs about the causes of osteoarthritis among primary care patients. Arthritis Rheum. 2007; 57(2):267–71.
15. Sale JEM, Gignac M, Hawker G. How "bad" does the pain have to be? A qualitative study examining adherence to pain medication in older adults with osteoarthritis. Arthritis Rheum. 2006;55(2):272–8.
16. Alami S, Boutron I, Desjeux D, Hirschhorn M, Meric G, Rannou F, Poiraudeau S. Patients' and practitioners' views of knee osteoarthritis and its management: a qualitative interview study. PLoS One. 2011;6(5):e19634.
17. National Clinical Guideline Centre (UK). Osteoarthritis: Care and Management in Adults. London: National Institute for Health and Care Excellence (UK); 2014 Feb. (NICE Clinical Guidelines, No. 177.) Available from: http://www.ncbi.nlm.nih.gov/books/NBK248069/.
18. Hamel M, Toth M, Legedza A, Rosen MP. Joint replacement surgery in elderly patients with severe osteoarthritis of the hip or knee: Decision making, postoperative recovery, and clinical outcomes. Arch Intern Med. 2008;168(13):1430–40.
19. Pivec R, Johnson AJ, Mears SC, Mont MA. Hip arthroplasty. Lancet. 2012; 380(9855):1768–77.
20. Fevang B-TS, Lie SA, Havelin LI, Engesæter LB, Furnes O. Improved results of primary total hip replacement. Acta Orthop. 2010;81(6):649–59.
21. NRL. Rapport Juni 2014. In: Nasjonal kompetansetjeneste for leddproteser og hoftebrudd. Helse-Bergen: Ortopedisk klinikk; 2014.
22. Shan L, Shan B, Graham D, Saxena A. Total hip replacement: a systematic review and meta-analysis on mid-term quality of life. Osteoarthr Cartil. 2014; 22(3):389–406.
23. Arden NK, Kiran A, Judge A, Biant LC, Javaid MK, Murray DW, Carr AJ, Cooper C, Field RE: What is a good patient reported outcome after total hip replacement? Osteoarthr Cartil. 2011;19(2):155–62.
24. Anakwe R, Jenkins P, Moran M. Predicting dissatisfaction after total hip arthroplasty: a study of 850 patients. J Arthroplasty. 2011;26(2):209–13.
25. Mäkelä KT, Matilainen M, Pulkkinen P, Fenstad AM, Havelin LI, Engesaeter L, Furnes O, Overgaard S, Pedersen AB, Kärrholm J et al: Countrywise results of total hip replacement. Acta Orthop. 2014;85(2):107–16.
26. Lane NE. Osteoarthritis of the Hip. N Engl J Med. 2007;357(14):1413–21.
27. Hawker GA, Badley EM, Borkhoff CM, Croxford R, Davis AM, Dunn S, Gignac MA, Jaglal SB, Kreder HJ, Sale JE: Which patients are most likely to benefit from total joint arthroplasty? Arthritis Rheum. 2013;65(5): 1243–52.
28. Montin L, Leino-Kilpi H, Suominen T, Lepistö J. A systematic review of empirical studies between 1966 and 2005 of patient outcomes of total hip arthroplasty and related factors. J Clin Nurs. 2008;17(1):40–5.
29. Fortin P, Clarke A, Joseph L, Liang M, Tanzer M, Ferland D, Phillips C, Partridge A, Belisle P, Fossel A et al: Outcomes of total hip and knee replacement: preoperative functional status predicts outcomes at six months after surgery. Arthritis Rheum. 1999;42(8):1722–8.
30. Fortin PR, Penrod JR, Clarke AE, St-Pierre Y, Joseph L, Belisle P, Liang MH, Ferland D, Phillips CB, Mahomed N et al: Timing of total joint replacement

affects clinical outcomes among patients with osteoarthritis of the hip or knee. Arthritis Rheum. 2002;46(12):3327–30.

31. Webster F, Perruccio AV, Jenkinson R, Jaglal S, Schemitsch E, Waddell JP, Bremner S, Mobilio MH, Venkataramanan V, Davis AM. Where is the patient in models of patient-centred care: a grounded theory study of total joint replacement patients. BMC Health Services Research 2013;13(1):1-8.
32. St.meld. nr. 47 (2008–2009). Samhandlingsreformen — Rett behandling – på rett sted – til rett tid (white paper in Norwegian). 2009. https://www.regjeringen.no/no/dokumenter/stmeld-nr-47-2008-2009-/id567201/. Accessed 07/10 2015.
33. Meld. St. 26 (2014–2015). The primary health and care services of tomorrow – localised and integrated. Report to the Storting (white paper). 2015. https://www.regjeringen.no/contentassets/d30685b2829b41bf99edf3e3a7e95d97/en-gb/pdfs/stm201420150026000engpdfs.pdf. Accessed 01/21 2016.
34. Braun V, Clarke V. Successful qualitative research : a practical guide for beginners. Los Angeles: Sage; 2013.
35. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
36. Regional Committees for Medical and Health Research Ethics 2013. https://helseforskning.etikkom.no/ikbViewer/page/prosjekterirek/prosjektregister/prosjekt?p_document_id=389132&p_parent_id=395011&_ikbLanguageCode=us. Accessed 01/27 2016.
37. Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. 2013. http://www.wma.net/en/30publications/10policies/b3/index.html. Accessed 06/14 2015.
38. DeSantis L, Ugarriza DN. The concept of theme as used in qualitative nursing research. West J Nurs Res. 2000;22(3):351–72.
39. Dieppe P, Doherty M. Contextualizing osteoarthritis care and the reasons for the gap between evidence and practice. Clin Geriatr Med. 2010;26(3):419–31.
40. Cuperus N, Smink AJ, Bierma-Zeinstra SMA, Dekker J, Schers HJ, de Boer F, van den Ende CH, Vliet Vlieland TPM: Patient reported barriers and facilitators to using a self-management booklet for hip and knee osteoarthritis in primary care: results of a qualitative interview study. BMC Fam Pract. 2013;14:181–1.
41. Sanders C, Donovan JL, Dieppe PA. Unmet need for joint replacement: a qualitative investigation of barriers to treatment among individuals with severe pain and disability of the hip and knee. Rheumatology (Oxford). 2004;43(3):353–7.
42. Hill J, Bird H. Patient knowledge and misconceptions of osteoarthritis assessed by a validated self-completed knowledge questionnaire (PKQ-OA). Rheumatology (Oxford). 2007;46(5):796–800.
43. Gronhaug G, Osteras N, Hagen KB. Quality of hip and knee osteoarthritis management in primary health care in a Norwegian county: a cross-sectional survey. BMC Health Serv Res. 2014;14:598.
44. French SD, Bennell KL, Nicolson PJ, Hodges PW, Dobson FL, Hinman RS. What do people with knee or hip osteoarthritis need to know? An international consensus list of essential statements for osteoarthritis. Arthritis Care Res (Hoboken). 2015;67(6):809–16.
45. Scott C, Bugler K, Clement N, Macdonald D, Howie C, Biant L. Patient expectations of arthroplasty of the hip and knee. J Bone Joint Surg (Br). 2012;94(7):974–81.
46. Hudak PL, Armstrong K, Braddock C, Frankel RM, Levinson W. Older patients' unexpressed concerns about orthopaedic surgery. J Bone Joint Surg Am. 2008;90(7):1427–35.
47. Slover J, Shue J, Koenig K. Shared decision-making in orthopaedic surgery. Clin Orthop Relat Res. 2012;470(4):1046–53.
48. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). Soc Sci Med. 1997;44(5):681–92.
49. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. JAMA. 1992;267(16):2221–6.

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Health and Quality of Life Outcomes

RESEARCH Open Access

Role of self-efficacy and social support in short-term recovery after total hip replacement: a prospective cohort study

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Abstract

Background: Despite the overall success of total hip replacement (THR) in patients with symptomatic osteoarthritis (OA), up to one-quarter of patients report suboptimal recovery. The aim of this study was to determine whether social support and general self-efficacy predict variability in short-term recovery in a Norwegian cohort.

Methods: We performed secondary analysis of a prospective multicenter study of 223 patients who underwent THR for OA in 2003–2004. The total score of the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) at 3 months after surgery was used as the recovery variable. We measured self-efficacy using the General Self-Efficacy Scale (GSES) and social support with the Social Provisions Scale (SPS). Preoperative and postoperative scores were compared using Wilcoxon tests. The Mann–Whitney *U* test compared scores between groups that differed in gender and age. Spearman's rho correlation coefficients were used to evaluate associations between selected predictor variables and the recovery variable. We performed univariate and multiple linear regression analyses to identify independent variables and their ability to predict short-term recovery after THR.

Results: The median preoperative WOMAC score was 58.3 before and 23.9 after surgery. The mean absolute change was 31.9 (standard deviation [SD] 17.0) and the mean relative change was 54.8% (SD 26.6). Older age, female gender, higher educational level, number of comorbidities, baseline WOMAC score, self-efficacy, and three of six individual provisions correlated significantly with short-term recovery after THR and predicted the variability in recovery in the univariate regression model. In multiple regression models, baseline WOMAC was the most consistent predictor of short-term recovery: a higher preoperative WOMAC score predicted worse short-term recovery ($\beta = 0.44$ [0.29, 0.59]). Higher self-efficacy predicted better recovery ($\beta = -0.44$ [−0.87, −0.02]). Reliable alliance was a significant predictor of improved recovery ($\beta = -1.40$ [−2.81, 0.01]).

Conclusions: OA patients' general self-efficacy and the expectation of others' tangible assistance predict recovery after THR. Researchers and clinicians should target these psychosocial factors together with the patients and their families to improve the quality of care and surgical outcomes.

Keywords: Osteoarthritis, Psychosocial predictors, Total hip replacement, Social support, Self-efficacy, WOMAC

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Background

Osteoarthritis (OA) is the most common form of arthritis and involves inflammation and major structural changes of the joint, which cause pain and functional disability. Pain, often in association with exercise, is a hallmark symptom and has a considerable effect on the ability to perform activities of daily living [1]. Moderate to severe OA is the most common indication for total hip replacement (THR). Although the prevalence and incidence may differ between populations, OA is considered to be a worldwide disease [2, 3].

According to recommendations, THR is indicated when the patient's OA-related functional limitations and pain levels are refractory to pharmacological and non-pharmacological treatment modalities [4, 5]. THR is a cost-effective treatment for hip OA and offers relief of pain and improved function and quality of life [6]. In Norway, 8,099 primary hip replacements were performed in 2014, about 80% (6,369) of which were for patients with primary hip OA [7].

Studies demonstrate good clinical outcomes [8, 9], but some patients fail to recover optimally from THR [10, 11]. Although THR generally resolves pain, function usually remains substantially suboptimal. For example, 24 months following total joint arthroplasty, patients with low preoperative function are five times more likely to require assistance from another person for their activities of daily living compared with those with high preoperative function. A systematic review reported that 7–23% of the patients undergoing THR experienced suboptimal outcomes 3 months to 5 years after the procedure [12]. Hawker et al. [11] reported that nearly half of their study participants had poor outcomes such as pain and function following total joint replacement; these were mostly elderly patients with additional comorbidities.

In general, patients with lower baseline function seem to experience greater pain and worse function compared with those with higher baseline function [13, 14]. This is called the "better in, better out" concept; that is, the better the condition of the patient coming into the hospital, the better and more quickly he/she leaves the hospital [15]. Therefore, improving each patient's health status before surgery should produce better outcomes at an individual level. Unfit patients might be advised to postpone surgery to optimize preoperative functional status, whereas other patients might benefit from undergoing surgery earlier in the course of functional decline [16].

Few studies have identified the psychosocial predictors associated with recovery following THR. In this study, we investigated the role of patients' social support and general self-efficacy because OA causes substantial physical disability and has considerable psychosocial consequences that can affect the patient's ability to maintain or improve physical health [17]. Self-efficacy refers to a person's confidence in his/her ability to successfully execute and accomplish a specific task [18]; a more generalized sense of self-efficacy is conceptualized as "a global confidence in one's coping ability across a wide range of demanding or novel situations" [19]. Social support can be defined as those resources in a person's environment that enable that person to deal with life's physical and psychological stresses. For example, a patient may be extremely disabled but may be able to maintain a high quality of life because of effective social support. Surgery, such as THR, magnifies the need for short-term support. The effect of social support on health is a complex phenomenon to investigate, and varies with the specific dimensions of support as well as with the exact outcome being considered [20]. The role of social support as a factor predicting postoperative outcomes in OA joint replacement patients has not been extensively studied. Various definitions and conceptualizations, and the use of different outcome measures contribute to the lack of conclusive evidence.

In this study, we used general measures of self-efficacy and social support. The overall aim was to determine whether perceived social support and general self-efficacy contribute to the variability in short-term postoperative recovery in a sample of OA patients who have undergone THR. A secondary aim was to determine whether recovery, social support, and self-efficacy differ according to gender, age group, or number of comorbidities.

Methods

Study design and sample

This study comprised a secondary analysis of longitudinal data from research conducted by one of the authors (HK), who prospectively explored changes in pain and health status among patients with hip or knee OA who underwent joint replacement [21–24]. In the present study, we analyzed the data for patients with hip OA who completed the study package of questionnaires preoperatively and at 3 months following primary THR (Fig. 1). Adult patients aged >18 years who were placed on the waiting list for a primary THR were recruited consecutively in 2003–2004 at six hospitals in three Norwegian counties.

Questionnaires

Patients completed a package of questionnaires that obtained sample characteristics, including gender, age, marital status, cohabitation, number of children, educational level, employment status, comorbidity, and number of years with hip pain and reduced mobility (before the decision to undergo THR). At baseline and at 3 months after surgery, they also reported overall satisfaction with life on a 7-point Likert scale, and pain and mobility levels on a 5-point Likert scale. Patients also completed the Western Ontario and McMaster

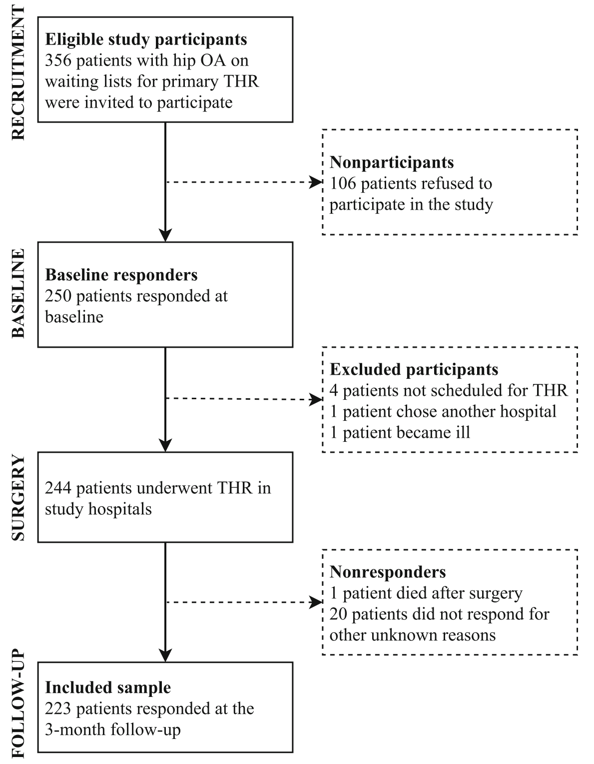

Fig. 1 Sample flowchart

Universities Osteoarthritis Index (WOMAC) [25], the General Perceived Self-Efficacy Scale (GSES) [26], and the Social Provisions Scale (SPS) [27].

WOMAC

WOMAC is a widely used disease-specific questionnaire developed to study health status in patients with hip or knee OA. It has a multidimensional scale comprising 24 items grouped into three dimensions: pain (five items), stiffness (two items), and physical function (17 items). We used the 3.0 Likert version with five response categories for each item representing different degrees of intensity (none, mild, moderate, severe, or extreme) and scored from 0 to 4 [25]. The total WOMAC score was chosen as an appropriate outcome measure of recovery after THR and was calculated by adding the aggregate scores for pain, stiffness, and physical function. The data were standardized to scales with values from 0 to 100, where 0 represents the best health status and 100 the worst health status. Missing data were handled according to the user's manual [25]. Previous research has shown WOMAC to be reliable, valid, and sensitive to changes in the health status of patients with hip or knee OA [28].

GSES

We measured patients' self-efficacy using the GSES with 10 items [26]. The GSES is widely used, reliable, homogeneous, and unidimensional [29, 30]. All items have the following response format: 1 = not at all true, 2 = hardly true, 3 = moderately true, and 4 = exactly true. The total GSES score is calculated by summing the item scores, and ranges between 10 (lowest GSES) and 40 (highest GSES). We calculated the sum score in this study for subjects with no more than three items missing [31]. Examples of items in the GSES are "I can always manage to solve difficult problems if I try hard enough" and "It is easy for me to stick to my aims and accomplish my goals".

SPS

Perceived social support was assessed using the revised SPS [27]. This 24-item instrument asks respondents to rate the degree to which their social relationships currently are supplying each of six relational provisions [32]: guidance, reliable alliance, reassurance of worth, attachment, social integration, and opportunity for nurturance. Each provision is assessed by four items: two describing the presence and two the absence of the provision. Respondents indicate on 4-point scales the extent to which each statement describes their current social relationships. For scoring purposes, the negative items are reversed and summed together with the positive items to form a score for each social provision, which gives a minimum score of 4 and a maximum score of 16. An aggregated social support score is also calculated with a minimum score of 24 points and a maximum score of 96. A high score indicates a high degree of perceived social support. Internal consistency (alpha coefficient) for the SPS has been reported to range from 0.85 to 0.92 across a variety of populations and from 0.64 to 0.76 for the individual subscales [33]. Evidence supports the reliability and validity of the SPS [27].

Statistical methods

We used IBM SPSS Statistics for Windows version 23.0 [34] to organize and analyze the data. Descriptive statistics were used to estimate the data for sample characteristics. We compared groups of responders and nonresponders using Pearson's chi-squared test, independent samples t test, or Mann–Whitney U test, where applicable. Preoperative and postoperative WOMAC total and dimension scores were compared using nonparametric related-samples (Wilcoxon) tests. The Mann–Whitney U test was used to compare scores between gender and age groups. We assessed internal consistency reliability of the questionnaires using Cronbach's coefficient alpha. Pearson and Spearman rank correlation coefficients were used to identify the variables for inclusion in the regression analyses based on associations between selected predictor variables and the primary measure of recovery at 3 months after THR, as appropriate. We included predictors based on the availability of data and on our theoretical hypothesis about possible relationships relating to the aim of the study: age, gender, cohabitation, number of children, education level, work status, number of comorbidities, years with hip pain, years with mobility problems, overall satisfaction with life and baseline scores (including WOMAC, SPS, and GSES). Linear regression models were used to study the associations between the predictors and the recovery variable WOMAC total. We applied the following steps after a thorough evaluation of the theoretical assumptions relevant to linear regression.

1. Predictor variables that correlated with the recovery variable ($\alpha = 0.10$) were included into a univariate linear regression model. This step identified how well each variable predicted recovery after THR without controlling for any confounding factors.
2. The next step was to proceed with a multiple linear regression model. We included all predictors with a significant association with the recovery variable ($\alpha = 0.05$) in the initial model. Residual plots were controlled.
3. To identify the best predictive model of recovery after THR, we used a backward elimination procedure. For each step in this stepwise procedure, we evaluated each β value and its 95% confidence interval. Nonsignificant predictors were omitted sequentially from the model until all remaining variables were statistically significant in explaining the variance in post-THR recovery.

Results

Sample characteristics

We invited 356 patients with hip OA to participate; 250 (70%) accepted and responded at baseline, and 223 (89%) patients returned the questionnaire at the 3-month follow-up. Twenty-seven patients did not respond; four of whom did not undergo THR, one chose another hospital, one became ill and one died after surgery (Fig. 1). Because the questionnaires were mailed to eligible participants, we do not know the reasons why the remaining twenty patients did not respond at follow-up. We compared differences in gender and age among baseline responders and patients who refused to participate [see Additional file 1]. There were no differences in gender ($\chi 2$ (1) = 0.27, p = 0.61). However, nonparticipants were older (73.6 years (SD = 8.9)) than baseline responders (69.3 (SD = 9.6), p = < 0.01). Table 1 presents the baseline characteristics of responders and nonresponders.

The responders and nonresponders had similar characteristics in our sample. Responders included 159 women and 64 men with a mean age of 69 years; 21% were younger than 60 years, and 29% were older than 75 years. The youngest patient was 41 years old at the time of surgery and the oldest was 91 years. Most reported being married and not living alone. One-third had a higher educational level. Most (78%) had 1–3 comorbid conditions, such as cardiovascular, gastrointestinal, pulmonary, or psychiatric conditions, cancer, skin diseases, or diabetes mellitus. Thirty-eight patients (17%) did not respond to this question, and we do not know whether this indicated no comorbidity or whether the question was left blank for other reasons. The patients had experienced hip pain for an average of about 6 years. At the time of the baseline assessment, 108 patients (48%) reported severe pain, and 20 patients (14%) reported extreme pain. When asked about mobility, 157 patients reported having severe (52%) or extreme (19%) problems; 61% reported being somewhat or less satisfied with life.

Table 1 Sample characteristics at baseline for responders 3 months after surgery, and nonresponders

	Responders	Nonresponders	*P*-value
N	223	27	
Age (mean ± standard deviation)	69.3 ± 9.8	69.1 ± 8.5	0.92
Female gender	159 (71.3)	20 (74.1)	0.83
Marital status			0.49
Married	149 (66.8)	17 (63.0)	
Widowed	38 (17.0)	5 (18.5)	
Divorced/separated	25 (11.2)	5 (18.5)	
Single	11 (5.0)	-	
Living with someone	156 (70.0)	19 (70.4)	1.0
Having children	194 (92.8)	27 (100)	0.23
Educational level			0.09
Primary school	54 (24.4)	13 (48.1)	
Secondary school	94 (42.5)	10 (37.0)	
University <4 years	41 (18.6)	2 (7.4)	
University ≥4 years	32 (14.5)	2 (7.4)	
Employment			0.60
Retired	144 (64.6)	17 (63.0)	
Full- or part-time work	35 (15.7)	2 (7.4)	
Sick leave	18 (8.1)	3 (11.1)	
Disability pension	26 (11.6)	5 (18.5)	
Number of comorbidities			0.11
1	91 (40.8)	17 (63.0)	
2	55 (24.7)	4 (16.0)	
3	29 (13)	4 (16.0)	
>3	10 (4.5)	–	
Missing data	38 (17)	2 (7.4)	

Number (%) unless otherwise stated

Comparison of responders and nonresponders' baseline WOMAC, SPS, and GSES scores

The responder and nonresponder groups were compared to account for any nonresponse bias. The two groups did not differ on any of the scales [see Additional file 2].

Short-term recovery following THR

Table 2 provides the baseline and postoperative scores for WOMAC and its subscales. Normality testing of the recovery variable showed a moderately skewed distribution with a positive skewness value of 0.96 (standard error of skewness = 0.17). Assessment of internal consistency reliability of the WOMAC baseline scores suggested satisfactory results, with Cronbach's alpha values of 0.78, 0.69, 0.93, and 0.94 for the subscales, pain, stiffness, physical function, and total score, respectively. Patients reported a mean WOMAC total score of 57.7 points at the baseline and 25.6 points at 3 months after THR, yielding a mean absolute change of 31.9 points (standard deviation [SD] 17.0) and a mean relative change of 54.8% (SD 26.6). Women had significantly higher mean scores than men both at the baseline and at 3 months (60.0 vs 51.9 [$P <$ 0.001] and 27.0 vs 22.4 [$P = 0.023$]). There was no difference in the mean absolute change between men and women (32.9 vs 30.0 points [$P = 0.41$]).

A comparison of patients younger and older than 70 years (median as the cut point) showed no differences in baseline scores between the two groups (57.5 vs 57.9 points [$P = 0.78$]). However, the older patients ($n = 109$) had a worse score at 3 months (23.3 vs 28.0 points [$P = 0.059$]). Younger patients had higher absolute change scores compared with older patients (34.4 vs 29.4 points [$P = 0.02$]). Patients who reported having two or more comorbidities (median as the cut point) had significantly higher mean scores (29.1) at 3 months compared with those reporting one comorbid condition (22.8 [$P = 0.032$]). Accordingly, these patients reported lower absolute change scores (28.8) than did patients with one comorbid condition (35.3 [$P = 0.014$]).

Change in social support and general self-efficacy

Normality testing of the baseline and postoperative SPS scores showed highly skewed distributions with negative skewness values of −1.27 and −1.74, respectively. As seen in Table 2, the internal consistency of the baseline scores was good for the aggregated social support score (0.85) and excellent for the GSES score (0.92). Patients' perceived social support remained stable across all dimensions and did not change significantly from the baseline to the 3-month follow-up. The same trend was observed for self-efficacy, although a small but significant absolute change was observed (0.6 points [$P = 0.02$]). A comparison between men and women showed no significant differences for baseline social support (86.1 vs 86.7 [$P = 0.53$]). However, women reported significantly lower self-efficacy scores than men (30.6 vs 31.8 [$P = 0.044$]). No significant difference in absolute change scores between men and women was observed.

A comparison between patients younger and older than 70 years showed significantly higher social support at the baseline in younger patients (88.1 vs 84.6 [$P = 0.001$]). This pattern was also evident for all SPS subscales except for reliable alliance (15.3 vs 15.2

Table 2 WOMAC, SPS and GSES scores at the baseline and 3 months after THR

	Baseline mean (SD)	Quartiles 1st, 2nd, 3rd	α	3 months post-THR mean (SD)	Quartiles 1st, 2nd, 3rd	α	*P*-value
	N = 218			*N* = 218			
WOMAC total	57.7 (14.5)	49, 58.3, 67.7	0.94	25.6 (16.1)	13.5, 23.9, 34.4	0.96	<0.001
Pain	56.3 (17.5)	45, 55, 69.7	0.78	16.8 (16.6)	5, 10, 25	0.88	<0.001
Stiffness	60.8 (17.8)	50, 62.5, 75	0.69	31.5 (17.2)	25, 25, 43.8	0.74	<0.001
Physical function	57.6 (15.2)	48.5, 58.8, 68.7	0.93	27.7 (17.3)	14.7, 25, 38.2	0.95	<0.001
	N = 220			*N* = 219			
SPS	86.3 (8.2)	82.6, 89, 92	0.85	86.1 (8.9)	82, 88, 93	0.86	0.96
Guidance	15.0 (2.0)	15, 16, 16	0.79	14.9 (2.2)	15, 16, 16	0.73	0.70
Reliable alliance	15.2 (1.6)	15, 16, 16	0.51	15.3 (1.7)	16, 16, 16	0.67	0.28
Attachment	14.9 (1.7)	14, 16, 16	0.56	14.7 (1.9)	14, 16, 16	0.62	0.22
Social integration	14.4 (1.7)	13, 15, 16	0.53	14.3 (1.8)	14, 15, 16	0.61	0.67
Reassurance of worth	14.6 (1.8)	14, 15, 16	0.67	14.7 (1.7)	14, 15, 16	0.69	0.28
Opportunity for nurturance	12.3 (2.9)	10, 13, 15	0.68	12.2 (3.1)	10, 13, 15	0.72	0.41
	N = 217			*N* = 216			
GSES	30.9 (5.2)	28, 30, 34,7	0.92	31.6 (4.7)	29, 31, 35	0.91	0.018

WOMAC (0–100): high score indicates worse recovery. SPS (24–96 [total score], 4–16 [subscores]: high score indicates a greater degree of perceived support. GSES (10–40): high score indicates a high level of self-efficacy

[*P* = 0.38]) and reassurance of worth (14.8 vs 14.3 [*P* = 0.064]). The scores for the significant subscales were: guidance (15.3 vs 14.7 [*P* = 0.006]); attachment (15.2 vs 14.7 [*P* = 0.007]); social integration (14.7 vs 14.0 [*P* = 0.006]); and opportunity for nurturance (12.8 vs 11.9 [*P* = 0.05]). The same trend appeared for baseline self-efficacy (31.8 vs 30.1 [*P* = 0.009]). There was no significant difference according to age in absolute change scores. The baseline and absolute changes in social support and self-efficacy scores did not differ according to comorbidity groups.

Prediction of short-term recovery after THR

Regression diagnostic analyses revealed an acceptable distribution of the residuals associated with the outcome variable.

Step 1. Univariate analysis

The following predictor variables correlated significantly with the recovery variable WOMAC total [see Additional file 3] and were included in the univariate regression analysis: age (Spearman rank-order coefficient [r_s] = 0.15 [*P* = 0.03]), female gender ($r_s = 0.15$ [*P* = 0.03]), educational level ($r_s = 0.17$ [*P* = 0.01]), cohabitation ($r_s = -0.12$ [P = 0.08]), number of comorbidities ($r_s = 0.16$ [*P* = 0.04]), baseline WOMAC ($r_s = 0.37$ [*P* < 0.001]), baseline GSES ($r_s = -0.18$ [*P* = 0.01]), baseline SPS total ($r_s = -0.13$ [*P* = 0.06]), reliable alliance ($r_s = -0.13$ [*P* = 0.06]), social integration ($r_s = -0.12$ [*P* = 0.07]), and reassurance of worth ($r_s = -0.14$ [*P* = 0.04]). No significant correlations were found with the remaining predictors considered: number of children, full- or part-time work, number of years with pain and mobility problems, guidance, attachment, and opportunity for nurturance. Table 3 shows that the baseline WOMAC scores were the most significant independent predictors of short-term recovery with an R^2 of 0.15. Patient characteristics such as older age, lower educational level, and increased number of comorbidities were associated with worse recovery. Being female was borderline significant and predicted worse recovery. Cohabitation did not reach statistical significance, but the coefficient indicates that living alone predicted better recovery. Greater baseline self-efficacy and perceived social support predicted better recovery. Of the six relational provisions measured by the SPS, the presence of reliable alliances, social integration, and reassurance of worth appeared to independently predict better recovery.

Steps 2 and 3: Multiple linear regression analysis

When we included predictors from the univariate analysis into a multiple regression model, the model explained about 29% of the variance in recovery 3 months after THR. Following the elimination procedure, gender, educational level, aggregate SPS score, social integration, and reassurance of worth did not contribute statistically to recovery after THR and were therefore omitted from the model. By contrast, self-efficacy and reliable alliance appeared to be significant predictors even after adjusting for age, number of comorbidities, and preoperative WOMAC. The final linear regression model explained 28.5% of the variance in short-term recovery (Table 4).

Discussion

To our knowledge, this is the first prospective study to evaluate whether general self-efficacy and perceived social support predict short-term recovery following THR in patients with hip OA. The data used in this study were gathered more than 10 years ago; however, the

Table 3 Univariate linear regression analysis

Predictors	WOMAC total score (0–100)						
	β	95% CI		Std. Error	*P*-value	R^2	N
		Lower	Upper				
Age	0.26	0.05	0.45	0.11	0.02	0.03	218
Female gender	4.56	−0.13	9.25	2.38	0.06	0.02	218
Living alone	−3.86	−8.60	0.89	2.41	0.11	0.01	218
Higher education	−5.30	−9.85	−0.74	2.31	0.02	0.02	218
Comorbidity	2.79	0.47	5.10	1.17	0.02	0.03	180
Baseline WOMAC total (0–100)	0.46	0.30	0.58	0.07	<0.001	0.15	213
Self-efficacy (10–40)	−0.52	−0.93	−0.11	0.21	0.01	0.03	212
Social support (16–96)	−0.26	−0.52	−0.003	0.13	0.05	0.02	215
Reliable alliance (4–16)	−2.13	−3.48	−0.78	0.69	0.002	0.04	214
Social integration (4–16)	−1.26	−2.54	0.02	0.65	0.05	0.02	212
Reassurance of worth (4–16)	−1.41	−2.63	−0.19	0.62	0.02	0.02	211

Table 4 Multiple regression model

Predictors	WOMAC total score (0–100)				
	β	95% CI		Std. Error	*P*-value
		Lower	Upper		
Constant	7.66	−24.81	40.13	16.45	0.64
Age	0.35	0.13	0.57	0.21	0.002
Comorbidity	2.12	0.06	4.19	1.05	0.04
Baseline WOMAC total (0–100)	0.44	0.29	0.59	0.08	<0.001
Self-efficacy (10–40)	−0.44	−0.87	−0.02	0.22	0.04
Social support					
Reliable alliance (4–16)	−1.40	−2.81	0.01	0.71	0.05

$R^2 = 0.285$, $N = 172$

patient care pathways have not changed to any appreciable extent, and the results should still be relevant.

Role of self-efficacy and social support

Higher preoperative levels of reliable alliances and general self-efficacy tended to independently predict better recovery from THR, even after adjusting for age, number of comorbidities, and preoperative WOMAC score. These are clinically relevant findings because these factors are considered as constructs that can be modified through behavioral interventions and tailoring of evidence-based treatment plans. A person's attitudes toward behavior change, self-efficacy, and social influences are modeled as vital factors within the integrated model for explaining motivational and behavioral change (I-Change Model) [35].

Neither social support nor general self-efficacy seemed to change as a consequence of undergoing THR. This result suggests that perceived social support is an indicator of stable social relationships and environment, and that general self-efficacy is a personal trait measure in this context. Self-efficacy is not considered to be a personality trait but rather a situation-specific construct [36, 37]. However, in contrast to other domain-specific instruments [38], the GSES maps self-efficacy as the global confidence in one's coping ability across a wide range of demanding or novel situations. Generalized positive beliefs of self-efficacy serve as a resource factor that buffers against distress experiences. Weak self-efficacy beliefs make a person vulnerable to distressing experiences by causing the person to be permanently worried, have weak expectancies of task-specific competence, interpret physiological arousal as an indicator of anxiety, regard achievement feedback as social evaluations of personal value, and feel more responsible for failure than for success [19, 26]. Further research is needed to determine the role of generalized self-efficacy beliefs in the self-management of hip OA. Treatment strategies that incorporate psychological factors initiated in the early phases of the disease continuum [39] and that include an explicit effort to increase patients' self-efficacy beliefs and supportive networks, will increase the probability that patients will enter surgery with more confidence and ultimately experience better recovery [40].

Most patients undergoing THR are discharged directly to their home. It is therefore not surprising that assurance of tangible assistance seems to predict outcomes after surgery. This quality of social support is usually obtained from family members [33] and has been reported to be a significant predictor of recovery after joint replacement surgery. One study, in which social support was measured by the Medical Outcomes Study Social Support Scale, found that worse postoperative WOMAC function scores were predicted by less tangible support, depression, and decreased problem-solving coping [41]. Escobar et al. took a different approach to measure this dimension of social support [42], and asked the responders whether they would have assistance during recovery after total knee replacement (TKR). Their analysis indicated that patients who expected assistance had better scores at 6 months after surgery in the three WOMAC domains and in four of the eight Short Form Health Survey (SF-36) domains. A cruder measure of social support can be obtained by dichotomizing patients who report being married or living with someone. Patients undergoing THR or TKR who were either married or living with someone were defined as having more social support than those who were not married or lived alone. The presence of social support was associated with improved SF-36 bodily pain and physical function outcomes [43]. McHugh, Campbell, and Luker [44] investigated the predictive factors of recovery after THR in a prospective study involving 206 patients. Social support, as measured by the ENRICHD Social Support Instrument, did not predict recovery at 6 or 12 months after surgery, where recovery was defined as gains in the total physical score dimension of the SF-36 questionnaire.

We found no other studies that have used the GSES or SPS questionnaires to identify predictors of recovery after THR; however, some studies have used other questionnaires or methods to measure these constructs. A Dutch study evaluated the contributions of preoperative and short-term postoperative self-efficacy in predicting long-term outcomes measured 6 months after THR or TKR [45]. The Self-Efficacy for Rehabilitation Outcome Scale was used to assess self-efficacy preoperatively and at 6 weeks after surgery. Preoperative self-efficacy was a significant predictor only of long-term postoperative walking speed; higher self-efficacy was associated with faster walking speed. Short-term postoperative self-efficacy was a significant predictor of the postoperative SF-36 subscales physical functioning and mental health, and of walking speed; higher self-efficacy was associated with a better long-term outcome. In another study of patients undergoing TKR, preoperative self-efficacy, as measured by the Pain Self-Efficacy Scale, was a significant predictor of functional ability but not pain 1 year after surgery [46]. These results were included in a systematic review [47] that concluded that preoperative self-efficacy was the least consistent predictor of functional outcomes, whereas postoperative self-efficacy was more consistently associated with recovery outcomes such as longer distance ambulation, exercise repetition and frequency, walking speed, and disability. However, as noted by the authors of that review, no statistical synthesis was possible because of the number of, and variation in, the measures used (both for predictor and outcome variables) and the different timing of the assessment of self-efficacy and outcome.

Clearly, different ways of conceptualizing and measuring self-efficacy and social support and the use of different outcome variables complicate comparisons with existing studies and the ability to draw firm conclusions about the predictive capacity of these constructs. Nevertheless, our findings suggest that self-efficacy and social support deserve more attention in future research and patient care planning.

Strengths and limitations

One strength of this study is that we used validated questionnaires to measure self-efficacy and social support. Power calculations were conducted to ensure that the planned sample size was large enough to detect clinically significant changes. The procedure is explained elsewhere [21]. Our findings supplement the limited literature on the role of social support and self-efficacy as predictors of recovery after THR. Importantly, our results can be used for comparisons in future studies. Except for the assessment of comorbidities, we achieved a low rate of missing data, with fewer than seven patients failing to complete the preoperative or postoperative WOMAC, SPS, and GSES assessments.

The study also has some limitations. The age difference between participants and nonparticipants may represent a selection bias in this study, and thus affect the representativeness of the sample. As also reported in the literature [48, 49], increasing age predicted worse recovery in this study. We can therefore assume that this does not directly impede the validity of our findings. The number of comorbidities is a significant risk factor for recovery after THR. However, 17% of the participants did not respond to the question about this, possibly because there was no response category to indicate zero comorbidities. This high percentage of missing data limits the validity of the findings, and our data should be confirmed in a new study with validated methods to assess comorbidity [50]. We note that there was no significant difference in the WOMAC, GSES, or SPS scores between the groups with and without missing data on comorbidity. As reported in the literature, previous joint surgeries can negatively affect outcomes following THR [44, 51]. However, this information was not available in the dataset, and we therefore could not control for this possible confounder variable. For the subscale reliable alliance, the internal consistency (Cronbach's alpha of 0.51) may be questioned. One explanation might be the negatively skewed distribution of the data (skewness value of −2.25). Inspection of the unusual cases led us to believe that some respondents misinterpreted the negatively worded statements or may have responded uncritically similarly across the whole subscale because their responses did not correspond with the equivalent positively worded statements. These results should be interpreted with caution because of this low alpha score.

Conclusions

Increasing age, preoperative WOMAC score, and number of comorbidities are factors associated with worse recovery after THR. By contrast, the presence of reliable alliances and higher general self-efficacy are associated with better recovery. For clinicians, these findings may provide indicators of the need for relevant interventions to be introduced at an early time point. Further studies should use valid measurements and test tailored interventions to enhance the outcomes of patients at risk of suboptimal recovery after THR.

Additional files

Additional file 1: Age and gender differences in baseline responders and nonparticipants. Table presenting a comparison of age and gender in patients who accepted to participate vs patients who refused to participate. (DOCX 12 kb)

Additional file 2: Baseline differences among responders and nonresponders. Table presenting baseline scores of WOMAC, SPS and GSES among responders and nonresponders and a comparison of group differences. (DOCX 13 kb)

Additional file 3: Spearman rank-order coefficient correlations, rs (*p*-value) between baseline predictors and the recovery variable. Table displaying correlations between baseline predictors and the recovery variable, WOMAC total. (DOCX 13 kb)

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Availability of data and materials

The datasets analyzed during the current study are not publicly available because consent was not obtained for the sharing of subject data from study participants. Datasets are available from the corresponding author on reasonable request.

Authors' contributions

All coauthors were involved in designing the study. The data were collected by HK and analyzed by EAB with assistance from HE and SvD. All coauthors contributed to data interpretation. EAB drafted the manuscript and is the guarantor for the overall content. All authors read, provided feedback on, and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent for participation

The Regional Committee for Medical Research Ethics and the Norwegian Social Science Data Services approved the original study. All participants provided informed consent. The procedures followed were in accordance with the ethical standards of the responsible committees and with the Helsinki Declaration of 1975, as revised in 2013 [52].

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References

1. Neogi T. The epidemiology and impact of pain in osteoarthritis. Osteoarthr Cart. 2013;21:1145–53. http://dx.doi.org/10.1016/j.joca.2013.03.018.
2. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M, et al. Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012;380:2163–96. doi:10.1016/S0140-6736(12)61729-2.
3. Cross M, Smith E, Hoy D, Nolte S, Ackerman I, Fransen M, et al. The global burden of hip and knee osteoarthritis: estimates from the Global Burden of Disease 2010 study. Ann Rheum Dis. 2014;73:1323–30. doi:10.1136/annrheumdis-2013-204763.
4. Zhang W, Doherty M, Arden N, Bannwarth B, Bijlsma J, Gunther KP, et al. EULAR evidence based recommendations for the management of hip osteoarthritis: report of a task force of the EULAR Standing Committee for International Clinical Studies Including Therapeutics (ESCISIT). Ann Rheum Dis. 2005;64:669–81. doi:10.1136/ard.2004.028886.
5. Zhang W, Moskowitz RW, Nuki G, Abramson S, Altman RD, Arden N, et al. OARSI recommendations for the management of hip and knee osteoarthritis, Part II: OARSI evidence-based, expert consensus guidelines. Osteoarthr Cart. 2008;16:137–62. doi:10.1016/j.joca.2007.12.013.
6. Ethgen O, Bruyere O, Richy F, Dardennes C, Reginster JY. Health-related quality of life in total hip and total knee arthroplasty. A qualitative and systematic review of the literature. J Bone Joint Surg Am. 2004;86-A:963–74.
7. NRL. The Norwegian Arthroplasty Register, Report 2015. 2015. http://nrlweb.ihelse.net/Rapporter/Rapport2015.pdf. Accessed 02 Dec 2015.
8. Shan L, Shan B, Graham D, Saxena A. Total hip replacement: a systematic review and meta-analysis on mid-term quality of life. Osteoarthr Cart. 2014; 22:389–406. http://dx.doi.org/10.1016/j.joca.2013.12.006.
9. Fevang B-TS, Lie SA, Havelin LI, Engesæter LB, Furnes O. Improved results of primary total hip replacement. Acta Orthop. 2010;81:649–59. doi:10.3109/17453674.2010.537807.
10. Judge A, Cooper C, Williams S, Dreinhoefer K, Dieppe P. Patient-reported outcomes one year after primary hip replacement in a European Collaborative Cohort. Arthritis Care Res. 2010;62:480–8. doi:10.1002/acr.20038.
11. Hawker GA, Badley EM, Borkhoff CM, Croxford R, Davis AM, Dunn S, et al. Which patients are most likely to benefit from total joint arthroplasty? Arthritis Rheum. 2013;65:1243–52. doi:10.1002/art.37901.
12. Beswick AD, Wylde V, Gooberman-Hill R, Blom A, Dieppe P. What proportion of patients report long-term pain after total hip or knee replacement for osteoarthritis? A systematic review of prospective studies in unselected patients. BMJ Open. 2012;2:e000435. doi:10.1136/bmjopen-2011-000435.
13. Fortin PR, Clarke AE, Joseph L, Liang MH, Tanzer M, Ferland D, et al. Outcomes of total hip and knee replacement: preoperative functional status predicts outcomes at six months after surgery. Arthritis Rheum. 1999;42: 1722–8. doi:10.1002/1529-0131(199908)42:8<1722::AID-ANR22>3.0.CO;2-R.
14. Holtzman J, Saleh K, Kane R. Effect of baseline functional status and pain on outcomes of total hip arthroplasty. J Bone Joint Surg Am. 2002;84-A:1942–8.
15. Hoogeboom TJ, Dronkers JJ, Hulzebos EH, van Meeteren NL. Merits of exercise therapy before and after major surgery. Curr Opin Anaesthesiol. 2014;27:161–6. doi:10.1097/ACO.0000000000000062.
16. Fortin PR, Penrod JR, Clarke AE, St Pierre Y, Joseph L, Belisle P, et al. Timing of total joint replacement affects clinical outcomes among patients with osteoarthritis of the hip or knee**.** Arthritis Rheum 2002;46; doi: 10.1002/art.10631.
17. Keefe FJ, Smith SJ, Buffington AL, Gibson J, Studts JL, Caldwell DS. Recent advances and future directions in the biopsychosocial assessment and treatment of arthritis. J Consult Clin Psychol. 2002;70:640–55.
18. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev. 1977;84:191–215. doi:10.1037/0033-295X.84.2.191.
19. Jerusalem M, Schwarzer R. Self-efficacy as a resource factor in stress appraisal processes. In: Schwarzer R, editor. Self-efficacy: thought control of action. Washington: Hemisphere Publishing Corporation; 1992. p. 195–213.
20. Weinberger M, Tierney WM, Booher P, Hiner SL. Social support, stress and functional status in patients with osteoarthritis. Soc Sci Med. 1990;30:503–8. http://dx.doi.org/10.1016/0277-9536(90)90353-T.
21. Kapstad H. Pain and health status in patients with osteoarthritis of the hip or knee undergoing joint replacement surgery: measurement issues and outcomes. PhD thesis. Bergen: University of Bergen; 2010.
22. Kapstad H, Rustøen T, Hanestad BR, Moum T, Langeland N, Stavem K. Changes in pain, stiffness and physical function in patients with osteoarthritis waiting for hip or knee joint replacement surgery. Osteoarthr Cart. 2007;15:837–43. http://dx.doi.org/10.1016/j.joca.2007.01.015.
23. Kapstad H, Hanestad BR, Langeland N, Rustøen T, Stavem K. Cutpoints for mild, moderate and severe pain in patients with osteoarthritis of the hip or knee ready for joint replacement surgery. BMC Musculoskelet Disord. 2008;9: 55. doi:10.1186/1471-2474-9-55.
24. Kapstad H, Rokne B, Stavem K. Psychometric properties of the Brief Pain Inventory among patients with osteoarthritis undergoing total hip replacement surgery**.** Health Qual Life Outcomes 2010;8; doi: 10.1186/1477-7525-8-148.
25. Bellamy N. WOMAC Osteoarthritis Index User Guide. Version V. Brisbane, Australia. 2002.
26. Schwarzer R, Jerusalem M, et al. Generalized Self-Efficacy Scale. In: Measures in health psychology: a user's portfolio. Causal and control beliefs. Windsor, UK: NFER-NELSON; 1995. p. 35–7.
27. Cutrona CE, Russell DW. The provisions of social relationships and adaptation to stress. In: Jones WH, Perlman D, editors. Advances in personal relationships, vol. 1. Greenwich, CT: JAI Press; 1987. p. 37–67.
28. Bellamy N, Buchanan W, Goldsmith C, Campbell J, Stitt L. Validation study of WOMAC: a health status instrument for measuring clinically important patient relevant outcomes to antirheumatic drug therapy in patients with osteoarthritis of the hip or knee. J Rheumatol. 1988;15:1833–40.
29. Scholz U, Doña BG, Sud S, Schwarzer R. Is general self-efficacy a universal construct? Psychometric findings from 25 countries. Eur J Psychol Assess. 2002;18:242–51. doi:10.1027//1015-5759.18.3.242.
30. Røysamb E, Schwarzer R, Jerusalem M. Norwegian version of the general perceived self-efficacy scale. 1998. http://userpage.fu-berlin.de/~health/norway.htm. Accessed 12 Oct 2015.

31. Schwarzer R. Everything you wanted to know about the General Self-Efficacy Scale but were afraid to ask. 2014. http://userpage.fu-berlin.de/~health/faq_gse.pdf. Accessed 26 May 2016.
32. Weiss RS. The provisions of social relationships. In: Rubin Z, editor. Doing unto others: Joining, molding, conforming, helping, loving. Englewood Cliffs, N.J.: Prentice-Hall; 1974. p. 17–26.
33. Cutrona C, Russell D, Rose J. Social support and adaptation to stress by the elderly. Psychol Aging. 1986;1:47–54.
34. IBM Corp. IBM SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp; 2015.
35. de Vries H, Kremers SP, Smeets T, Brug J, Eijmael K. The effectiveness of tailored feedback and action plans in an intervention addressing multiple health behaviors. Am J Health Promot. 2008;22:417–25. doi:10.4278/ajhp.22.6.417.
36. Bandura A. Self-efficacy: The exercise of control. New York, NY: W H Freeman/Times Books/ Henry Holt & Co; 1997.
37. Maddux JE, et al. Self-efficacy: the power of believing you can. In: Snyder CR, Lopez SJ, editors. Handbook of positive psychology. Oxford; New York: Oxford University Press; 2002. p. 277–87.
38. Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis Rheum. 1989;32:37–44.
39. Brembo EA, Kapstad H, Eide T, Månsson L, Van Dulmen S, Eide H. Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study. BMC Health Serv Res. 2016;16:1–15. doi:10.1186/s12913-016-1342-5.
40. Ayers DC, Franklin PD, Ring DC. The role of emotional health in functional outcomes after orthopaedic surgery: extending the biopsychosocial model to orthopaedics: AOA critical issues. J Bone Joint Surg Am. 2013;95:e165. doi:10.2106/JBJS.L.00799.
41. Lopez-Olivo MA, Landon GC, Siff SJ, Edelstein D, Pak C, Kallen MA, et al. Psychosocial determinants of outcomes in knee replacement. Ann Rheum Dis. 2011;70:1775–81. doi:10.1136/ard.2010.146423.
42. Escobar A, Quintana JM, Bilbao A, Azkarate J, Guenaga JI, Arenaza JC, et al. Effect of patient characteristics on reported outcomes after total knee replacement. Rheumatology (Oxford). 2007;46:112–9. doi:10.1093/rheumatology/kel184.
43. Fitzgerald JD, Orav EJ, Lee TH, Marcantonio ER, Poss R, Goldman L, et al. Patient quality of life during the 12 months following joint replacement surgery. Arthritis Rheum. 2004;51:100–9. doi:10.1002/art.20090.
44. McHugh GA, Campbell M, Luker KA. Predictors of outcomes of recovery following total hip replacement surgery: A prospective study. Bone Joint Res. 2013;2:248–54. doi:10.1302/2046-3758.211.2000206.
45. van den Akker-Scheek I, Stevens M, Groothoff JW, Bulstra SK, Zijlstra W. Preoperative or postoperative self-efficacy: which is a better predictor of outcome after total hip or knee arthroplasty? Patient Educ Couns. 2007;66:92–9. doi:10.1016/j.pec.2006.10.012.
46. Wylde V, Dixon S, Blom AW. The Role of Preoperative Self-Efficacy in Predicting Outcome after Total Knee Replacement. Musculoskeletal Care. 2012;10:110–8. doi:10.1002/msc.1008.
47. Magklara E, Burton CR, Morrison V. Does self-efficacy influence recovery and well-being in osteoarthritis patients undergoing joint replacement? A systematic review. Clin Rehabil. 2014;28:835–46. doi:10.1177/0269215514527843.
48. Buirs LD, Van Beers LW, Scholtes VA, Pastoors T, Sprague S, Poolman RW. Predictors of physical functioning after total hip arthroplasty: a systematic review. BMJ Open. 2016;6:e010725. doi:10.1136/bmjopen-2015-010725.
49. Hofstede SN, Gademan MGJ, Vliet Vlieland TPM, Nelissen RGHH, Marang-van de Mheen PJ. Preoperative predictors for outcomes after total hip replacement in patients with osteoarthritis: a systematic review. BMC Musculoskelet Disord. 2016;17:1–11. doi:10.1186/s12891-016-1070-3.
50. de Groot V, Beckerman H, Lankhorst GJ, Bouter LM. How to measure comorbidity. a critical review of available methods. J Clin Epidemiol. 2003;56:221–9.
51. Gordon M, Frumento P, Sköldenberg O, Greene M, Garellick G, Rolfson O. Women in Charnley class C fail to improve in mobility to a higher degree after total hip replacement. Acta Orthop. 2014;85:335–41. doi:10.3109/17453674.2014.931199.
52. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 2013;310:2191–4. doi:10.1001/jama.2013.281053.

Title:

Building ground for didactics in a patient decision aid for hip osteoarthritis. Exploring patient-related barriers and facilitators towards shared decision-making.

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Abstract

Objective:

The aim of the present study was to explore patient-related barriers and facilitators towards shared decision-making (SDM) during routine orthopedic outpatient consultations as part of the process of developing a patient decision aid (PDA) for patients with hip osteoarthritis (OA).

Methods:

Consultations with hip OA patients referred to an orthopedic surgeon for treatment decision-making were observed, audio recorded and transcribed. A combined deductive and inductive analysis proceeded, based on a taxonomy of generic patient-related barriers towards SDM grounded in the Theory of Planned Behavior (TPB).

Results:

Nineteen patients agreed to participate. A targeted taxonomy displays a structured set of 26 factors influencing hip OA patients' intention to engage in SDM. Patients' perceived capacity to change the agenda stood out as seminal factors in this sample.

Conclusion:

Using a TPB-based taxonomy, we were able to identify and structure generic and context specific SDM barriers. Addressing patients' communication self-efficacy should be included as didactic feature in PDAs.

Practice Implications:

PDAs for hip OA should address the decision-making support needs occurring throughout the continuum of the disease. The development of didactic features in a PDA for patients with hip OA may benefit from concrete empirical examples using a TPB-based generic taxonomy.

Keywords: Osteoarthritis; Patient preference; Practice improvement; Shared decision-making; Patient decision aids; DAfactory; Theory of Planned Behavior; Qualitative research

1. Introduction

Worldwide, osteoarthritis (OA) represents a major cause of chronic musculoskeletal pain and disability [1]. Decision-making in OA treatment requires active involvement of patients for many reasons. Due to the poor association between radiographic OA on the one hand, and the individual experience of symptoms on the other [2], the patients' burden of living with this disease is difficult to consider from the physician's viewpoint alone. The broad spectrum of treatment options for hip OA ranges from education, physical therapy, pacing of activities, weight reduction and pharmacological treatment – to invasive surgery involving total hip replacement (THR) [3-5]. With regard to their impact on lifestyle, and in particular the potentially extreme long timeframes within which such decisions can be made, all of them are considered sensitive to individual preferences [6, 7]. Decisions related to the different phases of the hip OA continuum [8] should therefore predominantly rely on patient preferences, rather than recommendations from medical guidelines alone. A major challenge is however the identification and optimal timing of appropriate decisions [9, 10], and how to adopt communication and collaboration strategies that support informed choice [11].

This communication is best captured by the shared decision-making (SDM) method – structuring the process where clinicians and patients share the best available evidence on the likely benefits and harms of each option, and where they negotiate how those options fit the patient's preferences [12]. Many steps have been taken to implement SDM internationally, but there is still a huge gap between aspiration and daily clinical practice [13]. The most cited barriers health care providers experience are 1) time constraints, 2) lack of agreement with the applicability of SDM to the patient, or 3) to the clinical situation [14, 15]. Patients' capacity to participate in SDM depends on two key factors: *knowledge* and *power* [16]. Knowledge refers to treatment options, and about personal values and preferences. Power refers to the patients' perceived capacity to influence the decision-making process. Reviewing the current evidence, there is a lack of studies that exclusively explores decision-making for patients with hip OA.

This study contributes to the development of a PDA to support hip OA treatment decisions, which is currently under development by the Decision Aid Factory (DAfactory) [17]. The DAfactory is an overarching concept providing guidelines to develop and implement SDM in the clinical practice; amongst which a detailed guide to develop PDAs complying with The International Patient Decision Aid Standards (IPDAS) Collaboration

[18] and applying the Theory of Planned Behavior (TPB) [19] in the design of didactics tailored to particular patient groups.

The aim of the present study was to explore barriers and facilitators influencing hip OA patients' capacity and opportunities to engage actively in SDM. A secondary aim was to determine if the observation method provided by the DAfactory was useful in this particular context. Two research questions were addressed: 1) How are patients involved in decisions related to treatment of hip osteoarthritis? 2) Which patient-related factors facilitate or impede SDM in hip OA?

2. Material and methods

2.1 Design and setting

The study had an observational design allowing for theory-driven in-depth investigation of real OA decision-making processes taking place at an orthopedic outpatient clinic. The chosen method intended to support ecological validity by capturing the immediate communication challenges patients with hip OA experience during short outpatient consultations. A guiding principle was to get as close and direct insight into the ongoing consultation as possible, without affecting it by potentially invasive presence.

2.2 Participants and data collection

We intended to observe and audio record about 20 outpatient consultations with orthopedic surgeons and cognitively unimpaired patients considering a decision for primary hip OA with more than one treatment option. An invitation letter to participate in the study was attached the scheduled appointment letter.

Data were obtained through direct observation by the main researcher (EAB) and audio recording. Direct observation enabled insight into structural features and the non-verbal events, whereas audio recordings allowed for subsequent comprehensive qualitative data analysis. Information about patients' age and gender was collected as well as doctors' extent of previous communication training in SDM.

2.3 Description of observation method and analysis

2.3.1 Observation

An observation guide included instructions on how to actively listen and process the ongoing consultation to identify events relevant with regard to the research questions. Each observation session was guided rigorously by using imagination of an ideal SDM process as a sensory corridor. The observer sought identification with the patient role and made field notes based on projections occurring from this state as data material for further analysis. Recognition of relevant events results from continuous comparison of the ideal with the actual process and identification of either divergence or accordance. Events are utterances or any other kind of communicative behaviors, including lack of behavior where it would have been appropriate. In order to relate in-depth observation through the patient's perspective, the consultations were described according to typical structural features and the extent and manner of the patient's involvement into making treatment decisions.

2.3.2 Taxonomy of barriers to SDM

A taxonomy of a priori categories representing generic patient-related barriers towards SDM was used as basis for a combined deductive and inductive analytic approach to identify and structure relevant events. This classification is based on corresponding observation sessions as part of DAfactory PDA developments in other clinical contexts (obesity, pancreatic cancer and prostate cancer). The taxonomy is structured according to three TPB constructs, proposed to determine an individual's intention (i.e., an indication of a person's readiness) to perform a particular behavior [19].

1) Attitude toward performing the behavior: the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior.
2) Subjective norm: the perceived social pressure to perform or not to perform the behavior.
3) Perceived behavior control: the perceived ease or difficulty of performing the behavior, assumed to reflect past experience as well as anticipated impediments and obstacles.

Moreover, the generic taxonomy is organized on three abstraction levels; the level of the three TPB theoretical constructs, the level of subcategories providing abstracted groups of beliefs and the level of condensed empirical descriptions. Figure 1 displays a modified TPB-model including eight main level a priori categories.

Place Figure 1 about here

2.3.3 Qualitative analysis

The transcribed audio recordings were independently analyzed by two researchers (EAB and JK) using an iterative thematic approach inspired by template analysis [20]. Template analysis allows for the definition of ‘a priori’ codes, represented by the generic taxonomy in this study. NVivo11 qualitative data analysis software was used for data management [21]. Divergences regarding recognition and allocation of essential events were resolved by discourse. The analysis consisted of three steps:

Step 1: The audio recordings were transcribed verbatim. Field notes were used to retrieve sequences of events considered potentially relevant with regard to the patient’s involvement in decision-making. Following an inductive approach, these events were interpreted and thematically labelled according to the main and subcategory level of the generic taxonomy.

Step 2: Using a deductive approach, additional events were identified by determining applicability of existing categories of the generic taxonomy. Condensed empirical descriptions of categories applicable to hip OA patients were constructed, leading to a targeted TPB taxonomy representing barriers specific for hip AO patients.

Step 3: Determine if new elements are applicable to the generic taxonomy through a final refinement process.

2.4 Ethical considerations

The Norwegian Centre for Research Data approved the study. The study complies with the ethical standards and principles stated in the Helsinki declaration [22]. All participants received both written and oral information about the study and patients gave informed written consent.

3. Results

3.1 Patient characteristics and decision outcomes

Of the 20 patients approached, 12 women and 7 men agreed to participate in the study, twelve on the first day and seven on the second day. The youngest was 40, the oldest 84 years old. The consultations lasted on average 22 minutes (range 11 – 40). Both surgeons were male, and had not received any specific SDM skill communication training. Nine patients ended up with the decision to undergo THR. The remaining patients were either scheduled for follow-up after further diagnostic interventions (n=3), considered medically unfit for surgery (n=1) or advised to postpone surgery by optimizing conservative treatment (n=6). Table 1 summarizes patient characteristics and decision outcomes, categorized as described in the Hip Osteoarthritis Continuum [8].

Place Table 1 here

3.2 Structural features of the consultation

The consultations had similar content and followed a logical structure arising from the given context, which included consideration of the patients' allocation within the disease continuum, and the specific nature of OA (Figure 2). Notably, each outpatient consultation was merely representing a sequence within a comprehensive decision-making process, where several health professionals are potentially involved over time.

Place Figure 2 here

The surgeons seemed to regard their task more or less explicitly to (just) considering the medical indication or contraindication for prosthetic surgery. As illustrated in Figure 2, this *diagnostic* decision-making proceeded simultaneously with the more implicit *treatment* decision-making process, which is concerned with reaching the most optimal treatment decision.

In our sample, phase one is predominantly used to confirm an OA diagnosis and to discuss its individual manifestation with regards to ADL and quality of life. This happened by consideration of available information in the referral document, the recent X-ray, history taking and structured clinical assessment.

In phase two, information about the surgical option was in most cases given priority. Depending on individual features and characteristics, engagement and arguments from both parties varied. In case of suspicion of other possible reasons for the troublesome symptoms, the doctors challenged the patient’s desire for surgery by spending more emphasis on explanation of the associated risks. If the medical indication seemed clear, the doctors prioritized encouragement of the patient by emphasizing possible benefit. Mutual engagement in critical negotiation of pros and cons appeared influenced by varying attitudes on the patients’ side.

In phase three, the patients’ subjective experience and concerns were discussed exhaustively and medical decisions for or against THR or additional diagnostic tests were made clear. In addition, the consultations included follow-up plans, and sometimes instructions about further evaluation of the decision. Both parties engaged in communicative activities to reassure mutual understanding in this process.

3.3 Facilitators and barriers towards SDM

We identified 25 of the 31 subcategories of the generic taxonomy and included one additional barrier relating to patients’ communication self-efficacy (marked with ^{Y}). This barrier occurs for most patients in this sample given the situation that two communication processes happens simultaneously as described in the previous section. The latter barrier was included in the revised version of the generic taxonomy leading to 32 subcategories (Table 2).

Place Table 2 about here

3.3.1 Patients’ attitudes towards SDM-behavior

This theme reflects patients’ awareness of options and that a decision must be made, possession of relevant knowledge, information and information processing skills, understanding of what SDM entails in practice, and expectations of potential outcomes of SDM. We identified 14 of the 18 factors relating to this category, and provided condensed typical empirical examples. A common observation was that patients seemed uninformed about OA and the available choices. This observation was based on the tendency of pursuing a passive role, implying an understanding that their contribution into the decision-making process was to answer the surgeons' questions. In addition, their primary agenda for the visit was hardly ever disclosed directly by the patients. In these cases, the patients tended to follow the surgeons lead. This apparent absence of initial talk about personal goals, and how they may relate to the available choices, seemed to limit patients' opportunities for active involvement in treatment decision-making. Previous experience with orthopedic consultations and a history of rejection for surgery seemed to influence patients' attitudes and facilitate involvement. A female patient (P3) had prepared for the consultation by bringing documentation from previous specialists and primary care visits. From the very start of the consultation, she was standing upright engaged actively during the initial history taking, and her agenda was explicitly stated.

> *O: What do you think is the solution for your problem?*
>
> *P: To replace my hip!*
>
> *O: And you are convinced about that?*
>
> *P: Mm, yes!*

From this point, the surgeon worked with the patient to make her understand the increased risks associated with smoking and obesity. However, this did not change the patient's motivation to undergo surgery, as she argued that previous surgeries had been successful despite smoking and that other overweight people in her social network had undergone hip surgery. With regard to the taxonomy, this is an example that illustrates a patient expecting a predetermined decision to be final. Furthermore, the discussion that takes place between the surgeon and the patient shows signs of strong conviction concerning prognosis, which in turn may reveal unawareness of what an SDM process could gain.

3.3.2 Subjective norms influencing SDM-behavior

This theme reflects the presence or absence of influence from significant others on the decision-making process. We identified six of the eight generic barriers and provided corresponding empirical examples. The surgeon's expert assessment and opinion about the indication for surgery was directive for the overall decision-making process, and many patients seemed to trust his judgement. This uncritical trust may result in passive behavior, and thus act as a barrier. The following example illustrates this finding. A male patient (P1) in his forties was told by the surgeon at the very beginning of the consultation that surgery was out of the picture, even before eliciting the patient's agenda for the visit.

> *O: There are some signs of wear and tear on the pictures [P: Yes]. But there isn't… there is still some cartilage left [Yes]. And that… that is a good thing– right? [Yes] You are simply too young for a hip replacement [P: Yes, yes...].*

Here, and in the following, the patient appeared to accept the judgement of the surgeon without any attempts to challenge the surgeons' arguments or conviction.

Another example (P10) illustrates how the surgeons' initial judgement about surgical indication directly influenced the treatment decision-making process. Alternatives to surgery were practically ruled out at the very beginning of the consultation, and the following information exchange circled around the surgical procedure and what to expect in terms of pain and physical function outcomes (i.e. not balanced against the potential benefit of non-surgical options).

> *O: It is… when we replace your hip joint- because that is the appropriate procedure for you now [P: Ok, mhm?]. It has progressed so much [P: Mhm], that there is nothing to do to fix it… we simply have to put in a prosthesis [P: Yes]. Right? I can almost say that even before doing any examinations.*

Three patients had a family member present during the consultation. This seemed to facilitate more discussions and deliberations around treatment alternatives.

> *O: I think that we should proceed with this plan, and then we can arrange a follow-up with a control [P: Mhm..]. Then we will see how it goes [P: Yes].*
>
> *Family member: Yes, but I want to mention one thing.. I mean, you are very keen to spend time at the cabin during the summer [P: Yes]. . and it is not easy for you to get up there- to stay there.. [P: No, it isn't]. So, as long as you have the cabin and want to stay there, it is…*
>
> *P: What are you thinking?*
>
> *Family member: I think that you have this pain and trouble walking, and to get around.. that makes it difficult for you to spend time there.. and that is something you really want*

> *to do – to stay there.. [P: Yes..] So, that is something that is part of the overall consideration* (Family member, P5).

Given this apparent facilitating effect, the absence of a third person who provides important perspectives relevant to the treatment decision-making process may act as a barrier towards SDM.

3.3.3 Perceived behavioral control influencing SDM-behavior

This theme represents patients' perceived control regarding treatment or coping with the consequences from treatment, and communication self-efficacy. We added one barrier at the subcategory level of the generic taxonomy, and provided corresponding empirical descriptions of a total of six factors. Any treatment for hip OA involves life-style changes; e.g. physical exercise, weight loss and smoking cessation. A request by others to engage in such behavior change-dependent treatment may cause emotional and cognitive distress and consequently influence their perceived control beliefs in communication with a medical specialist. Feelings of uncertainty, fear, shame and low confidence relating to previous management attempts is likely to influence the capacity or willingness to disclose these personal and potential sensitive issues during short outpatient consultations.

The patient's ultimate concern and reason to seek advice from a medical specialist is to determine the optimal treatment option. The following example shows a female patient with two previous orthopedic outpatient evaluations. The patient was clearly upset about how her condition affects her daily life, both privately and at work.

> *P: It is really bad atmosphere at our house, because I simply lose control when this pain comes [O: Yes]. And that bothers me! But if it turns out that there is nothing to do to improve my situation- then I just have to accept it, and I'll have to find ways to live with it…*
>
> *O: We have discussed this on the basis that it might be weak indication to support a decision for surgery – because that is what the other (orthopedic surgeons) have decided. However, it is not clear yet whether we arrive at the same conclusion [P: Right, we will see!]. We'll see, and maybe there are other things that can help. But now our concern is to determine if you should undergo surgery. There are of course several other things that might help you [P: And that is exactly?]. Everything from*

> *physiotherapy – and other things that maybe your GP is just as good as me to… but what I have to find out is the question of hip prosthesis [P: Mhm]. If that is a smart thing to do… [P: Yes].*

In this example, the patient responded to the surgeon's statement that there might be other helpful treatment options by asking what specific treatment he means. The surgeon briefly mentioned physiotherapy as alternative to surgery, but at the same time stated that his responsibility was to determine if there is indication for surgery. No details were provided about the potential pros and cons of non-surgical options. Given this situation, a patient may feel disempowered in changing the agenda and claim the necessary information about all possibilities that may help her problem.

4. Discussion and conclusion

4.1 Discussion

In this study, we explored patients' involvement in treatment decision-making for primary hip OA by direct observation and audio recording of routine orthopedic outpatient consultations. The ongoing communication was studied using observation of the patients' perspective and subsequently analyzed through a theoretical lens comprising SDM principles and the TPB. By means applying and refining a generic TPB-based taxonomy of SDM barriers, we identified a pool of factors that seemed to influence hip OA patients' involvement in treatment decision-making and provided a targeted version of the taxonomy.

The purpose of the surgeons' diagnostic procedures, and how these relate to treatment decision-making, may be unclear to the patients. In most of the consultations, the medical problem and its impact on individual patient's life became relatively clear during the history taking and additional physical examination. Patient involvement in this phase of the consultation seemed quite pronounced, but not in terms of the principles of SDM. The responsibility to determine whether surgery is medically indicated lies at the surgeon, and during these procedures, the patients answered multiple questions and participated quite actively. Furthermore, the strong focus on the question of whether prosthetic surgery was indicated, was somewhat blurring the fundamental message that an informed treatment decision is based on careful negotiations of all available treatment options. This results in the overlapping and implicit treatment decision-making process observed in these consultations. It includes some elements that correspond to essential SDM principles [23], but for the patient, it can be challenging to know when the actual treatment decision-making process starts and how to influence it by making own goals and preferences implicit.

Because hip OA has a long lasting disease continuum, treatment decision-making is occurring at multiple time-points and with different people involved. This has to be considered during data analysis, but also as part of the overall interpretation of the results. The chosen secondary care setting represents a late phase of the continuum, accompanied by moderate to severe symptoms, and the patient should have tried non-surgical treatment as a condition for a referral at this stage [3]. This may have implicated for some that the surgical option was the only realistic alternative to consider. Furthermore, the qualitative design used in this study limits the transferability of the findings. The current study only includes one particular context and it comprises only nineteen participants and two orthopedic surgeons. In addition, only one researcher performed the direct observations. However, audio recording of the consultations made it possible to transcribe the consultations verbatim and replay the recordings multiple times. This enabled a comprehensive qualitative analysis and several discussions within the research group to establish valid interpretations. The use of a generic taxonomy contributed to broaden the perspective and contextualize the findings. Hence, the particular method used to investigate patient related factors indicative of (ideal) intentions to engage actively in treatment decision-making seems feasible, and is a novel feature and regarded as an important strength of this study. There is however, a need for further validation of the findings by patients and that orthopedic surgeons provide their perspectives.

As the literature shows, patients' opportunities and capacity to become active participants in treatment decision-making is affected by several interrelated factors – the patient [16], the health professionals [24] and the organization/system [25]. In terms of implementation of SDM through tailored PDAs, there are arguments to target each of them. However, this present study is limited to factors influencing patients' decision-making behavior in the setting of an orthopedic outpatient clinic. Assuming the patient as a *shared decision-maker* and from this viewpoint to investigate particular barriers met in the attempt to engage in this role seems to us as an approach coherent with the SDM conceptual idea of the autonomous patient. It is not yet clear whether approaching the health professionals or the patients is more efficient to make implementation of SDM happen. However, we know from the literature that strategies focusing on the patient can work effectively, such as the three-question method [26, 27]. Furthermore, people exposed to PDAs feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision-making and more accurate risk perceptions [28]. A full discussion about which perspective and what mode of implementation strategy is most effective is not intended here, but it seems that combined approaches targeting both patients and health professionals are most promising as means to translate SDM into routine clinical practice [29].

4.2 Conclusion

The patients in this study are involved quite actively in the ongoing decision-making processes, but more concerning indication for surgery, and less about careful deliberations of benefit and harms associated with all available alternatives. We found that previously identified barriers towards SDM apply to patients making decisions on treatment for hip OA. Patient's ability to establish an own agenda in the outpatient consultation, that is predominantly framed within a diagnostic decision-making process, stood out as a seminal influencing factor towards SDM in patients with hip OA.

4.3 Practice implications

The study contributes to the process of the development of a PDA published at the Norwegian eHealth platform www.helsenorge.no/samvalg, aimed at supporting hip OA treatment decisions. The findings will inform the adjustment of the PDAs didactic approach; and the revised generic TPB taxonomy will be used in other developments. In particular, the knowledge is used to shape narratives (patient stories) presented in the PDA to enhance the users' motivation to engage in an SDM process.

Author contributions

EAB: study design, data collection, transcription, data analysis and interpretation, drafting and editing the article. HE: study design, interpretation of data and critical revision of the article for intellectual content. ML and SvD: critical revision of the article for intellectual content. JK: study design, data analysis and interpretation, and critical revision of the article for intellectual content. All authors read and approved the final draft.

Conflicts of interest

None

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5.0 References

[1] T. Vos, A.D. Flaxman, M. Naghavi, R. Lozano, C. Michaud, M. Ezzati, et al., Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010, Lancet 380(9859) (2012) 2163-2196.

[2] A. Litwic, M.H. Edwards, E.M. Dennison, C. Cooper, Epidemiology and burden of osteoarthritis, Br. Med. Bull. 105(1) (2013) 185-199.

[3] NICE, Osteoarthritis: Care and management in adults. Clinical guideline [CG177], 2014. https://www.nice.org.uk/guidance/cg177. (Accessed 15.05 2018).

[4] W. Zhang, R.W. Moskowitz, G. Nuki, S. Abramson, R.D. Altman, N. Arden, et al., OARSI recommendations for the management of hip and knee osteoarthritis, Part II: OARSI evidence-based, expert consensus guidelines, Osteoarthritis Cartilage 16(2) (2008) 137-162.

[5] L. Fernandes, K.B. Hagen, J.W.J. Bijlsma, O. Andreassen, P. Christensen, P.G. Conaghan, et al., EULAR recommendations for the non-pharmacological core management of hip and knee osteoarthritis, Ann Rheum Dis 72(7) (2013) 1125-1135.

[6] S. Watt, Clinical decision-making in the context of chronic illness, Health Expectations 3(1) (2000) 6-16.

[7] V.M. Montori, A. Gafni, C. Charles, A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes, Health Expect 9(1) (2006) 25-36.

[8] E.A. Brembo, H. Kapstad, T. Eide, L. Månsson, S.V. Dulmen, H. Eide, Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study, BMC Health Serv Res 16(1) (2016).

[9] P.R. Fortin, J.R. Penrod, A.E. Clarke, Y. St Pierre, L. Joseph, P. Belisle, et al., Timing of total joint replacement affects clinical outcomes among patients with osteoarthritis of the hip or knee, Arthritis Rheum 46 (2002).

[10] P.R. Fortin, A.E. Clarke, L. Joseph, M.H. Liang, M. Tanzer, D. Ferland, et al., Outcomes of total hip and knee replacement: preoperative functional status predicts outcomes at six months after surgery, Arthritis Rheum 42(8) (1999) 1722-1728.

[11] W. Levinson, P. Hudak, A.C. Tricco, A systematic review of surgeon–patient communication: Strengths and opportunities for improvement, Patient Education and Counseling 93(1) (2013) 3-17.

[12] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, et al., Shared decision making: a model for clinical practice, J Gen Intern Med 27(10) (2012) 1361-1367.

[13] M. Härter, N. Moumjid, J. Cornuz, G. Elwyn, T. van der Weijden, Shared decision making in 2017: International accomplishments in policy, research and implementation, Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 123–124 (2017) 1-5.

[14] K. Gravel, F. Légaré, I.D. Graham, Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions, Implement Sci 1 (2006).

[15] F. Legare, S. Ratte, K. Gravel, I.D. Graham, Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions, Patient Educ Couns 73(3) (2008) 526-35.

[16] N. Joseph-Williams, G. Elwyn, A. Edwards, Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making, Patient Education and Counseling 94(3) (2014) 291-309.

[17] J. Kasper, A.R. Lager, M. Rumpsfeld, S. Kienlin, K.H. Smestad, T. Bråthen, et al., Status report from Norway: Implementation of patient involvement in Norwegian health care, Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen 123–124 (2017) 75-80.

[18] International Patient Decision Aids Standards (IPDAS) Collaboration, 2013. http://ipdas.ohri.ca/. (Accessed 15. May 2018).

[19] I. Ajzen, The theory of planned behavior, Organ Behav Hum Decis Process 50 (1991).

[20] B.F. Crabtree, W.L. Miller, Using Codes and Code Manuals. A Template Organizing Style of Interpration, in: B.F. Crabtree, W.L. Miller (Eds.), Doing qualitative research, Sage Publications, Thousand Oaks, California, 1999, pp. 163-177.

[21] NVivo qualitative data analysis software, QSR International Pty Ltd. Version 11, 2015.

[22] Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects, 2013. https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/. (Accessed 06. June 2018).

[23] G. Makoul, M.L. Clayman, An integrative model of shared decision making in medical encounters, Patient education and counseling 60(3) (2006) 301-312.

[24] P. Thompson-Leduc, M.L. Clayman, S. Turcotte, F. Legare, Shared decision-making behaviours in health professionals: a systematic review of studies based on the Theory of Planned Behaviour, Health Expect 18(5) (2015) 754-74.

[25] I. Scholl, A. LaRussa, P. Hahlweg, S. Kobrin, G. Elwyn, Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them - a scoping review, Implement Sci 13(1) (2018) 40.

[26] H.L. Shepherd, A. Barratt, A. Jones, D. Bateson, K. Carey, L.J. Trevena, et al., Can consumers learn to ask three questions to improve shared decision making? A feasibility study of the ASK (AskShareKnow) Patient-Clinician Communication Model((R)) intervention in a primary health-care setting, Health Expect 19(5) (2016) 1160-8.

[27] H.L. Shepherd, A. Barratt, L.J. Trevena, K. McGeechan, K. Carey, R.M. Epstein, et al., Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial, Patient Educ Couns 84(3) (2011) 379-85.

[28] D. Stacey, F. Légaré, K. Lewis, M.J. Barry, C.L. Bennett, K.B. Eden, et al., Decision aids for people facing health treatment or screening decisions, Cochrane Database of Systematic Reviews (4) (2017).

[29] F. Legare, S. Turcotte, D. Stacey, S. Ratte, J. Kryworuchko, I.D. Graham, Patients' perceptions of sharing in decisions: a systematic review of interventions to enhance shared decision making in routine clinical practice, Patient 5(1) (2012) 1-19.

Figure 1:

Title: Modified Theory of Planned Behavior diagram, including the main categories of the taxonomy of patient-related barriers/facilitators towards SDM-behavior

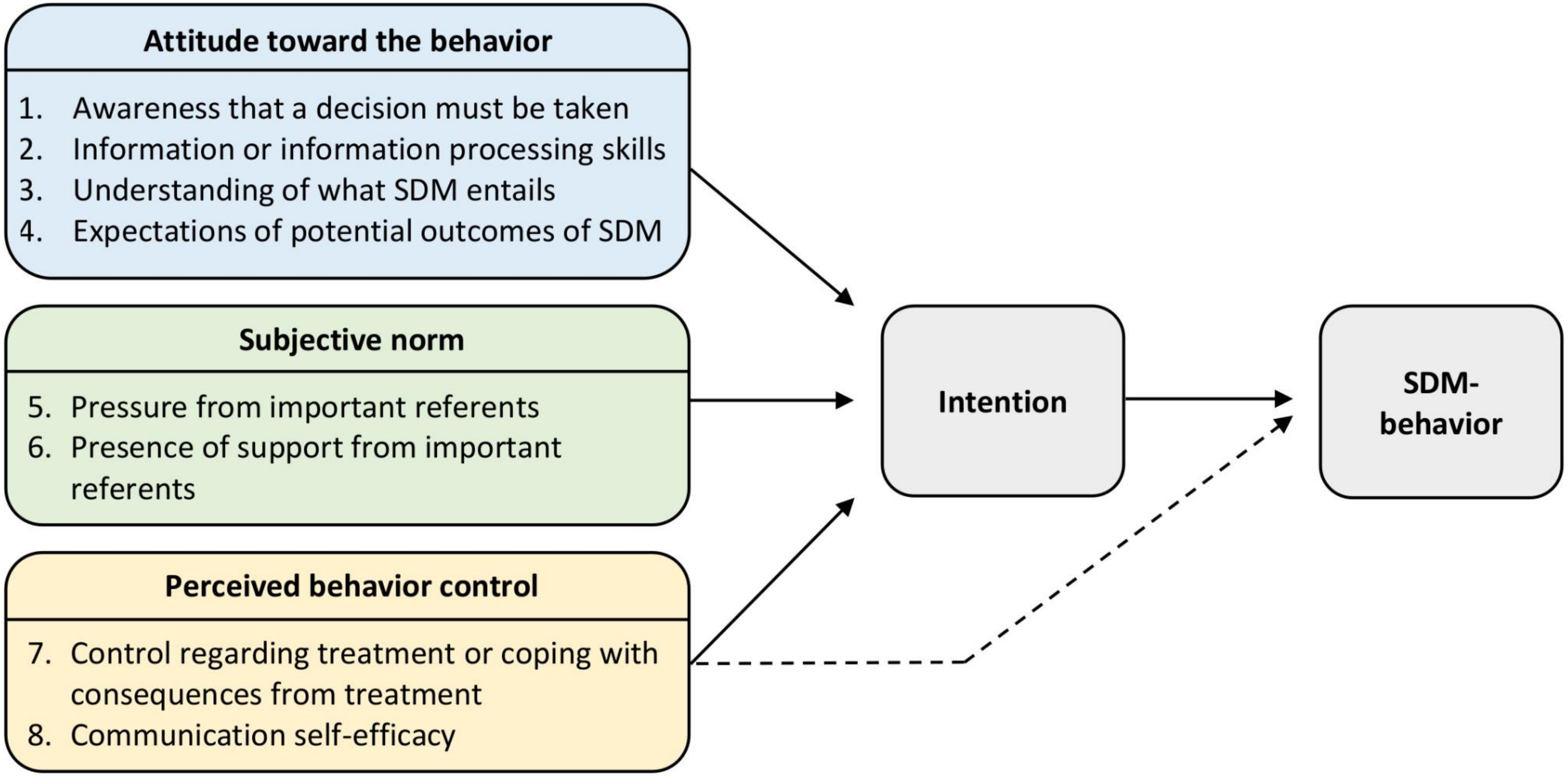

Figure 2:

Title: Overview of the typical course of an orthopedic outpatient consultation on hip OA, demonstrating two overlapping but also different decision-making processes.

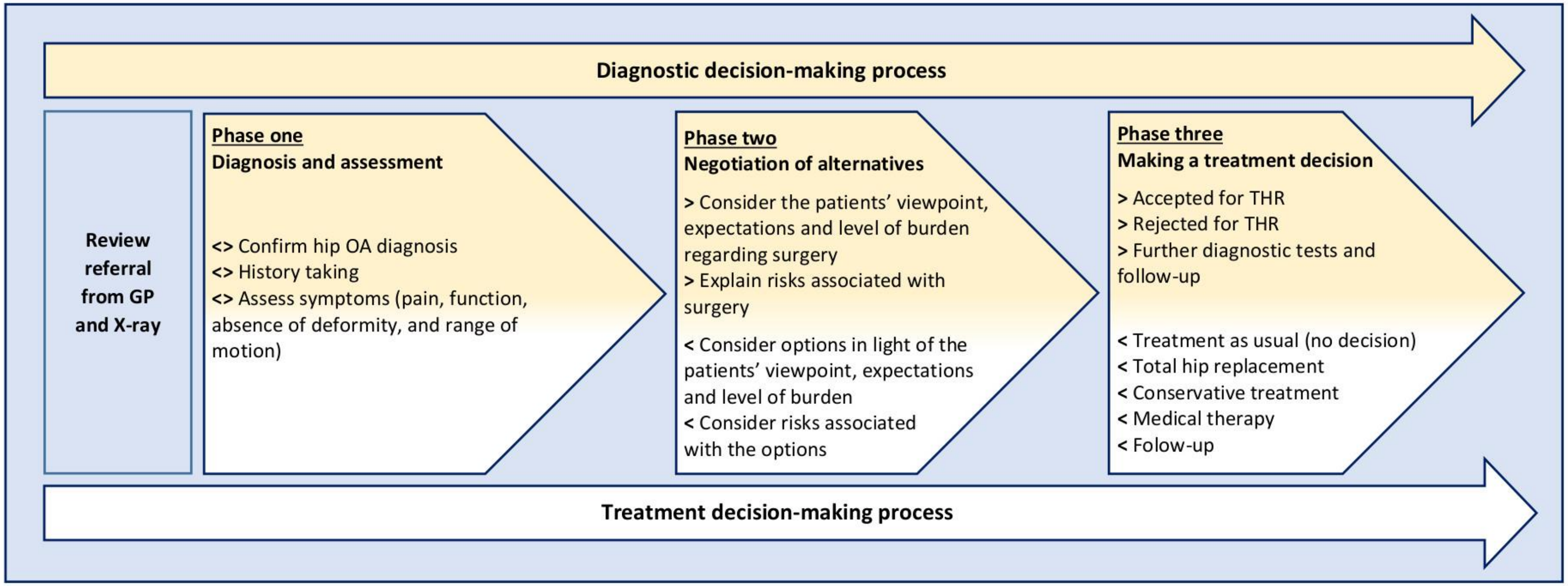

Table 1:

Title: Patient characteristics and decision-making outcomes.

ID	Age	Gender	Decision-making outcomes
1	40-44	Male	Postpone THR. Follow-up in six months. Physiotherapy, weight loss and increase dose of Etoricoxib.
2	80-84	Female	Not medically fit for THR. Increase pain medication.
3	50-54	Female	Accepted for THR and placed in the queue. Weight loss and smoking cessation.
4	75-79	Female	Postpone THR. Follow-up in six months after lumbar MRI scan. Continue with physiotherapy.
5	80-84	Female	Postpone THR. Follow-up in three months, continue physical therapy and start Etoricoxib.
6	65-69	Male	Accepted for THR and placed in the queue.
7	75-79	Female	Accepted for THR and placed in the queue. Smoking cessation.
8	70-74	Female	Accepted for THR and placed in the queue. Smoking cessation.
9	65-69	Female	Postpone THR. Follow-up in three months after MRI scan. Cortisone injection for trochanter bursitis.
10	75-79	Female	Accepted and agreed time for THR. Postoperative physiotherapy.
11	65-69	Female	Accepted and agreed time for THR. Smoking cessation.
12	60-64	Male	Accepted for THR and placed in the queue. Weight loss.
13	60-64	Female	Rejected for THR. Follow-up after hip MRI scan.
14	70-74	Male	Postpone THR. Follow-up in six months. Cortisone injection for trochanter bursitis.
15	70-74	Female	Patient do not prefer THR. Treatment as usual.
16	55-59	Male	Rejected for THR. Follow-up of back-pain after lumbar MRI scan.
17	55-59	Female	Accepted for THR and placed in the queue. Preoperative physical exercise.
18	50-54	Male	Accepted for THR and placed in the queue.
19	55-59	Male	Rejected for THR. Follow-up by general practitioner

Table 2:

Title: Revised DAfactory taxonomy of generic patient-related barriers towards SDM

Level 1: Main categories	Level 2: Subcategories of abstracted groups of beliefs	Level 3: Condensed empirical examples
1. Awareness that a decision must be made	Being aware of available treatment options	*My only concern is to receive treatment for my pain*
	Expecting that the decision is already made by the doctor	*Nothing I mean or say can influence whether or not I receive hip replacement*
	Expecting that my predetermined decision will be final	*I am convinced that the only solution for my problem is to replace my hip*
	Future-oriented focus (avoid any personal uncertainties that might arise in the decision-making process)	*My focus is what I can expect after undergoing total hip replacement*
	^{x} Unreadiness to make a decision (including to defer treatment decision) or avoiding negotiations of a decision	
2. Information and information processing skills	Being uninformed and/or lacking necessary knowledge	*I don't know much about osteoarthritis or which treatment alternatives exist*
	Having difficulties to understand the information (ex. medical jargon)	*It is sometimes difficult to understand what the surgeon means when he talks so quickly*
	Having difficulties to perceive the information (ex. present emotions are blocking)	*I am so excited about whether or not I receive the operation that I do not perceive what the doctor says*
	Having difficulties to evaluate the information (ex. too much information)	*It is difficult to concentrate when the surgeon both talks and asks questions while doing physical examinations*
3. Understanding of what SDM entails in practice	Expectation of a passive role in the decision-making process	*My contribution into the decision-making process is to answer questions.*
	Expectation of a traditional doctor-patient relationship: the patient disclose personal information and the doctor makes the decision	*I am here because I want an operation – I want to move on with my life. However, I do not have the authority to make this decision. It is the doctor's responsibility*
	^{x} Understanding of the doctor as specialist, but patient makes the decision	
4. Expectations of potential outcomes of SDM	Relying heavily on the opinions of the doctor over own preferences and values	*Ultimately, I don't think my views matter when it comes to deciding which treatment is best*
	Frustration about others expectations of being actively involved in the decision-making process	*I just want my doctor to decide what I should do*
	Strong conviction with regards to prognosis	*I do whatever it takes to get rid of this pain*
	^{x} Having concern of being self-responsible for any negative treatment outcomes	
	^{x} Assuming that all treatment options are equally effective	
	Expectation of not being entitled of control over own health-situation	*I am anxious and I need the surgeon to tell me what to do*

5. Pressure from important referents	Having excessive trust on others opinions/advice	*I believe that the surgeon can decide what is best for me*
	Feeling of responsibility for significant others	*My employer expects me to return to work in April. I need an operation before that.*
	[X] Avoiding conflicts or other social consequences	
	Being unfamiliar or uncomfortable with taking an active role in the decision-making process	*My doctor tells me what to do, and I usually agree with his decisions.*
	Assuming that the doctor take one's personal needs into account and makes the optimal decision	*I believe that the surgeon knows what it most important for me*
6. Presence of support from important referents	Lacking social support in the decision-making process (impacts motivation/self-efficacy)	*It would help to bring someone to the consultation so that I would remember what to ask the surgeon*
	[X] Lacking communication with important referents about to the forthcoming decision	
	Experiencing conflicting opinions among health professionals	*I have been to several doctors and they all have different opinions about what treatment I should receive.*
7. Control regarding treatment or coping with consequences from treatment	Being uncertain around possible challenges or demands of treatment options	*I do not believe that I can stop smoking or lose enough weight*
	Being uncertain around possible challenges or demands of the consequences of treatment	*I am afraid what it actually entails to put a prosthesis into my body*
8. Communication self-efficacy	Feeling of shame (self-image, lack of knowledge)	*I know that I should have done more to lose weight*
	Having low self-confidence	*I don't think my concerns are important enough to discuss with the orthopedic surgeon*
	Belief whether the outpatient consultation is an arena to discuss/disclose personal feelings and concerns	*The surgeon does not have time to listen to my concerns, so I keep them for myself.*
	[Y] **Feeling of being disempowered in changing the agenda**	***My main concern is that I want to discuss which of the available treatment options fits best to me in my current situation***

Description: Empirical examples in the third column are context specific. [X] Element not identified in this clinical context. [Y] New element of the generic taxonomy