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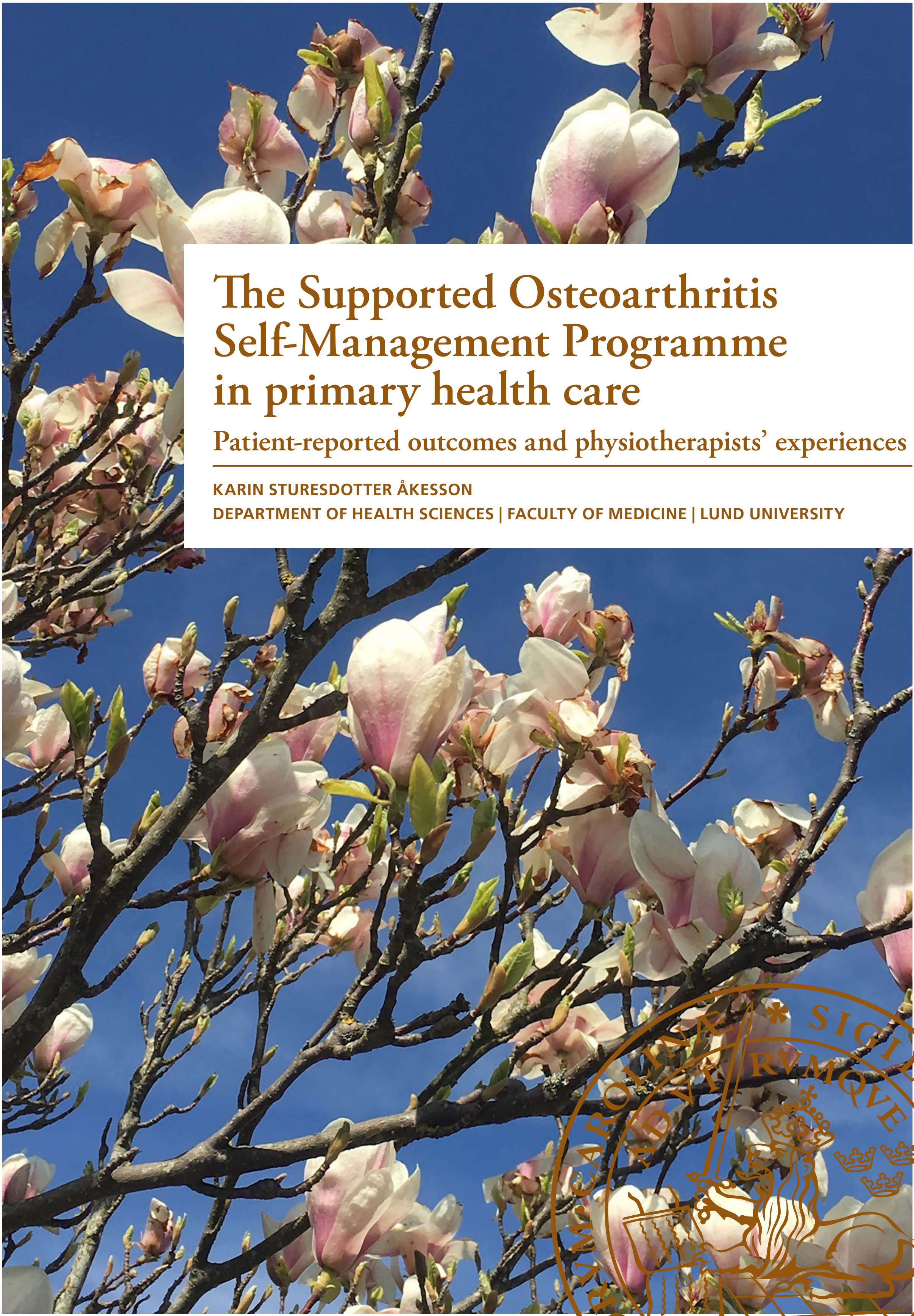

The Supported Osteoarthritis Self-Management Programme in primary health care

Patient-reported outcomes and physiotherapists' experiences

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The Supported Osteoarthritis Self-Management Programme in primary health care

Patient-reported outcomes and physiotherapists´ experiences

Karin Sturesdotter Åkesson

DOCTORAL DISSERTATION

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Abstract

Background: Osteoarthritis (OA) is a disabling joint disease affecting about 300 million people worldwide. Today, there is no cure for OA and treatment focuses on relieving symptoms. Guidelines recommend education, exercise, and weight control, as first-line treatment. In Sweden, first-line treatment is offered as a Supported Osteoarthritis Self-Management Programme (SOASP) combining education and exercise with the aim of supporting patients with hip and/or knee OA to cope with their disease, improve health-related quality of life (HRQoL) and increase physical activity level. The overall aim of this thesis was to increase knowledge about the SOASP delivered in clinical settings in primary health care from the perspectives of patients and physiotherapists.

Methods: All patients included in studies I–III had participated in a SOASP. Study I was based on a cohort (n = 7628) from the Swedish National Quality Registry, Better Management of patients with Osteoarthritis (BOA). Outcome measures were physical activity and HRQoL measured with the EQ-5D. Studies II and III were based on a cohort (n = 143) from two regions in the south of Sweden (Region Skåne and Region Blekinge). Outcome measures were enablement (PEI), empowerment (SWE-RES-23) and HRQoL (EQ-5D). In study IV, a purposive sampling was used. Eighteen physiotherapists were interviewed about their experiences of delivering the SOASP and about implementation of the OA treatment guidelines in Region Skåne. A patient partner was involved in studies II and III.

Results: A greater proportion of men changed to being physically active at three months follow-up. The proportion of women being physically active ≥ 150 activity minutes a week was larger than for men at baseline and at follow-up at 12 months. Women reported lower HRQoL than men at all measuring points. Patients reported moderate to high enablement and empowerment and an increase in empowerment and in HRQoL after participating in a SOASP. Enablement and empowerment as measured with the PEI and the SWE-RES-23 respectively were only partly related and could not predict change in HRQoL among patients participating in a SOASP. The interviewed physiotherapists were confident in their role as primary assessors of OA patients and the guidelines were aligned with their professional beliefs. The SOASP, was found to be efficient for patients. Physiotherapists followed the guidelines, but saw room for improvement as all patients with hip and/or knee OA did not receive treatment according to the guidelines. Furthermore, the physiotherapists emphasised the need for management's support and that guidelines should be easy to follow.

Conclusions: There were differences between men and women before and after participating in a SOASP. These differences should be considered when planning for how to support men and women with hip and/or knee OA to maintain or even increase physical activity and HRQoL in the long term. The results indicate that the SOASP is useful in enabling and empowering patients, at least in the short term, and that both the PEI and the SWE-RES-23 can be of use in evaluating interventions like SOASP. More research is needed to find outcome measures to predict OA treatment outcomes. The physiotherapists believed in the guidelines and were confident in providing first-line treatment to OA patients. However, information about the guidelines probably needs to be repeated to all health care providers and management. Data from the national quality registry on OA could probably be used to a greater extent in daily clinical work in primary health care to improve quality of care for OA patients.

Key words osteoarthritis, hip, knee, patient education, enablement, empowerment, patient partner

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To my family

"Knowing is not enough; we must apply.

Willing is not enough; we must do"

Johann Wolfgang von Goethe

Table of Contents

Abstract

Background: Osteoarthritis (OA) is a disabling joint disease affecting about 300 million people worldwide. Today, there is no cure for OA and treatment focuses on relieving symptoms. Guidelines recommend education, exercise, and weight control, as first-line treatment. In Sweden, first-line treatment is offered as a Supported Osteoarthritis Self-Management Programme (SOASP) combining education and exercise with the aim of supporting patients with hip and/or knee OA to cope with their disease, improve health-related quality of life (HRQoL) and increase physical activity level. The overall aim of this thesis was to increase knowledge about the SOASP delivered in clinical settings in primary health care from the perspectives of patients and physiotherapists.

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Conclusions: There were differences between men and women before and after participating in a SOASP. These differences should be considered when planning for how to support men and women with hip and/or knee OA to maintain or even increase physical activity and HRQoL in the long term. The results indicate that the SOASP is useful in enabling and empowering patients, at least in the short term, and that both the PEI and the SWE-RES-23 can be of use in evaluating interventions like SOASP. More research is needed to find outcome measures to predict OA treatment outcomes. The physiotherapists believed in the guidelines and were confident in providing first-line treatment to OA patients. However, information about the guidelines probably needs to be repeated to all health care providers and management. Data from the national quality registry on OA could probably be used to a greater extent in daily clinical work in primary health care to improve quality of care for OA patients.

Svensk populärvetenskaplig sammanfattning

Artros är en vanlig sjukdom och ungefär var fjärde person över 45 år i Sverige har artros i någon led. Sjukdomen kan drabba alla leder men är vanligast i höft, knä, rygg och fingrar. Personer som har artros kan få ont i lederna när de rör sig, känna sig stela och få svårt att göra olika vardagliga saker såsom att resa sig från sittande, gå i en trappa eller dammsuga. De som haft artros länge kan även ha ont i lederna i vila.

Det finns ingen behandling som botar artros idag men det finns ändå mycket att göra för att lindra besvären för att må så bra som möjligt. Eftersom artros är en vanlig sjukdom i hela världen så forskas det mycket om artros. Forskning har lett fram till riktlinjer för behandling av artros. Enligt dessa riktlinjer bör alla personer som har artros i höft och/eller knä få information om vad artros är och få hjälp med att komma i gång med träning men även med att gå ner i vikt om det behövs. Information, träning och viktkontroll räknas som grundbehandling vid artros.

Alla vårdcentraler i Region Skåne bör erbjuda grundbehandling till alla patienter med artros. Personer med artros i höft eller knä bör träffa en fysioterapeut för att få en diagnos och för att komma i gång med grundbehandlingen så tidigt som möjligt i sjukdomsförloppet.

Fysioterapeuter kan erbjuda grundbehandlingen i form av artrosskola som kombinerar information om vad artros är med träning. Det är viktigt att personer med artros vet vad de kan göra själva för att hantera sin sjukdom och därmed kunna må så bra som möjligt. Att komma i gång med träning i ett tidigt skede av sjukdomen bidrar till att bevara rörlighet, öka muskelstyrka och minska smärta.

I denna avhandling har artrosskolan studerats från både patienters och fysioterapeuters perspektiv. Personer som deltog i artrosskola fyllde i frågeformulär, så kallade patientrapporterade utfallsmått, före artrosskolans start, under artrosskolans gång och när artrosskolan var slut. Studierna visade att det var skillnad mellan män och kvinnor då fler män än kvinnor ökade sin fysiska aktivitet under artrosskolans gång. Fler kvinnor än män rapporterade lägre livskvalitet vid alla svarstillfällen. Personer med artros angav att de tyckte att de kunde hantera sina besvär bättre och att känslan av att ha makt att påverka sin situation ökade efter artrosskolan.

Vi samarbetade med en forskningspartner som är en person som själv har artros och vet hur det är att leva med sjukdomen. Forskningspartnern gav sina synpunkter på våra forskningsfrågor, de frågeformulär vi använde oss av i studierna och vår tolkning av resultatet utifrån sina erfarenheter av att leva med artros. En forskningspartner representerar alla personer med artros och samarbetet påminde oss om att alla personer med artros inte är lika, gav oss nya insikter och bidrog till att våra studier förankrades i verkligheten.

Alla patienter med artros får inte ta del av grundbehandlingen. Därför gjorde Region Skåne en satsning mellan åren 2016 – 2019 för att fler personer med artros skulle få tillgång till grundbehandling och artrosskola. Vi intervjuade fysioterapeuter om deras erfarenheter av att erbjuda artrosskola och deras erfarenheter av Region Skånes satsning att sprida kunskap om behandlingen. Fysioterapeuterna uppgav att de kände sig trygga med att patienter med artros kommer till dem direkt för diagnostisering och grundbehandling utan ha träffat läkare först. De tyckte även att artrosskolan var bra för de flesta patienter med artros men ibland behövde behandlingen anpassas för att stämma med patientens behov och förutsättningar. Ledningens stöd uppgavs vara viktigt för att fysioterapeuterna skulle kunna erbjuda, följa upp och förbättra artrosskolan.

Vår forskning kan komma till nytta vid planering av hur artrosvård kan bedrivas och följas upp samt vid planering av insatser för vidare spridning av information om grundbehandling. Män med artros kan behöva mer stöd vad gäller fysisk aktivitet för att bibehålla resultat på längre sikt. Kvinnor med artros kan behöva mer stöd vad gäller livskvalitet. Att delta i artrosskola verkar leda till att patienter med artros upplever att de kan hantera sina besvär bättre samt att deras känsla att ha makt att påverka sin situation ökar. All vårdpersonal verkar inte följa riktlinjer för behandling och därför behöver information om behandlingen upprepas till all vårdpersonal och till ledning.

Fler personer med artros bör få ta del av grundbehandlingen så tidigt som möjligt i sjukdomsförloppet och få lära sig att hantera och leva med sin sjukdom för att ha större möjlighet att minska smärta, bibehålla funktion och undvika försämring. Vi tror även att data från ett nationellt kvalitetsregister kan användas mer i det dagliga kliniska arbetet i primärvården för att utveckla och förbättra vården för patienter med artros. Studierna i denna avhandling har lett till fördjupad kunskap om artrosskolan utifrån patienters och fysioterapeuters perspektiv.

List of papers

I. Sturesdotter Åkesson K, Beckman A, Stigmar K, Sundén A, Ekvall Hansson E. Physical activity and health-related quality of life in men and women with hip and/or knee osteoarthritis before and after a supported self-management programme – A prospective observational study. Disabil Rehabil. 2021:1-9.

II. Sturesdotter Åkesson K, Sundén A, Stigmar K, Fagerström C, Pawlikowska T, Ekvall Hansson E. Enablement and empowerment among patients participating in a Supported Osteoarthritis Self-Management Programme – A prospective observational study. Submitted.

III. Sturesdotter Åkesson K, Sundén A, Stigmar K, Eek F, Pawlikowska T, Ekvall Hansson E. Empowerment and enablement as predictors of change in health-related quality of life among patients participating in a Supported Osteoarthritis Self-Management Programme – a prospective observational study. Submitted.

IV. Sturesdotter Åkesson K, Sundén A, Ekvall Hansson E, Stigmar K. Physiotherapists´ experiences of osteoarthritis guidelines in primary health care – an interview study. BMC Fam Prac. 2021; 22(1):259.

Description of contributions

All authors contributed to the manuscripts according to the International Committee of Medical Journal Edítors´ (ICMJE) recommendations [1].

Paper I	
Study design	Karin Sturesdotter Åkesson, Anders Beckman, Kjerstin Stigmar, Anne Sundén, Eva Ekvall Hansson
Data collection	Karin Sturesdotter Åkesson
Data analysis	Karin Sturesdotter Åkesson, Anders Beckman
Manuscript writing	Karin Sturesdotter Åkesson
Manuscript revision	Karin Sturesdotter Åkesson, Anders Beckman, Kjerstin Stigmar, Anne Sundén, Eva Ekvall Hansson
Paper II	
Study design	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Cecilia Fagerström, Teresa Pawlikowska, Eva Ekvall Hansson
Data collection	Karin Sturesdotter Åkesson
Data analysis	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Teresa Pawlikowska, Eva Ekvall Hansson
Manuscript writing	Karin Sturesdotter Åkesson
Manuscript revision	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Cecilia Fagerström, Teresa Pawlikowska, Eva Ekvall Hansson
Paper III	
Study design	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Teresa Pawlikowska, Eva Ekvall Hansson
Data collection	Karin Sturesdotter Åkesson
Data analysis	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Frida Eek, Teresa Pawlikowska, Eva Ekvall Hansson
Manuscript writing	Karin Sturesdotter Åkesson
Manuscript revision	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar, Frida Eek, Teresa Pawlikowska, Eva Ekvall Hansson
Paper IV	
Study design	Karin Sturesdotter Åkesson, Anne Sundén, Eva Ekvall Hansson, Kjerstin Stigmar
Data collection	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar
Data analysis	Karin Sturesdotter Åkesson, Anne Sundén, Kjerstin Stigmar
Manuscript writing	Karin Sturesdotter Åkesson
Manuscript revision	Karin Sturesdotter Åkesson, Anne Sundén, Eva Ekvall Hansson, Kjerstin Stigmar

Thesis at glance

Aims	Main results	Conclusions
Paper I		
To study differences between men and women in physical activity and health-related quality of life before and after participating in a SOASP.	A majority of both men and women were already sufficiently physically active before the SOASP, and a greater proportion of women were sufficiently physically active compared to men, both at baseline and at follow-up at 12 months. At follow-up at three months, there was no difference in proportion of men and women being sufficiently physically active. Women reported lower health-related quality of life (EQ-5D) than men, both at baseline and at follow-up at three and 12 months.	There were differences between men and women in physical activity and health-related quality of life before and after participating SOASP. These differences should be considered when planning how to support men and women to maintain or increase physical activity and health-related quality of life.
Paper II		
To study enablement and empowerment among patients with OA participating in a SOASP, and the relation between the Swedish version of the PEI and the SWE-RES-23.	Patients with OA reported having moderate to high enablement and empowerment both after the educational part of the SOASP and at three months follow-up after participating in a SOASP. There was a significant increase in empowerment at three months after participation in the SOASP. In addition, the relation between the PEI and the SWE-RES-23 was close to the cut-off point for strong correlation both after the educational part of the SOASP and at three months follow-up.	The results might indicate that the SOASP is useful to enable and empower patients with OA in the hip and/or knee at least in the short term. Since our results showed that the PEI and the SWE-RES-23 are only partly related, we believe that both instruments can be of use in evaluating interventions such as the SOASP depending on the outcome of interest.
Paper III		
To examine change in health-related quality of life after SOASP and if enablement and/or empowerment could predict change in health-related quality of life among patients participating in a SOASP.	The patients reported relatively high health-related quality of life (EQ-5D), at baseline and at follow-up at three and nine months. The change in health-related quality of life between baseline and three and nine months respectively, corresponded to a statistically significant but small effect size regarding both the EQ-5D-5L index and the EQ VAS. To the best of our knowledge, this is the first study to examine the association between empowerment, enablement and change in health-related quality of life among patients participating in a SOASP. Empowerment and enablement did not predict change in health-related quality of life in this context.	Health-related quality of life increased after participating in a SOASP. Empowerment and enablement as measured with the SWE-RES-23 and the PEI respectively could not predict change in health-related quality of life among patients participating in a SOASP.
Paper IV		
To explore physiotherapists´ experiences of the regional guidelines for treatment of OA and their experiences of the implementation of these guidelines.	The SOASP was generally a well-established and functioning part of the regional guidelines and the physiotherapists´ saw a great need for the treatment. The physiotherapists´ were confident in their professional role and as a primary assessor for patients with hip and/or knee OA. But the SOASP was not seen as appropriate for all patients with OA. Management support was considered important when it came to compliance with the guidelines, and to enable evaluation, development and sustaining knowledge among the health care personnel.	The physiotherapists´ believed in the guidelines and were confident in providing first-line treatment to patients with OA. Information about the guidelines needs to be repeated to all health care providers and management. Data from a national quality registry on OA could be used to a greater extent in daily clinical work to improve quality of care for patients with OA.

Definitions

Exercise	is a physical activity that is planned, structured, repetitive, and purposive in the sense that improvement or maintenance of one or more components of physical fitness is an objective [2]
Disease	abnormalities in the structure and function of body organs and systems [3]
Illness	experiences of disvalued changes in states of being and in social function [3]
Pain	an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage [4]
Person-centred care	care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health [5]
Self-care	the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider [6]
Self-management	the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions [7]

Abbreviations

ACR	American College of Rheumatology
BMI	Body Mass Index
BOA	Better Management of Patients with Osteoarthritis
EULAR	European League Against Rheumatism
HOD	Head of Department
HRQoL	Health-Related Quality of Life
ICF	International Classification of Functioning, Disability and Health
M.D.	Medical doctor
NICE	National Institute for Health and Care Excellence
OA	Osteoarthritis
OARSI	Osteoarthritis Research Society International
OT	Occupational therapist
PA	Physical activity
PARIHS	Promoting Action on Research Implementation in Health Services
PEI	Patient Enablement Instrument
PHC	Primary Health Care
PP	Patient Partner
PROM	Patient Reported Outcome Measure
PT	Physiotherapist
QCA	Qualitative Content Analysis
QoL	Quality of Life
RCT	Randomised Controlled Trial
SOASP	Supported Osteoarthritis Self-Management Programme
SWE-RES-23	Swedish Rheumatic Disease Empowerment Scale
VAS	Visual Analogue Scale
WHO	World Health Organization

Background

Osteoarthritis (OA) is a common and disabling joint disease affecting about 300 million people worldwide [8, 9]. About 10 % of men and 18 % of women over 60 years of age are affected by OA [10, 11]. Prevalence increases with age [11, 12] but OA also affects people of working age [13-15]. Globally, prevalence is expected to increase with the ageing and increasingly obese population [9, 16, 17]. It is a challenging disease both for the affected individuals, society, and health care systems with great socioeconomic costs [9, 17, 18]. Pain, stiffness, and loss of function are main symptoms for patients with OA [19] causing reduced quality of life (QoL) [20]. Today, there is no cure for OA [21] and treatment focuses on relieving symptoms [22]. This thesis focuses on hip and knee OA.

Osteoarthritis

The word osteoarthritis derives from Greek where *osteo* means ”of the bone”, *arthr* means “joint” and *itis* means “inflammation” [23, 24].

Definition

Osteoarthritis is a complex chronic disease [17] affecting the whole joint including the cartilage, subchondral bone, ligaments, capsule, synovium and periarticular muscles [17, 18, 25]. Although OA can affect all joints, it is most common in the hip, knee, and hand [16, 26]. The Osteoarthritis Research Society International (OARSI) has suggested the following standardised definition of OA to facilitate communication among researchers:

> “Osteoarthritis is a disorder involving movable joints characterized by cell stress and extracellular matrix degradation initiated by micro- and macro-injury that activates maladaptive repair responses including pro-inflammatory pathways of innate immunity. The disease manifests first as a molecular derangement (abnormal joint tissue metabolism) followed by anatomic, and/or physiologic derangements (characterized by cartilage degradation, bone remodelling, osteophyte formation, joint inflammation and loss of normal joint function), that can culminate in illness.” [27, 28].

Diagnosis

Diagnostic criteria and international and national guidelines have been developed for hip and knee OA [29-34]. The most applied are developed by the American College of Rheumatology (ACR), the European League Against Rheumatism (EULAR) and the National Institute for Health and Care Excellence (NICE) [29-33].

Osteoarthritis can be diagnosed based on clinical criteria and symptom-based case definitions or on radiological criteria [18, 35, 36]. Clinical diagnosis is recommended since there is a weak correlation between patient perceived symptoms and radiographic grading of OA [37]. Radiographic examination is not needed [17] unless other disease is suspected [38]. An overview of diagnostic criteria for the clinical diagnosis of hip and knee OA are presented in Table 1 and Table 2 respectively.

Table 1. Criteria for the clinical diagnosis of hip osteoarthritis.

Hip OA			
		NICE	**ACR**
	Age	**≥ 45 ●**	**≥ 50 □**
Symptoms	Activity/usage-related joint pain	●	●
	No EMS or EMS ≤ 30 minutes	●	
	No EMS or EMS ≤ 60 minutes		□
	Functional limitation		□
Clinical signs	Hip internal rotation ≤ 15°		□
	Pain present on internal rotation of the hip		□
Minimum criteria: all ● plus			≥ 1 □

NICE = National Institute for Health and Care Excellence
ACR = American College of Rheumatology
EMS = Early Morning Stiffness

Table 2. Criteria for the clinical diagnosis of knee osteoarthritis.

Knee OA				
		NICE	**EULAR**	**ACR**
	Age	**≥ 45 ●**	**≥ 40 ●**	**≥ 50 □**
Symptoms	Activity/usage-related joint pain	●	●	●
	No EMS or EMS ≤ 30 minutes	●	●	□
	Functional limitation		●	
Clinical signs	Crepitus		□	□
	Restricted range of motion		□	
	Bone enlargement		□	□
	Bone margin tenderness			□
	No palpable warmth			□
Minimum criteria: all ● plus			≥ 1 □	≥ 3 □

NICE = National Institute for Health and Care Excellence
EULAR = European League Against Rheumatism
ACR = American College of Rheumatology
EMS = Early Morning Stiffness

The Swedish National Board of Health and Welfare follows the international guidelines and recommends clinical OA diagnosis [39] based on an assessment of a combination of patient history and clinical examination where three common OA symptoms and three typical OA findings are present [34]. In Sweden, all health care professionals with sufficient knowledge about a disease, a disability or an injury may diagnose within their professional competence [40]. Swedish physiotherapists (PTs) are primary assessors for patients with musculoskeletal disorders and are qualified to diagnose OA [41] so Swedish patients do not need a referral from a medical doctor (M.D.) to consult at PT [41]. In clinical practice this means that Swedish OA patients can be diagnosed by PTs, occupational therapists (OTs) and M.D.s. Despite existing guidelines for diagnosis, OA can be difficult to diagnose especially at an early stage in the disease process [17, 18, 42]. The need for early diagnostic criteria has been raised [43-46].

Incidence and prevalence

Estimations of the incidence and prevalence of hip and knee OA differ between studies due to the use of various OA case definitions and population strata (age, sex, and geographical region) [26, 47, 48].

There are not many studies on incidence of OA [26]. Incidence is problematic to estimate since OA is a progressive disease that is difficult to diagnose clinically early in the disease process [18, 49]. In 2020, estimated global incidence was 203 per 10 000 person-years (95 % CI, 106 – 331) in individuals aged 20 years and over [50]. Incidence of clinically diagnosed hip and knee OA has been estimated [26]. Incidence (99 % CI) for hip OA was 2.1 (2.0 – 2.1) overall, 2.4 (2.4 – 2.5) for women, and 1.7 (1.7 – 1.8) for men [26]. For knee OA, incidence was 6.5/1000 person-years (6.4 – 6.6) overall, 8.3/1000 person-years (8.2 – 8.4) for women participants, and 4.6/1000 person-years (4.5 – 5.7) for men [26]. In women, hip and knee OA increased with age, more rapidly between the ages of 50 years to 70 years (more rapidly than for men) and peaked at 75 – 80 years for hip OA and at 80 – 85 years for knee OA to be followed by a decrease in the final years of life (age 85 years and older) [26]. In men, the patterns were similar with hip and knee OA a continuously increasing with age and peaked in the oldest ages (> 85 years) [26].

In 2010, global prevalence of radiographically confirmed symptomatic hip OA was 0.85 % (95 % UI 0.74 % to 1.02 %), increasing with age [19]. For knee OA, global prevalence was 3.8 % (95 % UI 3.6 % to 4.1 %), peaking at about 50 years of age [19]. Prevalence was higher in women (mean 4.8 %; 95 % UI 4.4 % to 5.2 %) than in men (mean 2.8 %; 95 % UI 2.6 % to 3.1 %) [19]. In 2020, prevalence of knee OA was 16.0 % (95 % CI, 14.3 % – 17.8 %) in individuals aged 15 and over and 22.9 % (95 % CI, 19.8 % – 26.1 %) in individuals aged 40 and over [50]. According to this estimate, there are about 654.1 (95 % CI, 565.6 – 745.6) million individuals (40 years and older) with knee OA in 2020 worldwide [50]. In the Nordic region, prevalence for hip OA and knee OA (case definition symptomatic hip or knee OA radiologically confirmed) increased by 43 % between 1990 – 2015 [51]. In 2032, 30 % of adults over 45 years are expected to have OA in Sweden [16]. The number might be an underestimate, as research has shown that all patients with OA do not seek health care [13].

Risk factors

Several risk factors for developing OA have been identified. Aging is the strongest risk factor for OA because of biological age-related changes in the joint structures and cumulative exposure to different risk factors [52]. For hip OA, factors like female sex and obesity are less notable whereas hip deformities strongly increase the risk [53]. Hip deformities such as cam deformity and dysplasia increase the risk of OA [54] and severe dysplasia is strong risk factor for hip OA development before the age of 50 years [55]. For knee OA, risk factors include female sex, obesity, knee malalignment, muscle weakness (knee extensor) and previous knee injury [56-59]. Both hip and knee OA are associated with heavy work activities [60]. For hip OA, employment in the construction industry or in farming is a risk factor [60] and for knee OA, work that involves frequent kneeling and heavy lifting is a risk factor [61]. Various high-impact sports, such as football, handball, hockey, wrestling, weight-lifting, and long-distance running, have shown to be associated with an increased risk of both hip [62] or knee OA [63]. The role of genetics in OA development has been estimated to between 40 % and 80 %, and to be stronger in hip OA than in knee OA [64]. To better understand and identify risk factors for OA development is a basis for preventive management and early treatment [18].

Prevention

Primary prevention of OA is in its early stage of development [17]. Obesity is the most studied risk factor, and for women, losing about 5 kilograms reduced the risk for knee OA by 50 % [65]. A reduction in bodyweight reduced the incidence of knee OA by 21 % in men and 33 % in women [66]. Globally, obesity is increasing and efforts at weight loss have not been successful at the population level [18]. Neuromuscular and proprioceptive exercise programmes might prevent 50 % of major knee injuries during sport [67]. More research is needed on the preventive effects of interventions for individuals at a high risk of developing OA [17].

Symptoms and consequences for the individual

Osteoarthritis is a challenging disease both for the affected individuals, society, and health care systems, with great socioeconomic costs [9, 18, 26, 68]. The United Nations has estimated that by 2050, 130 million people will suffer from OA worldwide, and 40 million will be severely disabled by the disease [69].

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains adopted by the World Health Organization (WHO) in 2001 [70] and replaced the former International Classification of Impairments, Disabilities and Handicaps (ICIDH) [71]. The ICF is an international framework and a tool for measuring health and disability at both individual and population levels [70]. This classification also includes environmental factors, as the functioning and disability of an individual occurs in a context [70]. The ICF can be applied to OA diagnosis and describes how the disease affects body function and structures, activity, and participation, as well as how environmental and personal factors might impact the disease [72, 73] as illustrated in Figure 1.

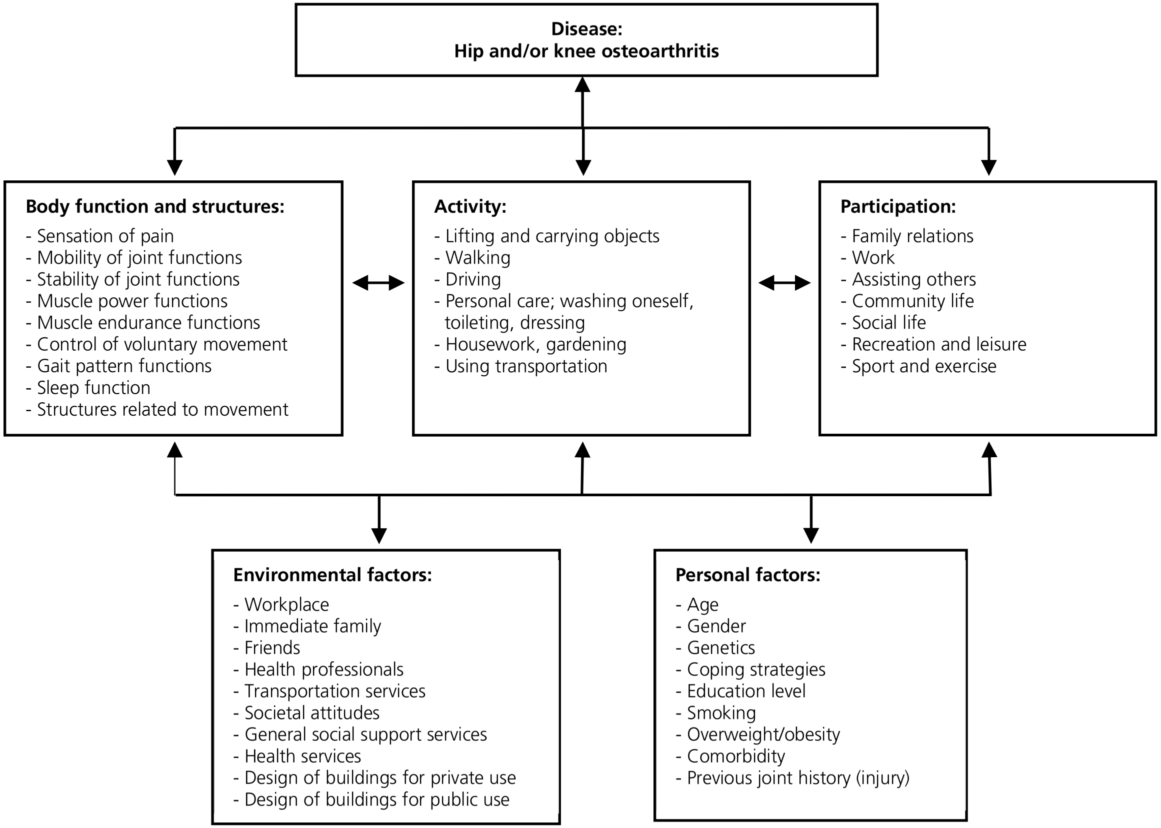

Figure 1. Osteoarthritis´ possible effects as illustrated with the International Classification of Functioning, Disability and Health (ICF).

Body function and structures

Pain is the main clinical symptom and the most disabling symptom for patients with OA [17, 49, 74-76] and is often what leads patients to seek health care [75]. In early stages of OA, pain is often intermittent, becoming more frequent and severe as the disease progresses [75]. Typically, OA pain is worsened by activity and relieved by rest [75]. In a study by Woolhead et al., 81 % of OA patients experienced night pain, becoming more serious as the OA progressed [77]. Women with OA report more pain and disability than men with OA [78-81]. Other common symptoms include morning stiffness, decreased range of motion, joint instability, crepitus, muscle weakness, swelling, fatigue and pain-related psychological distress [76].

Activity and participation

Research has shown reduced level of physical activity (PA) in patients with hip and knee OA [82]. Reduced PA might lead to other consequences and comorbidities including hypertension, cardiovascular disease, dyslipidaemia, diabetes, and mental health disorders including depression which are common in OA patients [83]. Patients 65 years and older usually have one or more comorbidity [83]. Patients with OA have a slightly increased risk of cardiovascular disease development and [84, 85] of cardiovascular death [85, 86] than people who do not have OA. A small increased risk of stroke has also been shown for patients with OA [87]. Osteoarthritis is a serious disease [21], leading to premature mortality [88, 89]. The severely debilitating symptoms and consequences, lead to lower QoL [20, 90-92]. Younger patients, 20 – 55 years of age, with hip or knee OA that have had the diagnosis for less than five years show a considerable decrease in health-related quality of life (HRQoL) [14]. Patients report finding knee OA more disabling than other chronic diseases such as heart disease, diabetes, or hypertension [93]. Women with OA tend to report lower HRQoL than men with OA [92, 94] and women also tend to wait longer and have more severe symptoms before they seek health care and treatment for their OA [95, 96]. In 2019, OA was the 15th highest cause of years lived with disability (YLDs) [97, 98].

Environmental factors

Work activities and environment are associated with hip and knee OA [60, 61]. Transportation systems, family, friends and health professionals can either be perceived as barriers or facilitators for patients with OA [73].

Personal factors

Obesity, age, gender, physical activity level, comorbidity, and previous joint injury are examples of risk factors for OA development [52, 53, 56, 60]. Some of these factors such as PA and obesity, are possible to affect through behavioural and lifestyle changes [99]. Patients with OA bear an economic loss because of lost income and a reduction of savings [100, 101].

Physical activity

The WHO defines PA as “any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity refers to all movement including during leisure time, for transport to get to and from places, or as part of a person’s work” [102]. Regular PA, both moderate- and vigorous-intensity, improve health and help prevent and manage several diseases such as heart disease, stroke, diabetes, and several cancers. It also helps maintain healthy body weight and can improve QoL [102]. The WHO recommends adults i.e., 18 – 64 years old, to be physically active at least 150 – 300 minutes at moderate intensity or 75 – 100 minutes of vigorous intensity or a combination of moderate and vigorous intensity activity throughout the week [102]. Physical activity has a positive effect on OA-related pain [78] and physical function at least in the short term [103, 104]. Research has shown that only a small to moderate proportion of people with OA met PA guidelines [82, 105, 106].

Treatment of osteoarthritis

Today, there is no cure for OA, so treatment focuses on relieving symptoms [22], and limiting functional, activity and participation restrictions. International and national evidence-based guidelines for treatment recommend non-pharmacological treatment such as education, exercise, and weight control, as first-line treatment of OA (Figure 2) [39, 107-109]. All patients with symptomatic or radiographic OA are to be recommended first-line treatment as early as possible in the disease process [39, 107-109]. Additional treatment, including assistive devices and pharmacological treatment, is recommended if first-line treatment is unsuccessful in increasing function and decreasing pain [39, 107-109]. First-line and additional treatment are often provided in primary health care (PHC) [49]. Surgery, total joint replacement, might be needed for severe cases and for end-stage OA [39, 108, 109]. The heterogeneity of OA patients and the small to moderate effect size of OA symptomatic treatments, has highlighted the need to predict response of treatment [17, 103] to tailor interventions according to individual characteristics.

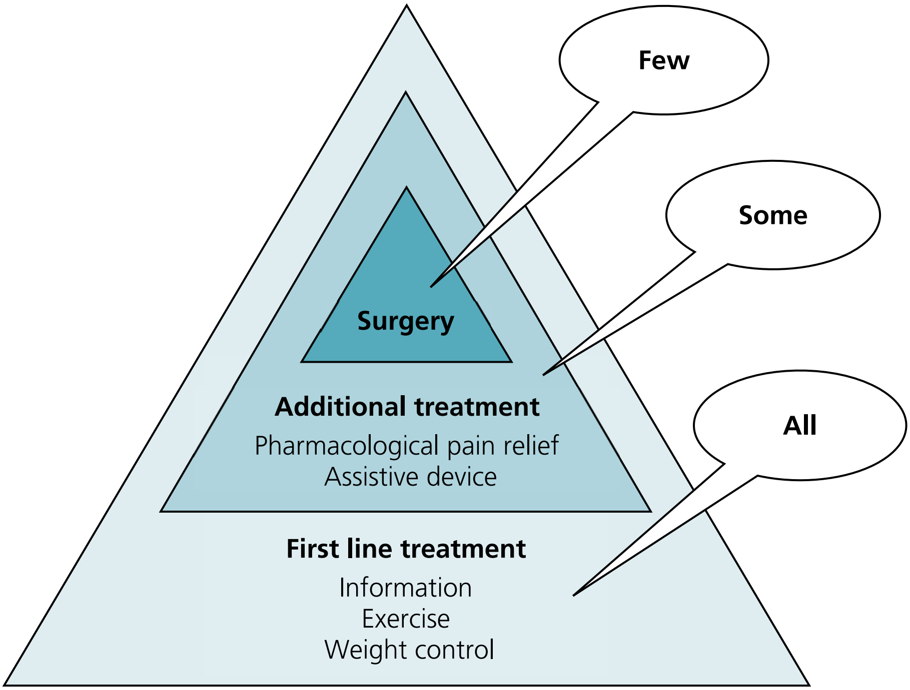

Figure 2. Illustration of guidelines for treatment of osteoarthritis.

First-line treatment

First-line treatment of OA, patient education exercise and weight control, involves all parts of the ICF. Non-pharmacological treatments of OA are generally considered to be safe, with little or no risk of adverse side effects [108, 110].

Patient education

Patient education as part of the management of all patients with chronic diseases is recommended by the WHO [111]. Education is part of first-line treatment for OA [39, 107-109] despite the lack of randomised controlled trials (RCTs) as to its efficacy [108]. Patient education for OA patients might increase self-management and promote positive expectations [108]. Consensus has been reached by patients with OA and experts on various key messages to be included in patient education such as different treatment approaches, disease information, pathophysiology, and diagnostic radiology [112]. The WHO defines patient education as:

> "helping patients acquire or maintain the competencies they need to manage as well as possible their lives with a chronic disease. It is an integral and continuing part of patient care. It comprises organised activities, including psychosocial support, designed to make

> patients aware of and informed about their disease and about health care, hospital organization and procedures, and behaviour related to health and disease, so that they (and their families) understand their disease and their treatment, collaborate with each other and take responsibility for their own care as a means of maintaining or improving their quality of life" [111].

Exercise

The effect of exercise therapy in hip and knee OA patients have been evaluated in RCTs, which concluded that pain and physical function are improved significantly following a supervised exercise intervention [103, 104]. Exercise has shown the same pain-relieving effect as pharmacological treatment [108, 113, 114] and is safer than pharmacological therapies with only mild side effects such as pain flares and muscle soreness [115]. Pain flares are often temporary and disappear after five to six weeks of regular exercise [116]. In addition, PA and exercise help prevent [117] and improve symptoms in several chronic conditions [118].

Individualised and structured land-based exercise including muscle strengthening, cardiovascular exercise, flexibility training, and neuromuscular exercise are recommended [108] as are aquatic exercise and mind-body exercises like Tai Chi and yoga [99, 119]. Supervised exercise is more effective than home-based training [120] and a minimum of 12 supervised sessions is more effective than a fewer number of sessions for patients with knee OA [113]. As there is limited evidence regarding optimal dosage, intensity [119], and exercise progression, more research is needed [99]. Exercise in combination with patient education seems to be more effective than exercise or patient education alone and is recommended for patients with hip and knee OA [108, 109].

Weight control

Weight loss is recommended if needed i.e., for individuals with a Body Mass Index (BMI) > 25 kg/m^2 [39, 107-109]. A weight loss around 5 % might result in a reduction in physical disability [121].

Additional treatment

Additional treatment, if needed, is to be offered in combination with first-line treatment.

Pharmacological treatment

Pharmacological treatments for pain relief might be needed as a compliment to first-line treatment. Paracetamol is associated with risks such as liver toxicity and gastrointestinal perforation [122]. Topical Non-steroidal Anti-Inflammatory Drugs (NSAIDs) provide superior pain relief than paracetamol, but prolonged NSAID use is associated with adverse cardiovascular events in the short- and long-term [123-125]. NSAIDs are recommended, as they have fewer side effects than other oral analgesics [108, 126]. Pharmacological treatment is not optimal and most patients with OA report persistent pain despite taking their prescribed medication [18].

Assistive devices and other treatments

Assistive devices for walking and adaptations at home and/or at work might be useful for patients with OA and should, according to some treatment guidelines, be considered as part of treatment for all patients with hip and/or knee OA [109].

There is insufficient evidence of the effectiveness of acupuncture as pain relief for patients with OA. Reviews have showed that for hip OA, acupuncture has little or no effect in reducing pain [127], and for knee OA there might be a small effect [128]. Even though evidence of the effectiveness of acupuncture is inconclusive, the ACR provides a conditional recommendation for acupuncture for pain relief for OA due to the minor risk of harm [107].

Passive treatments like ultrasound, laser, massage, neuromuscular electoral stimulation, transcutaneous electrical nerve stimulation should not be offered to patients with hip and knee OA since there is no evidence of the effectiveness of these treatments [108, 109].

Surgery

Total joint replacement might be an option at end-stage OA, or when first-line and additional treatments have been unsuccessful for patients who still experience low QoL and suffer from severe pain [39, 108, 109]. Total joint replacement relieves pain effectively and about 90 % of patients receiving total hip replacement (THR) and 80 % of patients receiving total knee replacement (TKR) report little to no persistent pain after these procedures [129].

The Supported Osteoarthritis Self-Management Programme

In Sweden, first-line treatment can be offered in the form of a Supported Osteoarthritis Self-Management Programme (SOASP) in PCH [130]. The aim of the SOASP is to support patients in coping with their disease, improve HRQoL, increase physical activity level and reduce healthcare consumption and sick leave due to OA [130, 131].

The SOASP combines patient education and exercise and is offered to patients with OA seeking health care due to in hip and/or knee disability (Figure 3). After an individual visit and clinical assessment by a PT, where the diagnosis is confirmed, patients are offered participation in the programme. The SOASP often consists of two to three educational group sessions, about 1 – 2 hours a time, held by a PT or an OT where information about OA, risk factors, symptoms, treatment, coping strategies and self-management is discussed. After the educational part of the SOASP, patients are offered an individually adapted exercise programme that they can choose to either do at home or at the PHC centre in a group, supervised by the PT for about 6 – 8 weeks [130].

Step 1:
BASELINE ASSESSMENT: INDIVIDUAL VISIT AT PHYSIOTHERAPIST'S (PT)

Step 2:
SUPPORTED OSTEOARTHRITIS (OA) SELF-MANAGEMENT PROGRAMME (SOASP)

2 a) EDUCATION

Session 1 (PT)
- What is OA
- Risk factors
- Symptoms
- Treatment

Session 2 (PT)
- Exercise
- Daily life activities
- Coping
- Self-management

Session 3 (OA communicator)
- To live with OA

2 b) INDIVIDUALLY ADAPTED EXERCISE – OPTIONAL

Exercise in a group
- Supervised by a PT for 6-8 weeks

OR

Exercise at home

Step 3:
FOLLOW-UP

3 month follow-up: Individual visit at PT´s
12 month follow-up: Postal questionnaire

Figure 3. Illustration of an outline of the Supported Osteoarthritis Self-Management Programme adapted from http://boa.registercentrum.se/

The first two educational sessions are seen as a "minimal intervention" that should be offered to all patients, but the programme also allows some flexibility. In clinical practice, the programme might be arranged depending on a patient´s needs and available health care personnel resources. For example, if needed a dietician or an M.D.

might participate by sharing their professional expertise about diet, weight reduction and medication for pain relief. Sometimes a so-called “OA communicator” participates in the SOASP, preferably during the third session, when the patients have received some background information about OA. The communicator is a person diagnosed with OA, who shares his/her experiences of living with OA and of OA treatment. The OA communicators are trained in the role by the European OA Communicator Programme with the idea of sharing the same information as professionals but from the perspective of their own lived experience of OA and of OA treatment [130]. The programme is mainly offered face-to-face but in recent years first-line treatment is also available digitally, through both public and private actors [132, 133]. The SOASP has been described in detail in an article by Thorstensson et.al. [130].

Until 2019, the BOA offered training for PTs and OTs in how to deliver the SOASP, how to record data in the BOA registry, and provided material for the educational part of the SOASP, supporting the implementation of delivering first-line treatment for OA patients. Since 2019, this training is provided by others, like the Swedish Rheumatism Association [134, 135].

The Swedish version of the SOASP has spread in Scandinavia, Europe and outside of Europe. In Denmark the programme is called “The Good Life with osteoarthritis” (GLA:D®) [136, 137] and in Norway it is called “Active living with OsteoArthritis” (ActiveOA) [138, 139]. The Scandinavian programmes are very similar and follow the international guidelines for OA treatment.

Evaluating treatment

Evaluating treatment of OA should include a combination of patient-reported outcome measures (PROMs) and performance-based outcome measures [140] of physical function of activities relevant to patients with hip and knee OA [140].

In 2016, the International Consortium for Health Outcome Measures (ICHOM) presented a standard set of patient-centred outcome measures for evaluating treatment of hip and knee OA [141]. The standard set enables comparison of treatment of hip and knee OA in clinical practice across health care providers, regions, and countries and includes outcome measures of joint pain, physical functioning, HRQoL, work status, mortality, reoperations, readmissions, and overall satisfaction with treatment results [141]. There are few reports of its implementation in clinical practice [142].

The OARSI recommends a set of five performance-based tests of physical function, i.e., the 30 second chair-stand test, the 40 meter fast-paced walk test, a stair-climb test, the timed up- and-go test, and the six-minute walk test, to be used in clinical practice [140]. The first three tests are recommended as the core set of tests and a complement to PROMs [140]. All the tests are adequate for measuring change over time in individuals with hip and knee OA [143].

The Swedish National Board of Health and Welfare evaluate health care using indicators as basis for follow-up to improve health care and to see if national guidelines make a difference [144]. According to regional guidelines (Region Skåne), PTs are recommended to evaluate OA treatment using tests of physical function, PROMs, and to record data to a national quality registry called *Better Management for Patients with OA* or “BOA” [145].

A national quality registry for osteoarthritis

In Sweden, there is a unique opportunity to evaluate first-line treatment for OA through the BOA registry [131]. Inclusion criteria in the BOA registry during the studied period, 2008 – 2013, were patients with symptoms from hip and/or knee OA who were diagnosed with symptomatic and/or radiographic OA. Exclusion criteria were patients with inflammatory joint disease, other serious injuries or illnesses, sequelae hip fractures, and patients who did not understand the Swedish language were not included in the registry.

The BOA registry includes data about baseline patient characteristics that might affect the treatment outcome for patients with OA of the hip and/or knee, such as sex, year of birth, affected joint, BMI, education, smoking habits, and comorbidity. The registry also includes data on pain (Visual Analogue Scale, VAS), PA, and HRQoL (EQ-5D) collected through PROMs [131]. Patient characteristics and PROMs are collected in questionnaires answered by the patients before participating in the SOASP at baseline and at follow-up at three and 12 months [146]. The questionnaires can either be answered by the patient at a face-to-face visit at the treating PTs´ who records the data in the registry, or as from 2018 by the patient digitally. As from May 2019 it is possible to also record first-line treatment given individually or digitally [147]. In addition to the PROMs, the treating PTs record data in the BOA registry about the patients´ most affected joint, previous treatment (including medication and previous joint operation) or medical investigations such as X-rays [131].

Data from patients from all of Sweden are included in the BOA registry [131]. The estimated coverage ratio for the BOA registry has been somewhere between 60 % – 70 % in the past few years [147]. In total, about 155 000 unique patients were recorded in the BOA registry in February 2022 [131].

Patient enablement and empowerment

The WHO has emphasised the need to enable and empower patients with chronic disease such as OA [148-150] which is aligned with person-centred care [5]. Patient enablement can be described as a person-centred quality outcome measure of patients´ ability to understand their illness and cope with their life, illness, and ability to help themselves after a health care consultation [151, 152]. Empowerment has been described as a process to gain control over decisions that affects one´s health and personal life [153]. Enablement and empowerment are closely related concepts [154-156]. There is a blurring of boundaries between the two concepts, and they have sometimes been used interchangeably [155]. Enablement is viewed as a subset of patient empowerment [155]. Enabled patients understand their illness and can participate in self-care, but they might not necessarily have the motivation and power to do so [155]. Both enablement and empowerment are core values of person-centred care [151, 152, 157-160].

Patient enablement can be measured with the Patient Enablement Instrument (PEI) [151, 152, 161]. Studies support use of the PEI in research, but not in clinical practice [162, 163]. The Patient Empowerment Scale (PES) and the Empowering Speech Practice Scale (ESPS) have been used to measure enablement for hospital in-patients, but are not suitable for PHC settings [164]. Other instruments such as the Physician Enabling Skills Questionnaire (PESQ) focuses on the healthcare professionals [165] and a recently developed Patient Enablement Scale needs further testing [166]. Patient empowerment can be measured with the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23) [167]. Other instruments developed to measure patient empowerment are, for example, the Patient Perceptions of Empowerment Scale (PPES) [168], the Health Empowerment Scale (HES) [169], and the Health care Empowerment (HCE) [170].

Patients with knee OA experience that their problems are not taken seriously and that little consultation time is spent on information [171]. Research has shown that patients welcome information about their health condition and want to be involved in health related decisions but they are not always active partners in their own care and are not given adequate tools to cope with their illness [172]. The aim with the SOASP is to support patients to cope with their disease and to improve physical function. How patients with hip and knee OA experience their ability to understand, cope and have control over decisions that affects their health and personal life is not routinely evaluated after participating in the SOASP today.

Implementation of treatment guidelines

There is a divergence between recommended evidence-based care for OA and clinical practice [173, 174]. Despite existing evidence-based guidelines for treatment of OA, estimates show that less than 40 % of patients with OA are offered education and exercise as treatments [175]. In 2008, the SOASP was initiated by the BOA in Sweden to fill the gap between clinical practice and treatment guidelines [130]. The programme has been implemented and disseminated geographically throughout all of Sweden [131].

In Sweden, estimations in 2013 showed that about 8.7 % of patients 45 years old and older seeking health care due to OA-related symptoms also participated in a SOASP [176]. There might be various reasons for this gap. For professionals, barriers might include a lack of expertise in evidence-based treatment regarding dosage of physical exercise and suboptimal organisation of care [177]. For patients, experiencing pain is a barrier to PA and exercise, and pain relief is a key in enabling patients to be physically active and exercise [177]. More people with symptomatic OA might benefit from participating in SOASP [13, 110].

In a region in southern Sweden, Region Skåne, an implementation project to further fill the gaps and meet future demands on the health care system was running between 2016 – 2019. The aim was to increase health care professionals' compliance with treatment guidelines and data recording in the BOA registry, and to make first-line treatment more accessible to OA patients [145]. Practically, the project meant that two to three appointed PTs or coordinators, who had many years of clinical experience of providing first-line OA treatment, spread information about treatment guidelines through visits at workplace meetings at PHC centres and network meetings. Training for PTs and OTs in how to organise the SOASPs was also provided, as were individual support, if needed. In addition, the coordinators assisted in enabling a direct transfer of the treating PT´s and OT´s BOA data from the electronic medical record to the BOA registry aiming to facilitate for health professionals in recording data in the registry. After the regional project was finished, a national programme for implementation was initiated to promote adherence to national guidelines [178].

Patient partner in research

A patient partner (PP) can be described as person with a lived experience of an injury, illness or disease who collaborates actively with researchers in as many stages and areas of the research process as possible and relevant [179].

The idea behind involving patient partners is that they are experts in their disease and, as such, provide complementary and in-depth knowledge leading to new approaches and a more nuanced picture of the research questions. The PP is a representative for other patients with the same diagnosis and is trained in how clinical research is conducted. Collaboration with a PP makes research more relevant and valid [180, 181]. To combine PROMs with involving a PP in research is a vital step in enhancing person-centred health care [182], and may lead to better health outcomes, including improvements in physical activity, pain, and self-care [183]. The PP can be involved in the whole research process, such as identifying and prioritising relevant research questions, designing studies, developing research grants, managing the research, analysing, and interpreting the results, disseminating and implementation of results [179]. A PP can also be acknowledged as a co-author if appropriate [184].

The thought of involving patients and the public in research and in decision-making about health care issues has been highlighted since the 1990s when the British Medical Journal (BMJ) published an issue on the subject [185-187]. Involving PPs in research has become an increasingly common approach [188] and is recommended by different stakeholders, such as the European League Against Rheumatism (EULAR) [189], the Outcome Measure for Rheumatoid Arthritis in Clinical trials (OMERACT) [190] and the Patient-Centered Outcomes Research Institute (PCORI) [191]. In Sweden, the Swedish Rheumatism Association trains PPs to be involved in research [135]. Collaboration between researchers, other stakeholders, and patient organisations is an evolving concept and there is no gold standard as to how this cooperation should be performed [184]. The WHO and the European Society for Clinical and Economic Aspects of Osteoporosis, Osteoarthritis and Musculoskeletal Diseases (ESCEO) have together outlined principles for engaging with patient partners [183] and a checklist for reporting PP involvement in research may be used as guidance [192].

Rationale

In line with the fact that OA is a common global disease with increasing prevalence, the interest in the disease and in OA research from different perspectives is high. Research has led to evidence-based international and national guidelines for OA treatment [107-109]. However, compliance with these guidelines is poor [173-175]. In Sweden, first-line treatment i.e., education, exercise, and weight control, is offered to OA patients in PHC often via SOASP [130].

When planning the studies included in this thesis, there were a few research gaps. At the time, there were not many published research studies using data from the BOA registry [130]. An annual BOA report [146] indicated that there were differences between men and women in self-reported outcome in SOASP which we decided to investigate further.

The SOASP aims to support patients with OA in being better able to cope with their disease, which is aligned with the WHO´s recommendation that health care should make efforts to enable and empower patients with chronic diseases [111, 149, 150] like OA. When planning our studies, there was no research on patient enablement or empowerment in relation to patients with OA after participating in SOASP. Moreover, there was a research gap regarding the association between enablement, empowerment, and HRQoL, after participating in a SOASP. Patients suffering from chronic diseases like OA will have to be able to take care of themselves to a greater extent in the coming years [150] since health care resources are limited and it is vital that they are used effectively and by those who need it the most [39, 144]. Consequently, it is important to be able to identify patients with the greatest need for additional support, medical care, and treatment [193]. So, following the need to predict treatment response to tailor treatment and personalise care [17, 194] we studied whether enablement and/or empowerment could predict change in HRQoL among patients participating in SOASP.

Since compliance to OA treatment guidelines was poor, there was an implementation held in southern Sweden (Region Skåne) in 2016 – 2019. We aimed to increase knowledge for future implementation strategies and explored PTs’ experiences of the OA treatment guidelines, and their experiences of the implementation of the guidelines in southern Sweden.

Aims

Overall aim

The overall aim of this thesis was to increase knowledge about the Supported Osteoarthritis Self-Management Programme delivered in clinical settings in primary health care from the perspectives of patients and physiotherapists.

Specific aims

- To study differences between men and women with hip and/or knee osteoarthritis in physical activity and health-related quality of life before and after participating in a Supported Osteoarthritis Self-Management Programme.
- To study enablement and empowerment among patients with hip and/or knee osteoarthritis participating in a Supported Osteoarthritis Self-Management Programme. An additional aim was to study the relationship between the Swedish version of the Patient Enablement Instrument (PEI) and the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23).
- To examine change in health-related quality of life from baseline to three- and nine-months follow-up after participating in a Supported Osteoarthritis Self-Management Programme. Furthermore, to examine if empowerment and/or enablement could predict change in health-related quality of life among patients participating in a Supported Osteoarthritis Self-Management Programme.
- To explore physiotherapists´ experiences of the regional guidelines for treatment of hip and/or knee osteoarthritis and their experiences of the implementation of the guidelines in a region in southern Sweden.

Methods

This thesis is based on four studies (papers I–IV) conducted with different study designs and analysis methods, depending on the research question for each study. For data included in studies I–III, we have no exact information neither about how hip and/or knee OA were diagnosed (i.e., clinically, or radiographically or a combination of the two), or by what health professional (i.e., PT or M.D.) patients were diagnosed.

Study design and setting

All four studies were conducted in the context of SOASP in PHC in Sweden. Prospective observational studies with two cohorts were used to study the patients´ perspective of the SOASP (papers I–III), and an interview study to explore the PTs´ perspective (paper IV). Studies II and III were retrospectively registered 28/11/2016 at ClinicalTrials.gov under identification number NCT 02974036. An overview of the study designs, study populations, data collections, and outcomes is presented in Table 3.

Table 3. Overview of the study designs, study populations, data collections, and outcomes.

	Study I	Study II	Study III	Study IV
Design	Prospective observational cohort	Prospective observational cohort		Interview study
Study population	Patients (n=7628) participating in SOASP[a] in primary health care and recorded in the BOA[b] registry	Patients (n=143) participating in SOASP[a] in primary health care Region Skåne och Region Blekinge		Physiotherapists (n=18) in primary health care in Region Skåne
Data collection	Questionnaires Baseline, 3- and 12-months follow-up	Questionnaires Baseline, after educational part, 3-months follow-up	Questionnaires Baseline, 3- and 9-months follow-up	Interview
Analysis	Descriptive, Chi-square-test, z-test, Student´s t-test	Descriptive, Spearman´s rho (r_2), Wilcoxon´s sign ranked test, effect size	Descriptive, paired sample t-test, effect size, multiple linear regression	Qualitative Content Analysis
Outcome	Physical activity, health-related quality of life	Enablement, empowerment	Enablement, empowerment, health-related quality of life	Informants´ experiences

[a] Supported Osteoarthritis Self-Management Programme
[b] Better Management of Patients with Osteoarthritis

The four studies were reported with the checklists recommended by the Enhancing the QUAlity and Transparency Of health Research network (EQUATOR) [195] as guidance. For the observational studies (papers I–III), the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist [196] was used, and for the qualitative study (paper IV), the Consolidated Criteria for Reporting Qualitative Research (COREQ) [197] was used. In addition, for studies II and III involving a PP, the Guidance for Reporting Involvement of Patients and the Public checklist (GRIPP2-SF) [179, 192] was used as basis when reporting the PP´s involvement in the study process.

Participants

All patients included in studies I–III had participated in a SOASP in PHC in Sweden and were from two different cohorts. Study I was based on a cohort from the national quality registry, BOA, between 2008 – 2013. Inclusion criteria in the BOA registry during the studied period were patients diagnosed with symptomatic and/or radiographic OA whereas patients with inflammatory joint disease, other serious injuries or illnesses, sequelae hip fractures, and patients who did not understand the Swedish language were not included in the registry. Studies II–III were based on a cohort from two regions in the south of Sweden between 2016 – 2018. Inclusion criteria in studies II and III were patients with hip and/or knee OA, who understood Swedish who were participating in the SOASP. There were no other exclusion criteria. In study IV, a purposive sampling was used. All 18 interviewed PTs in study IV had experience both from offering SOASP and from the implementation of the OA treatment guidelines in Region Skåne in the south of Sweden between the years 2017 – 2018.

Data collection

Data collected from the national quality registry

In study I, data from the BOA registry, between 2008 – 2013, were used. The registry includes data from most geographical parts of Sweden. Approval to use data from the registry for research purposes was first achieved through application. The BOA registry enables evaluation of SOASPs delivered in PHC. Physiotherapists and/or OTs collect PROMs answered by patients participating in SOASP. At the time when data was collected from the registry to be included in study I, the PROMs recorded in the registry measured pain (Visual Analogue Scale, VAS), HRQoL (EQ-5D), self-efficacy (Arthritis Self-Efficacy Scale, ASES-S), and PA [146]. The PROMs were answered prior to participating in the SOASP (baseline), at three months, and at 12 months after participating in a SOASP [130, 146]. The PROMs, together with information about age, sex, height, weight, and which joint is affected by OA [146], were recorded in the BOA registry by the PT responsible for delivering the SOASP or sometimes by administrative personnel. The coverage ratio for the BOA registry, estimated by the proportion of patients that were both attending SOASP and recorded in the registry during the study period, was 77 % [198]. During the study period, 25 862 patients were recorded in the BOA registry (29.9 % men and 70.1 % women).

Data on age, sex, BMI, most affected joint, PA, and HRQoL at baseline and at follow-up at three and 12 months, from patients recorded between the years 2008 and 2013 were collected from the BOA registry to be included in the study. We included data from patients that had three registrations (baseline and at follow-up at three and 12 months) on PA and/or HRQoL (n=7628). In the study cohort (n=7628), there were paired data for 6332 patients regarding the questions about PA and exercise available at baseline, and at follow-up at three and 12 months, respectively. For data regarding HRQoL, there were paired data for 6145 patients available. Flowchart for the inclusion of data for analysis in study I is presented in Figure 4.

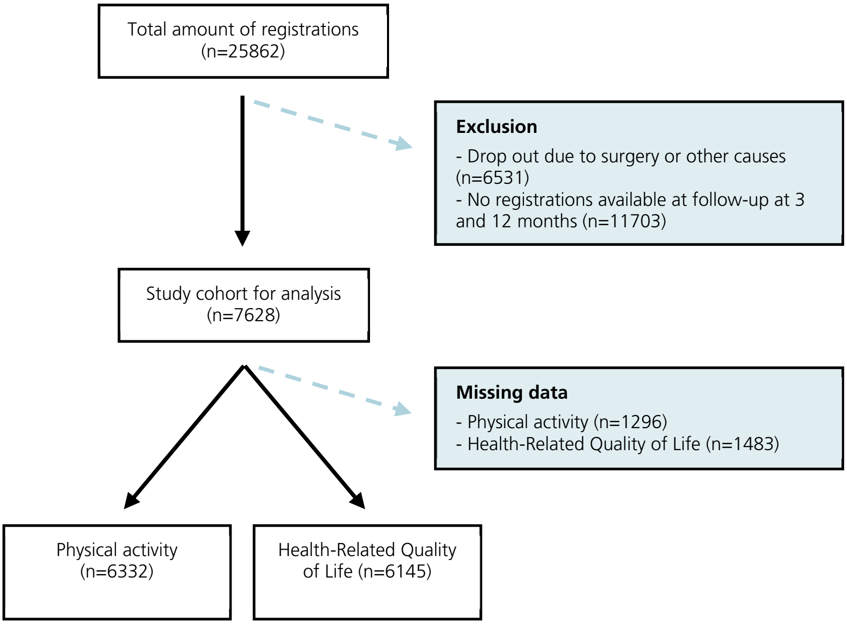

Figure 4. Flowchart for the inclusion of data for analysis in study I.

Data collected from the south of Sweden

Data for studies II and III were collected in Region Skåne (five PHC centres, n = 87) and Region Blekinge (two PHC centres, n = 56) between April 2016 and June 2018 (n = 143). Patients were recruited consecutively when joining the SOASP and asked to participate in the study by the PT responsible for the SOASP at the PHC centre. Data on age, sex, BMI, and most affected joint were collected at baseline. Prior to the participation in the SOASP at baseline, the patients participating in the studies answered questionnaires about HRQoL (EQ-5D and empowerment (Swedish Rheumatic Disease Empowerment Scale, SWE-RES-23). After the educational part of the SOASP patients answered the SWE-RES-23 and questions about enablement (the Patient Enablement Instrument, PEI). At follow-up at three months, the EQ-5D, the SWE-RES-23 and the PEI were answered and at follow up at nine months, the EQ-5D and the SWE-RES-23 were answered.

At baseline, after the educational part of the SOASP, and at three month follow-ups, data were collected by the PT responsible for the SOASP at the PHC centre, and at nine months follow-up data were collected by the first author (KSÅ) through a postal questionnaire with prepaid a return envelope. In study II, data collected at baseline (SWE-RES-23), after the educational part of the SOASP (SWE-RES-23, PEI) and at follow-up at three months (SWE-RES-23, PEI) were included in the analysis. In study III, patients with paired data, i.e., prior to the participation in the SOASP at baseline and at follow-up at nine months on HRQoL (n = 119), were included in the analysis. Flowchart for the inclusion of data for analysis in studies II and II is presented in Figure 5.

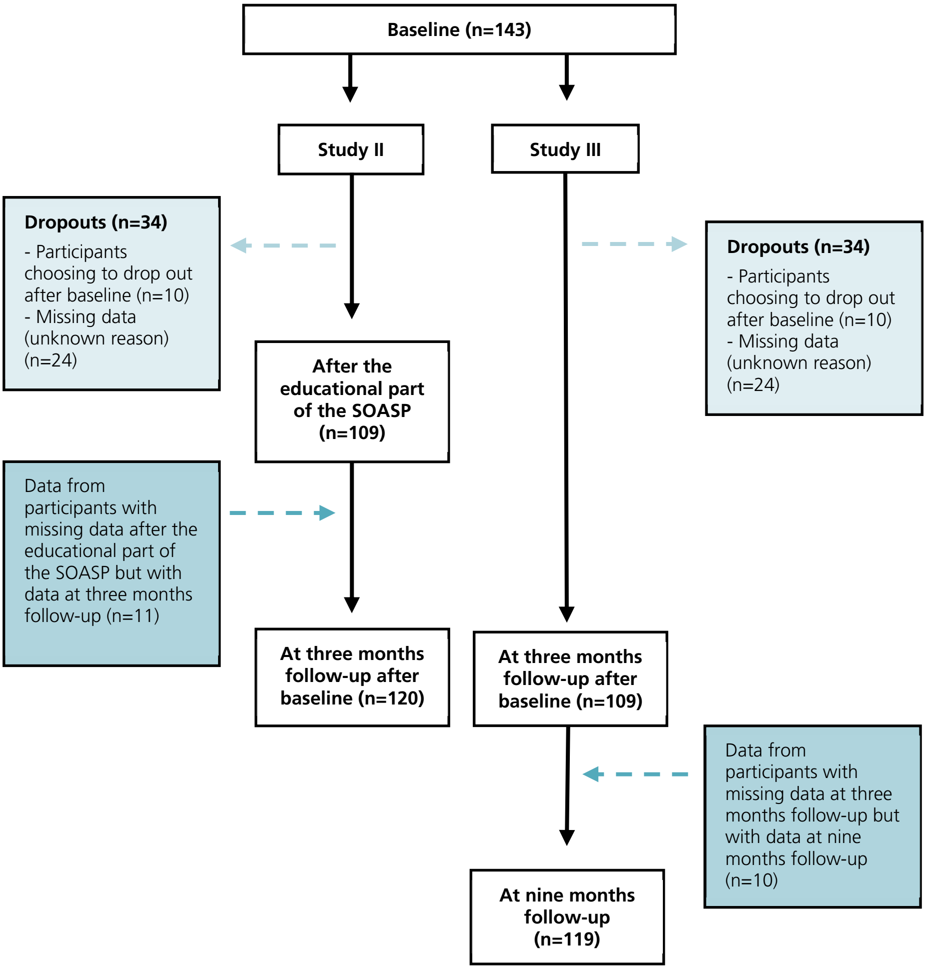

Figure 5. Flowchart for the inclusion of data for analysis in studies II and III.

Interviews with physiotherapists

Purposive sampling was used in the interview study (paper IV). Inclusion criteria were PHC centres in Region Skåne which experienced a visit from a coordinator informing about the regional guidelines for treatment of OA at a workplace meeting sometime between the years 2017 and 2018. First, the heads of department (HODs) were contacted via email with information about the study and asked for permission to letting the PT responsible for the SOASP at the PHC centre to participate in the study. In total, 43 HODs were emailed of which 20 did not reply despite a reminder being sent. One HOD answered that there was no PT at their PHC centre at the time of the study. Twenty-two HODs gave their consent and the PTs at these PHC centres were emailed, given written information about the study and asked to participate. About a week after, another email was sent to the PTs to set a date for the interview.

In total, 18 PTs were interviewed face-to-face once between February and September 2019. Four were not included in the study due to the PTs not answering (two), declining to participate (one) and being on parental leave (one). Eighteen semi-structured, individual interviews were conducted by two co-authors, AS (n = 10) and KS (n = 8), who are both registered PTs and PhDs with experience in qualitative research. All interviews were conducted in Swedish and took place either at the participant's workplace (n = 17) or at the Health Sciences Centre (n = 1) in Lund, Sweden, according to the participant's preferences, with no one else present. The interviews lasted between 22 and 60 minutes, with a mean duration of 40 minutes (SD 13.2). All interviews were recorded using a tape recorder and were transcribed verbatim by the first author (KSÅ). No field notes were made during or after the interviews. The transcripts were checked against the audio files twice. After the transcription, the participants´ record were separated from the transcribed interviews ensuring anonymisation throughout the analysis process.

Outcomes

Patient-reported outcome measures

Patient-reported outcome measures (PROMs) are questionnaires answered by patients about health care quality and intervention effectiveness. PROMs can be either generic (i.e., measuring health concepts that are relevant for various patient groups), or condition-specific (i.e., measuring health elements relevant to a specific condition or patient group) [199]. Both generic and condition-specific PROMs were used in studies I–III. An overview of the PROMs, i.e., the questionnaires, used in studies I-III are presented in Table 4.

Table 4. An overview of the patient-reported outcome measures i.e., the questionnaires, used in studies I-III.

Questionnaire	Study I	Study II	Study III
EQ-5D-3L index[a]	X		
EQ-5D-5L index[a]			X
EQ VAS[b]			X
PEI[c]		X	X
Physical activity and exercise[d]	X		
SWE-RES-23[e]		X	X

[a] EQ-5D-3L and EQ-5D-5L = EuroQol five dimensions, descriptive part
[b] EQ VAS = EuroQol five dimensions, visual analogue scale
[c] PEI = Patient Enablement Instrument
[d] Physical activity and exercise = questions recommended by the Swedish National Board of Health and Welfare
[e] SWE-RES-23 = Swedish Rheumatic Disease Empowerment Scale

Physical activity and exercise

Questions about PA and exercise follow the recommendation from the Swedish National Board of Health and Welfare in the BOA registry. Between 2008 and August 31, 2012, the one question about PA was “In an ordinary week, on how many days are you physically active for at least 30 minutes a day?” with the alternative answers: none to seven days. At that time the two questions about exercise were: 1) “In general, how often do you exercise so you are breathless or sweat?” with the seven alternative answers: never, less than once a month, once or twice a month, once a week, twice or three times a week, four to six times a week, and every day; and 2) “If you exercise, for how long do you exercise each time, in general?” with the four alternative answers: less than 15 minutes, 15 – 30 minutes, 31 – 60 minutes, more than an hour [34]. Since September 1, 2012, the questions were further developed by the Swedish National Board of Health and Welfare and changed accordingly to be included in the BOA questionnaires: 1) “How much time do you devote to PA that makes you short of breath, for example running, keep-fit exercises, or ball games?” The six alternative answers are no time, less than 30 minutes, 30 – 60 minutes, 60 – 90 minutes, 90 – 120 minutes, and > 120 minutes; 2) "How much time do you devote to everyday PA such as walking, bicycling, or gardening? Include all activities lasting 10 minutes at a time." The seven alternative answers are no time, less than 30 minutes, 30 – 60 minutes, 60 – 90 minutes, 90 – 150 minutes, 150 – 300 minutes, and > 300 minutes. The questions refer to an ordinary week, where the first question relates to exercise and the second to PA [34, 146]. The questions have been validated against accelerometer [200].

Health-related quality of life

The EQ-5D, a generic PROM [201, 202], was used to measure HRQoL. The EQ-5D has been translated to Swedish [203] and has shown sufficient reliability [204] and validity [205] for use in relation to OA.

The EQ-5D consists of two parts: the descriptive part (EQ-5D-5L) and the visual analogue scale (EQ VAS) [203]. The descriptive part consists of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression [203, 206]. There is a three-, and a five-level version of the instrument; the EQ-3D-3L [207] used by the BOA registry during the study period of study I [146] and the EQ-5D-5L [203, 207] used in study III.

There is a different number of alternative answers for each dimension depending on what version of the EQ-5D is used. For EQ-5D-3L, the alternative answers are "no problems", "moderate problems", and "severe problems", corresponding to numbers 1, 2 and 3 respectively [202]. For EQ-5D-5L, the alternative answers are "no problems", "slight problems", "moderate problems", "severe problems", and "extreme problems" or "unable to" corresponding to number 1, 2, 3, 4 and 5 respectively [203, 206]. These numbers can be combined into a five-digit health profiles number [202, 203, 206, 208] representing an index value where lower values reflect lower HRQoL and higher values reflect higher HRQoL [207]. The British tariff was used by the BOA registry at the time of study I, since there was no Swedish tariff available [209, 210] and the Swedish tariff was used in study III [203]. On the EQ VAS, the patients self-report their health on a vertical visual analogue scale ranging from 100 (best imaginable health) to 0 (worst imaginable health) [203]. In study I, the descriptive part of the EQ-5D (EQ-5D-3L) was included in the analysis and in study III, both the descriptive part (EQ-5D-5L) and the visual analogue scale (EQ VAS) were used.

Patient enablement

Patient enablement was measured using the Patient Enablement Instrument (PEI) [151, 152, 161] which is a generic instrument. The PEI measures a patient´s perceived ability to understand and cope with their disease and is answered after a health care consultation [151, 152, 161]. The instrument consists of six questions with four alternative answers: much better (scored 2), better (scored 1), same or less (scored 0), not applicable (scored 0), resulting in a possible total consultation score between 0 and 12 [151, 152, 161] where a higher score indicates higher enablement [151, 152, 161]. There is no baseline data reported for the PEI as the instrument is based on the patients′ own perception of change in enablement after a consultation [152]. The PEI has been translated to Swedish and tested for reliability [162] and validity [211].

Empowerment

Empowerment was measured using the Swedish Rheumatic Disease Empowerment Scale (SWE-RES-23) [167], a conditions-specific instrument developed from the Swedish Diabetes Empowerment Scale [167, 212]. In our study, the phrase "rheumatic disease" was replaced with "osteoarthritis". The SWE-RES-23 consists of 23 questions with five alternative answers ranging from "strongly disagree" (scored 1) to "strongly agree" (scored 5) [167]. The total score is calculated by summing the score of each question and dividing the sum by 23, resulting in a total score between 1 to 5, where a higher score indicates higher empowerment [167]. The SWE-RES-23 has been translated to Swedish and tested for reliability and validity [167].

Physiotherapists' experiences

The interviews followed a semi-structured interview guide, developed with inspiration from the framework Promoting Action on Research Implementation in Health Services (PARIHS) [213-215]. The PARIHS suggests that implementation is most likely to be successful when evidence is viewed as aligning with professional and patient beliefs, the health care context is receptive to implementation and mechanisms to facilitate implementation are in place [216, 217].

Analysis

In this thesis, both quantitative (papers I–III) and qualitative (paper IV) data analytical methods were used.

Statistical analyses

In studies I–III, statistical significance α was set at 0.05 and analyses were performed with IBM SPSS Statistics (version 21 in paper I, and version 27 in papers II–III) (SPSS

Inc., Chicago, IL, USA). An overview of the statistical analyses used in studies I-IV is presented in Table 5.

Table 5. Overview of statistical analyses used in studies I-IV

Statistical analysis	Study I	Study II	Study III	Study IV
Chi-square test	X			
Effect size (Cohen´s d (CI))			X	
Effect size (r)		X		
Linear regression			X	
Mean (SD)	X	X	X	X
Median (IQR)		X		
Paired sample t-test			X	
Range		X	X	
Spearman´s rho		X		
Student´s t-test	X			
Wilcoxon´s signed ranked test		X		
z-test	X			

CI = confidence interval
SD = standard deviation
IQR = interquartile range

In study I, a model for calculation of the questions on PA and exercise, was developed (Figure 6). Data on PA was dichotomised to being sufficiently physically active (≥ 150 activity minutes a week) based on the recommendations of WHO [102]. We calculated the proportion of patients being sufficiently or insufficiently physically active at baseline, and at three- and 12-months follow-up. This was also done for men and women separately.

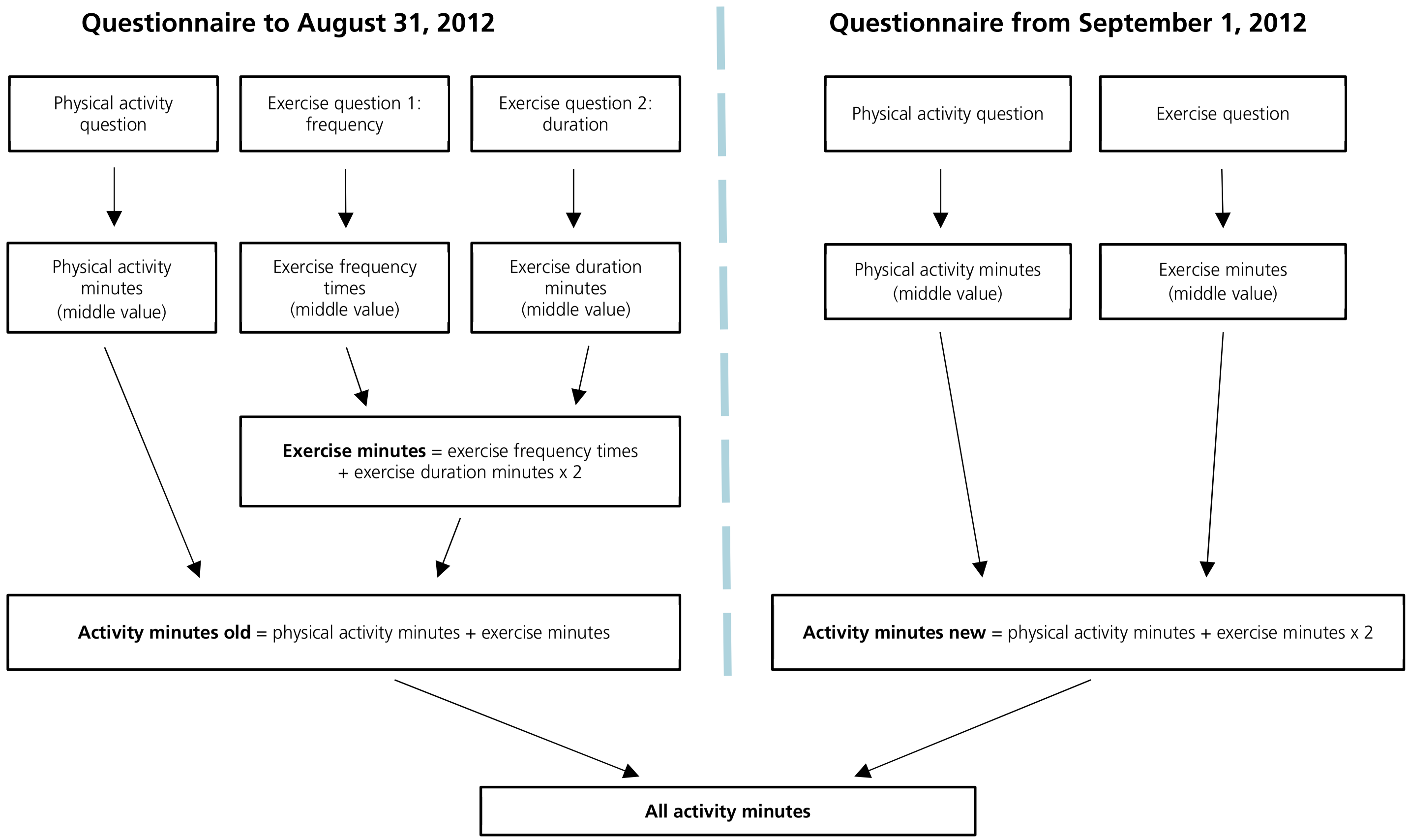

Figure 6. Model for calculation of activity minutes.

Both parametric and non-parametric tests and methods were used. In study II, we used non-parametric tests since the PEI and the SWE-RES-23 scales were treated as ordinal.

In study III, we used parametric methods since we conducted two sets of multiple linear regression models with the continuous dependent variables: change in EQ-5D-5L index and change in EQ VAS. For each set, the first model contained the independent variables: the PEI and the SWE-RES-23 at three months follow-up and change in the SWE-RES-23 score from baseline to three months follow-up. For the second model, we added the control variables: age, gender and the EQ-5D score at baseline (EQ-5D-5L index or EQ VAS, depending on the dependent variable).

For each regression analysis, the significance of the regression model was tested by the ANOVA. Associated p-values lower than 0.05 were considered significant and the strength of the linear relation was measured by the goodness of fit statistics, R^2 and adjusted R^2, indicating the proportion of the total variance that can be explained by the model. Since there were no multicollinearity problems, both B and standardised beta (ß) coefficients were reported and tested [218]. Preliminary analyses were performed to ensure there was no violations of the assumptions of normality, linearity, and homoscedasticity.

For studies II and III, which used the same study sample, a sample size calculation showed that 110 participants were needed to be able to detect a correlation coefficient between 0.3 and 0.5 with a power of 0.80 at a chosen significance level of 0.05. The calculation was performed with respect to multiple statistical analyses being planned on the same study sample. SAS Enterprise Guide 6.1 for Windows (SAS Institute Inc., Cary, NC, USA) was used for sample size calculation. Data from 143 participants were collected to compensate for potential missing data. No imputation was made for missing values since dropouts were less than 5 % [218].

Descriptive statistics were utilized as follows: as frequencies and percentages for categorical data; as means, standard deviations (SD), range, median and interquartile range (IQR) for numerical data.

Various tests were used in this thesis: the Chi-square test was used to compare proportions of categories regarding PA and HRQoL (paper I); the z-test (Bonferroni's adjusted) was used to test the significance of differences in proportions change in PA (paper I); the Student´s t-test (two-tailed) was used for analysing differences between men and women regarding HRQoL (paper I); and the Wilcoxon's signed rank test was used when analysing the change in empowerment (SWE-RES-23) (paper II). The effect size, based on the Wilcoxon's signed rank test, was computed according to the formula $r = Z / \sqrt{N}$ [219, 220] (paper II). The resulting values were categorised as small (0.1), medium (0.3) or large (0.5) [221].

The Spearman’s rho (r_s) was used when analysing the linear relationship between two PROMs, the PEI, and the SWE-RES-23 (paper II). The correlation values were categorised as weak (0.1–0.3), moderate (0.3–0.5) or strong (0.5 or more) [221]. Paired samples t-test was used for paired group comparisons for HRQoL (paper III). Effect sizes (Cohen´s d, CI 95 %) for HRQoL were analysed [221] and categorised as small (0.2), medium (0.5) or large (0.8) [221].

Qualitative content analysis

The qualitative data (paper IV) was analysed with qualitative content analysis (QCA) [222]. The software programme NVivo 12 was used in the analysis. The transcribed interviews were analysed with QCA, using an inductive approach as described by Graneheim and Lundman [223, 224]. All the transcripts, except for the opening questions, were considered as units of analysis [223]. The opening questions served two purposes; to make the participant feel comfortable and to collect descriptive background information about the participant.

First, all 18 interviews were read several times by three authors (AS, KS and KSÅ) to obtain an overall sense of the data. Then, the text was divided into meaning units, identified as “words, sentences or paragraphs containing aspects related to each other through content and context” [223]. Three authors (AS, KS and KSÅ) analysed two interviews separately, and two authors (KS and KSÅ) analysed two additional interviews. Coherence between the authors was sought and was a point of discussion. The first author (KSÅ) divided the remaining 14 interviews into meaning units and who then condensed and coded all the meaning units. The codes were compared for differences and similarities and sorted into subcategories based on similar manifest content by the first author (KSÅ). Subcategories were then sorted into categories reflecting their content, first by the first author (KSÅ) and then the sorting and labelling were discussed by three authors (AS, KS and KSÅ). The discussion led to led to some re-sorting and re-labelling of the subcategories. Finally, the subcategories were sorted into categories reflecting the content. Examples of meaning units, condensed meaning units, codes, subcategories, and categories are provided in Table 6.

Table 6. Examples of meaning units, condensed meaning units, codes, subcategories, and categories.

Meaning unit	Condensed meaning unit	Code	Subcategory	Category
Then it is the younger ones, those who are still more active and simply are unable to leave their place of work (ID 1)	It is the younger ones who are more active and unable to leave their work	Younger are unable to leave their place of work	The Supported Osteoarthritis Self-Management Programme does not suit all patients with OA	The Supported Osteoarthritis Self-Management Programme is overall a well-functioning part of the regional guidelines but there is room for improvement
I actually don´t really know what the nurses know about osteoarthritis. I mean when they meet patients and on the phone and what they might say to the patients (ID 2)	Don´t know what nurses know about osteoarthritis and what they say to patients	What do nurses know about osteoarthritis	Importance of knowledge and understanding of the guidelines	Management plays a key role when it comes to guideline compliance
One positive thing about having a group with only patients with osteoarthritis is that they were more close-knit. They supported each other and they also had social contact after the SOASP so they did things afterwards. Very positive (ID 3)	The positive thing about having only OA patients in the group was that they were more close-knit. They supported each other and met socially after the SOASP. Very positive.	An OA group was more close-knit	Physiotherapists are confident in their professional role and believe in the guidelines	The Supported Osteoarthritis Self-Management Programme is overall a well-functioning part of the regional guidelines but there is room for improvement
But we have requirements like everyone else, like at all other primary health care centres. If you work full time you are supposed to have about 8 to 10 patients a day and it is recorded and monitored statistically and so on (ID 4)	Have requirement that if you work full time you are supposed to have 8 to 10 patients a day which is recorded and monitored statistically	Physiotherapists have productivity requirements	More support is needed in order to prioritise and enable evaluation and development	Management plays a key role when it comes to guideline compliance

The analysis process went back and forth [223] during which various categories were tried before the final categorisation was determined. Quotations from the original transcribed interviews were chosen to illustrate the categories [223, 224]. Throughout the analysis process the research team (AS, KS, EEH and KSÅ) reflected and discussed the different steps in the analyses until agreement was achieved.

Involving a patient partner in research

A PP from the Swedish Rheumatism Association was engaged in studies II and III. The PP was actively involved in the whole research process from the planning phase to the interpretation of the results. We first met the PP face-to-face at a network meeting lasting three days to plan the study. Thereafter we kept in contact digitally and through email. The PP contributed with opinions on the aim, feasibility, and relevance of the study approach in relation to the SOASP and gave practical advice regarding the legibility of the written patient information and consent form. Throughout the data collection, we discussed the process with the PP, who was consulted when analysing the results to see if the PP´s interpretation was aligned with that of the research team.

Ethics

The four studies included in this thesis were conducted in accordance with the Declaration of Helsinki [225] and were assessed by a Regional Ethical Review Board.

Ethical approval

Study I was approved by the Regional Ethical Review Board in Gothenburg (Approval number 782-14). Since July 1, 2009, national quality registries are regulated by the Swedish Patient Data Act (Patientdatalagen, 2008:355) that states that all patients approving the reporting of data to the registry are to be given oral or written information about what their registration means prior to deciding to share their data with the registry. Patients must be informed about their right to decline reporting to the registry, their right to have their data obliterated from the registry and that their data might be subject to research. According to the law, informed consent to participate in a research study is not needed from each patient included in a registry. The law recommends national quality registries to provide information about ongoing research studies on their websites that are available to the public.

Studies II–III were approved by the Regional Ethical Review Board in Lund (Approval number 2015/918) in Sweden. All patients that were interested in participating in the studies were given written and verbal information about the study and gave their written informed consent for study participation prior to the start of the studies.

For study IV, the Regional Ethical Review Board in Lund declared that ethical vetting was not necessary according to the Ethical Review Act (Approval number 2018/700). All participating physiotherapists were given written and verbal information about the study and gave their written informed consent to participate prior to the start of the study.

Ethical considerations

All study participation was voluntary and based on informal consent. All data was pseudo-anonymised during data analysis.

In study I, data from the national quality registry, Better Management of Patients with Osteoarthritis (BOA) were analysed. Approval to use data from the registry for research purpose was obtained from the authorities in charge of the registry. Data was available through a two-factor authentication and all data were encrypted with a unique personal identification number without access to a patient´s personal information, e.g., name, social security number or address. Results were presented on an aggregate data level to prevent identification of any individual patient.

In studies II and III, data were collected in relation to patients participating in a SOASP. At the study period, I (KSÅ) was responsible for the SOASP at one of the PHC centres where data was collected. My dual role as a treating PT and a researcher might have affected the patients´ willingness to participate in the study.

In study IV, the heads of department were first informed about the study and asked for permission to contact the PT responsible for the SOASP at the PHC centre. The PTs were then contacted and asked to participate in the study. Since I (KSÅ) had been involved in the implementation of the guidelines, the interviews were conducted by two of my co-authors to minimise the risk of bias.

Given that research ethics are dynamic and continue to be developed as new ethical issues evolve or new laws are legislated, ethics need to be discussed continuously. Since the European Union General Data Protection Regulation (GDPR) [226] as taken in effect in 2018, all data included in the studies has been handled accordingly. Following the GDPR, all research studies involving personal data processing are to be registered in Personal Data Lund University (PULU) [227] at Lund University. The four studies included in the thesis have been registered in PULU.

Results

Participants

For the study cohort (n=7628) in study I, there were paired data for 6332 recorded patients regarding the questions concerning PA and exercise available at baseline, and at follow-up at three and 12 months, respectively. For data regarding HRQoL, there were paired data for 6145 recorded patients available. The study cohort consisted of 27.3 % men (n = 2079) and 72.7 % women (n = 5549). Mean age was 65.3 (SD 9.2) (men 65.7 (SD 9.3), women 65.2 (SD 9.2)). The majority (72.2 %) reported problems in the knee (men 71.6 %, women 72.4 %) and 27.0 % (men 27.6 %, women 26.8 %) reported problems in the hip. There were some missing data on most affected joint (n = 61, 0.8 %). Mean BMI was 28.0 (SD 4.8) (men 27.9 (SD 4.0), women 28.0 (SD 5.1)).

Studies II and III, were based on the same study cohort (n = 143). In study II, the total study cohort was included (n = 143) and in study III, patients with paired data on HRQoL were included (n = 119). Sample characteristics for the study sample in study II (n = 143) and in study III (n = 119) are presented in Table 7.

Table 7. Sample characteristics for the study sample in study II (n = 143) and study III (n = 119).

	Study sample Study II (n=143)	**Study sample Study III*** (n=119)
Gender % (*n*)		
Men	22 (32)	23 (27)
Women	78 (111)	77 (92)
Age (years)		
mean (SD)	65.9 (9.3)	66.4 (8.7)
min-max	40–90	40–90
Most affected joint % (n)		
knee	72.1 (101)	72.3 (86)
hip	25.7 (36)	25.2 (30)
hand	2.1 (3)	2.5 (3)
missing data	2.7 (3)	
BMI**		
mean (SD)	28.9 (6.3)	28.7 (6.4)

*the study sample in study III (n=119) includes patients with paired data on HRQoL
**BMI = Body Mass Index

The characteristics of the participating PTs in study IV are presented in Table 8.

Table 8. Characteristics of the participating physiotherapists in study IV.

Characteristics	(n=18)
Sex	
Male	5
Female	13
Work experience in PHC[a], mean (SD)	10.5 (7.2)
Work experience at this PHC[a] centre, mean (SD)	4.4 (2.6)
Work experience with SOASP[b], mean (SD)	4.25 (2.5)
Type of PHCa centre	
Public	16
Private	2
Education in providing SOASP[b]	13

[a] PHC=Primary Health Care

[b] SOASP=Supported Osteoarthritis Self-Management Programme

Patient-reported outcome measures (papers I-III)

Differences between men and women in physical activity (paper I)

There were differences between men and women in self-reported outcome of PA. The proportion of women reporting to be sufficiently physically active (≥ 150 activity minutes a week) was larger than for men at baseline (p = 0.003) and at follow-up at 12 months (p = 0.035) (Table 9).

Table 9. Differences in physical activity for men (n = 1721) and women (n = 4611), and in health-related quality of life (HRQoL)* for men (n=1654) and women (n = 4491) at baseline and at follow-up at three and 12 months.

	Baseline				3 months				12 months			
	Men	**Women**	**All**	**p-value****	**Men**	**Women**	**All**	**p-value****	**Men**	**Women**	**All**	**p-value****
Proportions of sufficiently physically active (%)												
≥150 activity min./week	80.8	84.0	83.1	.003	88.6	89.1	88.9	.605	76.8	79.2	78.5	.035
HRQoL												
Mean	0.67	0.64	0.65	<.001	0.73	0.71	0.72	<.001	0.70	0.69	0.69	.010
(SD)	(0.20)	(0.23)	(0.22)		(0.17)	(0.19)	(0.19)		(0.21)	(0.22)	(0.22)	

* HRQoL is measured by EQ-5D-3L index

**p-value for sufficient physical activity analysed with Chi-square test, and for HRQoL analysed with t-test

An analysis of change in PA, categorised in four groups (from insufficient to sufficient PA, still sufficient PA, still insufficient PA, and from sufficient to insufficient PA) showed that there were differences between men and women both between baseline and follow-up at three (p = 0.013) and 12 months (p = 0.009).

A test of significance of the differences in proportion (%) of men and women (n=6332) in change or no change of PA group (insufficient to sufficient PA, still sufficient PA, still insufficient PA, and sufficient to insufficient PA), showed that a larger proportion of men changed from being insufficiently to sufficiently physically active (men 13 %, women 10.2 %, p = 0.002) between baseline and three months (Table 10).

Table 10. Test of significance of the differences in proportion (%) of men and women (n = 6332) in change or no change of physical activity group (insufficient to sufficient PA, still sufficient PA, still insufficient PA, and sufficient to insufficient PA), between baseline, and follow-up at three and at 12 months.

	Physical activity % (n)							
	Insufficient to sufficient PA	**p-value***	**Still sufficient PA**	**p-value***	**Still insufficient PA**	**p-value***	**Sufficient to insufficient PA**	**p-value***
Baseline vs 3 months		0.002		0.006		>0.05		>0.05
Men	13.0 (224)		75.6 (1301)		6.2 (106)		5.2 (90)	
Women	10.2 (472)		78.8 (3635)		5.8 (266)		5.2 (238)	
Baseline vs 12 months		>0.05		0.015		0.002		>0.05
Men	8.9 (153)		67.9 (1168)		10.3 (177)		13.0 (223)	
Women	8.2 (378)		71.0 (3274)		7.8 (360)		13.0 (599)	

*p-value for z-test of differences of proportions of men and women

Differences between men and women in health-related quality of life (paper I)

There were differences between men and women in self-reported outcome of HRQoL. Women reported lower HRQoL (EQ-5D-3L index) than men at all measuring points (i.e., at baseline (p < 0.001), and at three months (p < 0.001) and at 12 months follow-up (p = 0.010)) (Table 9).

Outcome of patient enablement and empowerment (papers II–III)

The reported median value was 6 (IQR 3–6.5) for the PEI (n = 109) and 3.8 (IQR 3.6–4.1) for the SWE-RES-23 (n = 108) after the educational part of the SOASP. The reported median value was 6 (IQR 4–7) for the PEI and 3.9 (IQR 3.6–4.2) for the SWE-RES-23 at three months follow-up (n = 116). There was a statistically significant increase in empowerment from baseline to three months follow-up, Z = -4.07, p ≤

0.000 (n = 115), analysed with the Wilcoxon´s signed rank test, with an effect size close to medium (r = 0.27), (paper II).

The self-reported mean value was 6 (SD 3.2) for the PEI at three months follow-up (n = 105). For the SWE-RES-23 the self-reported mean value was 3.7 (SD 0.6) at baseline (n = 118) and 3.9 (SD 0.5) at three months follow-up (n = 105) (paper III).

The relation between patient enablement and empowerment (paper II)

There was a positive correlation between the PEI and the SWE-RES-23 both after the educational part of the SOASP ($r_s = 0.493$, $p < 0.00$, n = 108) (Figure 7) and at follow-up at three months ($r_s = 0.507$, $p < 0.00$, n = 116) (Figure 8). The analyses showed correlation close to the cut-off point for strong a correlation at both measuring points.

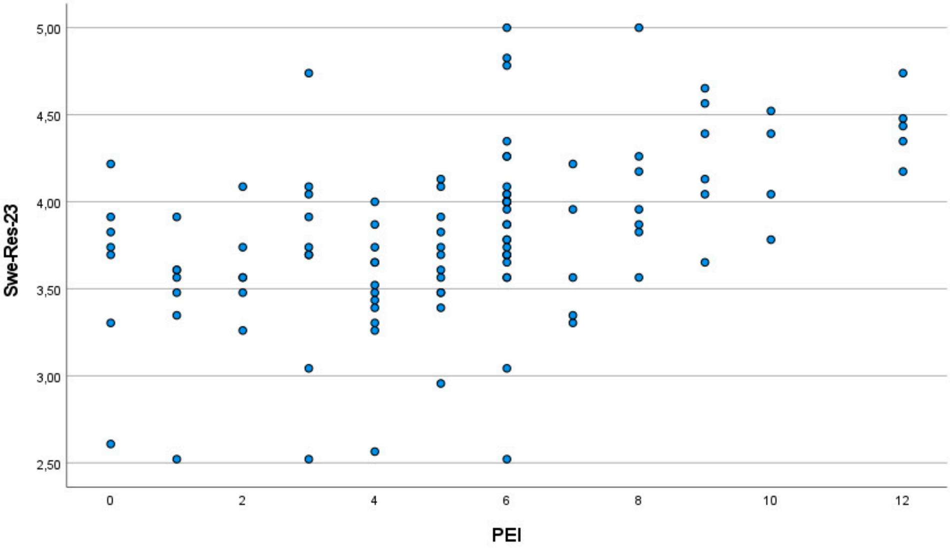

Figure 7. Scatterplot showing the correlation between the PIE and the SWE-RE-23 after the educational part of SOASP (Spearman´s rho (r_s) = 0.493; n = 108).

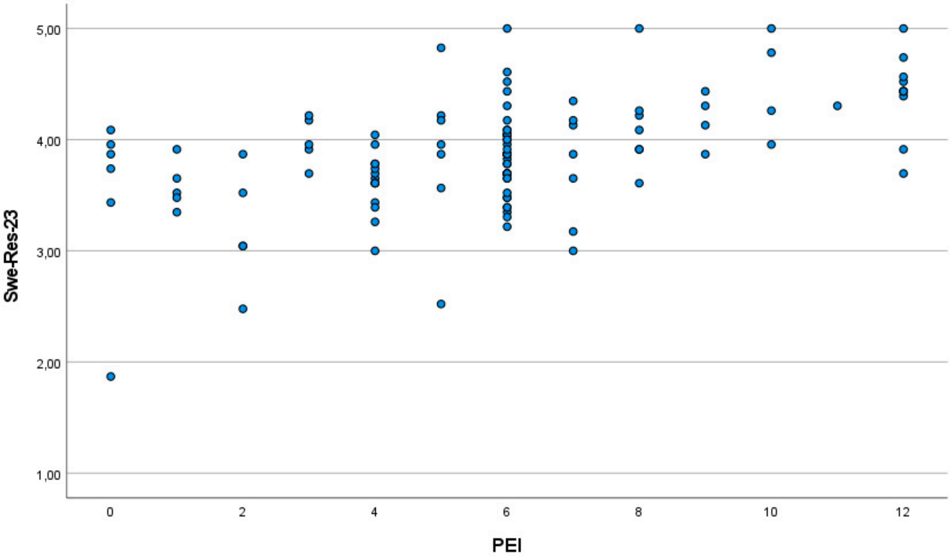

Figure 8. Scatterplot showing the correlation between the PIE and the SWE-RE-23 at follow-up at three months (Spearman´s rho (r_s) = 0.507; n = 116).

Outcome of health-related quality of life (paper III)

At three months follow-up, the highest average values for the EQ-5D-5L index and the EQ VAS were observed (Table 11).

Table 11. Descriptive data on health-related quality of life measured with the EQ-5D-5L index and the EQ VAS at baseline, 3 and 9 months follow-up and the mean change in the EQ-5D-5L index and the EQ VAS from baseline to 3 and 9 months follow-up.

	Baseline (n=119)	**3 months follow-up** (n=109)	**9 months follow-up** (n=119)	**Mean change baseline to 3 months** (n=109)	**95% CI**[c]	***p*-value**[d]	***d***[e]	**Mean change baseline to 9 months** (n=119)	**95% CI**[c]	***p*-value**[d]	***d***[e]
EQ-5D-5L[a]											
Mean (SD)	.810 (.128)	.852 (.118)	.832 (.127)	.040	.02, .06	≤.001	.43	.022	.00, .04	.041	.19
EQ VAS[b]											
Mean (SD)	68.9 (19.2)	72.7 (19.4)	71.9 (17.2)	3.5	.97, 6.1	.007	.26	3.0	-.04, 6.0	.053	.18

[a] total score range 0–1

[b] total score range 0–100

[c] CI= confidence interval for mean change baseline to 3 and 9 months respectively

[d] significance level p<.05, p-value for mean change baseline to 3 and 9 months respectively analysed with paired sample t-test

[e] d= Cohen´s d (effect size)

The mean EQ-5D-5L index score increased significantly from baseline to three months corresponding to a standardised effect size (Cohen´s d) of d = 0.43, 95 % CI [0.24, 0.63] (n = 109), and from baseline to nine months d = 0.19, 95 % CI [0.01, 0.37] (n = 119). The average EQ VAS score increased significantly from baseline to three months corresponding to a standardised effect size of d = 0.26, 95 % CI [0.07, 0.45] (n = 109), and from baseline to nine months d = 0.18, 95 % CI [0.00, 0.36] (n = 119).

Prediction of health-related quality of life (paper III)

Neither the SWE-RES-23 nor the PEI at three months follow-up or the change in the SWE-RES-23 score from baseline to three months follow-up predicted change in either EQ-5D-5L index ($p > 0.05$) or the EQ VAS ($p > 0.05$), and together explained 6.8 % (EQ-5D-5L index) ($p = 0.069$) and 2.9 % (EQ VAS) ($p = 0.399$) of the variation. When age, gender and EQ-5D baseline values were added, the models explained 34.4 % (EQ-5D-5L index) ($p = 0.000$) and 42 % (EQ VAS) ($p = 0.000$) of the variation, with baseline EQ-5D as the main significant predictor (Table 12, Table 13). Also, the PEI was significantly associated with change in EQ VAS (B = 1.26, 95 % CI [0.25, 2.28]) (Table 13, model 2).

Table 12. Multiple linear regression analysis for variables predicting change in health-related quality of life measured with EQ-5D-5L index from baseline to 9 months follow-up.

	Model 1				Model 2			
Variables	**B**	**95 % CI**	**ß**	***p-value*[e]**	**B**	**95 % CI**	**ß**	***p-value*[e]**
PEI[a] at 3 months (n=105)	.01	-.00, .02	.18	.128	.01	-.00, .01	.16	.111
SWE-RES-23[b] at 3 months (n=105)	.00	-.05, .06	.01	.953	.05	-.00, .10	.21	.054
Change in SWE-RES-23 score[c] (=104)	.03	-.01, .08	.15	.157	.02	-.02, .06	.10	.262
EQ-5D-5L[d] index at baseline (n=119)					-.50	-.67, -.33	-.55	.000
Age (n=119)					.00	-.00, .02	-.02	.852
Gender (n=119)					-.01	-.06, .02	-.05	.561
R^2	.068				.344			
Adjusted R^2	.040				.303			
ANOVA *p-value*[e]	.069				.000			

[a] PEI: Patient Enablement Instrument, measuring enablement

[b] SWE-RES-23: Swedish Rheumatic Disease Empowerment Scale, measuring empowerment

[c] Change in the SWE-RES-23 score during the SOASP (i.e., from baseline to 3 months follow-up)

[d] EQ-5D-5L: descriptive part of EQ-5D, measuring health-related quality of life

[e] significance level α =.05

Table 13. Multiple linear regression analysis for variables predicting change in health-related quality of life measured with EQ VAS from baseline to 9 months follow-up.

	Model 1				Model 2			
Variables	**B**	**95 % CI**	**ß**	***p-value*[e]**	**B**	**95 % CI**	**ß**	***p-value*[e]**
PEI[a] at 3 months (n=105)	.82	-.44, 2.07	.15	.199	1.26	.25, 2.28	.23	.015
SWE-RES-23[b] at 3 months (n=105)	-1.61	-9.60, 6.40	-.05	.690	5.08	-1.56, 11.72	.16	.132
Change in SWE-RES-23 score[c] (n=104)	3.03	-3.98, 10.05	-.09	.393	1.21	-4.31, 6.73	.04	.665
EQ VAS[d] at baseline (n=119)					-.55	-.70, -.41	-.64	.000
Age (n=119)					-.18	-.47, .12	-.10	.240
Gender (n=119)					-.91	-7.14, 5.32	-.02	.772
R^2	.029				.420			
Adjusted R^2	.000				.384			
ANOVA *p-value*[e]	.399				.000			

[a] PEI: Patient Enablement Instrument, measuring enablement

[b] SWE-RES-23: Swedish Rheumatic Disease Empowerment Scale, measuring empowerment

[c] Change in the SWE-RES-23 score during the SOASP (i.e., from baseline to 3 months follow-up)

[d] EQ-VAS: visual analogue scale part of EQ-5D, measuring health-related quality of life

[e] significance level α =.05

Physiotherapists’ experiences (paper IV)

The qualitative content analysis (QCA) resulted in two categories and four subcategories, presented in Table 14 (paper IV).

Table 14. Overview of the result, categories, and subcategories.

Category	The Supported Osteoarthritis Self-Management Programme is overall a well-functioning part of the regional guidelines but there is room for improvement	Management plays a key role when it comes to guideline compliance
Subcategory	*Physiotherapists are confident in their professional role and believe in the guidelines*	*More support is needed in order to prioritise and enable evaluation and development*
	The Supported Osteoarthritis Self-Management Programme does not suit all patients with osteoarthritis	*Importance of knowledge and understanding of the guidelines*

The PTs experienced that *the Supported Osteoarthritis Self-Management Programme is overall a well-functioning part of the regional guidelines but there is room for improvement.* The programme was established as treatment for patients with hip and knee OA and provided an effective work procedure for the PTs. The *physiotherapists are confident in their professional role and believe in the guidelines.* They followed the guidelines that were aligned with their professional beliefs for treatment of OA. The SOASP supported the PT´s in providing first-line treatment, which they experienced as effective for most patients with OA. The PTs saw that patients learned from and supported each other. Many patients asked to participate in the SOASP, and the PTs wished they could offer the programme more frequently. However, the PTs saw that *the Supported Osteoarthritis Self-Management Programme does not suit all patients with osteoarthritis* as they did not reach all patients with the programme. For example, it was difficult to reach patients in working age who neither had the possibility to attend the SOASP during working hours or find time to exercise. Other challenges were when patients were doubtful about their diagnosis or did not want to participate in the SOASP. The PTs experienced that the SOASP was not efficient for patients with severe pain or disability, and that it was difficult to reach patients with other native languages than Swedish. The PTs who engaged an interpreter when needed had various experiences although overall they thought it worked well. However, as the interpreters were not always authorised, the PTs were insecure about what information was delivered to the patients. Therefore, the PTs wished for written information in more languages than the already existing ones.

According to the PTs, *management plays a key role when it comes to guideline compliance* and management´s support to enable all health care personnel to work optimally according to guidelines, was emphasised. The PTs experienced that *more support is* *needed in order to prioritise and enable evaluation and development*. Only a few of the PTs that reported data to the BOA registry used it for analysis, evaluation, and further development of the SOASP due to lack of time. Management showed little interest in the results from the registry and not much time was spent on developing quality of care. The PTs emphasised the *importance of knowledge and understanding of the guidelines.* They felt uncertain about what knowledge nurses and M.D.s had about OA treatment guidelines, since not all health care personnel followed them. Triage could be improved, and treatment was sometimes delayed by M.D.s sending patients to X-ray instead of to the PT. The information about guidelines for treatment of OA given by the coordinators at workplace meetings was useful and the PTs thought it was best delivered by an external health care professional. However, some doubts were expressed regarding whether the M.D.s would have listened more carefully to information given by a fellow M.D. rather than by a PT. The network meetings arranged by the coordinators were much appreciated. The PTs welcomed the opportunity to get support as well as exchange knowledge and experiences with colleagues working with the SOASP.

Discussion

The overall aim of this thesis was to increase knowledge about the SOASP delivered in clinical settings in PHC from the perspectives of patients and PTs.

This thesis showed that there were differences between men and women in self-reported outcomes of PA and HRQoL. The patients with OA self-reported having moderate to high enablement and empowerment and both empowerment and HRQoL increased after participation in the SOASP. The relationship between the PEI and the SWE-RES-23 was close to the cut-off point for strong correlation. Moreover, we found that empowerment and enablement did not predict change in HRQoL in this context. The PTs expressed confidence in their professional role as a primary assessor for patients with hip and/or knee OA and saw a great need for the SOASP which was generally well-established, however it was not seen as appropriate for all patients with OA. In addition, management support was considered important for compliance with the guidelines, for enabling evaluation and development of the SOASP, and for sustaining knowledge among the health care personnel. In this chapter, the main results are discussed, as well as strengths and limitations.

General discussion

Patient-reported outcome measures

All outcome measures analysed in this thesis were PROMs. The questions about PA and the EQ-5D analysed are routinely used in clinical practice in relation to SOASP and are recorded in the BOA registry. The overall results of the thesis align with results from other studies using the same PROMs on patient education programmes and exercise for OA patients [228-233]. In 2014 – 2015, when planning the study to analyse data from the BOA registry, there were only a few published research studies using data from the registry [130]. In recent years, the number of studies using data from the BOA registry has increased [232, 234-236]. To our knowledge at the time when we were planning the studies, the PEI and the SWE-RES-23 had not been routinely used in the context of SOASP or in research studies on SOASP. Thus, our studies on the PEI and the SWE-RES-23 contribute with knowledge to be further built upon in future studies.

Differences between men and women in physical activity and health-related quality of life

In the study using data from the BOA registry, men and women followed the same pattern of change of both PA and HRQoL, which increased after the SOASP at follow-up at twelve months and with the largest increase during the SOASP (from baseline to three months follow-up). These patterns of change have been seen in other studies [228-233, 237]. However, we saw that a larger proportion of men changed from being insufficiently to sufficiently physically active between baseline and three months, which indicates that men might benefit more from participating in a SOASP when it comes to PA, at least in the short term. More women reported to be sufficiently physically active (≥ 150 activity minutes/week) and women reported lower HRQoL than men at all measuring points.

More women than men were represented in the BOA registry and included our study. A challenge for the clinic as well as for research is to reach more men with OA to participate in SOASP, in the BOA registry and in research. Another challenge is to reach both men and women as early as possible in the disease process to get started with first-line treatment. Interviews with men and women with OA might be needed to increase knowledge and to further explore the potential differences.

Different strategies have been suggested to encourage and sustain achieved level of PA such as booster sessions and digital reminders [238, 239]. However, it is unclear what effect those strategies have, and more research and efforts are needed to achieve a more sustainable result in the longer term. In Sweden, a national information campaign about OA targeting the public might be a way to get more men and women with OA struggling with their symptoms to seek health care earlier. Moreover, an increased collaboration between health care professionals, researchers, and the patient organisation, the Swedish Rheumatism Association, when designing information campaigns, research questions and plans, and implementation strategies might increase knowledge about barriers and facilitators to compliance to treatment guidelines thus enabling appropriate measures.

Patient enablement and empowerment

Patients self-reported moderate to high enablement and empowerment, and an increase in empowerment after participating in SOASP which is encouraging as SOASP aims to support patients in better coping with their disease [131, 146]. Whether these results are sustained in the long term is a topic for in future studies.

Our study showed a positive relation between the PEI and the SWE-RES-23, that was close to the cut-off point for strong correlation. This indicates that the two instruments might not be replaceable, but more research is needed to explore this further. Comparison with different studies is challenging for various reasons. The concepts of enablement and empowerment are complex and there seems to be some confusion as to their use in literature, as they are often used interchangeably [154-156]. To our knowledge, the PEI and the SWE-RES-23 have not been studied in the context of SOASP before, and the SWE-RES-23, being a relatively new instrument, makes comparison with other similar studies difficult.

Both enablement and empowerment are two relevant concepts to evaluate in relation to SOASP. Living with a chronic lifelong disease such as OA is challenging in various ways such as the potential need for behavioural change, and individual patients with OA might need support to varying degrees. Patient enablement and empowerment, measured with the PEI and the SWE-RES-23 respectively, might be useful to evaluate after SOASP, in addition to their use as tools for achieving more personalised treatment. Further studies are needed before it can be concluded if one of the instruments is more relevant for evaluation after SOASP, or the other.

Health-related quality of life after the Supported Osteoarthritis Self-Management Programme

In our observational study, using data from two regions in southern Sweden, Region Skåne and Region Blekinge, the highest HRQoL was self-reported at follow-up at three months. The average self-reported values on HRQoL were high already at baseline, before participating in the SOASP, which allows for less room for improvement after the SOASP due to potential ceiling effect. Even so, there was an increase in HRQoL which was somewhat sustained at nine months follow-up. In another Swedish study, showing an increase in HRQoL after SOASP, the change in HRQoL was sustained after a year [232].

A study on the Norwegian national quality registry showed that patients self-reported increased HRQoL and PA levels two years after entering the ActiveOA programme [138]. Studies using data from the GLA:D® in Denmark showed a sustained increase in hip and knee related QoL as measured with the Hip dysfunction and Osteoarthritis Outcome Score (HOOS) and the Knee injury and Osteoarthritis Outcome Score (KOOS) respectively [136]. The Scandinavian OA programmes, SOASP, ActiveOA and GLA:D®, are similar, following OA treatment guidelines, but there are some differences. In ActiveOA, PTs are educated in a multidisciplinary team and get a certification after completing the education [138]. Patients have access to videos on ActiveOA´s website with instructions on how to perform exercises [138]. The PTs involved in the GLA:D® are also certified after an education and are re-certified after three years [137]. The PROMs used for evaluation in the Scandinavian registries also differ. HRQoL is measured with the EQ-5D in the SOASP and the ActiveOA [131, 138] while the HOOS and the KOOS are used in the GLA:D® [136]. In 2021, mean age for entering the BOA registry was 64.9 years [147] and in a study using data from the Norwegian national registry from 2016 – 2019, mean age was 63.5 [138]. The annual report for 2020 for the Danish national registry reports an average age of 65 years [240].

Prediction of outcome of health-related quality of life

Patient enablement and empowerment, as measured with the PEI and the SWE-RES-23 respectively, could not predict HRQoL after participating in the SOASP.

In a study using the PEI for patients with chronic pain after a multimodal rehabilitation programme including both education and exercise and lasting for 6 – 8 weeks showed that higher PEI scores were related to better self-reported health after the treatment [211]. The SWE-RES-23 was used in a study including patients with rheumatoid arthritis concluding that empowerment was associated with HRQoL, physical function and level of PA [241]. Patients self-reporting lower levels of empowerment were older, more often women, and reported lower levels of HRQoL and more pain [241].

The timepoint used for the prediction testing for the PEI and the SWE-RES-23 might affect the results. The use of one single timepoint in prediction testing is common [242]. It has been suggested that using data from repeated timepoints might provide a more reliable basis following the capturing change over time and less sensitivity to measurement error [242-244]. Using other timepoints for the prediction testing or other PROMs than the PEI and the SWE-RES-23 might have rendered a different result. A study on self-efficacy, measured with the Arthritis Self-Efficacy Scale (ASES), showed that self-efficacy at three months follow-up after participating in the GLA:D®, predicted HRQoL at 12 months [245].

The approach to use enablement and empowerment in this context has, to our knowledge, not been used before so the results from the studies might be a basis for future studies. The research on relevant methods and PROMs to predict response to treatment of OA needs to be continued. Since the overall aim with the SOASP is to enable patients to cope with their disease it might be interesting to test if other PROMs such as pain, physical function or PA level can predict outcome of patient enablement and/or empowerment after participating in a SOASP.

Physiotherapists´ experiences

The results from our interview study indicates that the PTs believed in and followed the guidelines for treatment of OA and offered the SOASP accordingly. The PTs expressed their confidence as primary assessors for patients with OA in the hip and/or knee, which is in line with another study on PTs practice and adherence to guidelines [246]. In our study, the PT´s also found a great need for the SOASP, which was, in general, well-established. However, the SOASP was not suitable for all OA patients and treatment was individually tailored when needed. Other studies have concluded that first-line treatment for OA probably does not reach all patients with OA such as patients from a more socioeconomically disadvantaged group [234] and that all OA patients might not seek health care [13]. More effort should be made to make first-line treatment accessible to more patients with OA.

The PTs saw room for improvement and that knowledge and compliance to guidelines could be improved, especially regarding other health professionals. Moreover, the PTs regarded management support as essential for compliance to treatment guidelines, evaluation, development and for sustaining knowledge among health care providers. The importance of management support has been shown in other studies [247-250] and was confirmed in our interview study. Guidelines for treatment of OA are rather complex to follow since several health care professionals i.e., PTs, OTs, M.D.s, registered nurses, and HODs potentially might be involved in the treatment process or meet patients with OA in daily practice. It is fundamental that all health care professionals have knowledge about the guidelines to be able to follow them. Guidelines should be easy to follow and perhaps the digital medical record could be developed to support compliance to guidelines. There seems to be a need to repeat the information about the guidelines for OA treatment to all health care professionals and to management. To further improve and develop quality of care for patients with hip and knee OA, data from the BOA registry could probably be used to a greater extend in daily clinical practice in PHC. Increased knowledge among health professionals and HODs about how to analyse PROMs answered by OA patients´ and use data for development might increase quality of care for OA patients in the long term.

The knowledge drawn from our interview study might be basis for planning future implementation interventions of guidelines in PHC. In future studies, it would be interesting to interview patients about their experiences of participating in SOASP and their beliefs regarding the guidelines for OA treatment. It would also be interesting to interview patients with different sociodemographic backgrounds, and patients declining to participate in the SOASP to gain a better understanding and to be able to meet the needs of different OA patients.

Involving a patient partner in research

A PP was involved in the whole research process adding deeper meaning and relevance to the study. In the planning phase, the PP affirmed the importance of the research question, reviewed the questionnaires used in the study, gave feedback regarding feasibility to answer the questionnaires after participating in SOASP, estimated the time needed to answer them and commented on the proposed data collection methods. When analysing and interpreting data, the PP was consulted to see if she interpreted the results in the same way as the research team. Results and implications were validated by the PP, who also added new perspectives based on experiential knowledge of living with OA. Moreover, the PP offered valuable suggestions for future research. Engaging a PP in research was not common in Sweden when planning the studies in 2015 and there were not many PPs with adequate education available at the time. We believe that our study became more patient-centred since we involved a PP who added valuable feedback and advice in all stages of the study process. In future studies, we hope to incorporate more than one PP since we believe that it would enhance the research process considerably.

Methodological considerations

Strengths

One of the main strengths of this thesis is that both patients′ and PTs′ perspectives on SOASP are highlighted. Increased knowledge and a deeper understanding of experiences of SOASP from these perspectives are important to secure quality of care and to enable further development, evaluation, and treatment of the programme. Since there are few studies on differences between men and women in outcome after SOASP, and on patient enablement and empowerment after SOASP, this thesis can be a basis for further research in this context. Moreover, the lessons learned from our interview study on PTs′ experiences of SOASP and of implementation of guidelines, might be useful when developing the SOASP and planning implementation interventions for guidelines in PHC in the future.

Using national quality registry-based data from the BOA registry that collects PROMs to enable evaluation of first-line treatment for OA, enabled us to use a large study cohort based on a geographically diverse data collection from most parts of Sweden (paper I). Data was originally collected in clinical practice, independently from our research questions. The large study cohort increased power of our study. Another strength with registry-based data is that it enables prospective studies using data collected during several years, and that it is less time consuming, since data has already been collected [251]. Moreover, only data with complete paired data, i.e., from baseline and follow-up at three and 12 months respectively, were included in the analyses.

There were few missing data in studies II and III (papers II–III) and therefore no imputation was needed. Data was collected by PTs in clinical practice, experienced and used to collecting PROMs when offering the SOASP, and since the distribution of our questionnaires were added to the routine this might explain the small amount of missing data. Enablement and empowerment have not been studied in connection to SOASP before. Hence, our studies form a basis for further research in this context. The collaboration with a PP from the Swedish Rheumatism Association enhanced the patient perspective throughout the research process, from the planning phase to the analyses, and added deeper meaning and relevance to our studies.

In the interview study (paper IV), we chose QCA as method since we found it appropriate for the study. The method is flexible and enabled us researchers to explore differences and similarities of experiences among the interviewed PTs. There was also extended experience and knowledge about using the method within the research group. Qualitative Content Analysis includes both descriptions of the manifest content, i.e., close to the text, and interpretations of the latent content, i.e., distant from the text but still close to the participants′ lived experience [224]. The methodological approaches can be deductive (concept driven), inductive (data driven) or abductive (a combination of deductive and inductive) [224]. We used an inductive approach. There are some challenges when using an inductive approach such as avoiding superficial interpretations and descriptions, and overall summaries [224].

Several steps were taken to ensure trustworthiness in the interview study (paper IV) [252]. *Credibility* is about how well data and process of analysis address the focus of the research and was achieved by recruiting PTs with experience of the studied phenomenon. The PTs represented a variation of clinical work experience as well as experience in SOASP, and included both men and women, as well as public and private PHC. An illustration of meaning units, codes and categories was presented to facilitate for the reader to assess credibility. Moreover, quotes were presented to enable assessment of similarities within and differences between categories without possibility to identify the PTs. *Confirmability* and *dependability* were addressed by including several experienced researchers in the analysis process, critically discussing, and reviewing different interpretations until consensus was achieved. *Dependability* was also taken in consideration when deciding which researchers were to conduct the interviews. Since the first author (KSÅ) had pre-understanding of the studied phenomenon, two co-researchers conducted the interviews. The process of analysis went back and forth, data was read several times and the process was thoroughly described. *Transferability* refers to whether the findings can be applied to other settings, and it is up to the reader to decide if it is achieved or not. To facilitate transferability, a clear thick description of the context, recruitment of participants, data collection and process of analysis was reported to increase the ability for the reader to decide whether the result was applicable to other situations, groups, or contexts. The software programme, NVivo, was used in the analysis which we believe supports and ensures quality in the analysis process. Moreover, the study was reported in accordance with the checklist of Consolidated Criteria for Reporting Qualitative Research (COREQ) [197].

Limitations

There are some limitations in this thesis. All participating patients and PTs were Swedish speaking making respective samples rather selected and homogenous. The observational design of studies I–III (papers I–III), entails some issues to consider when interpreting the results. The lack of control groups means that no casual inferences can be made. There is also a risk of recall bias when patients answer the PROMs, and it is not known how well they understand the questions. Moreover, confounders not known to the researchers might have impacted the study process and the results.

In study I (paper I), the questions about PA and exercise follows the recommendation from the National Board of Health and Welfare in Sweden and have been changed over the years. The questions used between 2008 to August 31, 2012, were more general than the questions used since September 1, 2012, which make them difficult to compare. The middle values were chosen when the minutes of physical activity were added together with the minutes of exercise and some values might have been either over- or underestimated.

In study I (paper I), we only analysed the EQ-5D-3L´s descriptive part, which is not advisable since it is a two-part instrument [207]. In retrospect, we should have included an analysis of the EQ VAS.

In studies II and III (papers II–III), data was collected in clinical practice and blinding was not possible. According to routine, questionnaires to be reported in the BOA registry are distributed by the PT engaged in the SOASP, but not necessarily by the treating PT. For practical reasons, distribution of the questionnaires used in these studies, EQ-5D, the SWE-RES-23 and the PEI, was added to this routine. Additionally, distributing questionnaires after the educational sessions of the SOASP was added to the routine. These pragmatic choices were driven by following usual practice as much as possible.

It was not possible to report how many patients in all who were asked but declined to participate in the studies (papers II–III). Participating PTs responsible for data collection informed us that there were various reasons for missing data after the educational part of the SOASP (paper II). In everyday clinic work situations, various PTs were sometimes responsible for the different sessions of the SOASP and the person responsible for administrating the questionnaires was not always aware of having to do so.

We have no absolute information about potential local variations of the SOASP in either of the studies (papers I–III) regarding number of educational sessions offered, or which health professionals were engaged in the SOASP. Potential local differences in offering the SOASP might be a confounder, possibly affecting patients positively and/or negatively.

We did not analyse the potential impact of comorbidities on the results of our studies (papers I–III). It is known that comorbidities have a negative effect on HRQoL for patients with OA [253] and future studies should take that into account. Moreover, subgroup analyses on hip and knee, were not possible due to groups being too small (papers II–III). A review published in 2022, highlighted differences between hip and/or knee OA [254]. Treatment guidelines for hip and knee OA are mainly based on research on knee OA [107-109]. Another recently published study on data from the Danish equivalent, GLA:D®, of the BOA registry concluded that patients with hip and/or knee OA were more alike than different, as both achieved improvements after treatment, and should be equally prioritised for first-line treatment such as patient education and exercise [255]. It is not known if subgroup analyses of hip and knee OA in our studies would have led to different results.

Conclusions

This thesis contributes with knowledge about SOASP as delivered in clinical practice in PHC in Sweden, based on patient-reported outcomes and physiotherapists experiences.

There were differences between men and women before and after participating in SOASP. More men increased their physical activity during the SOASP. More women were physically active ≥ 150 activity minutes/week at baseline and at 12 months follow-up, even though more women also reported lower HRQoL at all measuring points. These differences should be considered when planning for how to support men and women with hip and/or knee OA to maintain or even increase PA and HRQoL in the long term.

Patients reported moderate to high enablement and empowerment and an increase in empowerment after participating in SOASP, which might indicate that the SOASP is useful to enable and empower patients with hip and knee OA, at least in the short term. Since our results showed that the PEI and the SWE-RES-23 and are only partly related, both instruments can be of use in evaluating interventions such as SOASP depending on the outcome of interest.

There was an increase in HRQoL for patients with OA after participating in SOASP. Moreover, enablement and empowerment, measured with the PEI and the SWE-RES-23 respectively, could not predict change in HRQoL among patients participating in SOASP.

The PTs believed in the guidelines and were confident in providing first-line treatment to patients with OA. Still, there was room for improvement. The SOASP did not suit all patients and therefore an individualisation of treatment for OA patients was sometimes needed. Moreover, compliance to guidelines could be increased, since not all health care providers followed them. Hence, there is a need to repeat information about the guidelines to all health care providers and management. We believe that data from the national quality registry, BOA, could probably be used to a greater extent in daily clinical work in PHC for continuous learning and evaluation and to improve quality of care for OA patients.

Clinical implications

Men might benefit more than women from participating in a SOASP, when it comes to PA, at least in the short term (baseline to three months). The differences between men and women imply a need to individualise the SOASP, and that booster sessions might be required.

Even though the main objective of the SOASP is to support patients´ ability to cope and self-manage their disease, this is not routinely evaluated after participating in the programme today. We find it important to evaluate patient enablement and empowerment after participating in SOASP and suggest using the PEI and/or the SWE-RES-23, together with the PROMs that are used currently. We believe that involving a PP in the study process, from the planning phase to the interpretation of the results, enhances the constructive learning experience of health care professionals and researchers, and we highly recommend other researchers to incorporate a PP in their studies.

In contemporary practice patients included in SOASP today might not be representative of the average patient with OA, and therefore more effort should be made to reach out to struggling patients with OA who may be less motivated and especially in need of support. More research is needed to identify OA patients with greatest need for additional support, and to find outcome measures to predict outcome for OA treatment.

Future research

- A challenge for future studies is to develop strategies to identify people with hip and/or knee OA who are insufficiently physically active and/or report low HRQoL, preferably early in the disease development, and to find efficient strategies to support, and enable them to maintain or even increase their level of PA in the long term. More research is also needed to study what factors affect differences between men and women in outcome of SOASP.
- Today, enablement and empowerment are not routinely evaluated in relation to SOASP, and the PEI and the SWE-RES-23 could possibly be used in the clinic to ensure evaluation of these relevant outcomes. However, more research is needed before it can be concluded which of the two outcomes is the most relevant to measure in this context.
- In the future, it would be interesting to study the time relationship between diagnosis and self-reported enablement and empowerment.
- Three months follow-up is a short time when it comes to a chronic disease like OA, and it would be interesting to follow the development of enablement and empowerment after participating in a SOASP over the long term. In the future, it would also be interesting to study those who report lower values on the PEI and the SWE-RES-23 more closely, since it might be important to identify these patients as early as possible to optimise the support and care.
- An even further longitudinal perspective on all the PROMs prior to, and after the SOASP should be taken to study the association between enablement, empowerment and HRQoL. A larger longitudinal sample would also permit subgroup analysis regarding gender, level of education, socioeconomic status, most affected OA joint, and BMI.
- It would be interesting to explore the patients´ perspective on the SOASP as it is delivered today and also explore the reasons behind patients´ choice to decline participation in SOASP.

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