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A Multi-Method Analysis of the Cultural, Sociodemographic and Economic Elements in Osteoarthritis Care

### **SIMONE BATTISTA**

DINOGMI | SCHOOL OF MEDICAL AND PHARMACEUTICAL SCIENCES | UNIVERSITY OF GENOVA ORTHOPAEDICS | CLINICAL SCIENCES | FACULTY OF MEDICINE | LUND UNIVERSITY



# Joint Degree of *Doctor of Philosophy* (PhD) in: *Neurosciences* – Motor and Sports Activities Sciences



A Multi-Method Analysis of the Cultural,

Sociodemographic and Economic Elements in Osteoarthritis Care

Medical Science



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Title: A Multi-Method Analysis of the Cultural, Sociodemographic and Economic Elements in Osteoarthritis Care

#### Abstract:

**Background:** Osteoarthritis (OA) quality of care is influenced by various cultural, sociodemographic, and economic elements that shape the context in which first-line interventions are implemented. This thesis aims at providing insights to improve OA care quality by analysing the role of healthcare professionals' knowledge and adherence to clinical practice guidelines and patients' sociodemographic (e.g., sex and age) and economic factors (e.g., income), and their experience and beliefs of OA care, through four studies.

**Methods:** The four studies analysed: 1) physiotherapists' knowledge of and adherence to OA clinical practice guidelines (survey-based study in Italy); 2) patients' experience of the OA care process (qualitative study in Italy); 3) association between demographic, socioeconomic and disease-related factors and exercise adherence in OA (register-based study in Sweden); 4) income inequalities in people attending an OA first-line intervention and whether these inequalities changed after attending it (cohort study in Sweden).

**Results:** Study 1 revealed that Italian physiotherapists knew but did not always apply first-line interventions. Study 2 suggested that people with OA experience an uncertain care process due to the lack of clear explanations, resulting in a negative attitude towards first-line interventions. Study 3 found associations between exercise adherence and age, sex, socioeconomic status, disease severity and self-efficacy. All the investigated factors explained 1% of the exercise adherence variability. Study 4 indicated income inequalities among participants to an OA first-line intervention that widened after it.

**Conclusion:** Several areas in the OA care process require attention. Physiotherapists must bridge the gap between their knowledge of and adherence to OA clinical practice guidelines. Patients need to be guided throughout their care process to be more empowered. Further studies on the factors associated with OA exercise adherence are necessary. Finally, we need to address inequalities in OA care, prioritising upstream interventions.

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Paper 1 <sup>(a)</sup> by the Authors Paper 2 <sup>(a)</sup> by the Authors Paper 3 <sup>(a)</sup> by the Authors Paper 4 <sup>(a)</sup> by the Authors (Unpublished manuscript)

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### Dedication

"Let everything happen to you Beauty and terror Just keep going No feeling is final"

- Rainer Maria Rilke

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### Abstract

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## Popular Science Summary

Patients' quality of care does not depend only on healthcare professionals' knowledge and skills. It also depends on what the patient thinks and wants and the context they are in. Osteoarthritis is the most common joint disease worldwide. Still, only 40% of the patients receive first-line interventions (exercise, education on self-management strategies and diet). This poor care quality can result from cultural, sociodemographic and economic reasons belonging to the healthcare professionals and the patients.

Therefore, we investigated Italian physiotherapists' knowledge of and adherence to osteoarthritis evidence-based intervention with a web survey. Physiotherapists seemed to know the importance of adopting an evidence-based intervention, but they did not always use it in practice. Then, we interviewed patients to understand their beliefs about osteoarthritis. Patients reported exercise as a way to pass the time until they could have surgery. Moreover, they highlighted that healthcare professionals refrained from explaining the role of evidence-based interventions in osteoarthritis care.

Finally, we analysed the 'Swedish Osteoarthritis Registry' (SOAR), with data from approximately 200,000 people with osteoarthritis who attended a first-line intervention in different Swedish hospitals. From this register, we tried to understand if the demographic (e.g., sex and age), lifestyle (e.g., hours of physical activity per week), socioeconomic (e.g., income), and disease-related (e.g., pain intensity) factors could influence adherence to exercise. Furthermore, we tried to understand if people from lower socioeconomic backgrounds experienced more severe symptoms and less benefit from this Swedish osteoarthritis intervention. The factors we investigated in the SOAR influenced only minimally exercise adherence. On top of that, people from lower socioeconomic backgrounds seemed to experience less benefit from the intervention, resulting in a worsening of the inequality that was observed even before the intervention.

# List of Papers

#### Paper I

**Battista S**, Salvioli S, Millotti S, Testa M, Dell'Isola A. Italian Physiotherapists' Knowledge of and Adherence to Osteoarthritis Clinical Practice Guidelines: a Cross-Sectional Study. BMC Musculoskelet Disord. 2021. 22:380. doi: 10.1186/s12891-021-04250-4

#### Paper II

**Battista S**, Manoni M, Dell'Isola A, Englund M, Palese A, Testa M. Giving an account of patients' experience: A qualitative study on the care process of hip and knee osteoarthritis. Health Expect. 2022, 1-17. doi: 10.1111/hex.13468

#### Paper III

**Battista S**, Kiadaliri A, Jönsson T, Gustafsson K, Englund M, Testa M, Dell'Isola A. Factors Associated with Adherence To a Supervised Exercise Intervention for Osteoarthritis: Data from the Swedish Osteoarthritis Registry. Accepted in Arthritis Care Res. 2023. doi: 10.1002/acr.25135

#### Paper IV

**Battista S**, Kiadaliri A, Jönsson T, Gustafsson K, Englund M, Testa M, Dell'Isola A. Income-Related Health Inequality and Osteoarthritis Intervention Outcomes: a Cohort Study. Under Review in Archives of Physical Medicine and Rehabilitation.

The full-texts of the papers are reported at the end of the thesis, after the acknowledgements.

# Author's Contribution to the Papers

#### Paper I

Simone Battista made a substantial contribution to the concept or design of the article, and the acquisition, analysis, and interpretation of data for the article. He drafted the article or revised it critically for important intellectual content. He approved the version to be published.

#### Paper II

Simone Battista made a substantial contribution to the concept or design of the article, and the acquisition, analysis, and interpretation of data for the article. He drafted the article or revised it critically for important intellectual content. He approved the version to be published.

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# Abbreviations

OA	Osteoarthritis
YLD	Years Lived with Disability
NSAIDs	Non-Steroidal Anti-Inflammatory Drugs
CPG	Clinical Practice Guidelines
SEP	Socioeconomic Position
BMI	Body Mass Index
HRQoL	Health-Related Quality of Life
RMD	Rheumatic and Musculoskeletal Diseases
NICE	National Institute for Health and Care Excellence
EULAR	European Alliance of Associations for Rheumatology
OARSI	Osteoarthritis Research Society International
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
COREQ	Consolidated Criteria for Reporting Qualitative Research
WHO	World Health Organisation
TJR	Total Joint Replacement
SOAR	Swedish Osteoarthritis Registry
LISA	Longitudinal Integration Database for Health Insurance and Labour Market Studies'
VAS	Visual Analogue Scale
RRR	Relative Risk Ratio

### Preface

Osteoarthritis (OA) is an inflammatory disease that can affect any joint in its whole [1-3]. It has a significant global impact [4-6], accounting for 2.2% of all years lived with disability worldwide (YLD) [5, 6]. Thus, OA is hastily becoming the third largest contributor to disability after diabetes and dementia [7]. As a result, high-income countries invest up to 2.5% of their gross domestic product in the care of OA — mostly in response to the growing demand for joint replacements — an expanse that will become unsustainable if we do not reverse this trend [8].

In this context, first-line interventions for OA — which include exercise, education and weight loss (when needed) — are safe and low-cost treatments that are at least as effective as analgesic and non-steroidal anti-inflammatory drugs (NSAIDs) devoid of their side effects [9–11]. Nonetheless, a marked discrepancy between what is known and what is translated into clinical practice remains, as only a limited proportion of people with OA receive appropriate care [12–14]. This disparity can be attributed to many factors that encompass cultural, sociodemographic, and economic influences affecting clinicians and patients. Healthcare providers' knowledge of and adherence to OA clinical practice guidelines (CPGs) are critical contributors to inadequate care [15–17]. Additionally, patient-related factors such as awareness, beliefs, and barriers to first-line interventions play a crucial role in determining the success of OA treatment [18, 19]. Further, sociodemographic and economic aspects can influence an individual's adherence to OA management strategies [20–24]. Finally, it is well established that individuals in lower socioeconomic positions (SEPs) often face inequalities in healthcare, regardless of the healthcare system [25–28].

Therefore, this thesis arises from the need to better understand how to improve the OA care process, with a focus on hip and knee, two of the most common forms of OA. To do so, we have combined different quantitative and qualitative methodologies to gain a comprehensive understanding of the cultural, sociodemographic, and economic factors that shape OA care.

### Background

### Osteoarthritis Clinical Practice Guidelines

To improve the quality of care of people with OA, different international CPGs have been developed [10, 11, 29]. All OA CPGs recommend exercise, education and diet (when necessary) as first-line interventions to reduce people's symptoms and levels of disability [10, 29, 30].

Exercise is considered a first-line intervention as it can improve people's symptoms and levels of functionality [31, 32]. Exercise has a positive local effect on the joint, improving muscle strength and balance, joint load capacity and stiffness perception [31, 32]. But exercise has shown benefits beyond joint health [33, 34]. It positively affects body weight, lipid metabolism, hyperglycaemia, mood and systemic inflammation [32, 35, 36]. However, people with OA struggle with meeting the recommended levels of exercise [37–39].

The role of diet in managing OA among those overweight is getting more and more attention [40, 41]. Elevated high body mass index (BMI) has been associated with low-grade systemic inflammation, higher biomechanical overload and increased symptoms of OA [40, 41]. Therefore, weight reduction can positively impact joint health by reducing the biomechanical load and restoring functional inflammation response, particularly when combined with exercise [42]. Additionally, OA is frequently accompanied by comorbidities such as metabolic syndromes and type-2 diabetes [41]. Thus, dietary management of these conditions (preventive or curative) is crucial [41]. However, maintaining optimal or losing weight can be challenging, especially for those with impaired mobility [43].

To achieve optimal health outcomes, people with OA must integrate exercise and diet into their lifestyles as part of their self-management approach. Moreover, first-line interventions are always recommended due to their positive impact on symptoms and OA-related comorbidities, regardless of the severity of the disease [44].

### Symptoms and Comorbidities

In OA, pain is the most common symptom [45, 46]. People with OA tend to feel intermittent but severe or constant background pain [47, 48]. The former has the most significant impact on people's health-related quality of life (HRQoL), is typical of OA early stages and is triggered by specific activities [46]. The latter tends to be present in the middle stages of OA, typically at night [46]. People with advanced stages of OA feel a combination thereof compounded by episodes of unpredictable pain [49]. These wide varieties of pain responses suggest the presence of different pain phenotypes associated with OA [50].

The pathogenesis of pain seems to be multifactorial and stems from several mechanisms: 1) joint nociception (structural changes, inflammation, neovascularisation, new nerve growth) [51–53]; 2) peripheral sensitisation (neuronal hyperexcitability) [54, 55]; 3) central sensitisation (pain hypersensitivity in the spinal cord and brain, dysfunction of ascending and descending pain pathways) [56]; 4) types of pain mechanisms (nociceptive, inflammatory and neuropathic); 5) chemical mediators (cytokines, TRPV1, NGF, serotonin, TNF, substance P) [46, 57]; 6) contextual aspects (psychosocial, economic and cultural factors) [58, 59]. Nevertheless, the pain mechanisms of OA are still enigmatic, and further research is needed [60].

Additionally, people with OA may experience other physical symptoms such as stiffness, reduced function (e.g., walking difficulties), joint instability, reduced movement, swelling, deformity and crepitus [45]. One out of two people with knee or hip OA has other rheumatic and musculoskeletal diseases (RMD), such as low back pain, arthropathies, and synovial and tendon disorders [61–63]. Beyond physical functions, OA also has negative impacts on mental health. People with OA experience a broader array of symptoms that profoundly impacts their life, including low mood [64], depression [65], and poor-quality of sleep [66]. Finally, 67% of people with OA have at least one other chronic condition [61, 67]. In their systematic review, Hall *et al.* found that approximately 40% of people with OA concurrently have cardiovascular diseases [68]. Furthermore, metabolic conditions such as obesity, diabetes, hypertension, and dyslipidaemia are more prevalent in people with OA than those without it [69].

Therefore, the care process of hip and knee OA must encompass a holistic approach that considers the various aspects of an individual's life that this condition may impact. It is imperative to address not only the affected joints but also to take into account the various spheres of a person's life that may be affected, such as physical function, and overall health.

### Care Process

By implementing a high-quality and holistic care process, healthcare providers can ensure that individuals with hip and knee OA receive the most effective treatments, achieving optimal outcomes and improved HRQoL [70]. However, Basedow et al. found the quality of OA care to be suboptimal in all treatment domains [12]. The authors analysed its quality through various indicators gathered from multiple sources such as medical records, patient questionnaires and interviews, and administrative databases and expressed with pass-rate scores [12]. First-line interventions (i.e., exercise, education and diet) achieved the lowest pass-rate scores [12].

Therefore, to improve the quality of the OA care process, it is essential to investigate and address the factors that can impact it. Other than the efficacy of the treatments *per se*, different cultural, sociodemographic, and economic factors that are specific to clinicians and people with OA might play a role in this matter (Figure 1).

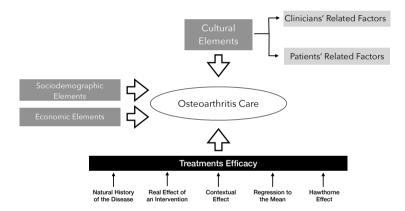


Figure 1 Factors affecting the OA care process

As far as clinicians are concerned, their knowledge of and adherence to OA CPGs represent one of the critical points to providing people with OA with proper care. When it comes to patients, their awareness, beliefs and barriers to first-line interventions represent additional factors that can hinder or improve adherence to first-line interventions. As these treatments are lifestyle interventions, people with OA must be aware of their importance and integrate them into their daily routines. Also, people's sociodemographic and economic elements may influence their adherence to OA first-line interventions such as exercise. Finally, people in lower SEP experience inequalities in healthcare, no matter the healthcare system (public or private). Healthcare interventions addressing behavioural changes (e.g., exercise) can even widen these inequalities ('intervention-generated' inequalities).

### Aims

This PhD project aims at understanding how different cultural, sociodemographic and economic elements can influence OA care process through four papers. As per the cultural elements, **Study 1** analysed Italian physiotherapists' knowledge of and adherence to OA CPGs (cross-sectional survey-based study in Italy). **Study 2** explored the experience of OA care process giving an account of those who live it first-hand i.e., people with OA (qualitative study based on semi-structured interviews). As per the sociodemographic and economic elements, **Study 3** investigated the associations between demographic, socioeconomic and disease-related characteristics with exercise adherence in OA (register-based study in Sweden). **Study 4** investigated intervention-generated income-related inequalities in a Swedish OA first-line intervention (cohort study in Sweden).

# Cultural Elements

Clinicians' knowledge of and adherence to OA CPGs represent one of the main issues in providing people with OA with proper care. Physiotherapists are one of the main healthcare professionals involved in OA care. However, implementing CPGs for RMD appears suboptimal among physiotherapists [71]. Therefore, Study 1 examined the knowledge of and adherence to OA CPGs in a cohort of Italian physiotherapists.

Patients' expectations, beliefs and emotions revolving around their care process represent other factors that can hinder or improve their adherence to first-line interventions [18, 19, 72–75]. People with OA must be aware of the importance of these interventions and learn how to integrate them into their daily routines. In OA, efforts to assess and understand patients' experiences of the care process could help policymakers foster improvements in healthcare providers' interpersonal aspects and patients' expectations of how healthcare should be delivered [74]. Therefore, study 2 explored people's experience of the OA care process.

### Study 1: Italian Physiotherapists' Knowledge of and Adherence to Osteoarthritis Clinical Practice Guidelines: a Cross-Sectional Study

#### **Background and Rationale**

#### Clinical Practice Guidelines: Meaning and Application

CPGs are "statements that include recommendations intended to optimise patient care. These statements are informed by a systematic review of evidence and an assessment of the benefits and costs of alternative care options" [76]. In the last few decades, several OA CPGs have been released by the European Alliance of Association for Rheumatology (EULAR), Osteoarthritis Research Society International (OARSI) and the National Institute for Health and Care Excellence (NICE) [10, 11, 29]. These CPGs recommend exercise and education as first-line interventions, no matter the severity of the disease [77, 78]. However, OA is often under-treated and underdiagnosed, hindering its care process [12–14, 79]. Egerton et al. highlighted that clinicians who work with people with OA perceived themselves as under-prepared and unfamiliar with CPGs [80].

#### Physiotherapists' Attitudes to Clinical Practice Guidelines

Physiotherapists are paramount in the OA care process due to their unique training in exercise regimen prescription. However, implementing CPGs for RMD appears suboptimal among physiotherapists [71]. RMD care is complex as clinicians are called to balance knowledge of the best evidence with patients' preferences and beliefs [81–83]. This issue is compounded by several barriers, such as clinical applicability, English language knowledge and lack of time to retrieve and read evidence [81–84]. Zooming in on OA CPGs, similar results were found on the knowledge of and adherence to CPGs [85–89]. However, these studies are inconclusive. They only examined the knowledge of and adherence to CPGs in isolation [86–89] or solely focused on specific treatments (e.g. therapeutic exercise) [90]. Thus, analysing the knowledge of and adherence to CPGs in the same cohort would allow for a better understanding of the so-called *evidence-to-practice gap* [81], which, if unaddressed, can lead to suboptimal care for people with OA [91].

#### What Do We Know about OA Management in Italy?

Italy is a large southward Mediterranean country with the most significant proportion (21.4%) of older adults (aged>65) in Europe [92]. From 2001 to 2016, 812,639 total knee replacements were performed on people over 40 in Italy. The total number of surgeries increased by 262%, with an average annual growth rate of 6.6% and an increase of 45% in incidence rate is expected by 2050 [93]. This data suggests the urge

to understand how OA is treated in Italy. Moreover, gathering information from this country might allow for our results to be generalised to other Mediterranean countries, which appeared to have higher educational needs than the Northern-European ones regarding RMD management [94]. Thus, we conducted this study to explore the knowledge of and adherence to OA CPGs among Italian physiotherapists to identify the possible existence of an evidence-to-practice gap in OA interventions.

#### **Study Design**

We carried out a web-based cross-sectional study investigating Italian physiotherapists' knowledge of and adherence to OA CPGs. We decided to use a web survey as they are a valuable resource for understanding people's cultural contexts outside of an experimental setting in a real-world scenario [95]. We created the survey using the 'International Handbook of Survey Methodology', one of the most central guides for survey creation [96]. Finally, we reported our study following the 'Checklist for Reporting Results of Internet E-Survey' and the 'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) recommendations for reporting observational studies [97, 98].

We based this survey on the EULAR, OARSI and NICE guidelines [10, 11, 29]. The survey was delivered in Italian and divided into two sections investigating (1) the knowledge of and (2) the adherence to OA CPGs, respectively. Before the first section, we included questions investigating the physiotherapists' sociodemographic factors (e.g. sex, age, years of experience) and whether they had read any OA CPG. The last draft of the questionnaire was tested for clarity on a sample of six physiotherapists specialised in RMD rehabilitation, and no significant changes were made.

We delivered the online survey through Microsoft 365 Forms, as it is a secure web application to build and manage online surveys and databases, respecting the European General Data Protection Regulations [99]. In the beginning, the questionnaire read a brief cover letter and the informed consent outlining the aim of the study. The cover letter emphasised that participation in the survey was voluntary and that anonymity and confidentiality were guaranteed. Our study followed the 'Declaration of Helsinki' and granted by the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (approval date: 15/06/2020; CERA2020.07).

#### **Participants and Recruitment**

We delivered the online questionnaire through the Italian Association of Physiotherapists (AIFI) and the newsletter of the 'RMD rehabilitation' post-graduate degree of the University of Genova newsletters. Using the latter newsletter might have led to possible 'sampling error' as these physiotherapists received thorough training in RMD rehabilitation. To be included, physiotherapists had to treat at least one person with OA in the six months before the questionnaire. A preliminary question on the survey assured this eligibility criterion. Those who flagged 'No' could not partake in the other part of the questionnaire. Hence, we reached 822 physiotherapists between June and July 2020 (Table 1).

Age (years)(mean,(SD))	35.77 (13.3)	
Assigned sex (at birth) (female) (N (%)):	387 (47)	
Years of practice (N (%)):		
Less than 1 year	87 (11)	
From 1 to 5 years	319 (39)	
From 6 to 10 years	149 (18)	
More than 10 years	267 (32)	
Post-graduate degrees (N (%))*:		
I Level Master Degree†	382 (47)	
Master of Science (MSc)/II Level Master:	122 (15)	
Doctor of Philosophy (PhD)	36 (4)	
Others	282 (34)	

Table 1 Participants' demographic characteristics

Legend: N, number; %, percentage; \*, Percentages calculated based on the highest Post-Graduate Degrees achieved; †, Academic degree that can be gained after BSc (Italian education system); ‡, Academic degree that can be gained after MSc (Italian education system).

#### Italian Physiotherapists' Knowledge

To test Italian physiotherapists' knowledge, participants expressed agreement with 24 CPG statements through a 1 (completely disagree) to 5 (completely agree) Likert scale (Table 2). Participants who wholly or partially agreed (scores 4–5) were considered to agree with the statements. However, we added eleven reversed statements to avoid any possible acquiescence bias (i.e. the tendency to agree with all the survey statements) [100]. In this case, disagreement with reversed statements (scores 1–2) would indicate an agreement with the CPGs. Without a standard threshold, we defined a  $\geq$  70% agreement with a statement as consensus [15, 84, 101, 102]. The frequencies of answers were calculated, and a visual representation through a bar chart graph was reported.

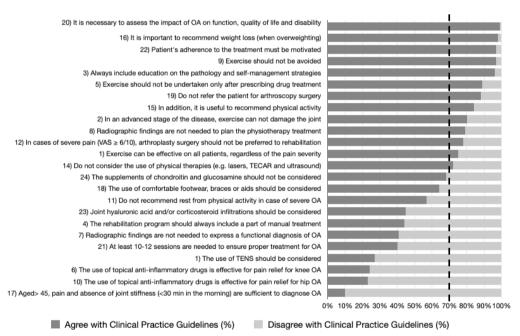
	Statements	<b>Clinical Practice Guidelines</b>		
1)	Exercise can be effective on all patients, regardless of the pain severity.	NICE (1.2.5-1.4.1); EULAR (3-6-7);		
2)	In an advanced stage of the disease, exercise can damage the joint (reverse statement).	NICE (1.2.5-1.4.1); EULAR (2-3-6-7);		
3)	The rehabilitation programme must always include a part of education on the pathophysiology of osteoarthritis and self-management strategies.	NICE (1.3.1-1.3.2-1.3.3); EULAR (3-5); OARSI (tables 2-3)		

#### Table 2 Statements derived from OA CPGs

4)	The rehabilitation programme should always include a part of manual treatment ( <b>reverse statement</b> )	NICE (1.4.2); EULAR (-); OARSI (-)
5)	Exercise should only be undertaken after prescribing drug treatment to control pain ( <b>reverse statement</b> ).	NICE (1.2.5-1.4.1); EULAR (3-6- 7);
6)	The use of topical anti-inflammatory drugs is effective for pain relief for knee osteoarthritis.	NICE (1.5.3); EULAR (-); OARSI (table 2)
7)	Radiographic findings are needed to express a functional diagnosis of osteoarthritis (reverse statement).	NICE (1.1.1); EULAR (1); OARSI (-)
8)	Radiographic findings are needed to plan the physiotherapy treatment ( <b>reverse statement</b> ).	NICE (1.1.1); EULAR (1); OARSI (-)
9)	Physical activity should be avoided because it can damage the joint (reverse statement).	NICE (1.2.5-1.4.1); EULAR (3-6-7);
10)	The use of topical anti-inflammatory drugs is effective for pain relief for hip osteoarthritis.	NICE (-); EULAR (-); OARSI (-)
11)	In case of severe joint degeneration, it is necessary to recommend rest from physical activity (reverse statement).	NICE (1.2.5-1.4.1); EULAR (2-3- 6-7);
12)	In cases of severe pain (VAS $\ge 6/10$ ), arthroplasty surgery should be preferred to rehabilitation ( <b>reverse statement</b> ).	NICE (1.6); EULAR (-); OARSI (- )
13)	The use of TENS should be considered.	NICE (1.4.4); EULAR (-); OARSI (-)
14)	The use of physical therapies such as lasers, TECAR and ultrasound therapy should be considered ( <b>reverse</b> statement).	NICE (1.4.4); EULAR (-); OARSI (-)
15)	In addition to the rehabilitation treatment, it is useful to recommend physical activity (for example, yoga, swimming, Nordic walking).	NICE (1.2.5-1.3.2-1.4.1); EULAR (-);
		OARSI (tables 2-3)
16)	It is important to recommend weight loss to overweight or obese patients.	NICE (1.2.5-1.4.3); EULAR (3-8); OARSI (tables 2-3)
17)	Age> 45, pain and absence of joint stiffness (or <30 min)	
	in the morning are sufficient to diagnose osteoarthritis.	NICE (1.1.1); EULAR (-); OARSI (-)
18)	The use of comfortable footwear, braces or aids should be considered.	NICE (1.3.2-1.4.7-1.4.8-1.4.9); EULAR (3-9-10); OARSI (tables 2-3)
19)	It is advisable to refer the patient for arthroscopy surgery to reduce symptoms and start/continue treatment ( <b>reverse</b> statement).	NICE (1.4.10); EULAR (-); OARSI (-)
20)	It is necessary to assess the impact of osteoarthritis on function, quality of life and disability.	NICE (1.2.1); EULAR (1); OARSI (-)

21)	At least 10-12 sessions are needed to ensure proper treatment for osteoarthritis.	NICE (1.4.1); EULAR (6); OARSI (-)
22)	In the treatment for osteoarthritis, the patient's adherence to the treatment must be motivated.	NICE (1.3.2-1.4.1-1.7.1); EULAR (-); OARSI (-)
23)	Joint hyaluronic acid and/or corticosteroid infiltrations should be considered.	NICE (1.5.12-1.5.13); EULAR (-); OARSI (table 2)
24)	The supplements of chondroitin and glucosamine should be considered (reverse statement).	NICE (1.4.5); EULAR (-); OARSI (-)

A consensus was achieved for 13/24 statements (Figure 2). These statements addressed the role of clinical assessment, exercise, education, weight loss, and the effectiveness of physical therapies in OA. A consensus was not reached on the role of supplements, radiographic findings, manual therapy, topical non-steroidal drugs, TENS, the number of sessions and the criteria for clinical diagnosis.



#### Figure 2 Levels of agreement with the reported statements

\* The black dashed line represent the line of agreement

### Italian Physiotherapists' Adherence

Clinical Sconarios

To test Italian physiotherapists' adherence, participants were shown a clinical case with different interventions (Figure 3). Clinical vignettes are valuable for assessing physiotherapists' treatment adherence [103]. Participants were classified as 'Delivering' (all core treatments selected), 'Partially Delivering' (some core treatments missing) and 'Non-Delivering' (at least one selected non-core treatment), the recommended intervention, depending on chosen interventions.

Management:		
<ul> <li>Core Treatment</li> <li>Evaluation and planning of the rehabilitation treatment;</li> <li>Weight loss advice.</li> </ul>	<ul> <li>Partially Core Treatment</li> <li>Referral to the physician for drug therapy.</li> </ul>	<ul> <li>Non-Core Treatment</li> <li>Referral to the physician for arthroscopic surgery (joint debridement);</li> <li>Referral to the physician for prosthetic intervention.</li> </ul>
Assessment:		
<ul> <li>Assessment of the quantity and quality of pain;</li> <li>Assessment of the function;</li> <li>Assessment of disability and participation.</li> </ul>		
Freatment:		
<ul> <li>Core Treatment</li> <li>Specific exercise on the joint (muscle strengthening);</li> <li>Generic exercise (aerobic exercise or generic physical activity);</li> <li>Education on the pathophysiology of osteoarthritis.</li> </ul>	<ul> <li>Partially Core Treatment</li> <li>Manual therapy (mobilisation and/or massage);</li> <li>TENS;</li> <li>Load reduction devices (braces, insoles or walking aids);</li> <li>Hyaluronic acid and corticosteroid injections.</li> </ul>	<ul> <li>Non-Core Treatment</li> <li>Activity rest (reduce the load on the joint);</li> <li>Other physical therapies (Laser, Ultrasound etc.);</li> <li>Supplement integration: glucosamine and chondroitin.</li> </ul>

Figure 3 Clinical case scenario

We classified the interventions as 'core treatment, 'partially core treatment', and 'noncore treatment' following OA CPG grading (Figure 4) [10, 11, 29, 104]. This grade is based on the level of evidence that CPGs attribute to each treatment combined with interventions' benefits and harms, patients' and clinicians' values and preferences and resource implications [105]. As we can see, exercise, education and weight loss are considered by all CPGs as 'strongly recommended' (core treatments). However, not the same happened for the other treatments where disagreements are present. For these treatments, the most updated CPG was considered to develop the questionnaire.

Treatments	OARSI (2019)		NICE (2016)		EULAR (2013)	
Non-Pharmacological Treatments	Hip	Knee	Hip	Knee	Hip	Knee
Physical Activity		$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Patient Education		$\bigcirc$	$\bigcirc$	0	$\bigcirc$	$\bigcirc$
Weight Loss	Ō	Ō	Ō	Ō	Ō	Ō
Manual Therapy			Ŏ	Ŏ		
СВТ						
TENS						
Orthosis and Aids						
Tai-Chi	0	$\bigcirc$				
Yoga		$\bigcirc$				
Acupunture						
Pharmacological Treatments						
Oral NSAIDs					$\bigcirc$	
Topic NSAIDs					$\circ$	
Joint Supplements						
Hyaluronic Acid Injection		Ŏ	Ŏ	Ŏ		
Glucocorticoid Injection						
Surgical Treatments						
Total Joint Replacement						
Debridment						

#### Figure 4 CPG position on OA interventions

Legend: OARSI, Osteoarthritis Research Society International; NICE, National Institute for Health and Care Excellence; EULAR: European Alliance of Association for Rheumatology; White dot: strongly recommended; Grey dot: partially recommended; Black dot: partially or strongly not recommended.

Based on their answers, 25% of the participants were classified as 'Delivering', 22% as 'Partially Delivering' and 53% as 'Non-Delivering'. The 'Delivering' group provided the patient with all the CPGs' recommended treatments. Only half delivered weight loss advice in the 'Partially Delivering' group. Most of the sample assessed functionality, disability, participation, and pain and offered muscle-strengthening exercises and education. About half of the group prescribed general exercise (e.g., aerobic exercise and general physical activity). Finally, in the 'Non-Delivering Group', most participants advised load reduction (rest) and other physical therapies (e.g., ultrasound and laser) not recommended by CPGs.

### Study 2: Giving an Account of Patients' Experience: A Qualitative Study on the Care Process of Hip and Knee Osteoarthritis

#### **Background and Rationale**

#### The Care Process

The expression of care is a fundamental aspect of human ontology, as individuals are interdependent on one another [106, 107]. Care is rooted in human anthropology, and Benedetti views the care process as a "ritual" performed around the patient, encompassing their intricate psychosocial context [108]. Positive beliefs, expectations, and emotions experienced by patients around the care process can amplify the specific effect of treatments [59, 108, 109]. Conversely, once negative beliefs, expectations and emotions step in, they can hinder patients' progress.

#### Understanding Patients' Experience

More and more efforts have been put into assessing and understanding patients' experience of their care process, focusing on their expectations, beliefs and emotions around their healthcare [74]. Through this, researchers and health-policy makers can collect significant evidence on how to improve patients' care process, starting from the experience of those who live it first-hand. Qualitative studies are considered the optimal study design for investigating people's experiences and understanding their perspectives on a given topic, as they provide an in-depth exploration of the subject matter [110].

With regards to the Italian healthcare system, it affords its citizens comprehensive coverage with minimal fees. However, the lack of nationally recognised CPGs for the management of OA by the Italian Higher Institute of Health creates an absence of standardised care processes for this condition. As a result, healthcare professionals must resort to utilising international CPGs, which we have indicated in Study 1 to have limited adherence among Italian physiotherapists [15]. Hence, this qualitative study examines people's experiences of the OA care they received within the Italian healthcare system.

#### **Study Design**

A qualitative study was conducted with semi-structured interviews analysed through a descriptive phenomenological approach. The descriptive phenomenological inquiry aims at ensuring "direct explorations, analysis, and descriptions of particular phenomena [as in this case – the care process], as free as possible from unexamined presuppositions, maximising intuitive presentation" [110–114]. The underpinning intent of the phenomenological researcher is to give voice and power to people who experienced, or

are experiencing, first-hand the phenomenon of interest as, in this instance, the care process as lived by people with OA [113]. Although we had aimed at getting a deeper understanding of the participants' experience, we must acknowledge that most of the final retrieved themes remain on a surface level of significance.

The semi-structured interview protocol was created for this study based on prior literature on OA [10, 11, 15, 18, 29, 80, 104, 115–117] and input from a diverse group of experts, including physiotherapists, psychologists, nurses, and individuals with osteoarthritis (OA). The interview guide consisted of open-ended questions exploring various aspects of the OA care process, including experiential and emotional dimensions, expectations, and beliefs. Further exploration of participants' experiences was facilitated using follow-up questions such as "Can you give me an example?" or "Can you explain what you mean by that?" At the beginning of each interview, participants were asked to provide informed consent and demographic information, such as age, gender, nationality, and living location, as well as clinical information, such as height, weight, and joint(s) affected by OA. Only the interviewer and participant were present during the interview, and no follow-up interviews were conducted. The interviews were conducted remotely and recorded via Microsoft Teams, and saved in multimedia format on a University of Genova OneDrive folder, which only researchers had access to. Then, they were transcribed, and the transcriptions were anonymised in chronological order (P1, P2 etc.). Once the transcription was over, the recordings were deleted. Ethical approval was granted by the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (approval date: 15/06/2020; CERA2020.07). The research was conducted in respect of the Declaration of Helsinki and reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) [118].

The interviews were conducted by SB. To ensure impartiality, participants were unaware of SB's professional background and had no prior close relationships with him. The interviews were performed through videoconferencing and were recorded for transcription. Both audio and visual recordings were transcribed *verbatim* and analysed by SB and MM. SB and MM are both PhD candidates, with SB trained in physiotherapy and MM in psychology. They both received training in qualitative research methodologies and identified themselves as men.

To ensure the study rigour and trustworthiness, we adopted multiple strategies. First, we documented and shared field notes ("Memos") after completing each interview to promote reflexivity [119]. Then, the research team met frequently to refine the themes and subthemes before agreeing on the final themes. Afterwards, an audit trail containing meeting notes, analysis discussions, and research decisions was continuously reorganised [119]. Lastly, a Synthesised Member Checking was performed to improve the credibility of the analysis [120]. Specifically, we provided the participants with a one-page summary highlighting the main themes and subthemes identified in the study and a plain explanation of the key findings. Thus, we asked the interviewees to send us

back any comments about the results and doubts and concerns about our findings. All participants agreed with what was retrieved, and we did not change the final themes and subthemes.

#### **Participants and Recruitment**

A purposeful sampling method was employed to attain a wide range of experiences and maximum variation [121]. Participants with hip, knee, or hip and knee OA residing in urban and suburban areas were contacted to encompass a diverse understanding of the phenomenon being studied. An alliance was formed with physicians specialised in orthopaedics, rheumatology, general practitioners, and other healthcare professionals, such as physiotherapists and nurses, to create a network for recruiting participants. Healthcare professionals were initially approached by the research team and informed about the study's objectives and data collection procedures. After obtaining their cooperation, eligible participants were informed about the study's aim, the interview process, and the confidentiality and anonymity of the data by the healthcare professionals in the network. Participants were free to withdraw from the study and encouraged to voice any questions or concerns. Only those who expressed interest in participating were personally contacted by the researcher to obtain informed consent and arrange the interview. A snowball sampling technique was also employed to reach individuals within the network of participants with OA who agreed to participate [121].

Eligible participants for this study were individuals with a physician diagnosis of hip or knee OA who could speak Italian and willing to participate. Patients reporting primary OA symptoms in joints other than the hip or knee were excluded from the eligibility criteria. The recruitment process was terminated once data saturation was achieved, as determined by the two authors (SB and MM) analysing of the interviews. The data saturation was evaluated using an inductive thematic saturation method, in which SB and MM continued to conduct interviews and analyse the data simultaneously until no new themes emerged [122]. Hence, we interviewed eleven Italian people from northern Italy (table 3).

Patient	Age	Gender	BMI	Retirement	Affected Joint(s)	Diagnosis
P1	49	М	26.3	No	Hip	X-Ray
P2	68	W	26.0	Yes	Hip and Knee	MRI
P3	73	W	27.3	Yes	Knee	X-Ray
P4	47	W	28.7	No	Hip	MRI
P5	72	W	25.8	No	Hip	X-Ray and CT
P6	55	М	34.0	No	Hip and Knee	X-Ray
P7	45	W	25.1	No	Hip	X-Ray and MRI
P8	66	М	28.7	Yes	Knee	X-Ray
P9	73	W	28.7	Yes	Knee	X-Ray
P10	65	М	24.7	No	Hip	X-Ray
P11	56	М	22.2	No	Hip and Knee	X-Ray

 Table 3 Interviewees' demographic and clinical characteristics

Legend: P, person; M, man; W, woman; BMI, Body Mass Index; OA, Osteoarthritis; MRI, magnetic resonance Image; CT, computed tomography.

#### Themes

The transcriptions of the interviews were thoroughly analysed by SB and MM. The analysis of the transcripts involved an initial independent analysis by each author, followed by a joint review. This process involved the identification of subthemes, themes, concepts, and patterns through line-by-line examination of the data, with meaning units framed into codes representing essential aspects of the participants' experiences. The emerging codes were compared with previously identified codes to provide a deeper understanding of the phenomenon of interest and to generate focused codes. The focused codes were then synthesised and merged to extract final subthemes and themes. Representative quotes were selected for each theme and reported anonymously, with the themes derived from the data and not predetermined.

Analysis of the interview data revealed seven main themes (Figure 5) related to the OA care process: 1) Experiencing a sense of uncertainty; 2) Establishing challenging relationships with the self and the other; 3) Being stuck in one's own or the health professionals' beliefs about the disease management; understanding; 4) Dealing with one's own attitudes towards the disease; Understanding 5) the facilitators of and 6) the barriers to the adherence to therapeutic exercise; 7) Developing an uneasy relationship with food. The themes (and related subthemes) are discussed and explored hereafter.

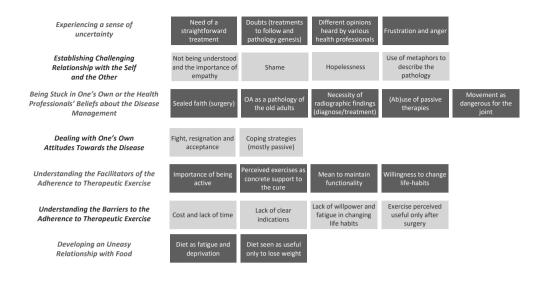


Figure 5 Themes and subthemes in a glance

### Theme 1: Experiencing a Sense of Uncertainty

The study participants shared a common perception of uncertainty regarding the care process for OA, specifically regarding the appropriate approach and treatments to take. Participants reported a lack of clear evidence-based recommendations compounded by healthcare professionals' personal biases and attitudes in the OA decision-making process.

"There is an almost religious way of thinking about how to deal with the pathology. It is not an exact science; when you choose the physicians, you choose the treatment" (P1, male, age 49)

The study participants generally lacked an understanding of the underlying causes of their disease. Despite this, they attributed the condition to factors such as overuse and poor posture, with a primarily biomechanical perspective. Additionally, the explanations given to them by healthcare professionals were perceived to be vague and unsatisfactory.

"I thought [OA] was a consequence of bad posture, as I've been using my leg wrongly after slipping on ice once." (P6, male, 55)

"They tried to explain to me how OA works somehow, but I still don't have a clear idea of how it works." (P3, female, 73)

The participants reported feeling uncertain and apprehensive about managing OA due to a lack of clear and consistent indications from healthcare professionals and conflicting opinions from various sources.

"I was worried because we, as patients, hear different opinions coming from our friends and acquaintances that give us their personal point of view on how they take care of their disease." (P9, female, 73)

As a result of their feelings of uncertainty, the interviewees sought information from multiple sources, including healthcare professionals, personal recommendations, and the Internet.

"In my experience, I've had to consult two or three physicians unless the first two agree." (P5, female, 72)

"No, the doctors did not explain it [OA] to me. But, eventually, I looked it up on the Internet and found answers to my questions." (P8, male, 66)

The participants experienced frustration and anger due to the absence of a precise treatment plan. The lack of specific indications and the presence of conflicting opinions among various sources of information led the interviewees to either neglect their condition or make decisions based on personal assumptions and instincts.

"It is very frustrating for a patient [not to have a precise indication] because you expect to have a disease, and a common one too, so the care process should be clear." (P1, male, 49)

"Eventually, I did not do anything anymore, just nothing." (P5, female, 72)

"... Yes, I would like to have a precise guideline, also regarding nutrition... It looks as if there are some things that are left to our intuition." (P2, female, 68)

#### Theme 2: Establishing Challenging Relationships with the Self and the Other

Concerning their relationship with themselves and others, the interviewees shared everyday experiences of shame and hopelessness, articulated with different nuances. The former feeling was more prevalent when the participants were in the presence of loved ones. At the same time, the latter was more pronounced due to the sense of despair conveyed by the healthcare professionals they consulted. Participants reported embarrassment stemming from exhibiting their conditions and limitations to others.

"I felt it [shame] recently. I went to the beach with my granddaughter [...] she wanted me to be involved in her games, and she said, "Grandma come, sit down next to me". I had to kneel down to play in the sand with her... I felt, how can I say... erm... like a piece of wood, like someone who can no longer manage their body." (P2, female, 68)

Additionally, the participants expressed a feeling of hopelessness regarding the prognosis they received and the belief among physicians that the condition was irreversible and would inevitably worsen.

#### "Erm.. Yes [I can only do surgery].. because I dragged it on for too long, and they told me that I have no other possibilities with other [non-surgical] interventions." (P10, male, 65)

Both shame and hopelessness were closely tied to a perceived lack of empathy from their social network and healthcare providers. Specifically, the interviewees reported that their acquaintances failed to acknowledge certain aspects of their OA (such as limping), causing them to feel ashamed of their condition.

"What annoys me the most is when people that know my condition ask me, "What did you do? Why are you limping?" This makes me really upset because others see what I sometimes don't even notice." (P1, male, 49)

Additionally, they felt they were being treated as mere numbers rather than human beings by healthcare providers, contributing to their hopelessness.

"The orthopaedic surgeon did not give me much attention, and they told me that I have OA and that I have to live with it." (P2, female, 68)

Finally, some participants expressed their self-into-the-pathology using relevant metaphors that helped them better understand their condition.

"I see it [the joint affected by OA] as a mountain which is crumbling." (P3, female, 73)

*Theme 3: Being Stuck in One's Own or the Health Professionals' Beliefs about the Disease Management* 

The interviewees held a widespread belief that resulted from their interactions with health professionals: surgery was an inevitable outcome for individuals with OA and represented a permanent and inescapable fate.

"It [OA surgery] is something you think about every day, something you try to resist, but that is your fate." (P1, male, 49)

"And so when I went to see him [the physician], he said, "no madam, your joint is ruined... try and get on with it for as long as you can, but sooner or later you will have to do it [surgery]." (P9, female, 73)

Another widely held belief among the participants was that OA is an age-related condition. This perception made them feel like they were undergoing an abnormal ageing process, even if they still felt active and vibrant.

"The doctor told me: "You know that if I did not know that these x-rays belong to you, I would think that they belong to another person who is at least 30 years older than you"... but, I guess I did not feel as bad as he was describing me." (P11, male, 56)

In fact, based on the narratives gathered, it was revealed that health professionals were taken aback by the presence of radiographic evidence of OA in younger participants. The reliance on radiographic findings to diagnose OA and formulate a care plan was perceived by the interviewees as a primary focus for physicians rather than the symptoms they reported.

"They told me: here we have the problem, and it is evident as we can see from the x-ray." (P11, male, 56)

Two other prevalent perceptions held by the interviewees based on their experiences with healthcare professionals were related to the management of OA. These were the frequent utilisation of passive treatments to delay surgical interventions and the limited recommendation for physical activity, which was perceived as a risk factor for early surgery. "And he [the doctor] told me that I was too young for surgery, and he recommended I do this therapy, to put some ice on my joint." (P5, female, 72)

"The doctor told me: "You have to try to postpone surgery for as long as you can. So please stop [any physical exercise]." (P1, male, 49)

#### Theme 4: Dealing with One's Own Attitudes Towards the Disease

The interviewees displayed varying attitudes towards OA. Older patients perceived OA as an indication of surrendering to the ageing process, whereas younger patients viewed it as something they either must or can resist.

"Maybe I am accepting my becoming old, what can I say..." (P3, female, 73)

"From a certain perspective, I took it [OA] positively since it is something I have to fight against." (P1, male, 49)

However, they all matured a sense of acceptance sooner or later, as if OA was something they could not change.

"Besides, I am also a fatalist, things happen in life, and when they do, you face them." (P4, female, 47)

All interviewees adopted primarily passive coping strategies to manage their symptoms of OA. The predominant features of their care process were the utilisation of medication to relieve pain and the implementation of various physical therapies, with limited scope for active therapies.

"It's not an issue for me to take some pills not to feel any pain." (P4, female, 47)

"I thought that by doing some thermal treatments [...] mud treatments [...] mesotherapy and other things ... I thought that with them I would sort the disease out." (P5, female, 72)

#### Theme 5: Understanding the Facilitators of the Adherence to Therapeutic Exercise

According to the interviewees, various facilitators were identified in their exercise adherence, with the perceived benefit from the exercises being the most reported. In particular, the experience of being active was viewed as an essential requirement of the body to preserve functionality and provide tangible and immediate support to the care process, in contrast to taking medication, which can take time to produce noticeable results.

"... The body has to move..." (P3, female, 73)

"It [physical exercise] is not like taking supplements with hyaluronic acid, those (supplements) you do not see what they do." (P1, male, 49)

Additionally, the role of determination was emphasised by all participants as a crucial factor in adhering to therapeutic exercise. Their perception of willpower varied; some viewed willpower as a facilitator, and others as a hindrance. However, they all concurred that a solid resolution to alter their lifestyle was essential for sustained adherence to an exercise regimen, and that determination was a necessary component in making such life changes.

"...Determination and willpower [to change life-habits]." (P7, female, 45)

#### Theme 6: Understanding the Barriers to the Adherence to Therapeutic Exercise

The interviewees identified several barriers that hindered their adherence to therapeutic exercise, including the cost of therapy, the required time investment, unclear guidelines, a lack of motivation to modify their lifestyles, and the belief that exercise was only proper after surgery. They noted that participating in physical activity required a significant allocation of time, energy, and resources, often conflicting with their work and familial responsibilities.

"Yes... but also from an economic point of view [it is difficult to do supervised exercises]." (P2, female, 68)

"We are trapped into a spiral in which work, we can say, takes up a lot of energy and a lot of time, and then that time is taken away from us..." (P6, male, 55)

According to the interviewees, one of the major barriers to engaging in therapeutic exercise was the absence of explicit directions from health professionals regarding the specific exercises to be performed, their intensity and frequency. This lack of clear guidance caused confusion and uncertainty among the interviewees, who felt they were left to rely solely on their instincts.

"My doctor told me to "go for a walk", or maybe to "move", but never specifically, something like "it would be better in your case to do something more targeted." (P11, male, 56)

The interviewees highlighted that the lack of determination and the hindrance in changing life habits were some of the main reasons behind not adhering to the exercise plan.

"I think so, for laziness... Because if you want to, you are able to find the time. So it is, therefore, laziness." (P5, female, 72)

Finally, a few participants felt exercise to be valid only after surgery, therefore, not worth doing prior to total joint replacement.

"It is useless to start doing physiotherapy/exercise if I am undertaking surgery in a month." (P9, female, 73)

In fact, they only saw exercise as applicable after surgery, with little to no utility in its own right.

"But I imagine that someone can do this... let's call it preventive activity. Activity that can help with the recovery process following the intervention." (P6, male, 55)

#### Theme 7: Developing an Uneasy Relationship with Food

Some of the participants had developed an unhealthy relationship with food. In fact, they perceived diet as a deprivation, a time-consuming and tiresome sacrifice. Moreover, some of our interviewees overeat "to eat their feelings".

"To follow a diet is a mental fatigue [...] and eating is an easy outlet to manage the stress of daily life." (P4, female, 47)

Furthermore, the participants considered following a diet only as a way to reduce weight on their joints without feeling its positive effects on inflammation. As a result, they tended to draw a direct association between weight and joint load.

"Of course, there is a relationship [between weight and OA]. The heavier the body, the more the knee suffers, it's a matter of physics." (P2, female, 68)

# Sociodemographic and Economic Elements

Sociodemographic and economic elements (e.g., age, HRQoL, BMI, educational attainment etc.) may influence the OA care process. For instance, some of them (e.g., assigned sex (at birth), age, self-efficacy, educational attainment etc.) has been hypothesised to be associated with exercise adherence in conditions other than OA [8, 21, 123–126]. Poor adherence to exercise might limit its benefits [127]. Considering the rising prevalence [67] and the economic burden of OA [128], identifying factors associated with exercise adherence is fundamental to creating specific intervention programmes to improve it. Therefore, Study 3 explored the association between different lifestyle, demographic, socioeconomic and disease-related factors with adherence to the supervised exercise of an OA management programme delivered nationwide in Swedish primary care [129]. Besides, this study explored these factors' ability to explain exercise variability.

Preliminary evidence indicated that people with OA in low SEP generally experience inequalities in care [27, 28, 130, 131], and that healthcare interventions may inadvertently exacerbate pre-existing inequalities [132]. This phenomenon is known as 'intervention-generated inequalities', and it is more likely to happen with interventions targeting behavioural changes such as exercise [25, 133]. Given this, it is essential to examine the impact of the care process on inequalities to understand how to structure the management of OA. Hence, Study 4 shed some light on income-related intervention-generated inequality in the outcomes (i.e., pain intensity, arthritis-specific self-efficacy, the desire for surgery and the use of NSAIDs) of the abovementioned OA management programme.

# Study 3: Factors Associated with Adherence to a Supervised Exercise Intervention for Osteoarthritis: Data from the SOAR

#### **Exercise Adherence: Why is it Fundamental in OA?**

The World Health Organisation (WHO) describes adherence as "the extent to which a person's behaviour-taking medication, following a diet and/or executing lifestyle changes [exercise], corresponds with agreed recommendations from a health care provider" [134]. In OA, poor adherence to exercise can hamper its benefits [127]. Therefore, it is fundamental to study which factors might be associated with exercise adherence to create specific interventions to improve it.

Several factors, including lifestyle, demographic characteristics, socioeconomic status, and disease-related factors, have been posited to influence exercise adherence [8, 21, 123–126]. Demographic and lifestyle factors such as female sex, higher age and BMI and low HRQoL appear to be associated with lower adherence [123, 124, 135]. Similarly, low SEPs (e.g., educational attaiment and income) have been suggested to influence people's attitudes, experiences, and exposure to several health risk factors [125] and be associated with insufficient exercise levels [8, 125, 126]. Finally, different disease-related factors could impact exercise adherence. People with chronic pain seem to avoid exercise due to maladaptive coping strategies such as fear avoidance, kinesiophobia and low levels of self-efficacy [21, 136, 137].

However, all the evidence mentioned above is primarily derived from conditions other than OA, qualitative studies whose aims are not to generalise knowledge and studies with small sample sizes [8, 18, 19, 21, 123–126]. Besides, the WHO stated that adherence is influenced by the interplay of various factors, not just a single element [134]. Notwithstanding, prior studies concentrated on single factors and their average association with adherence, as evidenced by the use of measures of association such as odds ratio (OR), ignoring the variability of effects at the individual level [138]. Therefore, this study investigated the associations between lifestyle and demographic, socioeconomic and disease-related factors with adherence to the supervised exercise of an OA management programme delivered nationwide in Swedish primary care. Furthermore, we investigated these factors' ability to explain exercise adherence variability.

#### **Study Design**

This register-based study uses individual-level data from two Swedish registers, the 'Swedish Osteoarthritis Registry' (SOAR) and the 'Longitudinal Integration Database for Health Insurance and Labour Market Studies' (LISA). SOAR contains information on approximately 200,000 people with OA who participated in an OA management programme offered by the Swedish healthcare system [139]. The LISA is a valuable resource for health and labour market research. LISA is a crucial tool that allows for a better understanding of individuals' life situations in relation to the labour market, working life, and ill-health. The registry provides researchers with annual data that tracks important aspects of individuals' lives, such as educational attainment, income, occupation, and employment status by calendar year [140, 141]. The datasets were merged using unique personal identity numbers (PINs) assigned to all Swedish citizens. The research was conducted in respect of the Declaration of Helsinki and reported following the Strengthening the Reporting of Observational studies in Epidemiology (STROBE). Ethical approval was granted by the Swedish Ethics Committee (Dnr: 2019-02570).

The OA management programme in SOAR consists of two parts: education and exercise [142, 143]. The education component involves three sessions that focus on the pathophysiology of the disease and its self-management. The first two are mandatory and led by a physiotherapist, and the third session is optional and led by an OA communicator. The optional exercise component begins with a one-on-one session with a physiotherapist to tailor the programme to participants' needs and preferences and can be performed either at home or in supervised group sessions with a physiotherapist twice a week for 6-8 weeks for up to 12 sessions, following OA Swedish guidelines [144].

#### Variables

The 'Levels of Adherence' to the supervised exercise part, reported in the SOAR, is the dependent variable of this study. The collected independent variables are reported hereafter and divided as 'Demographic and Lifestyle Characteristics', 'Socioeconomic Characteristics' and 'Disease-Related Characteristics' (Table 4).

Variable	Туре	Measured	Register
		Dependent variable	
Levels of adherence	Categorical	<ul> <li>Low levels of adherence (1-6 training sessions)</li> <li>Medium Levels of Adherence (7-9 training sessions)</li> <li>High Levels of Adherence (10-12 sessions)</li> </ul>	SOAR
	I	ndependent variables	
Demographic and life	estyle factors		
Assigned sex (at birth)	Binary	- Male - Female	SOAR
Age	Continuous		SOAR
BMI	Continuous		SOAR
EQ5DVAS (HRQoL)	Continuous	VAS 0 (worst possible HRQoL) - 100 (best possible HRQoL)	SOAR
Socioeconomic factor	s		
Living Alone	Binary	<ul><li>Living alone</li><li>Living with someone</li></ul>	LISA
Educational Attainment	Categorical	<ul> <li>Low (primary school [0–9 years])</li> <li>Medium (secondary school up to postsecondary education &lt;3 years [10–14 years])</li> <li>High (postsecondary education [&gt;=15 years])</li> </ul>	LISA
Employment	Binary	<ul><li>Employed</li><li>Retired/unemployed</li></ul>	LISA
Residential area	Categorical	- Suburban - Urban	LISA
Individual yearly net income*	Categorical	<ul> <li>Lowest income quartile (&lt; 146,500 SEK)</li> <li>Second income quartile (146,501-198,100 SEK)</li> <li>Third income quartile (198,111 – 278,800 SEK)</li> <li>Highest income quartile (&gt; 278,800 SEK)</li> </ul>	LISA
Disease-related factor	°S		
Index joint [139]	Binary	- Hip - Knee	SOAR
Numbers of painful joints [139]	Continuous		SOAR
<b>Desire for surgery</b> [139]	Binary	- Yes - No	SOAR

## Table 4 Variables included in the study

Pain intensity in their index joint [145]	Continuous	VAS 0 (no pain) - 10 (unbearable pain)	SOAR
Painfrequency[139]	Binary	<ul> <li>Infrequent pain [less than every week]</li> <li>Frequent pain [almost every day</li> </ul>	SOAR
Fear of movement [139]	Binary	- Yes - No	SOAR
Charnley score (disease that affects their walking) [146]	Categorical	<ul> <li>A = unilateral hip or knee OA</li> <li>B = bilateral hip or knee OA</li> <li>C = multiple joint OA or some other condition</li> </ul>	SOAR
<b>Self-efficacy</b> [147, 148]	Continuous	Arthritis self-efficacy scale (ASES), 'self- efficacy pain' and 'other symptoms' subscales combined score	SOAR
		10 (low levels of self-efficacy) -100 (high levels of self-efficacy)	

Legend: SOAR, Swedish Osteoarthritis Registry; VAS, Visual Analogue Scale; HRQoL; health-related quality of life; LISA, Longitudinal Integration Database for Health Insurance and Labour Market Studies; \*The individual yearly net income was categorised into quartiles based on the sample income distribution.

#### Levels of Adherence

The 'Levels of Adherence' is a categorical variable recorded by the physiotherapists and stratified on the number of sessions the participants partook in (Low levels of adherence (1-6 training sessions) / Medium Levels of Adherence: (7-9 training sessions) / High Levels of Adherence: 10-12 sessions).

#### Demographic and Lifestyle Characteristics

Participants' demographic and lifestyle characteristics were reported by the participants at the baseline and recorded in the SOAR. These outcomes were 'assigned sex (at birth)' (binary variable – Male / Female), 'age' (continuous variable), body mass index ('BMI') computed from participants' height and weight (continuous variable), 'weekly physical activity' (continuous variable – hour) and 'HRQoL' (continuous variable - EuroQol5-visual analogue scales, EQ5DVAS). The EQ5DVAS is part of the EQ-5D scale. The EQ-5D is an instrument that assesses HRQoL [149]. In the EQ5DVAS, the respondents report their perceived HRQoL on a VAS scale that scores from 0 (the worst possible HRQoL) to 100 (the best possible HRQoL).

#### Socioeconomic Factors

Each SEP indicator from the year before the enrolment to the SOAR register was considered for the analysis. In particular, the following SEP factors were retrieved: 'living alone' (binary variable - living alone / living with someone), 'educational attainment' (categorical variable - low (primary school [0–9 years]) / medium (secondary school up to postsecondary education <3 years [10–14 years]), / high (postsecondary education [>=15 years]), 'employment' (binary variable - employed / retired-unemployed), 'residential area' (categorical variable – rural / suburban / urban)

and the 'individual yearly net income' (see below for description). 'Residential area' is classified based on the 'Swedish Association of Local Authorities and Regions' (SALAR) classification of Swedish municipalities. Specifically, 'rural' areas are smaller towns/urban areas and rural municipalities, 'suburban' areas are medium-sized towns ( $\geq$ 40,000 inhabitants) and municipalities near medium-sized towns, 'urban' areas are large cities ( $\geq$ 200,000 inhabitants) and municipalities near medium-sized towns, 'urban' areas are large cities ( $\geq$ 200,000 inhabitants) and municipalities near large cities [150]. The individual yearly net income was categorised into quartiles based on the sample income distribution: lowest income quartile (<146,500 SEK) / second income quartile (146,501-198,100 SEK) / third income quartile (198,111 – 278,800 SEK) / highest Income Quartile (> 278,800 SEK) [150].

#### Disease-Related Characteristics

The physiotherapists recorded the 'index joint' (categorical variable - hip or knee) [139], namely, the joint with OA. They assessed this variable based on the participant's medical history, symptoms, and clinical assessment. In the case of multiple joints with OA, the most symptomatic joint was considered the index joint for the treatment. The participants self-recorded the 'number of painful joints' (continuous variable), their 'desire for surgery' (binary variable - yes/no) that was assessed by asking them: "Are your knee/hip symptoms so severe that you wish to undergo surgery?" [139]; their 'pain intensity' (continuous variable 0-10, Numeric Rating Scale (NRS) [145]) in their 'index Joint'; their 'pain frequency' (binary variable – infrequent pain [less than every week] / frequent pain [almost every day]) that was assessed with the question: "How often do you have pain in your knee/hip" [139]; their 'fear of movement' (binary variable – yes / no) that was assessed with the question "Are you afraid your joints will be injured by physical training/activity?"; the 'Charnley score' (categorical variable - Charnley score; A = unilateral hip or knee OA / B = bilateral hip or knee OA / C = multiple joint OA or some other condition) that categorises people with OA into three classes based on the disease(s) that affect walking ability [146]; and the 'arthritis-specific self-efficacy' (continuous variable 10-100 – pain and symptom arthritis self-efficacy scale, ASES) the Swedish version of the scale was adopted [147]. The ASES scale is a reliable instrument that assesses patients' arthritis-specific self-efficacy, namely, their beliefs about their ability to perform a specific task and cope with OA [148]. The full version is composed of three subscales: 1) 'self-efficacy pain scale' (5 items); 2) 'function scale' (9 items); 3) 'other symptoms scale' (6 items). Participants indicate to what extent they feel confident they can do the different tasks reported in the items from 10 ('very uncertain') to 100 ('very certain). In the SOAR, only 1) and 3) were adopted and combined as suggested in the scale instruction [148]. As per the psychometric properties of the Swedish ASES, the three factor structure was confirmed. Cronbach's alpha for internal consistency ranged between 0.82-0.91 and test-retest correlations between 0.81-0.91, similarly to the original version [148], showing that the Swedish ASES met satisfactorily psychometric standards. Similar results are reported in the two subscales adopted with a Cronbach's alpha of 0.92 for the 'self-efficacy pain scale' and 0.82 for the 'other symptoms' scale [147].

#### **Participants and Recruitment**

Our cohort gathered all the participants in the SOAR with a first registration (baseline) between 2012 and 2015. We included only those who started the exercise group sessions supervised by the physiotherapists after the initial encounter. We selected participants with knee or hip OA who were recorded in the SOAR only once.

Specifically, between 1st January 2012 and 31st December 2015, 46,905 people with OA were recorded in the SOAR. However, we excluded n=7 participants as they had joints other than the hip and knee as their first cause of pain, n=27,147 as they did not perform any supervised exercise session(s) and n=1 because they attended the programme more than once. Hence, among them, only 19,750 (73% Female sex; age: 67 (SD: 8.9)) participants with the knee (69%) or hip (31%) OA started the supervised exercise sessions. Figure 6 reports the participants' selection process.

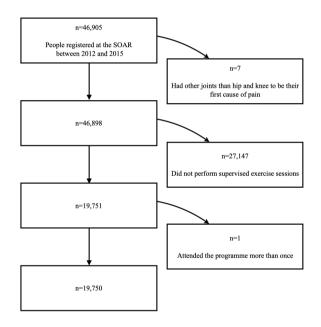


Figure 6 Participants' selection

Table 5 presents the characteristics of the whole cohort and stratified by the levels of adherence. Specifically, 5,862 (30%) reached a low level of adherence, 3,947 (20%) a medium level and 9,941 (50%) a high level.

Variables	Total Sample	Low Levels of	Medium Levels of	High Levels of
	ŕ	Adherence	Adherence	Adherence
	(n=19,750)	(n=5,862)	(n=3,947)	(n=9,941)
	Demographic an	d Lifestyle Character	istics	
Assigned sex (at birth)	n=19,750	n=5,862	n=3,947	n=9,941
Male, n(%)	5,421 (27.45)	1,519 (25.91)	925 (23.44)	2,977 (29.95)
Female, n(%)	14,329 (72.55)	4,343 (74.09)	3,022 (76.65)	6,964 (70.05)
Age	n=19,750	n=5,862	n=3,947	n=9,941
Mean(SD)	66.86 (8.94)	65.87 (9.39)	66.47 (9.01)	67.60 (8.57)
BMI	n=19,381	n=5,735	n=3,867	n=9,779
Mean(SD)	27.56 (4.76)	27.73 (4.90)	27.75 (4.89)	27.43 (4.63)
HRQoL (EQ5DVAS, 0-100)	n=17,933	n=5,317	n=3,592	n=9,024
Mean(SD)	65.82 (19.22)	65.84 (19.37)	65.74 (19.35)	65.85 (19.07)
Weekly physical activity (hour)	n=18,050	n=5,364	n=3,606	n=9,080
Mean(SD)	4.11 (2.53)	4.14 (2.53)	4.03 (2.49)	4.13 (2.54)
	Socioeconomic C	Characteristics		
Educational attainment (n)	n=19,699	n=5,862	n=3,938	n=9,918
Low, n(%)	4,331 (21.99)	1,170 (20.02)	795 (20.19)	2,366 (23.86)
Medium, n(%)	9,843 (49.97)	2,962 (50.69)	2,007 (50.96)	4,874 (49.14)
High, n(%)	5,525 (28.05)	1,711 (29.28)	1,136 (28.85)	2,678 (27.00)
Income – quartile (n)	n=19738	n=5858	n=3945	n=9935
Lowest income quartile, n(%)	4,942 (25.04)	1,345 (22.96)	1,022 (25.91)	2,575 (25.92)
Second income quartile, n(%)	4,936 (25.01)	1,393 (23.78)	982 (24.89)	2,561 (25.78)
Third income quartile, n(%)	4,929 (24.97)	1,517 (25.90)	976 (24.74)	2,436 (24.52)
Highest income quartile, n(%)	4,931 (24.98)	1,603 (27.36)	965 (24.46)	2,363 (23.78)
Area of living (n)	n=19,738	n=5,858	n=3,945	n=9,935
Rural, n(%)	6,047 (30.64)	1,667 (28.46)	1,180 (29.91)	3,200 (32.21)
Suburban, n(%)	8,252 (41.81)	2,435 (41.57)	1,708 (43.30)	4,109 (41.36)

## Table 5 Descriptive Statistics

Urban, n(%)	5,439 (27.56)	1,756 (29.98)	1,057 (26.79)	2,626 (26.43)
<b>Employment</b> (n)	n=19,738	n=5,858	n=3,945	n=9,935
Unemployed, n(%)	12,244 (62.03)	3,275 (55.91)	2,394 (60.68)	6,575 (66.18)
Employed, n(%)	7,494 (37.97)	2,583 (44.09)	1,551 (39.32)	3,360 (33.82)
Living alone (n)	n=19,738	n=5,858	n=3,945	n=9,935
Living alone, n(%)	7,754 (39.28)	2,411 (41.16)	1,457 (36.93)	3,886 (39.11)
Living with someone, n(%)	11,984 (60.72)	3,447 (58.84)	2,488 (63.07)	6,049 (60.89)
	Disease-Related	Characteristics		
Worst joint (n)		n=5,862	n=3,947	n=9,941
Hip, n(%)	6,049(30.63)	1,708 (29.14)	1,188 (30.10)	3,153 (31.72)
Knee, n(%)	13,701 (69.37)	4,154 (70.86)	2,759 (69.90)	6,788 (68.28)
Pain intensity (NRS 0-10)	n=19,686	n=5,843	n=3,935	n=9,908
Mean(SD)	5.25 (1.83)	5.23 (1.85)	5.24 (1.87)	5.26 (1.80)
Pain frequency (n)	n=19,700	n=5,842	3,940	n=9,918
Infrequent, n(%)	3,436 (17.44)	1,100 (18.83)	723 (18.35)	1,613 (16.26)
Frequent, n(%)	16,264 (82.56)	4,742 (81.17)	3,217 (81.65)	8,305 (87.34)
Number of painful joints	n=19,750	n=5,862	n=3,947	n=9,941
Mean(SD)	1.94 (1.29)	1.95 (1.28)	2.00 (1.32)	1.91 (1.27)
Charnley score (n)	n=19,735	n=5,855	n=3,946	n=9,934
A, n(%)	6,814 (34.53)	2,000 (34.16)	1,340 (33.96)	3,474 (34.97)
B, n(%)	3,437 (17.42)	1,009 (17.23)	686 (17.38)	1,742 (17.54)
C, n(%)	9,484 (48.06)	2,946 (48.61)	1,920 (48.66)	4,718 (47.49)
Walking difficulties (n)	n=19,651	n=5,835	n=3,932	n=9,884
No, n(%)	3,472 (17.67)	1,105 (18.94)	731 (18.59)	1,636 (16.55)
Yes, n(%)	16,179 (82.33)	4,730 (81.06)	3,201 (81.41)	8,248 (83.45)
Fear of movement (n)	n=19,651	n=5,821	n=3,928	n=9,902
No, n(%)	16,562 (84.28)	4,871 (83.68)	3,303 (84.09)	8,388 (84.71)
Yes, n(%)	3,089 (15.72)	950 (16.32)	625 (15.91)	1,514 (15.29)
<b>Desire for surgery</b> (n)	n= 19,558	n=5,798	n=3,906	n=9,854

No, n(%)	14,936 (76.37)	4,441 (76.60)	3,017 (77.24)	7,478 (75.89)
Yes, n(%)	4,622 (23.63)	1,357 (23.40)	889 (22.76)	2,376 (24.11)
Self-efficacy	n=19.149	n=5,660	n=3,834	n=9,655
(ASES 10-100)		- ,	- )	- ,
Mean(SD)	65.54 (16.43)	65.44 (16.54)	65.51 (16.62)	65.61 (16.28)

Legend: n, number; SD, standard deviation; HRQoL, health-related quality of life; EQ5DVAS, EuroQol-5D Health Visual Analogue Scale; IQ, income quartile; OA, osteoarthritis; NRS, numeric rating scale; ASES, Arthritis Self-Efficacy Scale.

#### Factors Associated with Exercise Adherence – Average Association

A multivariable exploratory analysis was performed to identify which independent variables were independently associated with exercise adherence in the SOAR [151]. Multivariable exploratory analyses detect patterns and identify relationships between independent variables and outcomes [151–153]. Stata 17 was used for the analysis.

Since the proportional odds assumption was not met, an ordered logistic regression could not be performed. Hence, we ran a multinomial logistic regression with a listwise deletion (stata function 'mlogit') to determine the association between the independent variables and the adherence to exercise. No missing data were reported in the outcome (adherence). Less than 1% of the data on 'socioeconomic' characteristics was missing, primarily due to an error during the data upload process in 'LISA'. 'Demographic and lifestyle' and 'disease-related' characteristics missing data in the SOAR are most likely a result of a mistake by the physiotherapists responsible for uploading the data at the local unit. Hence. missing data in both registers could be considered missing completely at random, introducing no or minimal bias in our analysis. Table 6 reports the descriptive statistics of the total sample and the samples included in and excluded from the analysis, highlighting minimal differences between them.

Variables	Total Sample	Included in the Analysis	Excluded from Analysis	
	(n=19,750)	(n=16,685)	(n=3,065)	
Demographic and Lifestyle Characteristics				
Assigned sex (at birth)	n=19,750	n=16,685	n=3,065	
Male, n(%)	5,421 (27.45)	4,662 (27.94)	759 (24.76)	
Female, n(%)	14,329 (72.55)	1,2023 (72.06)	2,306 (75.24)	
Age	n=19,750	n=16,685	n=3,065	
Mean(SD)	66.86 (8.94)	66.79 (8.90)	67.24 (9.15)	
BMI	n=19,381	n=16,685	n=2,696	
Mean(SD)	27.56 (4.76)	27.57 (4.76)	27.50 (4.81)	
HRQoL (EQ5DVAS, 0-100)	n=17,933	n=16,685	n=1,248	
Mean(SD)	65.82 (19.22)	65.87 (19.15)	65.10 (20.02)	
Weekly physical activity (hour)	n=18,050	n=16,685	n=1,365	
Mean(SD)	4.11 (2.53)	4.13 (2.52)	3.87 (2.56)	
Socioeconomic Characteristics				
Educational attainment (n)	n=19,699	n=16,685	n=3,014	
Low, n(%)	4,331 (21.99)	3,581 (21.46)	750 (24.88)	
Medium, n(%)	9,843 (49.97)	8,382 (50.24)	1,461 (48.47)	
High, n(%)	5,525 (28.05)	4,722 (28.30)	803 (26.64)	
Income – quartile (n)	n=19,738	n=16,685	n=3,053	
Lowest income quartile, n(%)	4,942 (25.04)	4,018 (24.08)	924 (30.27)	
Second income quartile, n(%)	4,936 (25.01)	4,163 (24.95)	773 (25.32)	
Third income quartile, n(%)	4,929 (24.97)	4,187 (25.09)	742 (24.30)	
Highest income quartile, n(%)	4,931 (24.98)	4,317 (25.87)	614 (20.11)	
Area of living (n)	n=19,738	n=16,685	n=3,053	
Rural, n(%)	6,047 (30.64)	5,150 (30.87)	897 (29.38)	
Suburban, n(%)	8,252 (41.81)	6,818 (40.86)	1,434 (46.97)	
Urban, n(%)	5,439 (27.56)	4,717 (28.27)	722 (23.65)	
Employment (n)	n=19,738	n=16,685	n=3,053	
Unemployed, n(%)	12,244 (62.03)	10,243 (61.39)	2,001 (65.54)	
Employed, n(%)	7,494 (37.97)	6,442 (38.61)	1,052 (34.46)	
Living alone (n)	n=19,738	n=16,685	n=3,053	
Living alone, n(%)	7,754 (39.28)	6,522 (39.09)	1,232 (40.35)	
Living with someone, n(%)	11,984 (60.72)	10,163 (60.91)	1,821 (59.65)	

 Table 6 Descriptive statistics of the total sample and the samples included in and excluded from the analysis

Worst joint (n)	n=19,759	n=16,685	n=3947
Hip, n(%)	6,049(30.63)	5,129 (30.74)	920 (30.02)
Knee, n(%)	13,701 (69.37)	11,556 (69.26)	2,145 (69.98)
Pain intensity (NRS 0-10)	n=19,686	n=16,685	n=3,001
Mean(SD)	5.25 (1.83)	5.25 (1.82)	5.24 (1.86)
Pain frequency (n)	n=19,700	n=16,685	n=3,015
Infrequent, n(%)	3,436 (17.44)	2,957 (17.72)	479 (15.89)
Frequent, n(%)	16,264 (82.56)	13,728 (82.28)	2,536 (84.11)
Number of painful joints	n=19,750	n=16,685	n=3,065
Mean(SD)	1.94 (1.29)	2.11 (1.21)	1.03 (1.32)
Charnley score (n)	n=19,735	n=16,685	n=3,050
A, n(%)	6,814 (34.53)	5,745 (34.43)	1,069 (35.05)
B, n(%)	3,437 (17.42)	2,705 (16.21)	732 (24.00)
C, n(%)	9,484 (48.06)	8,235 (49.36)	1,249 (40.95)
Walking difficulties (n)	n=19,651	n=16,685	n=2,966
No, n(%)	3,472 (17.67)	2,942 (17.63)	530 (17.87)
Yes, n(%)	16,179 (82.33)	13,743 (82.37)	2,436 (82.13)
Fear of movement (n)	n=19,651	n=16,685	n=2,966
No, n(%)	16,562 (84.28)	14,088 (84.44)	2,474 (83.41)
Yes, n(%)	3,089 (15.72)	2,597 (15.56)	492 (16.59)
Desire for surgery (n)	n= 19,558	n=16,685	n=2,873
No, n(%)	14,936 (76.37)	12,738 (76.34)	2,198 (76.51)
Yes, n(%)	4,622 (23.63)	3,947 (23.66)	675 (23.49)
Arthritis-specific self-efficacy			
(ASES Pain and Symptoms,	n=19,149	n=16,685	n=2,464
0-100)			
Mean(SD)	65.54 (16.43)	65.74 (16.42)	64.18 (16.38)

Legend: n, number; SD, standard deviation; HRQoL, health-related quality of life; EQ5DVAS, EuroQol-5D Health Visual Analogue Scale; OA, osteoarthritis; NRS, numeric rating scale; ASES, Arthritis Self-Efficacy Scale.

Variable selection in the model was informed by previous literature on exercise adherence in other chronic pain conditions [8, 21, 123–126] and the evidence for action on adherence by the WHO [134]. Then, the variables were clustered in 'demographic and lifestyle', 'socioeconomic and 'disease-related' following the dimensions proposed by the WHO [134]. The multicollinearity assumption between continuous variables was tested, and none of the continuous variables was highly correlated. The relative risk ratio (RRR) of being in 'medium level of adherence' or 'high level of adherence' with respect to 'low level of adherence' and 95% confidence intervals (CIs) were estimated for each covariate in the model. For the variables 'HRQoL' and 'arthritis-specific self-efficacy',

the RRR is presented as a 10-point change in these scales. Hence, After the listwise deletion, the multinomial logistic regression was run on n=16,685 (85%) with low levels of adherence as the reference category (Table 7).

	Variables	p-value	Relative Risk Ratio	95% C.I. for EXP(B)	
n=16,685	variables	p-value		Lower	Upper
Levels of erence	(Base Outcome)				
lium Levels of erence					
	Assigned sex (at birth)				
	Male	(Base Cat	egory)		
	Female	0.03	1.13	1.02	1.27
	Age	0.14	1.00	0.99	1.01
	BMI	0.37	0.99	0.99	1.01
	HRQoL (EQ5DVAS, 0-100)*	0.57	0.99	0.97	1.02
	Weekly physical activity (hour)	0.02	0.98	0.96	0.99
	Educational attainment				
	Low	(Base Cat	egory)		
	Medium	0.88	0.99	0.88	1.12
	High	0.63	0.97	0.84	1.11
	Income – quartile				
	Lowest income quartile	(Base Cat	egory)		
	Second income quartile	0.71	0.98	0.86	1.11
	Third income quartile	0.63	0.97	0.84	1.11
	Highest income quartile	0.41	0.94	0.81	1.09
	Area of living				
	Rural	(Base Cat	egory)		
	Suburban	0.27	0.94	0.85	1.05
	Urban	0.02	0.87	0.78	0.98
	Employment				
	Unemployed	(Base Cat	egory)		
	Employed	< 0.01	0.82	0.72	0.93
	Living alone				
	Living alone	(Base Cat	egory)		
	Living with someone	< 0.01	1.21	1.10	1.32

Table 7 Association between exercise adherence and investigated variables

Hip	(Base Ca	itegory)		
Knee	0.35	0.95	0.86	1.05
Pain intensity (NRS 0-100) *	0.49	1.01	0.98	1.04
Pain frequency				
Infrequent	(Base Ca	itegory)		
Frequent	0.80	0.98	0.87	1.11
Number of painful joints	0.01	1.06	1.01	1.10
Charnley score				
A	(Base Ca	itegory)		
В	0.99	0.99	0.97	1.15
С	0.13	0.91	0.81	1.03
Walking difficulties				
No	(Base Ca	itegory)		
Yes	0.93	0.99	0.88	1.13
Fear of movement				
No	(Base Ca	itegory)		
Yes	0.49	1.04	0.92	1.18
Desire for surgery				
No	(Base Ca	itegory)		
Yes	0.26	0.94	0.83	1.05
Arthritis-specific self-efficacy				
ASES Pain and Symptoms, 0-100)*	0.29	1.02	0.99	1.05
Assigned sex (at birth)				
Aale	(Base Ca	(tegory)		
Semale	<0.01	0.82	0.75	0.89
Age	<0.01	1.01	1.01	1.02
BMI	0.01	0.99	0.98	0.99
HRQoL (EQ5DVAS, 0-100)*	0.18	0.98	0.96	1.01
Hours physical activity / week	0.79	0.99	0.98	1.01
Educational attainment	0.13	0.77	0.90	1.01
Low	(Base Ca	(tegory)		
Medium	(Base Ca 0.02	0.89	0.81	0.98
	< 0.02	0.89	0.81	0.98
High	~0.01	0.04	0.70	0.94
ncome – quartile				

High Levels Adherence

Third income quartile	0.61	1.03	0.92	1.15
Highest income quartile	0.95	1.00	0.89	1.14
Area of living				
Rural	(Base Ca	ategory)		
Suburban	< 0.01	0.79	0.73	0.86
Urban	< 0.01	0.78	0.71	0.86
Employment				
Unemployed	(Base Ca	ategory)		
Employed	< 0.01	0.71	0.64	0.78
Living alone				
Living alone	(Base Ca	ategory)		
Living with someone	0.29	1.04	0.97	1.12
Worst joint				
Hip	(Base Ca	ategory)		
Knee	0.03	0.92	0.85	0.99
Pain intensity (NRS 0-10)	0.12	1.02	0.99	1.04
Pain frequency				
Infrequent	(Base Ca	ategory)		
Frequent	0.02	1.13	1.02	1.25
Number of painful joints	0.50	1.01	0.98	1.05
Charnley score				
A	(Base Ca	ategory)		
В	0.74	1.02	0.91	1.14
С	0.11	0.93	0.84	1.02
Walking difficulties				
No	(Base Ca	ategory)		
Yes	0.03	1.12	1.01	1.24
Fear of movement				
No	(Base Ca	ategory)		
Yes	0.93	1.00	0.91	1.11
Desire for surgery				
No	(Base Ca	ategory)		
Yes	0.44	0.96	0.88	1.06
Arthritis-specific self-efficacy				
(ASES Pain and Symptoms, 0-100)*	< 0.01	1.04	1.02	1.07

Legend: n, number; EQ5DVAS, EuroQol-5D Health Visual Analogue Scale; IQ, income quartile; \*, RRR are reported as an increase of 10 points in the scale; OA, osteoarthritis; NRS, numeric rating scale; ASES, Arthritis Self-Efficacy Scale.

We found that 'female' sex (RRR=1.13, 95% CI [1.02-1.27]), 'living with someone' (1.21, [1.10-1.32]) and an increase of one 'number of joints with OA' (1.06, 95% CI [1.01-1.10]) were positively associated with achieving medium levels of adherence. Conversely, an increase in an hour of 'weekly physical activity' (0.98, 85% CI [0.96-0.99]), living in an 'urban' area (0.87, 95% CI [0.78-0.98]) and being 'employed' (0.82, 95% CI [0.72-0.93]) were negatively associated with achieving medium levels of adherence.

An increase of one year in 'age' (1.01, 95% CI [1.01-1.02]), having 'frequent' pain (1.13, 95% CI [1.02-1.25]), having 'walking difficulties' (1.12, 95% CI [1.01-1.24]) and with a 10-point increase on the 'arthritis-specific self-efficacy' scale (1.04, 95% CI [1.02-1.07]) were positively associated with high levels of adherence. Instead, 'female' sex (0.82, 95% CI [0.75-0.89]), an increase of one point in 'BMI' (0.99, 95% CI [0.98-0.99]), living in a 'suburban' (0.79, 95% CI [0.73-0.86]) or 'urban' area (0.78 95% CI [0.71-0.86]), being 'employed' (OR=0.71, 95% CI [0.64-0.78]), having a medium (0.89, 95% CI [0.81; 0.98] or a high 'educational attainment' (0.84, 95% CI [0.76-0.94]) and having 'knee' as 'worst joint' (0.92, 95% CI [0.85-0.99]) were negatively associated with high levels of adherence.

#### Factors Associated with Exercise Adherence – Variability Explanation

The McFadden  $R^2$  (stata function 'fitstat') was employed to assess the capacity of the models to explain the variability of exercise adherence. This metric indicates the extent to which the variance of the dependent variable (adherence) can be explained by the independent variables in the model using a 0-100% scale. The McFadden  $R^2$  was calculated for the full model, which included all variables. Subsequently, a set of variables (demographic and lifestyle, socioeconomic and disease-related) were excluded from the model, and the difference in McFadden  $R^2$  was calculated to determine the contribution of each set of variables to the explanatory power of the full model.

The McFadden  $R^2$  of the full model indicated that the participant's demographic and lifestyle characteristics, socioeconomic characteristics, and disease-related characteristics collectively explained approximately 1.2% of the variation in adherence. When each variable set was removed from the model, there was a difference in McFadden  $R^2$  with respect to the full model of 0.3%, 0.4%, and 0.2%, respectively. Of these, disease-related characteristics contributed the most to the explanatory power of the full model, although the overall explanatory ability was low.

# Study 4: Income-Related Health Inequality and Osteoarthritis Intervention Outcomes: a Cohort Study

#### **Inequalities in OA Care**

SEPs are central determinants of health [154, 155]. They are defined as the position of an individual within a society stemming from different factors such as educational attainment and income [154, 156, 157]. The uneven distribution of health or health resources between individuals or groups due to genetic or other factors such as SEPs is defined as 'health inequality' [158]. It is worth noticing that this term does not consider whether this difference is just or unjust. Therefore, it notices that there is a difference among individuals or groups. Conversely, unfair, avoidable differences arising from poor governance, corruption or cultural exclusion are defined as 'health inequity' [159].

In OA, preliminary findings indicated that people in lower SEP experienced health inequalities in pain intensity, self-efficacy and desire for surgery [27, 28, 130, 131]. Moreover, healthcare interventions can widen pre-existing inequalities gaps between people in different SEPs [132]. This phenomenon is known as 'intervention-generated inequalities', and it is more likely to happen with healthcare interventions targeting behavioural changes, such as exercise and education [25, 133]

However, as per the adherence to exercise, these studies on inequalities focused on measures of average association [27, 28, 130, 131]. In contrast, one of the definitions of inequalities reported by the WHO defined inequalities as differences in the distribution of health determinants among different socioeconomic groups (rather than the average association thereof) [160]. Besides, these studies did not investigate inequalities regarding the use of non-steroidal anti-inflammatory (NSAIDs) drugs, though broadly used in OA treatment, despite their adverse-associated events [161]. Finally, these studies did not explore intervention-generated inequalities and adopted SEPs (e.g., education) other than income.

#### Income

Income is a straightforward measure of social class that plays a critical role in maintaining people's health[162]. This role is twofold: a direct effect on the material resources needed for survival, and an indirect impact on social opportunities and ability to cope with life events [162]. In healthcare, income suggested a 'dose-response' association with health [163, 164]. The mechanisms through which income could affect health are several. It allows for 1) buying access to higher-quality material recourses (e.g., food); 2) increasing access to service (e.g., health services); 3) providing materials that are 'relevant' for society, fostering individuals' self-esteem and social standing

[164]. However, income is difficult to gather as people might refrain from providing this information [164]. Moreover, disposable income might be more interesting to collect than gross income as the latter represents how much a(n) individual / family can spend [164]. Nevertheless, gross income is mainly collected.

This study investigated income-related inequality in the outcomes (i.e., pain intensity, arthritis-specific self-efficacy, the desire for surgery and the use of NSAIDs) of the SOAR, using concentration index analysis and income information from LISA [163]. LISA allowed for having accurate individuals' disposable income. Specifically, we analysed how the concentration index changed throughout the different time points in the SOAR to see whether 'intervention-generated inequalities' arose.

#### **Study Design**

A cohort study on individual-level register data. The SOAR (for data on the OA firstline intervention) was merged with LISA (for income information) using personal identity numbers (PINs) unique to all citizens in Sweden. The research was conducted in respect of the Declaration of Helsinki and reported following the Strengthening the Reporting of Observational studies in Epidemiology (STROBE). Ethical approval was granted by the Swedish Ethics Committee (Dnr: 2019-02570).

#### Variables

#### Descriptive Characteristics

Participants reported their demographic characteristics at the baseline. Specifically, they reported their 'Assigned sex (at birth)'(categorical variable – Male / Female), 'Age' (continuous variable), and height and weight, which were merged into the 'BMI' (continuous variable). The physiotherapists established participants' 'Index Joint' (categorical variable - hip or knee) based on medical history, symptoms, and clinical assessment. In the case of multiple joints with OA, the most symptomatic joint was considered the index joint for the treatment. At the inspections of q-q plots (Stata command 'qnorm'), continuous variables followed a normal distribution and were reported as mean  $\pm$  standard deviation (SD). Categorical variables are reported as absolute and percentage frequencies.

#### OA Outcomes

The OA outcomes were retrieved from the SOAR and reported by the participants and the physiotherapists. We retrieved mean 'Pain intensity' during the last week (continuous variable) in patients' 'Index joint' (continuous variable 0-10, Numeric Rating Scale (NRS) [145]) and their 'Desire for surgery' (binary variable - yes / no) assessed by asking them: "Are your knee / hip symptoms so severe that you wish to undergo surgery?" [139], and the 'Self-efficacy' with the 'Arthritis self-efficacy scale

(continuous variable 10-100 – pain and symptom arthritis self-efficacy scale, ASES). The ASES scale is a reliable instrument that assesses patients' arthritis-specific selfefficacy, namely, their beliefs about their ability to perform a specific task and cope with OA [148]. The full version is composed of three subscales: 1) 'self-efficacy pain scale' (5 items); 2) 'function scale' (9 items); 3) 'other symptoms scale' (6 items). Participants indicate to what extent they feel confident they can do the tasks reported in the items from 10 ('very uncertain') to 100 ('very certain'). In the SOAR, only 1) and 3) were adopted and combined as suggested in the scale instruction [148]. Cronbach's alpha for internal consistency ranged between 0.82-0.91 and test-retest correlations between 0.81-0.91, similar to the original version [148], showing that the Swedish ASES met satisfactorily psychometric standards. Similar results are reported in the two subscales adopted with a Cronbach's alpha of 0.92 for the 'self-efficacy pain scale' and 0.82 for the 'other symptoms' scale [147]. This scale was used from 2012 to 2015. Participants report all these variables. The physiotherapists collect the 'Use of NSAIDs'. They reported whether patients had taken any medications for their joint pain in the last three months and whether or not they were NSAIDs (binary variable - yes / no) [139]. All these variables but 'Use of NSAIDs' were measured at baseline, 3- and 12-month follow-ups, that was collected at the baseline and 3-month follow-up.

#### Income

'Individuals' disposable income' (continuous variable) in the year before the enrolment to the SOAR was retrieved from LISA and considered for the analysis. The disposable income is the part of an individual's income used for saving or consumption. Specifically, disposable income considers income from employment, social welfare, pension (both public and private), sickness benefits, income from business activities and capital minus taxes and deductions and several other benefits. The household's disposable income per consumption unit is calculated by dividing the sum of all family members' disposable incomes by the total consumption weight of the family. Specifically, one adult weighs 1.0, two adults as 1.51 and children as 0.56-0.76(depending on age) in the household [165]. The income is reported in SEK (10 SEK  $\approx 1 \in$ ).

#### **Participants and Recruitment**

Our cohort gathers all the participants in the SOAR with a first registration (baseline) between 2008 and 2018. Specifically, we selected participants with knee or hip OA as the primary cause of their pain, who were recorded in the SOAR only once and did not perform the programme digitally. Hence, we identified 126,308 participants, of whom 7,639 reported joints other than the hip and knee as their first cause of pain and were excluded. Moreover, we excluded 2,663 who attended exercises digitally and 603 that participated in the programme more than once. Finally, 115,403 (age: 66.2 years (SD: 9.7); sex: female 67.8%) people with knee and hip OA were identified (Figure 7). Table 8 presents the characteristics of the whole cohort. Table 9 reports the characteristics of those with and without missing values in the OA outcomes of interest.

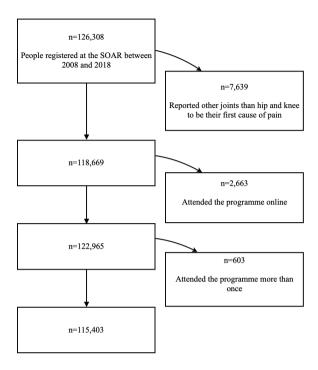


Figure 7 Selection of the study population

Variables	Baseline	3-months	12-months
Descriptive Variables			
Assigned sex (at birth)	n=115,403		
Female, n (%)	78,233 (67.8)		
Male, n (%)	37,170 (32.2)		
Age	n=115,403		
Mean (SD)	66.2 (9.7)		
BMI	n=107,354		
Mean (SD)	27.7 (5.0)		
Worst joint (n)	n=115,402		
Hip, n (%)	37,212 (32.4)		
Knee, n (%)	78,191 (67.8)		
Income	n=115,356		
Mean (SD)	241,414.2 (271,223)		
OA Outcomes			
Pain intensity (NRS 0-10)	n=114,908	n=80,588	n=47,648
Mean (SD)	5.5 (2.1)	4.4 (2.3)	4.4 (2.3)
Arthritis self-efficacy			
(ASES Pain and Symptoms,	n=45,286	n=33,465	n=26,074
10-100)			
Mean (SD)	64.8 (17.0)	69.1 (17.7)	65.0 (18.8)
Desire for surgery (n)	n=113,713	n=79,425	n=47,246
No, n (%)	82,327 (72.4)	62,027 (78.1)	36,907 (78.1)
Yes, n (%)	31,386 (27.6)	17,398 (21.9)	10,339 (21.9)
Use of NSAIDs (n)	n=113,560	n=80,428	
No, n (%)	64,460 (56.8)	54,890 (68.3)	
Yes, n (%)	49,100 (43.2)	25,538 (31.2)	

#### Table 8 Descriptive statistics of the included population

Abbreviations: n, number; SD, standard deviation, ASES, Arthritis-Specific Self-Efficacy; NSAIDs, non-steroidal antiinflammatory drugs.

Variables	Baseline VS 3-mont	ths	Baseline VS 12-mor	nths	
	Complete cases	Missing cases	<b>Complete</b> Cases	Missing cases	
		Pain	Intensity		
	n=80,329	n=35,074	n=47,499	N=67,904	
Assigned sex (at birth)					
Female, n(%)	54,972 (68.43)	23,261 (66.32)	33,270 (70.04)	44,963 (66.22)	
Male, n(%)	25,357 (31.57)	11,813 (33.68)	14,229 (29.96)	22,941 (33.78)	
Age					
Mean (SD)	67.01 (9.35)	65.96 (10.32)	66.76 (9.15)	66.64 (10.02)	
BMI					
Mean (SD)	27.58 (4.84)	27.90 (5.22)	27.44 (4.80)	27.85 (5.07)	
Worst joint					
Hip, n(%)	25,584 (31.85)	11,628 (33.15)	13,802 (29.06)	24,410 (34.48)	
Knee, n(%)	54,745 (68.15)	23,446 (66.85)	33,697 (70.94)	44,494 (65.52)	
Income					
Mean (SD)	238,435.9	248,234.3	235,810.5	245,333.4	
	(241,621.3)	(329,055.5)	(238,387.4)	(291,948.1)	
	Self-Efficacy*				
	n=32,614	N=14,283	n=25,381	n=21,516	
Assigned sex (at birth)					
Female, n(%)	22,720 (69.66)	9,492 (66.46)	17,904 (70.54)	14,308 (66.50)	
Male, n(%)	9,894 (30.34)	4,791 (33.54)	7,477 (29.46)	7,208 (33.50)	
Age					
Mean (SD)	66.59 (9.29)	66.18 (10.17)	66.55 (9.12)	66.37 (10.09)	
BMI					
Mean (SD)	27.53 (4.85)	27.78 (5.34)	27.44 (4.90)	27.80 (5.12)	
Worst joint					
Hip, n(%)	10,135 (31.08)	4,529 (31.71)	7,250 (28.56)	7,414 (34.46)	
Knee, n(%)	22,479 (68.92)	9,754 (68.29)	18,131 (71.44)	14,102 (65.54)	
Income					
Mean (SD)	229,400.9	227,699.0	231,166.4	226,187.8	
	(224,671.7)	(244,566.4)	(234,631.4)	(226,384.9)	
			for Surgery		
	n=78,461	n=36,942	n=46,751	n=68,652	
Assigned sex (at birth)					
Female, n(%)	53,742 (68.50)	24,491 (66.30)	32,784 (70.12)	45,449 (66.20)	
Male, n(%)	24,719 (31.50)	12,451 (33.70)	13,968 (29.88)	23,203 (33.80)	

## Table 9 Descriptive statistics per OA outcomes confronting complete VS missing cases

Age					
Mean (SD)	67.00 (9.36)	66.03 (10.27)	66.74 (9.13)	66.66 (10.02)	
BMI					
Mean(SD)	27.57 (4.84)	27.89 (5.21)	27.43 (4.85)	27.86 (5.03)	
Worst joint					
Hip, n(%)	25,041 (31.92)	12,171 (32.95)	13,589 (29.07)	23,623 (32.41)	
Knee, n(%)	53,420 (68.08)	24,771 (67.05)	33,162 (70.93)	45,029 (65.59)	
Income					
Mean (SD)	238,300.4 (240,809.5)	248,026.5 (326,472.1)	235,724.3 (239,065.9)	245,880 (291,036.8)	
	Use of NSAIDs				
	N=80,243	N=35,160			
Assigned sex (at birth)					
Female, n(%)	54,885 (68.40)	23,348 (66.41)			
Male, n(%)	25,358 (31.60)	11,812 (33.59)			
Age					
Mean (SD)	66.98 (9.38)	66.03 (10.28)			
BMI					
Mean (SD)	27.59 (4.85)	27.88 (5.21)			
Worst joint					
Hip, n(%)	25,573 (31.87)	11,639 (33.10)			
Knee, n(%)	54,670 (68.13)	23,521 (66.90)			
Income					
(Mean (SD))	238,048.3 (242,607.1)	249,094.9 (327,178.8)			

#### **Income-Related Inequalities**

Wagstaff et al. (1991) reviewed and assessed different inequality measures suggesting that these measures need: (1) to reflect the socioeconomic dimension of inequalities in health; (2) to mirror the experiences of the whole population; and (3) to be sensitive to modification in the distribution of the population across different socioeconomic classes [166]. They concluded that only the concentration index meets these requirements [166].

The concentration index represents a measure of inequality that highlights how much a health outcome is distributed across a population ranked through a socioeconomic measure (e.g., income) [167]. The standard concentration index is derived from the Gini coefficient of income inequalities. This index requires the investigated health variables

to be on the same scale as the socioeconomic variable (i.e., income – ratio-scaled measure) without an upper bound, and it is calculated as follows [168].

$$C(h|y) = \frac{2cov(h_i, R_i)}{\bar{h}} = \frac{1}{n} \sum_{i=1}^{n} [\frac{h_i}{\bar{h}} (2R_i - 1)]$$

Legend: C, concentration index;  $h_i$ , health variables where the inequality is measured;  $R_i$ , fractional (income) rank.

However, in health economics, health measures are often bounded and either ordinal or cardinal, classified as either attainments (when the observed level of a health variable meets or surpasses the target level) or shortfalls (when the observed level falls below the target level) [169]. Moreover, the concentration index measures relative inequality, invariant to equiproportionate changes in the health variable and reflecting the proportional difference in health variables between subgroups (poor and rich people). Addressing only relative changes provides a limited vision of the extent of inequality. On the other hand, absolute health inequality reflects the absolute magnitude of difference in health variables. Therefore, both relative and absolute health-inequality indices are necessary. To account for these issues, Erreygers proposed his modified concentration index for bounded variables and an absolute and relative indicator of inequality [170].

$$E(h|y) = \frac{1}{n} \sum_{i=1}^{n} \left[ \frac{4h_i}{(h^{max} - h^{min})} (2R_i - 1) \right]$$

Legend: E, Erreygers' concentration index;  $h_i$ , the health variable,  $h^{max}$ , the upper limit for the health variable,  $h^{min}$ , the lower limit of the health variable;  $R_i$ , fractional (income) rank.

Erreygers' concentration index (E) values range from -1 to +1. A positive (negative) sign indicates an unequal concentration of the variables of interest among those in higher (lower) SEP. A zero value means no socioeconomic inequality. Larger the magnitude of the concentration index, the greater the extent of income-related inequality [170].

The analysis was performed with Stata 17. We calculated this index using the Stata command 'conindex' [167]. We calculated Erreygers' concentration index for the variables 'Pain intensity', 'Self-efficacy' and 'Use of NSAIDs' when these variables were reported at baseline and 3- and 12-month follow-ups. Specifically, we focussed on on Erreygers' concentration index changes over time to see if any 'intervention generated inequalities' might be present in this Swedish OA first-line intervention. Therefore, we calculated Erreygers' concentration indices and their differences at baseline and 3-month follow-up. We excluded participants with missing values in the SOAR outcomes at either of these time points (listwise deletion). We repeated this process for the baseline and 12-month follow-up, excluding participants with missing values in the SOAR outcomes at either of these time points. To calculate the confidence intervals (CIs) of the indices' differences, we used 1000 bootstrap replications as the

Stata command 'conindex' does not provide this parameter. As for 'Use of NSAIDs', we only calculated baseline vs 3 months as data after one year were not reported in the registry. However, before analysing the inequalities through Erreygers' concentration index, we compared those included and excluded in this analysis, and no clinical differences were found among them (Table 10).

	Baseline	3 months	Baseline	12 months		
	Pain Intensity (NRS 0-10)					
	Included					
	n=80,329	n=80,329	n=47,499	n=47,499		
(Mean (SD))	5.4 (2.1)	4.4 (2.3)	5.2 (2.0)	4.4 (3.3)		
		F	Excluded			
	n=34,579	n=259	n=67,409	n=149		
(Mean (SD))	5.7 (2.1)	4.7 (2.4)	5.7 (2.1)	4.5 (2.4)		
		Self-efficacy (ASES	Pain and Symptoms, 10-1	00)		
		I	ncluded			
	n=32,614	n=32,614	n=25,381	n=25,381		
(Mean (SD))	65.5 (16.6)	69.2 (17.7)	66.8 (16.2)	65.1 (18.7)		
		F	Excluded			
	n=12,672	n=851	n=19,905	n=693		
(Mean (SD))	62.9 (17.8)	67.0 (18.6)	62.2 (17.7)	62.8 (20.2)		
		Desire	e for Surgery			
	Included					
	n=78,461	n=78,461	n=46,751	n=46,751		
No (n (%))	58,242 (74.2)	61,343 (78.2)	37,504 (80.2)	36,565 (78.2)		
Yes (n (%))	20,219 (25.8)	17,118 (21.8)	9,247 (19.8)	10,186 (21.8)		
		F	Excluded			
	n=35,252	n=964	n=66,962	n=495		
No (n (%))	24,085 (68.3)	684 (71.0)	44,823 (66.9)	342 (69.1)		
Yes (n (%))	11,167 (31.7)	280 (29.1)	22,139 (33.1)	153 (30.9)		

Use of NSAIDs

Table 10 OA outcomes in those included and excluded in the CI analysis

			Included		
	n=80,243	n=80,243			
No (n (%))	45,458 (56.7)	54,749 (68.2)			
Yes (n (%))	34,785 (43.4)	25,494 (31.8)			
		Excluded			
	n=33,317	n=185			
No (n (%))	19,002 (57.0)	141 (76.2)			
Yes (n (%))	14,315 (43.0)	44 (23.8)			

Abbreviations: CI, Concentration index; n, number; ASES, arthritis self-efficacy scale; NSAIDs, non-steroidal antiinflammatory drugs.

Then, Erreygers' concentration indices were calculated for the four investigated OA outcomes in the included cohort (Table 11 and Figure 8). Specifically, the variable 'pain' was more concentrated among people with lower income at the baseline (E=-0.027) and became even more concentrated among them after attending the intervention at 3-month follow-up (difference with baseline: E=-0.011 [95% CI: -0.015; -0.007]) and 12-month follow-up (difference with baseline: E=-0.016 [95% CI: -0.021; -0.012]). Similarly, 'Desire for surgery' was more concentrated among people with lower income at the baseline (E=-0.008) and became even more concentrated in this group at 3-month follow-up (difference with baseline: E=-0.012 [95% CI: -0.018; -0.005]) and 12-month follow-up (difference with baseline: E=-0.012 [95% CI: -0.022; -0.002]). Conversely, the variable 'Self-efficacy' was more concentrated among people with higher income at baseline (E=0.057) and became even more concentrated among them after attending the intervention at 3-month follow-up (difference with baseline: E=0.008 [95% CI: 0.004; (0.0012]) and 12-month follow-up (difference with baseline: E= 0.017 [95% CI: 0.012; 0.021]). Finally, the variable 'Use of NSAIDs' was more concentrated among people with lower income at the baseline (E=0.068), but this concentration narrowed after attending the intervention at 3-month follow-up (difference with baseline: E=-0.029 [95% CI: -0.038; -0.021]).

	Ν			Differences	Ν			Differences	
	Baseline		3-month	3-month	Baseline		12-month	12-month follow-up	
Variables	-	Baseline	follow-up	follow-up	-	Baseline	follow-up	<b>- p</b>	
	3-month			-	12-month			_	
	follow-up			Baseline	follow-up			Baseline	
		Eri	reygers' Concent	ration Index		Е	rreygers' Concent	ration Index	
Pain	n=80,329			-0.011	n=47,499			-0.016	
		-0.027	-0.039	[-0.015; -0.007]		-0.027	-0.043	[-0.021; -0.012]	
		Erreygers' Concentration Index			Erreygers' Concentration Index				
Self-Efficacy	n=32,614			0.008	n=25,370			0.017	
		0.05	0.057	0.065	[0.004; 0.012]		0.058	0.075	[0.012; 0.021]
		Erreygers' Concentration Index			Erreygers' Concentration Index				
Desire for	N=78,461			-0.012	n=46,751			-0.012	
Surgery		-0.008 -0.0	-0.020	[-0.018; -0.005]		-0.012	-0.024	[-0.022; -0.002]	
		Eri	reygers' Concent	ration Index					
Use of NSAIDs	n=80,243			-0.029	-				
MSAIDS			0.068	0.038					

#### Table 11 Concentration indices in the OA outcomes

Abbreviations: N, number; NSAIDs, non-steroidal anti-inflammatory drugs.

Pro-Lov	v-Income Inequality	Pro-High-Income	Inequality		
	Pain				
3-months – baseline (n=80,329)	f: -0.039 b: -0.027				
	d: -0.011 [-0.015; -0.007]				
12-months – baseline (n=47,499)	f: -0.043 b: -0.027				
	-0.05 d: -0.016[-0.021; -0.012] 0	C	0.05		
	Self-effi	cacy			
3-months – baseline (n=32,614)			b: 0.057 f: 0.065		
			d: 0.008 [0.004; 0.012]		
12-months – baseline (n=25,370)			0.058 0.075		
	-0.05 0	C	d: 0.017 [0.012; 0.021]		
	Desire for	surgery			
3-months – baseline (n=78,461)	f: -0.020 b: -0.008				
	d: -0.012 [-0.018; -0.005]				
12-months – baseline (n=46,751)	f: -0.024 b: -0.012				
	-0.05 d: -0.012 [-0.022; -0.002] 0	C	.05		
	Use of N	SAIDs			
3-months – baseline (n=80,423)		f: 0.038	b: 0.068		
	-0.05 0	d: -0.02	d: -0.029 [-0.038; -0.021]		

#### Figure 8 Concentration index values and changes throughout timepoints

Abbreviations: n, number; f, follow-up value; b, baseline value; d: the difference between baseline and reported follow-up; NSAIDs, non-steroidal anti-inflammatory drugs.

# **Ethical Considerations**

Albeit the studies of this thesis could not harm patients, several strict procedures were put in place to conduct this thesis ethically. Regarding data protection, the online survey (Study 1) was delivered through RedCap, a secure web application to build and manage online surveys and databases, respecting the European General Data Protection Regulations. Only the participants who agreed to partake in the study could gain access to it. Moreover, we did not record their IP. Regarding the qualitative study (Study 2), patients were thoroughly instructed and informed about the aim of the research and about how we would treat their data. They had to sign an informed consent and were assigned an identifier (ID). All their data was related to this ID and stored anonymously in a University of Genova OneDrive folder, which was only accessible to those who analysed the interviews. Moreover, all the other documents (i.e., video and audio recordings) were deleted once the interviews were transcribed and anonymised. The register-based studies in Sweden (Studies 3 and 4) generally do not require informed consent. Still, it is assumed that the study participants do not object to registry-based research, provided that such research is deemed ethical by an Ethics Committee. Therefore, we asked for ethics committee approval in Sweden for studies 3 and 4 (Dnr: 2019-02570) and in Italy for studies 1 and 2 (CERA2020.07).

# **General Discussions**

This thesis highlighted some critical areas in the OA care process that have been largely neglected but require further attention. As per the cultural factors, physiotherapists acknowledged the importance of first-line interventions but failed to implement them. Meanwhile, patients have often viewed these interventions merely as a way to pass the time until surgery, with little understanding of their fundamental role. Then, our investigation into the sociodemographic and economic factors affecting adherence to OA treatment did not yield any definitive answers. Therefore, there is a need for further research to identify the underlying factors at play. Finally, although OA self-management programmes have been developed to empower patients, they may inadvertently deepen pre-existing inequalities. Therefore, it is crucial to address these inequalities head-on and ensure that self-management interventions are implemented in a way that does not exacerbate inequalities. Focusing on a more comprehensive and inclusive approach to OA care can improve patients' HRQoL and help them manage their condition effectively.

CPGs are essential to bridge the gap between best evidence and clinical practice. Therefore, clinicians need to be aware of their recommendations to provide high-quality care. In Study 1, over 90% of our sample seemed aware of the importance of exercise and education, consistent with findings from other studies worldwide [87–89, 171]. However, this knowledge was not consistently reflected in their clinical practice. Physiotherapists often excluded weight loss advice, and rest was often considered, although the patient in the clinical vignette had a high BMI and presented moderate symptoms. In fact, some physiotherapists may consider recommending weight loss to be beyond their clinical scope [17]. Also in previous studies, physiotherapists suggested muscle-strengthening exercises, but they refrained from recommending aerobic exercise and weight loss [17, 88]. Providing physiotherapists with specific recommendations for managing people with high BMI can be a strategy to improve patients' outcomes and increase the overall level of adherence to CPGs.

On the other hand, drawing conclusions on the relatively high inclusion of rest and load reduction in the treatment is challenging. A possible explanation is that OA CPGs do not provide specific guidance to tailor exercises to patients' conditions. As a result, physiotherapists may feel unsure and unprepared to deal with exercise in OA [172]. On top of that, different barriers exist to implementing OA CPGs in the complex primary care setting [115]. Just to mention a few, patients' preferences, resource availability, discrepancies between guidelines, lack of English knowledge and access to information

[84, 173]. Furthermore, we found an insufficient level of knowledge of the criteria for the OA clinical diagnosis: only 10% of our sample considered NICE criteria (i.e., being older than 45, having pain and joint stiffness for less than 30 minutes in the morning) sufficient to diagnose OA. The lack of agreement on clinical diagnostic criteria may explain the relatively high percentage (>40%) of physiotherapists considering radiographic findings essential to diagnose OA. This finding about the importance of imaging in OA is coherent with the result of a similar survey by Ayanniyi *et al.* [89]. In OA, radiographic findings should be considered if other diseases are the suspected cause of the symptoms (e.g. infection, cancer, rheumatoid arthritis) or once planning surgical intervention [11]. Likewise, establishing clinical decisions on imaging reinforces the perception of OA as a wear-and-tear disease and may promote fear-avoidance behaviours [116, 174].

Finally, more than 70% of our sample would provide manual therapy in OA. From a cultural perspective, manual therapy is a core physiotherapists' competence that historically set the basis of this healthcare profession. Thus, patients often expect manual therapy [175]. Meeting patients' expectations can improve clinician-patient relationships and enhance the care process [59, 176]. In fact, the quality of the care process depends not only on the appropriateness of treatments delivered by health professionals (technical aspects) but also on different relational and functional aspects investigated in Study 2 [177].

The functional aspects are the basic expectations about how care should be delivered, and they underscore the delivery of effective treatments by trustworthy professionals [74, 177]. Our interviewees did not perceive the treatment indications they received from healthcare professionals to be based on evidence, leading to a sense of uncertainty. Uncertainty is a poorly addressed issue in healthcare that can result in patients' inefficient coping strategies, dysfunctional adaptation to illness and conflicting relationships with healthcare professionals [178–180]. Moreover, our interviewees resorted to looking for information from different sources (e.g., different professionals, the Internet and word-of-mouth) as a result of this perceived uncertainty. Patients' need to interrogate various sources can stem from dissatisfaction with the information received from a healthcare professional [181].

The relational aspect includes all the interactions between the patient and the health professional(s) [177]. The interviewees complained about a lack of empathy in the health professionals they met. Treatments devoid of empathy jeopardise the relationship between patients and health providers, leading to dissatisfied patients that might not adhere to the recommended interventions [182]. In particular, this lack of empathy was specifically perceived during the diagnosis and prognosis of OA. The people who were interviewed sensed a feeling of despair after encountering some healthcare providers. This feeling stemmed from viewing OA as an inevitable consequence of ageing,

treatable only through surgery. In addition, this feeling was reinforced by the structural degeneration shown by their X-rays, which doctors deemed necessary for making a diagnosis and commented on using phrases such as "if I did not know that these x-rays belonged to you, I would think that they belong to someone who is at least 30 years older than you". However, as reported above, radiographic findings are considered by CPGs as complementary to the assessment of OA [11].

Regarding the technical aspects, patients reported a treatment that was mainly (if not entirely) based on passive therapies while waiting for surgery. Not only was movement considered as dangerous, it was also considered a possible risk factor for anticipated surgery and valuable only after joint replacement. However, people with OA seemed open to undergoing exercise and physiotherapy interventions once educated on their benefits [181, 183]. In our interviews, patients shared a similar experience as they understood the importance of being active and saw exercise as a real support to their care.

According to the findings of this paper, several aspects may function as facilitators or barriers to patients' exercise adherence, such as the lack of time and unwillingness to change life habits. The former is a well-known cause of lack of adherence to exercise [184–186]. The latter is a shared barrier to implementing diet strategies into patients' care. Individuals are reluctant to engage in health-promoting behaviours, even though they can reduce mortality and improve their well-being [187].

Study 3 examined exercise adherence in OA. This study was unique as it sought to investigate to what extent demographic, lifestyle, socioeconomic, and disease-related factors were related to adherence to a face-to-face supervised exercise programme for OA in a large group of people with the condition. In our sample, almost 30% had low, 20% had medium, and 50% had high adherence levels. This distribution of adherence levels aligns with that of participants in a similar Danish intervention[188]. Still, it is different from the distribution observed in the online version of the same intervention, which had a higher proportion of people with high levels of adherence [189]. Although multiple factors were linked to adherence, the complete model only accounted for 1% of the variation, indicating that these factors are unlikely to impact exercise adherence substantially.

As far as the demographic and lifestyle factors were concerned, the female sex was negatively associated with a high level of adherence. Women may face societal expectations of caregiving responsibilities, making it harder to find time to exercise[190–194]. However, in the digital version of the investigated Swedish interventions, the female sex was positively associated with high levels of exercise

adherence [189], suggesting that the delivery modality may play a role in the association between sex and adherence. Nevertheless, addressing the root causes of the gender disparities is essential rather than focusing solely on the delivery mode. It is worth noticing that our study only collected information on participants' assigned sex (at birth), limiting generalisability to non-cisgender individuals. Further research is needed to explore gender identity and exercise adherence in people with OA. Then, according to the study's findings, there was a positive correlation between participants' age and high levels of adherence. This result is consistent with previous research that suggested older adults to be more likely to adhere to self-paced exercises, such as those offered in this study, as opposed to moderate-intensity exercise [195]. Finally, BMI was negatively associated with high levels of adherence, as people with high BMI seemed less keen on engaging in physical exercise [196]. In the digital version of the Swedish first-line intervention, BMI was negatively associated with high levels of adherence [189]. Therefore, there is a need to find new strategies to motivate people with high levels of BMI to partake to exercise.

Among the socioeconomic factors, people with lower SEP seemed to adhere more to this intervention. These results contrast the previous literature, where higher SEP seemed to be linked with higher exercise engagement [137, 197]. However, these findings arise primarily from secondary analyses of RCTs not designed to investigate adherence [198]. RCTs per se tend to enhance adherence to treatment which bias the observed associations [199]. Furthermore, in RCTs, people are volunteers selected on specific inclusion and exclusion criteria that may not accurately reflect the socioeconomic diversity of the population from which the sample was drawn [200]. Moreover, individuals with lower SEP may experience a more severe burden of OA than their higher counterparts [27]. Severe symptoms can motivate and drive exercise adherence [197, 201]. Also our study revealed this phenomenon once examining disease-related factors, as frequent pain and difficulty walking were associated with high levels of adherence.

Moreover, we found self-efficacy to be associated with exercise adherence, as in previous evidence [202], but with a modest RRR. Bandura defines self-efficacy as "an individual's belief in his or her own ability to organise and implement action to produce the desired achievements and results", such as a behavioural change [203]. Self-efficacy seems characterised by a u-shaped relationship with task accomplishment [204]. People with low self-efficacy tend to doubt their ability to complete a task successfully [204]. In contrast, those with high self-efficacy may exhibit complacency, inadequate preparation, and a focus solely on achieving task-related goals [204]. As a result, low and high levels of self-efficacy may result in a similar outcome, such as low adherence to a task (e.g., exercise). Considering the large number of people in our study, the effect of someone's self-efficacy might be diluted due to the significant heterogeneity within our population.

However, our model could explain only 1% of the variability, as pointed out by the McFadden  $R^2$ . Thus, it is unlikely to improve adherence significantly by designing strategies based on demographic and lifestyle, socioeconomic and disease-related factors. Therefore, other factors should be taken into account and are further discussed in the 'Future perspective' section of this thesis.

Finally, the socioeconomic factors were further investigated in Study 4 with a concentration index approach. Specifically, we analysed income inequalities in different OA outcomes (i.e., 'Pain intensity', 'Self-efficacy', 'Desire for Surgery' and 'Use of NSAIDs') before and after attending an OA first-line intervention. Our results suggested that pain and desire for surgery were more concentrated among people with lower income, while self-efficacy and use of NSAIDs were more concentrated among people with higher income. Attending the intervention widened income-related inequalities in pain, self-efficacy and desire for surgery, while a narrowing income-related inequality was seen for the use of NSAIDs. In line with that, our data suggest the possible presence of intervention-generated inequalities in the SOAR.

Regarding pain, previous evidence indicated that people in Sweden with lower SEP experienced a higher disease burden, regardless of the socioeconomic index [27, 28]. In Unevik et al., people with lower educational attainment and foreign-born experienced higher pain levels than their higher educated and non-foreign counterparts [27]. In Kiadaliri et al., they found educational attainment and occupation inequalities in the prevalence of knee pain [28]. Hence, our study indicated a similar trend using income as a measure of SEP. Similar scenarios of the association between SEP and higher OA pain were also found worldwide [205–207].

The greater perceived pain intensity can be one potential explanation for the higher concentration of the desire for surgery among individuals with lower income [208, 209]. There is a correlation between total joint replacement (TJR) and health-seeking behaviour, and those with lower SEP require TJR the most due to their more severe symptoms [131]. Our results support those reported in Sweden and other European and non-European countries, showing an association between lower SEP and a stronger desire for surgery [131, 210, 211]. Another reason for the higher willingness for surgery in those with lower income can be the lower reported self-efficacy. In first-line interventions for OA, individuals with this condition play an active role in their care process by collaborating with healthcare providers, sharing expertise, setting goals, and taking responsibility for their treatment by selecting and adopting self-management strategies that impact their lifestyle. Therefore, individuals with higher income and higher levels of self-efficacy may be more self-assured in their ability to manage the

burden of their disease by adopting active treatments (such as those proposed in OA first-line intervention programmes) rather than opting for surgery.

The greater reported benefits experienced by individuals with higher income may also explain why the pro-rich inequality in the use of NSAIDs was reduced after attending the intervention. Prior to the intervention, individuals with higher income had a higher prevalence of NSAID use. This tendency could be explained by the fact that people with higher income may have greater access to healthcare services, resulting in more opportunities to receive prescriptions for NSAIDs. However, following the intervention led to a reduction in these pro-rich inequalities, underscoring the fact that people with higher income derived the greatest benefit from the intervention. Existing research on the link between income and NSAID use has yielded inconsistent findings. Bonnesen et al. found that the lowest-income people had a lower probability of getting additional NSAID prescriptions [212]. Nielsen et al. found that having a low income was slightly associated with the prescription of NSAID but not with their over-the-counter use [213]. Finally, Fosbøl et al. found no differences in NSAID use among those in the highest or lowest income categories [214]. Previous studies on income and health outcomes have often categorised or dichotomised income instead of treating it as a continuous variable. However, such an approach may result in statistical analysis limitations, including reduced statistical power due to the loss of information [215]. In addition, the other studies used average association measures such as OR, which may not effectively capture differences in the distribution of NSAID use across the entire population, as they rely only on average associations between different income groups [216].

## Studies' Limitations

In Study 1, our sample was mainly composed of physiotherapists with a post-graduate degree (47%). Therefore, we might have overestimated the real level of knowledge of and adherence to osteoarthritis CPGs. In Study 2, we gathered a small sample size that limits the generalisability of the results [217]. However, qualitative studies do not aim at data generalisation [110]. Besides, all the interviewees lived in a similar geographical area (i.e. northern Italy) and were mostly women and Caucasian. This is particularly important since meanings attached to an experience might be influenced by gender, ethnicity and geographical location. Finally, the interviewees were at different stages of their care process. However, all patients agreed with what emerged during the member checking phase that was held at the end of the study by sending our results to all the interviewees. Additionally, some variables had missing values, but the missingness of our data is likely to be completely at random and not introduce significant bias in our results. Furthermore, our study lacks data on other predictors of adherence, and certain reported variables (e.g., weekly physical activity) may have limited explanatory power due to the way they were measured. Our results may not generalise to other forms of exercise (e.g., unsupervised home exercise) due to the specific focus of our study. Finally, while certain variables were found to have medium but not high levels of association with adherence (such as 'physical activity hours', 'number of painful joints', and 'living alone'), this finding may be influenced by chance or the adherence categorisation used in the SOAR study. In Study 4, those registered in the SOAR have higher SEP than the general Swedish population [150]. Therefore, our results might underestimate the impact of this OA first-line intervention in generating inequalities. Then, this intervention does not have a comparable control group. Thus, we do not know whether the observed results can be attributed to the intervention itself. Moreover, a few variables were missing as per Study 3. To conclude, the observational nature of our studies, did not allow us to identify any causal relationship. Overall, this thesis included studies from two countries that are very different to one another. Nevertheless, we compared our results to similar studies conducted worldwide, rather than focussing on Italy and Sweden solely.

## **Future Perspectives**

This thesis further proves the need to improve OA care at various levels. Healthcare professionals could be targeted to bridge the gap between evidence and clinical practice. Therefore, future studies should investigate new strategies for accomplishing this and are discussed hereafter. CPGs should include essential practical elements, such as algorithms for clinical decision-making in complicated cases and inclusion-exclusion criteria for patients, once compiling CPGs. Providing physiotherapists with CPGs in their native language and promoting their use in university programmes may be another possible solution to improve compliance with recommendations. There is also a need to reconceptualise the professional image of physiotherapists within society. Specifically, we need to shift towards a new vision of physiotherapists no longer associated solely with physical and manual therapy but focused on improving patients' functioning through active treatment strategies such as exercise and education, tailored to specific contexts and grounded in scientific evidence.

As per the patients, this thesis sheds some light on common themes in the experience of people with OA. People with hip and knee OA often encounter an uncertain care process, characterised by the lack of clear explanations, insufficient empathy, and negative attitudes towards first-line non-surgical treatments. These factors underscore the importance of implementing effective communication and providing patients with adequate information about treatment options. As a result, patients' beliefs can be positively impacted, increasing their awareness and compliance with first-line interventions.

Moreover, we need to understand which factors are associated with exercise adherence to create tailored interventions to improve it. Modern and well-designed RCTs are exposing the weaknesses in the evidence supporting the effectiveness of exercise in curbing OA pain [218–220]. However, exercise leads to benefit that goes beyond joint health as exercise positively affects body weight, lipid metabolism, hyperglycaemia, mood and systemic inflammation, preventing different OA-related comorbidities (e.g., diabetes and depression) [33, 34]. In this thesis, we indicated that strategies based on demographic, lifestyle, socioeconomic and disease-related factors are unlikely to improve adherence significantly. On the other hand, preliminary evidence suggested that improving mindsets about exercise can increase adherence [221]. Mindsets are "core assumptions about a domain or category that orient individuals to a particular set of attributions, expectations, and goals" [221, 222]. Mindsets are responsible for encoding contextual factors (e.g., the facility's structure, the clinician's communication style, and the ability to motivate patients), affecting people's outcomes via a placebo (or nocebo) response if positively (placebo) or negatively (nocebo) judged by one's brain [109]. Booster sessions, reminders, and behavioural change techniques can also improve exercise adherence by increasing motivation to engage in exercise [223, 224]. These strategies seem to ground their efficacy on contextual factors too (e.g., communication with the clinicians, feeling to be taken care of by them etc.). Future studies should explore the relationship between contextual factors, mindsets, and exercise adherence to understand better how to improve adherence in patients with OA.

Finally, we need to reduce inequalities in OA care. Bearing in mind that there is no society without inequalities, it is essential to find new strategies to reduce them in OA care. Our results suggested the possible presence of intervention-generated inequalities in this OA first-line intervention. Moreover, past evidence showed that people in socially disadvantaged backgrounds might not even begin this intervention, though delivered in the public healthcare system [150]. Therefore, we need to evaluate the systemic, institutional, and power-related harms of interventions by adopting a health-equity approach to make these interventions more accessible to underserved populations. Past evidence showed that upstream interventions are necessary to tackle the root causes of health disparities [133, 225, 226]. These interventions involve political, social, and economic policies (e.g., fiscal food policies, urban planning policies, transport policies, increase wage etc.) [133, 227]. Conversely, downstream interventions like healthcare and individual behaviour change play a limited (to no) role in reducing inequalities and should not be the main focus of decision-making related to health inequalities [133].

## Conclusions

Several areas in the OA care process require attention and are currently being neglected. To improve the quality of OA care, we need to take further actions. Firstly, we need to close the evidence-to-practice gap among healthcare professionals working with people with OA. Secondly, we need to raise awareness among people with OA of their active role in their care and the importance of first-line interventions. Thirdly, we need to acknowledge that adherence to exercise is a complex behaviour that cannot be explained solely by people's lifestyle, demographic, socioeconomic and disease-related status. Therefore, we need to invest more resources in understanding which factors are related to exercise adherence and develop tailored interventions to target and improve it. Finally, while self-management programmes have been designed to empower patients, they may inadvertently exacerbate existing inequalities. Therefore, we need to find new ways to reduce inequalities in OA care, prioritising upstream interventions.

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# Manuscripts

Study 1

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### **RESEARCH ARTICLE**

BMC Musculoskeletal Disorders

### Italian physiotherapists' knowledge of and adherence to osteoarthritis clinical practice guidelines: a cross-sectional study





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#### Abstract

**Introduction:** Implementation of clinical practice guidelines (CPGs) to manage musculoskeletal conditions among physiotherapists appears suboptimal. Osteoarthritis is one of the most disabling conditions worldwide and several studies showed a lack of knowledge of and adherence to osteoarthritis CPGs in physiotherapists' clinical practice. However, those studies are not conclusive, as they examine the knowledge of and adherence to CPGs only in isolation, or only by focussing on a single treatment. Thus, analysis of the knowledge of and adherence to CPGs in the same sample would allow for a better understanding of the evidence-to-practice gap, which, if unaddressed, can lead to suboptimal care for these patients. This study aims at assessing Italian physiotherapists' evidence-to-practice gap in osteoarthritis CPGs.

**Methods:** An online survey divided into two sections investigating knowledge of and adherence to CPGs was developed based on three high-quality, recent and relevant CPGs. In the first section, participants had to express their agreement with 24 CPG statements through a 1 (completely disagree) to 5 (completely agree) scale. We defined a  $\geq$  70% agreement with a statement as consensus. In the second section, participants were shown a clinical case, with different interventions to choose from. Participants were classified as 'Delivering' (all recommended interventions selected), 'Partially Delivering' (some recommended interventions missing) and 'Non-Delivering' (at least one non-recommended interventions selected) the recommended intervention, depending on chosen interventions.

**Results:** 822 physiotherapists (mean age (SD): 35.8 (13.3); female 47%) completed the survey between June and July 2020. In the first section, consensus was achieved for 13/24 statements. In the second section, 25% of the participants were classified as 'Delivering', 22% as 'Partially Delivering' and 53% as 'Non-Delivering'.

(Continued on next page)

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**Conclusions:** Our findings revealed an adequate level of knowledge of osteoarthritis CPGs regarding the importance of exercise and education. However, an adequate level of adherence has yet to be reached, since many physiotherapists did not advise weight reduction, but rest from physical activity, and often included secondary treatments (e.g. manual therapy) supported by low-level evidence. These results identify an evidence-to-practice gap, which may lead to non-evidence based practice behaviours for the management of patients with osteoarthritis.

Keywords: Osteoarthritis, Osteoarthritis, knee, Osteoarthritis, hip, Practice guidelines as topic, Clinical governance, Physical therapy specialty, Physical therapists, Education, public health professional

#### Introduction

Osteoarthritis is the most prevalent joint disease, and one of the most common causes of disability worldwide [1], for whose management several international Clinical Practice Guidelines (CPGs) have been released [2–4]. CPGs are collections of graded recommendations supported by a systematic review of evidence, intended to help clinicians to optimise patient care [5]. In osteoarthritis, the European League Against Rheumatism (EULAR), Osteoarthritis Research Society International (OARSI) and the National Institute for Health and Care Excellence (NICE) CPGs [2–4] recommend exercise and education [6] as first-line interventions for their ability to reduce pain and disability, regardless of the severity of the disease [7, 8].

Despite the differences in grading the strength of recommendations between them, all abovementioned CPGs categorised the level of evidence, of the different treatments, into six categories from Ia to IV [2-4]. Treatments categorised as Ia are derived from systematic reviews of randomised controlled trials (RCTs) [2-4, 9]; whereas, treatments categorised from IIa to IV are based on lower quality RCTs, cohort studies or the opinion of experts in the field [2-4, 9]. The level of evidence in all CPGs is one of the factors that contribute to defining the strength of the recommendations together with the balance between benefits and harms, considerations of values and preferences, and resources implications [10]. By taking into account all these factors, treatments such as therapeutic exercise and patients education (Ia, level of evidence) are categorised as first-line interventions, whereas treatments such as hyaluronic acid injection and manual therapy (IV, level of evidence) are categorised as conditional recommendations [2-4].

In spite of the availability of several high-quality osteoarthritis CPGs, Egerton et al. highlighted that clinicians who work with patients with osteoarthritis perceived themselves as under-prepared and unfamiliar with CPGs [11]. Besides, implementation of CPGs for the management of musculoskeletal conditions among physiotherapists appears suboptimal [12] and osteoarthritis often remains under-diagnosed and under-treated, with less than 40% of people with osteoarthritis receiving the recommended first-line intervention [13, 14].

Several studies have explored physiotherapists' knowledge of and adherence to osteoarthritis CPGs, showing major gaps in the implementation of weight reduction strategies, therapeutic exercise and patients education, as opposed to what has been noticed for other passive modalities (e.g. manual therapy) [15–19]. The reasons behind this gap are several. First of all, the care of people with knee and hip osteoarthritis is a complex process in which the clinician is required to balance knowledge of the best evidence with the patients' preferences and beliefs [20]. Secondly, clinicians may face several barriers to the implementation of CPGs, such as clinical applicability, language and lack of time, which can widen this gap even further [21–23].

However, the aforementioned studies on the application of osteoarthritis CPGs are not conclusive, as they either examined the knowledge of or adherence to CPGs, [16–19] or focus solely on a particular treatment (e.g. therapeutic exercise) [15]. In fact, knowledge of the CPGs does not automatically translate into clinical practice [24, 25], thus an analysis of the knowledge of and adherence to CPGs in the same sample would allow for a better understanding of the so-called *evidence-topractice gap* [21].

In line with this, this study aimed at exploring the knowledge of and adherence to osteoarthritis CPGs in a cohort of Italian physiotherapists in order to identify the possible evidence-to-practice gap. By analysing this gap in Italy, this study gathered information that might be more easily transferred to other Mediterranean countries which seem to have higher educational needs compared to the Northern-European ones [26].

#### Methods

#### Study design

A quantitative web-basedcross-sectional survey investigating physiotherapists' knowledge of and adherence to osteoarthritis CPGs was developed according to the *International Handbook of Survey Methodology* and to the *Checklist for Reporting Results of Internet E-Survey*  through the use of distinct and iterative steps [27, 28]. The study was conducted following the Declaration of Helsinki. Ethical approval was obtained from the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (approval date: 15/06/2020; CERA2020.07) and follows the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations for reporting observational studies [29].

#### Survey development

The questionnaire was developed based on the EULAR, OARSI and NICE CPGs [2–4]. Before the online dissemination, the survey was tested on a sample of six physio-therapists specialised in musculoskeletal rehabilitation. The online version of the questionnaire was delivered through *Microsoft 365 Forms*, a secure web application to build and manage online surveys and databases, respecting the European General Data Protection Regulations [30]. The questionnaire included a brief cover letter, and the informed consent outlining the aim of the study. The cover letter emphasised that participation in the survey was voluntary and that anonymity and confidentiality were guaranteed.

The questionnaire was delivered in Italian and it was divided into two sections investigating (1) the knowledge of and (2) the adherence to osteoarthritis CPGs. Before the first section, a paragraph investigating the sociodemographic variables (e.g. sex, age, years of experience) and if the physiotherapists read, at least, one osteoarthritis CPG, was included. The first section comprised 24 statements on knee and hip osteoarthritis management, adapted from the aforementioned CPGs. Each statement was acquired from the synoptic review of the three CPGs (Table 1).

If disagreement was found between the CPGs, the most recent recommendation was considered when phrasing the statement. To measure agreement with the statement, we used a 5-point Likert scale ranging from completely disagree (score 1) to completely agree (score 5) [31]. Participants who partially or completely agreed (scores 4–5) were considered to agree with the statements. Furthermore, to limit acquiescence bias, i.e. the tendency to agree with all the survey statements, eleven reversed statements were put into the questionnaire so that disagreement with those statements (scores 1–2) would indicate an agreement with the CPGs [32].

The second section presented a clinical vignette illustrating a case of knee osteoarthritis (Table 2). Clinical vignettes are considered a valid tool to assess healthcare professionals' clinical reasoning and behaviour, including physiotherapists, as they are easy to administer, and all the variables within them can be easily manipulated [33]. The participants were, therefore, invited to express how they would manage that specific patient by selecting from a list of options. The options were grouped into three sub-sections representing three different clinical moments (management, assessment and treatment). In the management section, the participants were asked whether they would opt to treat the presented patient or refer her to a specialist for pharmacological or surgical treatment. Participants who decided to refer the patient to a specialist without performing any assessment or treatment were directed to the end of the questionnaire, considered non-delivering any possible clinical options.

#### Participants

An online version of the questionnaire, attainable through a hyperlink, was delivered through the Italian Association of Physiotherapists (AIFI) and the University of Genova newsletters. We included physiotherapists who had treated at least one person with osteoarthritis in the previous six months within the targeted population. To do so, after the cover letter, the questionnaire included a preliminary question asking the respondents if they had treated any patients, with hip or knee osteoarthritis in the last six months. Participants who answered "No" were shown a Thank-You page and were not allowed to continue the questionnaire.

#### Variables

The primary outcome of the present study was the level of knowledge of and adherence to CPGs of a sample of Italian physiotherapists.

#### Analysis

Descriptive analysis was carried out to understand the sample's characteristics. Moreover, the frequencies of physiotherapists who declared to have read at least one osteoarthritis CPG was reported.

### Section 1: level of knowledge of clinical practice guidelines – statement consensus

In section one, participants who partially or completely agreed with a statement (scores 4–5) or partially or completely disagreed (scores 1–2) with a reversed statement were considered to agree with the CPGs recommendation. The overall consensus with each statement was investigated. In the absence of a standard threshold, we defined  $a \ge 70\%$  agreement with a statement as consensus [34].

#### Section 2: level of adherence to clinical practice guidelines – clinical vignette

In section two, participants were classified as 'Delivering', 'Partially Delivering' and 'Non-Delivering' the core treatments depending on the interventions chosen. Table 1 Section 1: Statements and synoptic review of Clinical Practice Guidelines

Statements	Clinical Practice Guidelines				
1) Exercise can be effective on all patients, regardless of the pain severity.	NICE (1.2.5–1.4.1) [4]; EULAR (3–6-7) [2]; OARSI (Tables 2-3) [3]				
2) In an advanced stage of the disease, exercise can damage the joint (reversed statement).	NICE (1.2.5–1.4.1) [4]; EULAR (2–3–6-7) [2]; OARSI (Tables 2-3) [3]				
<ol> <li>The rehabilitation programme must always include a part of education on the pathophysiology of osteoarthritis and self-management strategies.</li> </ol>	NICE (1.3.1–1.3.2–1.3.3) [4]; EULAR (3–5) [2]; OARSI (Tables 2-3) [3]				
4) The rehabilitation programme should always include a part of manual treatment (reversed statement)	NICE (1.4.2) [4]; EULAR (); OARSI ()				
5) Exercise should only be undertaken after prescribing drug treatment to control pain (reversed statement).	NICE (1.2.5–1.4.1) [4]; EULAR (3–6-7) [2]; OARSI (Tables 2-3) [3]				
6) The use of topical anti-inflammatory drugs is effective for pain relief for knee osteoarthritis.	NICE (1.5.3) [4]; EULAR (); OARSI (Table 2) [3]				
7) Radiographic findings are needed to express a functional diagnosis of osteoarthritis (reversed statement).	NICE (1.1.1) [4]; EULAR (1) [2]; OARSI (-)				
8) Radiographic findings are needed to plan the physiotherapy treatment (reversed statement).	NICE (1.1.1) [4]; EULAR (1) [2]; OARSI (-)				
9) Physical activity should be avoided because it can damage the joint (reversed statement).	NICE (1.2.5–1.4.1) [4]; EULAR (3–6-7) [2]; OARSI (Tables 2-3) [3]				
10) The use of topical anti-inflammatory drugs is effective for pain relief for hip osteoarthritis.	NICE (); EULAR (); OARSI ()				
11) In case of severe joint degeneration, it is necessary to recommend rest from physical activity ( <b>reversed</b> statement).	NICE (1.2.5–1.4.1) [4]; EULAR (2–3–6-7) [2]; OARSI (Tables 2-3) [3]				
12) In cases of severe pain (VAS $\geq$ 6/10), arthroplasty surgery should be preferred to rehabilitation ( <b>reversed</b> statement).	NICE (1.6) [4]; EULAR (); OARSI ()				
13) The use of TENS should be considered.	NICE (1.4.4) [4]; EULAR (); OARSI ()				
14) The use of physical therapies such as lasers, TECAR and ultrasound therapy should be considered ( <b>reversed statement</b> ).	NICE (1.4.4) [4]; EULAR (-); OARSI (-)				
15) In addition to the rehabilitation treatment, it is useful to recommend physical activity (for example, yoga, swimming, Nordic walking).	NICE (1.2.5–1.3.2–1.4.1) [4]; EULAR (–); OARSI (Tables 2- 3) [3]				
16) It is important to recommend weight loss to overweight or obese patients.	NICE (1.2.5–1.4.3) [4]; EULAR (3–8) [2]; OARSI (Tables 2-3) [3]				
17) Age > 45, pain and absence of joint stiffness (or < 30 min) in the morning are sufficient to diagnose osteoarthritis.	NICE (1.1.1) [4]; EULAR (-); OARSI (-)				
18) The use of comfortable footwear, braces or aids should be considered.	NICE (1.3.2–1.4.7–1.4.8–1.4.9) [4]; EULAR (3–9-10) [2]; OARSI (Tables 2-3) [3]				
19) It is advisable to refer the patient for arthroscopy surgery to reduce symptoms and start/continue treatment (reversed statement).	NICE (1.4.10) [4]; EULAR (); OARSI ()				
20) It is necessary to assess the impact of osteoarthritis on function, quality of life and disability.	NICE (1.2.1) [4]; EULAR (1) [2]; OARSI (-)				
21) At least 10-12 sessions are needed to ensure proper treatment for osteoarthritis.	NICE (1.4.1) [4]; EULAR (6) [2]; OARSI (-)				
22) In the treatment for osteoarthritis, the patient's adherence to the treatment must be motivated.	NICE (1.3.2-1.4.1-1.7.1) [4]; EULAR (-); OARSI (-)				
23) Joint hyaluronic acid and/or corticosteroid infiltrations should be considered.	NICE (1.5.12–1.5.13) [4]; EULAR (–); OARSI (Table 2) [3]				
24) The supplements of chondroitin and glucosamine should be considered (reversed statement).	NICE (1.4.5) [4]; EULAR (-); OARSI (-)				

Legend: (n), CPGs paragraph into which the statements were originally reported; (--), the CPGs did not adopt a position on that statement; [n], CPGs reference

Briefly, they were considered as delivering the recommended intervention if they chose all the treatments recommended by the CPGs for the patient described in the vignette, without selecting non-recommended treatments. They were considered partially delivering the recommended intervention if they chose only some of the recommended treatments but none of the nonrecommended ones. Lastly, they were considered as non-delivering the recommended intervention if they chose at least one of the non-recommended treatments or if they decided either not to treat the patient or to treat her for fewer than five sessions, and therefore the percentage of physiotherapists' Delivering', 'Partially Delivering' and 'Non-Delivering' the recommended intervention was calculated.

### Results

#### Participants

Through the AIFI and the University of Genova newsletter, we were able to reach a total of 1582 physiotherapists, of which 1062 (response rate: 67%) completed the online survey between 16 June 2020 and 6 July 2020. Among them, 40 (4%) had not treated any patient with osteoarthritis in the previous six months, and 200 (19%) did not complete the survey in all its sections. Thus, 822 (77%; (mean age (SD):35.8 (13.3); female 47%; male 53%) physiotherapists compiled the questionnaire in all its sections (Fig. 1) and were included in the analysis (Table 3). Of these, 465 physiotherapists (57%) declared to have read at least one osteoarthritis CPG, whereas 357 (43%) did not.

#### Table 2 Section 2: Clinical vignette proposed treatments

#### Clinical Scenario:

Maria, a 72-year-old housewife, lives with her husband, who is in good health. She cultivates the hobby of gardening. For the past ten years, she has been suffering from knee pain which, in certain periods, forces her to take NSAIDs and to limit daily activities for a few days. Over the past two years, the pain has become increasingly frequent (VAS 5/10), so that she has decided to find some help with the housework and she is struggling to take care of the garden. She also suffers from diabetes and is overweight (BMI 28). She decides to consult her physician, who recommends her to do a visit to the physiotherapist.

Management:		
Core Treatment	Partially Core Treatment	Non-Core Treatment
<ul> <li>Evaluation and planning of the rehabilitation treatment;</li> <li>Weight loss advice.</li> </ul>	Referral to the physician for drug therapy.	<ul> <li>Referral to the physician for arthroscopic surgery (joint debridement);</li> <li>Referral to the physician for prosthetic intervention.</li> </ul>
Assessment:		
Core Treatment		
<ul> <li>Assessment of the quantity and quality of pain;</li> <li>Assessment of the function;</li> <li>Assessment of disability and participation.</li> </ul>		
Treatment:		
Core Treatment	Partially Core Treatment	Non-Core Treatment
Specific exercise on the joint (muscle strengthening); Generic exercise (aerobic exercise or generic physical activity); Education on the	<ul> <li>Manual therapy (mobilisation and/or massage);</li> <li>TENS;</li> <li>Load reduction devices (braces, insoles or walking aids);</li> </ul>	<ul> <li>Activity rest (reduce the load on the joint);</li> <li>Other physical therapies (Laser, Ultrasound etc.);</li> <li>Supplement integration: glucosamine and chondroitin</li> </ul>

For how many sessions would you treat this patient?

For less than 5 sessions;

Between 5 and 10 sessions;
 For more than 10 sessions

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### Section 1: level of knowledge of clinical practice guidelines – statement consensus

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Overall, consensus was achieved for 13 (54%) statements (1–3, 5, 8, 9, 12, 14–16, 19, 20, 22) out of 24 (Fig. 2).

These statements addressed the role of clinical assessment, exercise, education, weight loss, and the effectiveness of physical therapies in the management of people with knee or hip osteoarthritis. Conversely, the consensus was not reached for those statements dealing with the role of supplements, radiographic findings, manual therapy, topical non-steroidal drugs, TENS, the number of sessions and the criteria for clinical diagnosis.

### Section 2: level of adherence to clinical practice guidelines – clinical vignette

Demographic characteristics, percentages of the selection of each item and the classification of the participants in 'Delivering', 'Partially Delivering' and 'Non-Delivering' the recommended intervention are reported in Table 4 and Table 5.

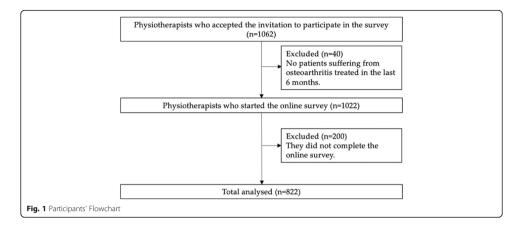
The 'Delivering' group (N = 202; 25%) provided the patient with all the CPGs recommended treatments. In the 'Partially Delivering' group (N = 181; 22%), all the participants performed the physiotherapy treatment, but only half delivered weight loss advice. The majority of the sample assessed functionality, disability, participation, pain and, delivered muscle-strengthening exercises and education. General exercise (e.g. aerobic exercise and general physical activity) was prescribed by about half of the group. Finally, in the 'Non-Delivering Group' (N =439; 53%), the majority of participants performed the physiotherapy treatment. As far as non-recommended treatments are concerned, load reduction (rest), and other physical therapies (e.g. ultrasound and laser) were the most often delivered. Among the recommended treatments, the ones that were delivered by the majority of the members of the group were muscle strengthening and pathophysiology education. About half of this group prescribed generic exercises (aerobic exercise or generic physical activity).

#### Discussions

Clinical practice guidelines are an important tool that aims at bridging the gap between best evidence and clinical practice. Although our study highlighted an overall good level of knowledge of the core first-line intervention, adherence to CPGs was low. Many physiotherapists did not advise losing weight, but advised rest, while often including secondary treatments (e.g. manual therapy) supported by low-level evidence.

Most physiotherapists (> 90%) participating in the survey were aware of the importance of therapeutic exercise, education and enhancing patients' adherence to the treatment, in the caretaking process of people with hip or knee osteoarthritis. These results are in line with the ones reached by other physiotherapists worldwide [16-19]. Despite this, 56% of the physiotherapists participating in the survey considered it essential to include manual therapy (e.g. manual mobilisation, massage) in the treatment. Current evidence shows that when manual therapy is compared with exercise therapy alone, it provides only short term benefits in reducing pain, improving function, and physical performance [35]. However, this conclusion on manual therapy is gathered from lowquality evidence, and therefore CPGs rated it as lower quality when compared to the evidence supporting exercise, which makes manual therapy only a conditional treatment [3, 4]. In line with this, prioritising manual therapy in patients' management may reduce the time allocated to exercise. However, we did not ask the participants whether they considered manual therapy more





effective than exercise, or which treatment they would prioritise, thus leaving uncertainties regarding the clinical impact of this finding. Future studies, with a mixedmethod design are needed to better understand how different treatments are weighed by clinicians in the management of people with osteoarthritis.

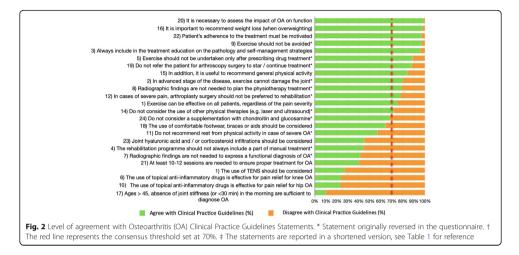
Furthermore, we found an insufficient level of knowledge in three distinct areas: a) the criteria for the clinical diagnosis of osteoarthritis, b) the role of other nonsurgical interventions that could enhance therapeutic exercise benefits (e.g. topical anti-inflammatory drugs and TENS), c) the number of sessions needed to ensure an optimal outcome. As far as the clinical diagnosis and drug prescription are concerned, this lack of knowledge might be due to the fact that, in Italy, physiotherapists are not allowed to perform clinical diagnosis and prescribe drugs. However, they are often the first health care professionals that people with osteoarthritis refer to. Thus, they should be aware of the recommended pharmacological management to facilitate the integration of drug therapy with physiotherapy and the proper clinical diagnostic criteria in order to refer patients to relevant healthcare professionals, when necessary.

Our study showed that only 10% of the respondents considered being 45 years old or older, having pain, and joint stiffness for less than 30 min in the morning,

 Table 3 Participants' demographic characteristics

Demographic Characteristics	
Age (years)(mean,(SD))	35.77 (13.3)
Sex (female); (male) (N (%)):	387 (47); 435 (53)
Years of Practice (N (%)):	
Less than 1 year	87 (11)
From 1 to 5 years	319 (39)
From 6 to 10 years	149 (18)
More than 10 years	267 (32)
Highest Academic Level Reached (N (%)):	
Bachelor of Science (BSc)/Equivalent title	282 (34)
Post-Graduate I Level Degree*	382 (47)
Master of Science (MSc)/Post-Graduate II Level Degree†	122 (15)
Doctor of Philosophy (PhD)	36 (4)
Read at least one osteoarthritis CPGs (N (%)):	
Yes	465 (57)
No	357 (43)

Legend: N, number; %, percentage; \*Academic degree that can be gained after BSc (Italian education system); † Academic degree that can be gained after MSc (Italian education system)



sufficient criteria for the diagnosis of osteoarthritis, as recommended by the NICE CPGs. These seemed to be the most appropriate criteria to ensure that even younger patients with osteoarthritis woul receive appropriate care in line with CPGs [36]. The lack of agreement regarding clinical diagnostic criteria may partially explain the relatively high percentage (> 40%) of physiotherapists who considered radiographic findings necessary to express a clinical diagnosis of osteoarthritis. This data is consistent with the findings of a similar survey conducted by Ayanniyi et al. [19]. Radiographic findings should be taken into account only when other diseases are the suspected cause of the symptoms (e.g. infection, cancer, rheumatoid arthritis) or when surgical intervention is planned [4]. These recommendations are based on evidence that shows a weak association between the

Table 4 Participants' profile by level of adherence for the Clinical Vignette

	'Delivering' (N = 202)	'Partially Delivering' (N = 181)	'Non-Delivering' (N = 439)
Age (years)(mean,(SD))	31.2 (10.9)	37.4 (13.7)	37.2 (13.7)
Sex (N (%)):			
Female	81 (40)	86 (48)	220 (50)
Male	121 (60)	95 (52)	219 (50)
Years of Practice (N (%)):			
Less than 1 year	30 (15)	18 (10)	39 (9)
From 1 to 5 years	100 (50)	71 (39)	148 (34)
From 6 to 10 years	40 (20)	28 (16)	81 (18)
More than 10 years	32 (15)	64 (35)	171 (39)
Highest Academic Level Reached (N (%)):			
Bachelor of Science (BSc)/Equivalent level	57 (28)	64 (35)	161 (37)
I Level Master Degree*	115 (57)	79 (44)	188 (43)
Master of Science (MSc)/II Level Master†	23 (11)	32 (18)	67 (15)
Doctor of Philosophy (PhD)	7 (4)	6 (3)	23 (5)
Read at least one osteoarthritis CPGs (N (%))	:		
Yes	124 (61)	114 (63)	240 (55)
No	78 (39)	67 (37)	199 (45)

Legend: N, number; %, percentage; \*Academic degree that can be gained after BSc (Italian education system); † Academic degree that can be gained after MSc (Italian education system)

Question		All (N = 822; 100%)		ing' 2; 25%)	'Partial Delivering' (N = 181; 22%)		'Non- Delivering' (N = 439; 53%)	
	YES	NO	YES	NO	YES	NO	YES	NO
Section 1: Management (N (%))								
1) Physiotherapy treatment	794 (97)	28 (3)	202 (100)	0 (0)	181 (100)	0 (0)	411 (94)	28 (6)
2) Referral pharmacological	159 (19)	663 (81)	40 (20)	162 (80)	15 (8)	166 (92)	104 (24)	335 (76)
3) Referral for debridment	15 (2)	807 (98)	0 (0)	202 (100)	0 (0)	181 (100)	15 (3)	424 (97)
4) Referral for surgery	26 (3)	796 (97)	0 (0)	202 (100)	0 (0)	181 (100)	26 (6)	413 (94)
5) Weight Loss	645 (79)	177 (21)	202 (100)	0 (0)	90 (50)	91 (50)	353 (80)	86 (20)
Section 2: Assessment (N (%))								
1) Pain	727 (88)	95 (12)	202 (100)	0 (0)	138 (76)	43 (24)	387 (88)	52 (12)
2) Functionality	756 (92)	66 (8)	202 (100)	0 (0)	164 (91)	17 (9)	390 (89)	49 (11)
3) Disability and Partecipation	722 (88)	100 (12)	202 (100)	0 (0)	149 (82)	32 (18)	371 (85)	68 (15)
Section 3: Treatment (N (%))								
1) Load reduction (rest)	244 (30)	578 (70)	0 (0)	202 (100)	0 (0)	181 (100)	244 (56)	195 (44)
2) Manual therapy	612 (75)	210 (25)	145 (72)	57 (28)	135 (75)	46 (25)	332 (76)	107 (24)
3) Muscles strengthening	702 (85)	120 (15)	202 (100)	0 (0)	143 (79)	38 (21)	357 (81)	82 (19)
<ol> <li>Generic exercise (e.g. aerobic exercise or generic physical activity)</li> </ol>	525 (64)	297 (36.)	202 (100)	0 (0)	92 (51)	89 (49)	231 (53)	208 (47)
5) Education on the pathophysiology of osteoarthritis	698 (85)	124 (15)	202 (100)	0 (0)	142 (78)	39 (21)	354 (81)	85 (19)
6) TENS	111 (14)	711 (86)	25 (12)	177 (88)	27 (15)	154 (85)	59 (13)	380 (87)
7) Other Physical Therapies (e.g. ultrasound and laser)	137 (17)	685 (83)	0 (0)	202 (100)	0 (0)	181 (100)	137 (31)	302 (69)
8) Load reduction devices (e.g. braces, insoles or walking aids).	185 (23)	637 (77)	30 (15)	172 (85)	34 (19)	147 (82)	121 (28)	318 (72)
9) Hyaluronic acid and corticosteroids	111 (14)	711 (86)	7 (4)	195 (96)	19 (11)	162 (89)	85 (19)	354 (81)
10) Treatment: Supplements	279 (34)	543 (66)	0 (0)	202 (100)	0 (0)	181 (100)	77 (18)	362 (82)
Section 4: Number of sessions (N (%))*								
Less than 5 sessions	71 (9)	0 (0)	0 (0)	71 (17)	Less than 5 sessions	71 (9)	0 (0)	0 (0)
Between 5 and 10 sessions	465 (58)	138 (68)	121 (67)	206 (50)	Between 5 and 10 sessions	465 (58)	138 (68)	121 (67)
More than 10 sessions	258 (33)	64 (32)	60 (33)	134 (33)	More than 10 sessions	258 (33)	64 (32)	60 (33)

 Table 5 Frequencies of answers to Clinical Vignette by level of adherence with Clinical Practice Guidelines

Legend: N, number; %, percentage; "Percentage calculated on N = 794; N = 28 could not access to this section as they didn't check the "Management section: 1) Physiotherapy treatment" option

severity of radiographic findings and pain and disability levels [37, 38]. Furthermore, basing clinical decisions on imaging fosters the perception of osteoarthritis as a wear-and-tear disease which may, in turn, induce fearavoidance behaviours [38, 39]. However, since physiotherapists in Italy are unable to prescribe radiographic investigations, the impact of this finding on the clinical management of the patients is uncertain.

The second section of the survey showed mismatching between the knowledge of CPGs and their application in clinical practice. Although most physiotherapists showed adequate knowledge of first-line interventions, only a minority (25%) wholly adhered to CPGs, whereas more than 50% included at least one non-recommended strategy or treatment.

One of the challenges in the implementation of CPGs seems to be the fact that health care professionals view osteoarthritis as a "non-serious" disease. This may depend on inadequate preparation at undergraduate level [11, 20, 40]. These erroneous beliefs might be carried on in post-graduate degrees, since the percentage of "Non-Delivering" did not change throughout the different levels of academic degrees achieved (> 50%). Moreover, in Italy, there are no MSc degrees available, specifically on musculoskeletal and rheumatic conditions, and PhD curricula are very specific, therefore, if not focussed on osteoarthritis. thev cannot bridge the preexistingevidence-to-practice gap. In addition, implementing osteoarthritis CPGs in the complex setting of clinical care can be challenging [20] since clinicians have to face several barriers among which patients' preferences, resource availability, discrepancies between CPGs, lack of English knowledge and limited access to information [22].

Although the patient in the clinical vignette was overweight and presented with moderate symptoms, the interviewed physiotherapists often excluded advising weight loss, whilst rest was often considered. In fact, recommending weight loss may be considered by some physiotherapists as beyond their clinical scope [41]. This data is in line with other studies showing that both Australian and British physiotherapists recommended muscle strengthening exercises, but seemed less confident in prescribing aerobic exercise and recommending weight loss [18, 41]. Providing physiotherapists with additional specific training aimed at dealing with overweight patients may enhance the patients' outcomes and increase the overall level of adherence to CPGs.

The interpretation of the relatively high inclusion of rest as well as the load reduction in the treatment is difficult to explain, especially in light of the good level of knowledge shown in the first part of the questionnaire. However, the CPGs available do not specify how to adapt the therapeutic exercise in those cases with severe osteoarthritis symptoms, where pain can be easily triggered by joint movement or weight-bearing activities. This is also highlighted by the fact that about 50% of the physiotherapists in the "Non-Delivering" group declared to have read at least one osteoarthritis CPG. Thus, in light of these results, it can be hypothesised that physiotherapists may feel unsure and unprepared when having to deal with this pain condition [42]. Discrepancies between CPGs knowledge and application may also depend on factors that are external to the physiotherapist, and they may vary by country. Regarding osteoarthritis CPGs, this is the first study that pointed towards this discrepancy, starting from several CPGs and by considering a plethora of treatments.

Beneath the differences between the three groups, a transversal trait was found regarding the application of manual therapy which was delivered by more than 70% of the sample. From a cultural perspective, manual therapy is a core competence of physiotherapy, which set the basis of this professional figure in the past, and patients often expect this type of treatments from physiotherapists [40]. Meeting patients' expectations is thought to foster a positive clinician-patient relationship while enhancing the treatment outcome by inducing analgesia, regulating patients' emotions, and reorganising the body's mental representations [43, 44]. Therefore, this data may reflect the contrast between treatments recommendations and patients' expectations, which can be itself the results of a specific cultural belief that needs to be investigated.

Some limitations of this study need to be discussed. Firstly, our sample was mainly based on physiotherapists who completed a post-graduate degree, therefore our results might overestimate the real level of knowledge of and adherence to osteoarthritis CPGs. Secondly, we did not investigate the participants' clinical practice setting (e.g. private practice, public care etc.) which might have had an impact on the participants' level of adherence to CPGs.

Our findings revealed that Italian physiotherapists are aware of the core treatments for patients with osteoarthritis. However, they showed a low level of knowledge of the clinical diagnostic criteria and of the usefulness of other non-surgical treatments that can support first-line intervention (e.g. TENS and non-steroidalantiinflammatory medications). Moreover, an adequate level of adherence is yet to be reached. These results identify an evidence-to-practice gap which may lead to non evidence-based practice behaviours for the management of the patients with hip and knee osteoarthritis.

Finding new strategies to bridge the gap between evidence and clinical practice appears to be necessary, therefore providing physiotherapists with CPGs in their native language and fostering their use through university programmes could be one of the possible solutions proposed. Moreover, the use of recognised manuals aimed at developing CPGs is advocated. These should ascertain that all search stages are documented for transparency and reproducibility and that the most important elements for a real practical implementation, such as algorithms for clinical decision-making for complicated cases, and patients' inclusion-exclusion criteria, are included [45].

Finally, the professional image of physiotherapists within society should be reconceptualised. In particular, we should continue to foster a new vision of physiotherapists, as no longer anchored to treatments that are mainly based on physical and manual therapy, but as figures whose treatment paradigm focusses on improving the patient's individual functioning by specific treatment strategies, such as exercise and education, that take into account scientific evidence conveyed into specific contexts.

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#### Authors' contributions

SB, SS, SM, MT and AD made substantial contributions to the conception and design, data acquisition, or analysis and interpretation of data. SB, MT and AD participated in drafting the article or revising it critically for important intellectual content. SS, SM, MT and AD gave final approval of the version to be published. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The author(s) read and approved the final manuscript.

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#### Availability of data and materials

The datasets used and analysed during the current study are available from the corresponding author on reasonable request.

#### Declarations

### Ethics approval and consent to participate

Ethical approval was obtained from the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (approval date: 15/06/2020; CERA2020.07). The participants signed digital informed consent before participation.

#### Consent for publication

The participants signed digital consent for publication by inclusion in the study.

#### **Competing interests**

The authors report no conflicts of interest.

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## ORIGINAL ARTICLE

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# Giving an account of patients' experience: A qualitative study on the care process of hip and knee osteoarthritis

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#### Abstract

Introduction: Despite the publication of clinical practice guidelines, the quality of the care process as experienced by patients with osteoarthritis (OA) appears suboptimal. Hence, this study investigates how patients with OA experience their disease and care process, highlighting potential elements that can enhance or spoil it, to optimise their guality of care.

Methods: A qualitative study based on semi-structured interviews. Patients with hip and knee OA in Italy were interviewed. The interview guide was created by a pool of health professionals and patients. The interviews were analysed through a themebased analysis following a philosophy of descriptive phenomenological research.

**Results:** Our analysis revealed seven main themes: (1) *Experiencing a sense of uncertainty,* as interviewees perceived treatment choices not to be based on medical evidence; (2) *Establishing challenging relationships with the self and the other,* as they did not feel understood and felt ashamed or hopeless about their condition; (3) *Being stuck in one's own or the health professionals' beliefs about the disease management,* as a common thought was the perception of movement as something dangerous together with a frequent prescription of passive therapies; (4) *Dealing with one's own attitudes towards the disease; Understanding (5) the barriers to and (6) the facilitators of the adherence to therapeutic exercise,* which revolve around the therapy cost, the time needed and the patients' willingness to change their life habits and (7) *Developing an uneasy relationship with food* since the diet was considered as something that "you force yourself to follow" and overeating as a way "to eat your feelings".

**Conclusion:** The lack of clear explanations and a negative attitude towards first-line nonsurgical treatments (mainly physical exercise), which are considered as a way to fill the time while waiting for surgery, underlines the importance of providing patients with adequate information about OA treatments and to better explain the

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role of first-line intervention in the care of OA. This will enhance patient-centred and shared decision-making treatments.

Patient Contribution: Patients with hip and knee OA participated in creating the interview and contributed with their experience of their care process.

## KEYWORDS

clinical governance, osteoarthritis, phenomenology, physical therapists, physical therapy specialty, policy making, practice guidelines as topic

# 1 | INTRODUCTION

The care process is often a complex and intimate experience as lived by patients. Caring is one of the expressions of the ontology of human beings since people are dependent on one another.<sup>1,2</sup> Due to its grounded origin in anthropology, the care process can be considered as a 'ritual' performed around the patient.<sup>3</sup> It is a complex psychosocial context with a nonspecific effect on patients' brain that can amplify or reduce the specific effect of the treatment, tapping into people's beliefs, expectations and feelings.<sup>3–5</sup> An example of this complexity can be found in the care of individuals with hip and knee osteoarthritis (OA).

OA is the most common form of arthritis and one of the foremost causes of compromised health-related quality of life worldwide.<sup>6,7</sup> Its first-line intervention includes therapeutic exercises and education programmes, often delivered by physiotherapists, and diet when needed.<sup>8-11</sup> Therefore, this intervention is grounded on highly demanding nonsurgical treatments in terms of patients' compliance and on a cultural change at the individual and societal levels that need to accept and foster the importance of these interventions.<sup>12,13</sup>

To answer this need, several national and international clinical practice guidelines (CPGs) were published all over the world.<sup>6-11</sup> However, different international studies brought to the forefront that only one-third of patients are receiving the recommended first-line interventions.<sup>14–16</sup> Basedow and Esterman<sup>14</sup> analysed the appropriateness of OA care through the synthesis of quality indicators retrieved from global medical records, administrative databases and patient questionnaires and interviews. These indicators are generally expressed as pass-rates, and they concluded that the quality of OA care was suboptimal for all treatment domains, with first-line interventions reaching the lowest pass-rate.<sup>14</sup>

The reasons behind the failure of the implementation of first-line interventions are several. They include, among others, patients' preferences, beliefs and experiences about their disease and the care process behind it.<sup>4</sup> In the healthcare setting of musculoskeletal conditions, such as OA, efforts on assessing and understanding patients' experience could help health policy-makers foster improvements in healthcare providers' interpersonal aspects and patients' expectations on how healthcare should be delivered.<sup>17</sup>

Therefore, it is essential to investigate the experience of people with OA about their disease, focussing on the care process they received, exploring their experiences, preferences and beliefs, so as to highlight potential elements that affect it, both positively or negatively. For what concerns the Italian healthcare system, it provides its citizens with universal coverage essentially free of charge.<sup>18</sup> However, Italy lacks national CPGs for OA management that are officially recognised by the Italian Higher Institute of Health. This results in the absence of a standardised care process for this disease. Therefore, health professionals can only rely on international CPGs, which we showed elsewhere to be scarcely followed by Italian physiotherapists.<sup>10</sup> Hence, this qualitative study explored the experience of people with OA about the care process they received in Italy.

## 2 | METHODS

## 2.1 | Study design

A descriptive phenomenological study was performed from October 2020 to March 2021. The descriptive phenomenological inquiry aims at ensuring "direct explorations, analysis and descriptions of particular phenomena (as in this case—the care process), as free as possible from unexamined presuppositions, maximising intuitive presentation".<sup>20–24</sup> The underpinning intent of the phenomenological researcher is to give voice and power to individuals who experienced, or are experiencing, at first-hand the phenomenon of interest as, in this instance, people with OA.<sup>22</sup>

The research was conducted in respect of the Declaration of Helsinki and reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ; Table S1).<sup>25</sup> Ethical approval was obtained from the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (Approval date: 15 June 2020; CERA2020.07).

#### 2.2 | Participants

A purposeful sampling method was adopted to ensure the maximum variations of the experiences.<sup>26</sup> Participants living in different geographic locations, both urban (core areas of cities) and suburban (residential areas that surround main cities), with hip OA, knee OA or

hip and knee OA, were considered eligible according to the need to reach a broad understanding of the studied phenomenon, which stems from different experiences.<sup>26</sup> Specifically, individuals with physician-diagnosed knee and hip OA, able to speak Italian and willing to participate were considered eligible to join this study. Those patients reporting joints other than hip or knee as the primary joints for OA symptoms were not considered eligible.

A network, including physicians (i.e., orthopaedics, rheumatologists and general practitioners) and other health professionals (i.e., physiotherapists and nurses), specialised in the rehabilitation of rheumatic and musculoskeletal diseases was created to help with the participants' recruitment. Health professionals were first approached individually by the research team and informed about the study aims and procedures of data collection. After obtaining their collaboration. the eligible participants were contacted by the health professionals in the network and informed on the aim of the study, the interview process (i.e., places and proposed dates) and the data confidentiality and anonymity. Eligible participants were left free to join the research and to withdraw from it at any time. Only those who expressed their interest in partaking in the study were contacted by S. B. to collect the informed consent and arrange the interview. Then, a snowball sampling was also adopted to access individuals in the network of participants with OA who had been contacted and agreed to participate first.<sup>26</sup> The recruitment was concluded once the data saturation was reached, as judged by the two authors (S. B. and M. M.) who analysed interviews. An inductive thematic saturation was followed to assess the data saturation: S. B. and M. M. kept interviewing and analysing the interviews simultaneously until no new themes were found 24

#### 2.3 | Data collection method

A semi-structured interview was designed based on the existing literature. An interview guide (Table 1) was specifically developed for this study by a pool of physiotherapists, psychologists, nurses and people with OA.8-11,13,19,27-30 The interview guide consisted of open questions exploring different topics related to the OA care process: (a) experiential and emotional dimensions; (b) expectations and (c) beliefs. Follow-up questions were frequently asked to investigate participants' experiences further. Examples of these questions were, 'Can you give me an example?' and 'Can you explain to me what you mean with this sentence?'. At the beginning of each interview, the participants filled in the informed consent and provided their demographic (i.e., age, gender, nationality, retirement, area of living) and clinical information (i.e., height and weight to calculate body mass index, joint(s) with OA and years living with the pathology) which were registered on an electronic sheet. Only the interviewer and the interviewee were present during the interview process. No follow-up interviews were performed.

The interviews were performed by S. B. and lasted approximately one hour each. S. B. is a physiotherapist and a PhD candidate trained in advanced qualitative methodologies, with proficiency in conducting qualitative studies. S. B. recognises himself as male. Participants were not aware of his professional background, and none of them had close relationships with him. The interviews were performed online, by videoconferencing, and they were conducted only with the interviewee. An audio-visual recording of each interview was produced and transcribed verbatim by two authors (S. B. and M. M.).

# 2.4 | Data analysis

As far as the analysis was concerned, a theme-based analysis was performed.<sup>31</sup> Thematic analysis is an independent qualitative descriptive approach described as "a method for identifying, analysing and reporting patterns (themes) within data".<sup>32</sup> Since this study explored the experience of the care process, the thematic analysis was conducted within the framework of a descriptive phenomenology study, as reported and explained above.

Two authors (S. B. and M. M.) read the transcribed interviews several times to obtain a global impression of the content. S. B. and M. M. are PhD candidates (S. B. is a physiotherapist, M. M. is a psychologist), trained in qualitative methods, who both identify themselves as male. They both analysed first independently, and then jointly, the interview transcripts. Specifically, initial coding involved examining the data line by line to search for subthemes, themes, concepts and patterns. Meaning units (i.e., words, phrases and sentences that described the phenomenon of interest) were identified and framed into codes, representing significant and central aspects of the reported statements.33 Throughout this process, emerging codes were compared to previous codes to understand the experiences of the OA care process as lived by the participants and to generate focussed codes. Finally, the focussed codes and coding were merged and synthesised to extract final subthemes and themes. For each theme, exemplary quotes were identified and reported anonymously. The themes were derived from the data and not determined in advance.

# 2.5 | Rigour and trustworthiness

To ensure the study rigour and trustworthiness, multiple strategies were promoted. Firstly, S. B. documented field notes ('Memos') after completing each interview to promote reflexivity.<sup>34</sup> These memos were shared during research meetings for reflexive thoughts. Secondly, the research team met frequently to refine the themes and subthemes until a consensus on the final themes was achieved. Thirdly, an audit trail containing meeting notes, analysis discussions and research decisions was continuously reorganised by the two authors who analysed the interviews (S. B. and M. M.) to stress the dependability and confirmability of the study.<sup>34</sup> An example of it is reported in Table 2. Lastly, a Synthesised Member Checking was exploited to improve the credibility of the analysis.<sup>35</sup> At the end of each interview, participants were asked if they wanted to participate in the member checking phase. All of them agreed to partake in it.

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ould like to start this interview by asking you how you realised that you have OA? Ex w did you manage your disease? Ex	omains xperiential and emotional experiences
w did you manage your disease? Ex	xperiential and emotional experiences
	xperiential and emotional experiences
hat prompted you to go to a physician/health professional?	xperiential and emotional experiences
nat did you expect from your physician/health professional the first time you saw them for OA?	xpectations
w were you diagnosed? Ex	xperiential and emotional experiences
buld you like to tell me how you believed your disease would evolve in the future? Be	eliefs
I you have any family or friends that supported you during your care process?	xperiential and emotional experiences
buld like to tell how you felt when you received your diagnosis?	xperiential and emotional experiences
w would you describe the impact of OA in your life/work?	xperiential and emotional experiences
/ould you like to tell me which treatments you expected to be suggested to manage your disease? Example 1 and 1 and 2 an	xpectations
ventually, which treatments were in fact suggested?	xperiential and emotional experiences
/ould you like to describe which treatments you deem useful in the management of OA? Be	eliefs
For example, physical activity? Manual therapy?	
/hat did you expect from the treatments that you have received so far?	xpectations
/ould you like to tell me which roles physical activity and diet play in the management of OA? Be	eliefs
/hat does a healthy diet mean for you? Be	eliefs
/ould you like to tell me the reasons why a person with OA may not be willing to change their Be estyle, integrating physical activity and a healthy diet into their daily routine?	eliefs
/ould you like to tell me the role of the physiotherapist in the management of OA? And what Bo ould you expect from this professional figure?	eliefs
/hich attitudes did you expect from the health professionals you met during your care process Exwards OA? And which one(s) did they adopt?	xpectations
you've ever been shown, would you like to tell me how you felt when you saw your radiographic Ex dings?	xperiential and emotional experiences
your opinion, how important were radiographic findings in your OA care process? How Be portant were they for the health professionals you met?	eliefs/experiential and emotional experiences
/ould you like to tell me how you live with OA now?	xperiential and emotional experiences
there anything else you would like to add? Cl	losing question

Abbreviation: OA, osteoarthritis.

The member checking phase was yielded at the end of the interview and analysis process. The participants were provided with a one-page summary, highlighting the main themes and subthemes identified in the study, together with a brief plain explanation of the key findings. They were then asked to read it thoroughly, feeding back the researchers with any doubts or concerns they might have had about this summary. All the participants agreed with what was retrieved, and no further modifications to the results were done.

# 2.6 | Patient and public involvement

Two people with both knee and hip OA (one identified herself as female whilst the other one as male), representatives of two different patients associations focussed on rheumatologic and musculoskeletal diseases, were involved in the design of the study and participated in the creation of the interview guide to ensure that the questions included were relevant for the studied population.<sup>36</sup> The patients' representatives did not attend the interviews and did not participate in the study.

# 3 | RESULTS

Thirteen Italian people from northern Italy agreed to participate in the interviews. Two participants were not able to do the interviews because they did not understand the questions on both telephone and videoconference since they had critical auditory impairments. Therefore, eleven participants were included. Table 3 reports the sample's demographic and clinical characteristics in detail for each participant.

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TABLE 2 Data synthesis by extracting and abstracting findings in common themes and subthemes

Abstraction: Themes	Abstraction: Subthemes	Codes defined by researchers	Example of quotes extracted from the interview
Experiencing a sense of uncertainty	Need of a straightforward treatment	Need of guidelines to follow	' Yes, I would like to have a precise guideline, also regarding nutrition It looks as if there are some things that are left to our own intuition'. (P2, female, 68)
		Precise treatment	'Erm. I expected them to give me clear indication on how to deal with my disease'. (P8, male, 66
	Doubts (treatments to follow and pathology genesis)	Lack of understanding of the disease's mechanisms	'They tried to explain to me how OA works somehow, but I still don't have a clear idea o how it works'. (P3, female, 73)
		Need to hear several health professionals to have a definitive answer	'In my experience, I've had to consult two or thre physicians, unless the first two agree'. (P5, female, 72)
		Need to explain the disease set- up biomechanically	'I thought [OA] was a consequence of bad posture as I've been using my leg wrongly after slippin on ice once'. (P6, male, 55)
	Different opinions heard by various health professionals	Feeling that the physicians' decisions are not evidence- based	'There is an almost religious way of thinking abou how to deal with the pathology. It is not an exact science; when you choose the physicians, you choose the treatment'. (P1, male, 49)
		Confusion caused by consulting different physicians	'Maybe the fact that I did not have only one physician at the very beginning did not help me to understand how to deal with OA'. (P9 female, 73)
	Frustration and anger	Worrying for hearing different opinions	'I was worried because we, as patients, hear different opinions coming from our friends an acquaintances that give us their personal poi of view on how they take care of their disease'. (P9, female, 73)
		Anger/frustration for different opinions	'It is very frustrating for a patient [not to have a precise indication] because you expect to hav a disease, and a common one too, so the car process should be clear'. (P1, male, 49)
Establishing a challenging relationship with the self and the other	Not being understood and the importance of empathy	Seeing the patients as a diagnosis and not as human beings	'There I seemed to be like Erm a number, a gear in the mechanism Maybe they didn't consider me as a human being (laugh)'. (P3, female, 73)
		Lack of empathy	'The orthopaedists did not give me much attention, and they told me that I have OA an that I have to live with it'. (P2, female, 68)
	Shame	Feeling shameful	'I felt it [shameful] recently. I went to the beach with my granddaughter [] she wanted me be involved in her games, and she said "Grandma come, sit down next to me". I had I kneel down to play in the sand with her I fe how can I say erm like a piece of wood, lik someone who can no longer manage their body'. (P2, female, 68)
		Limping as an unpleasant sensation	'It is an unpleasant sensation, it feels as if you ar limping. mentally though, you see? Because do not know if it is visible or if that is only a perception [that I am limping]'. (P4, female, 4)
	Hopelessness	Hopelessness for the prognosis	

(Continues)

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Abstraction: Themes	Abstraction: Subthemes	Codes defined by researchers	Example of quotes extracted from the interviews
			"When I received my diagnosis, they told me I had only few years left (before the surgery), and they told me "Chill and don't do anything". I asked the second orthopaedic who visited me "If I keep on being active will I undergo surgery in 5 years instead of 10 years?" and he answered, "You are quite optimistic in both scenarios". (P1, male, 49)
		No possibilities to do other interventions	'Erm. Yes [I can only do surgery]. because I dragged it on for too long and they told me that I have no other possibilities with other [nonsurgical] interventions'. (P10, male, 65)
	Use of metaphors to describe the pathology	Using a relevant metaphor/ simile	'I see it [the joint affected by OA] as a mountain which is crumbling'. (P3, female, 73)
		Associating OA to something realistic to understand it	'My physiotherapist once told me that [OA] is like having a rusty gate, the orthopaedist decides to break it open, but if you try to grease it, it can last longer. I think that this gives you the idea'. (P1, male, 49)
Being stuck in one's own or the health professionals' beliefs about the disease management	Sealed faith (surgery)	Surgery as an obtrusive thought	'It [OA surgery] is something you think about every day, something you try to resist, but the is your fate'. (P1, male, 49)
		Surgery as the final and obvious stage of OA	'However, everyone told me: try and resist for a long as you can, but sooner or later you will have to undergo surgery, and end up under th knife, full stop'. (P10, male, 65)
	OA as a pathology of the old adults	Misperception between radiographic findings and patients' perception	'The doctor told me: "You know that if I did not know that these x-rays belong to you, I woul think that they belong to another person wh is at least 30 years older than you" but, I guess I did not feel as bad as he was describin me'. (P11, male, 56)
		OA as an ageing process	'They told me that I was starting to get old'. (P3 female, 73)
	Necessity of radiographic findings (diagnose/ treatment)	Diagnosis only through X-ray	'They told me: here we have the problem, and it i evident as we can see from the x-ray'. (P11, male, 56)
		OA as a wear and tear disease	'Well, I had some medical check-ups through x- rays and from them you could see some wear and tear joint surfaces, but they weren uniform, nor regular, right? And so it was clea that there was something special even for a neophyte like me, right? And he [the doctor] said to me, "look, this is linked to this pathology." And by looking at it 1 became aware of what my problem was'. (P6, male, 55)
	(Ab)use of passive therapies	Recommendation of ice instead of movement in young patient	'And he [the doctor] told me that I was too youn for surgery and he recommended I do this therapy, to put some ice on my joint'. (P5, female, 72)
		Recommended physical therapy for OA	'The same rheumatologist I saw in September confirmed that the only thing I could do for m hip was Extracorporeal Shockwave Therapy'. (P4, female, 47)

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Abstraction: Themes	Abstraction: Subthemes	Codes defined by researchers	Example of quotes extracted from the interviews
	Movement as dangerous for the joint	Refrain from moving to postpone surgery	'The doctor told me: "You have to try to postpone surgery for as long as you can. So please stop [any physical exercise]". (P1, male, 49)
		Avoiding exercise with a load on the joint	"They recommended I do pilates, go swimming etc. so as to go easy on the joint, not to go to the gym, not to run etc. Basically, avoid everything that could have a violent stress on the joint at the moment". (P4, female, 47)
Dealing with one's own attitudes towards the disease	Fight, resignation and acceptance	Disease as something to fight	'From a certain perspective, I found it [OA] positive, since it is something that I have to fight against'. (P1, male, 49)
		Resignation towards getting older	'Maybe I am accepting my becoming old, what can I say'. (P3, female, 73)
		Acceptance of the future	'Besides, I am also a fatalist, things happen in life and when they do, you face them'. (P4, female, 47)
	Coping strategies (primarily passive)	(Over)use of drugs	'It's not an issue for me to take some pills not to feel any pain'. (P4, female, 47)
		Impromptu strategies to manage OA	'I proceeded by myself with some clay, with some palliatives like unguents and things like that'. (P8, male, 66)
Understanding the facilitators of the adherence to therapeutic exercise	Importance of being active	Movement as an intrinsic need of the body	'The body has to move'. (P3, female, 73)
		The awareness of the importance of movement	'And, this kind of movement (walking), I realised, was good for me'. (P2, female, 68)
	Perceived exercises as concrete support to the cure	Witnessing the importance of training	'Then the situation improved, always with training thanks to the workouts'. (P7, female, 45)
		Difference between active and passive treatments	'It [physical exercise] is not like taking supplements with hyaluronic acid, those (supplements) you do not see what they do'. (P1, male, 49)
	Mean to maintain functionality	The importance of movement to maintain good functionality	'OA is difficult to cure, even impossible, it is a natural tear, only some palliatives exist. I believe that the only way, or rather, the best way is to strengthen the muscle structure so that bones and joints suffer less from the weight load on them'. (P11, male, 56)
		Movement as a way to reduce OA's impact	'I felt well, because I kept on walking and this allowed for reducing OA impact'. (P10, male, 65)
	Willingness to change life- habits	The importance of determination and willpower in active care	'Determination and willpower [to change life- habits]'. (P7, female, 45)
		Willpower as a compulsory step to change life habits	'A great willpower is necessary [to change life- habits]'. (P9, female, 73)
Understanding the barriers to the adherence to therapeutic exercise	Cost and lack of time	Economic consequences of the care process	'Yes but also from an economic point of view [i is difficult to do supervised exercises]'. (P2, female, 68)
		Being overwhelmed with life duties and forgetting about the self	'We are trapped into a spiral in which work, we can say, takes up a lot of energy and a lot of time, and then that time is taken away from us'. (P6, male, 55)

(Continues)

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Abstraction: Themes	Abstraction: Subthemes	Codes defined by researchers	Example of quotes extracted from the interviews
	Lack of clear indications	Do not know what to do with exercise	'That is, there were some, just some things [decisions in the care process] Erm I don't know they were left to our intuition, to our perception but just because you understand that by acting in a certain way, maybe you wil limit its progress [of OA] <sup>1</sup> . (P2, female, 68)
		Missing the health professionals' real intention	'The doctor told me: "You know that if I did not know that these x-rays belong to you, I would think that they belong to another person who is at least 30 years older than you" but, I guess I did not feel as bad as he was describing me'. (P11, male, 65)
	Lack of willpower and fatigue in changing life habits	Losing the motivation with ageing	'So it is that maybe when you are old, people back down, they lie on the couch, Surely such a pain affecting someone who does not have that drive [motivation to stay fit] makes people unwilling to get up from the couch'. (P1, male, 49)
		Laziness and fatigue in changing life habits	'I think so, for laziness. Because if you want to, you are able to find the time. So it is, therefore laziness'. (P5, female, 72)
	Exercise perceived useful only after surgery	Exercise useful only after undergoing surgery	'But I imagine that someone can do this let's cal it preventive activity. Activity that can help with the recovery process following the intervention'. (P6, male, 55)
		Exercise useless before surgery	'It is useless to start doing physiotherapy/exercise if I am undertaking surgery in a month.' (P9, female, 73)
Developing an uneasy relationship with food	Diet as fatigue and deprivation	Eating to eat your own feelings	'To follow a diet is a mental fatigue [] and eating is an easy outlet to manage the stress of daily life'. (P4, female, 47)
		Diet as deprivation	"Think about it, if someone tells you something like "From tomorrow you will eat only these things [tasteless food]", I will only get a third of the satisfaction I normally get from eating". (P2, female, 68)
	Diet seen as useful only to lose weight	Diet to reduce the weight on the joints	'Being overweight makes it worse, so obviously, the lighter I feel, the better I eat, and I also dr my exercises, than [by doing so] I can see the difference'. (P7, female, 45)
		Relationship between weight and OA	'Of course, there is a relationship [between weight and OA]. The heavier the body, the more the knee suffers, it's a matter of physics'. (P2, female, 68)

Abbreviation: OA, osteoarthritis.

Analysis of the interview data revealed seven main themes related to the OA care process (Figure 1): (1) Experiencing a sense of uncertainty; (2) Establishing challenging relationships with the self and the other; (3) Being stuck in one's own or the health professionals' beliefs about the disease management; understanding;

(4) Dealing with one's own attitudes towards the disease; Understanding (5) the facilitators of and (6) the barriers to the adherence to therapeutic exercise; (7) Developing an uneasy relationship with food. Hereafter, the different themes that stemmed from the synthesis of their related subthemes are discussed and explored.

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TABLE 3 Participants' demographic

and clinical characteristics

Patient Age Gender вмі Retirement Disease Diagnosis Hip OA P1 49 м 26.28 No X-rav P2 68 F 25.95 Yes Hip and knee OA MRI P3 73 F 27.34 Yes Knee OA X-ray P4 47 F 28.71 No Hip OA MRI P5 F Hip OA X-ray and CT 72 25.81 No 34.02 Hip and knee OA P6 55 м No X-ray P7 45 F 25.09 No Hip OA X-ray and MRI P8 66 м 28.70 Yes Knee OA X-ray Knee OA P9 28.66 73 F Yes X-ray P10 65 24.69 Hip OA м No X-rav P11 22.22 Hip and knee OA X-ray 56 м No

Abbreviations: BMI, body mass index; CT, computed tomography; F, female; M, male; MRI, magnetic resonance image; OA, osteoarthritis; P, person.



FIGURE 1 Themes and subthemes stemmed from the analysis of the interviews

#### Theme 1: Experiencing a Sense of Uncertainty

A general sense of uncertainty regarding the care process and, precisely, how to deal with OA and which treatments should have been taken, was a transversal perception among all the interviewees. They felt that the indications they had been given were not based on evidence and that health professionals' preferences and attitudes played a crucial role in the decision-making process of OA management.

> There is an almost religious way of thinking about how to deal with the pathology. It is not an exact science; when you choose the

physicians, you choose the treatment. (P1, male, age 49)

Participants were typically unaware of the causes of their disease. However, in general, they considered it to be a consequence of overuse and wrong posture, and they tried to motivate it only through a biomechanical rationale. Moreover, the explanations provided to them by the health professionals seemed fuzzy and unclear.

I thought [OA] was a consequence of bad posture, as I've been using my leg wrongly after slipping on ice once. (P6, male, 55)

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They tried to explain to me how OA works somehow, but I still don't have a clear idea of how it works. (P3, female, 73)

The interviewees felt doubtful because, on the one hand, they had not received any specific indication regarding the management of OA, and, on the other, the different and not coherent opinions retrieved from the various health professionals and acquaintances increased this sense of doubtfulness and worry about their condition.

> I was worried because we, as patients, hear different opinions coming from our friends and acquaintances that give us their personal point of view on how they take care of their disease. (P9, female, 73)

Besides, this sense of uncertainty led the patients to retrieve information from a plethora of different professionals, word-of-mouth and also from the Internet.

In my experience, I've had to consult two or three physicians, unless the first two agree. (P5, female, 72)

No, the doctors did not explain it [OA] to me. But, eventually, I looked it up on the Internet and found answers to my questions. (P8, male, 66)

As a result, they felt frustrated and angry since they wanted to receive a straightforward treatment. The lack of clear indications and the presence of the conflicting opinions heard, eventually, led them not to take care of their disease or to base their care on their intuition.

It is very frustrating for a patient [not to have a precise indication] because you expect to have a disease, and a common one too, so the care process should be clear. (P1, male, 49)

Eventually, I did not do anything anymore, just nothing. (P5, female, 72)

...Yes, I would like to have a precise guideline, also regarding nutrition... It looks as if there are some things that are left to our intuition. (P2, female, 68)

Theme 2: Establishing Challenging Relationship with the Self and the Other

As far the relationship with the self and the other is concerned, common feelings across the interviewees revolve around a sense of shame and hopelessness that were described with two different nuances: the former was more concerned and present in front of their beloved ones, the latter was more evoked by the lack of hope conveyed by the health professionals they consulted. Participants expressed a sense of shame caused by showing their conditions and limitations to others.

> I felt it [shame] recently. I went to the beach with my granddaughter [...] she wanted me to be involved in her games, and she said 'Grandma come, sit down next to me'. I had to kneel down to play in the sand with her... I felt, how can I say... erm... like a piece of wood, like someone who can no longer manage their body. (P2, female, 68)

At the same time, they expressed a sense of hopelessness in regard to the received prognosis and the fact that physicians took for granted that this was a pathology that sees no other possibility apart from deteriorating.

> Erm. Yes [I can only do surgery]. because I dragged it on for too long and they told me that I have no other possibilities with other [non-surgical] interventions. (P10, male, 65)

Both of them were strictly related to a lack of empathy shown by both their acquaintances and health professionals. The former, since the interviewees reported that their acquaintances did not miss a chance to highlight some features related to OA (e.g., limping) that make them feel ashamed of their condition.

> What annoys me the most is when people that know my condition ask me, 'What did you do? Why are you limping?' This makes me really upset because others see what I sometimes don't even notice. (P1, male, 49)

The latter, since the participants felt as if they were being considered as a mere number, rather than as human beings by the health professionals, they consulted, almost as if they were not worth their attention.

The orthopaedic surgeon did not give me much attention, and they told me that I have OA and that I have to live with it. (P2, female, 68)

Finally, some of the participants expressed their self-into-thepathology through the use of relevant metaphors that helped them to understand their condition better.

I see it [the joint affected by OA] as a mountain which is crumbling. (P3, female, 73)

Theme 3: Being Stuck in One's Own or the Health Professionals' Beliefs about the Disease Management

The participants held some core beliefs that arose after consulting with their health professionals. In particular, the most

shared and common belief carried out was regarding the surgery that represented a sealed fate from which there is no escape, something that anyone with OA must eventually face.

> It [OA surgery] is something you think about every day, something you try to resist, but that is your fate. (P1, male, 49)

> And so when I went to see him [the physician] he said, 'no madam, your joint is ruined... try and get on with it for as long as you can, but sooner or later you will have to do it [surgery]'. (P9, female, 73)

Another shared belief was considering OA as a disease typical of old age. Having this belief made participants feel as if they were going through an unhealthy ageing process, even if some of them felt active and alive.

The doctor told me: 'You know that if I did not know that these x-rays belong to you, I would think that they belong to another person who is at least 30 years older than you'... but, I guess I did not feel as bad as he was describing me. (P11, male, 56)

In fact, according to the narratives collected, health professionals have been reported to be surprised when they saw a sign of OA radiographic findings in the younger interviewees. Besides, these radiographic findings were considered necessary to diagnose OA and to decide how to plan the care process, since interviewees reported that physicians were more focussed on radiographic findings than on the symptoms they were complaining about.

> They told me: here we have the problem, and it is evident as we can see from the x-ray. (P11, male, 56)

Two other common beliefs emerged from the interviewees' encounters with their health professionals, concerned the management of OA. Firstly, the (ab)use of passive therapies that were recommended to postpone as much as possible the surgical interventions and, secondly, the low prescription of movement that was seen as dangerous as a risk factor for an anticipated surgery.

> And he [the doctor] told me that I was too young for surgery, and he recommended I do this therapy, to put some ice on my joint. (P5, female, 72)

> The doctor told me: 'You have to try to postpone surgery for as long as you can. So please stop [any physical exercise]'. (P1, male, 49)

Theme 4: Dealing with One's Own Attitudes Towards the Disease Interviewees showed different attitudes towards the pathology that were linked by them to their age. The older patients perceive OA as a sign of resignation towards becoming old, the younger ones as something they have to or can still fight against.

Maybe I am accepting my becoming old, what can I say... (P3, female, 73)

From a certain perspective, I took it [OA] positively since it is something I have to fight against. (P1, male, 49)

However, besides these differences, at a certain point, they all matured a sense of acceptance, as if OA is something they cannot change.

Besides, I am also a fatalist, things happen in life, and when they do, you face them. (P4, female, 47)

Both younger and older interviewees developed passive primarily coping strategies to manage their symptomatology. In particular, overuse of medications to control pain and the use of different physical therapies seemed to be the main traits of their care process, with partial room left to active therapies.

It's not an issue for me to take some pills not to feel any pain. (P4, female, 47)

I thought that by doing some thermal treatments [...] mud treatments [...] mesotherapy and other things... I thought that with them I would sort the disease out. (P5, female, 72)

Themes 5: Understanding the Facilitators of the Adherence to Therapeutic Exercise

Different facilitators of the adherence to therapeutic exercise were pointed out by the interviewees, among which the perceived benefit of doing exercises was the most shared one. In particular, being active was perceived as an intrinsic need of the body, allowing individuals to maintain a good level of functionality and as real and concrete support to the care process, something whose benefits could be seen in real-time compared to taking medications.

... The body has to move ... (P3, female, 73)

It [physical exercise] is not like taking supplements with hyaluronic acid, those (supplements) you do not see what they do. (P1, male, 49)

Moreover, all the interviewees highlighted the importance of willpower, which was seen as either a facilitator or a barrier depending on its presence or lack thereof (see next theme). All interviewees agreed that their willingness to change their life habits was the key to sticking to the exercise plan and that willpower was a compulsory step to change life habits. ...Determination and willpower [to change lifehabits]. (P7, female, 45)

Theme 6: Understanding the Barriers to the Adherence to Therapeutic Exercise

The barriers to the adherence to therapeutic exercise revolved around the cost of the therapy, the time needed, the lack of clear indications, the lack of willingness to change life habits and the perception of OA exercises useful only after surgery. The interviewees complained about the fact that exercise needs time, energy and money. Being absorbed in their jobs and family daily routines jeopardised their willingness to start doing physical exercises.

Yes... but also from an economic point of view [it is difficult to do supervised exercises]. (P2, female, 68)

We are trapped into a spiral in which work, we can say, takes up a lot of energy and a lot of time, and then that time is taken away from us... (P6, male, 55)

The lack of clear indications from specialists regarding the type of exercise to perform, as well as its intensity and frequency, were another barrier to starting any physical activity. The interviewees felt lost, as they perceived that they were missing precise guidelines to follow and that everything was left to their intuition.

> My doctor told me to 'go for a walk', or maybe to 'move', but never specifically, something like 'it would be better in your case to do something more targeted'. (P11, male, 56)

The interviewees highlighted that the lack of willpower and the fatigue in changing life habits were some of the main reasons behind not sticking to the exercise plan together with losing the motivation with the ageing process.

I think so, for laziness... Because if you want to, you are able to find the time. So it is, therefore, laziness. (P5, female, 72)

Finally, feeling that exercise is useful only after surgery was another barrier to sticking to the exercise plan. The interviewees perceived that it was not valuable to invest time and energy in doing exercise if surgery was their final destiny.

It is useless to start doing physiotherapy/exercise if I am undertaking surgery in a month. (P9, female, 73)

The only preventive function that exercise seemed to have was to facilitate the recovery process after the surgery. The interviewees reported little to no appreciation of exercise as a treatment in its own right. But I imagine that someone can do this... let's call it preventive activity. Activity that can help with the recovery process following the intervention. (P6, male, 55)

Theme 7: Developing an Uneasy Relationship with Food Participants had developed an unhealthy relationship with food. As a matter of fact, they perceived diet as a deprivation, a sort of sacrifice in terms of time and mental fatigue, something that they forced themselves to follow. Moreover, for some of them, overeating was being used 'to eat your feelings'.

To follow a diet is a mental fatigue [...] and eating is an easy outlet to manage the stress of daily life. (P4, female, 47)

Furthermore, when it came to the management of OA, the participants considered following a diet only as a way to reduce weight on their joints, drawing a direct relationship between weight and joint load.

Of course, there is a relationship [between weight and OA]. The heavier the body, the more the knee suffers, it's a matter of physics. (P2, female, 68)

# 4 | DISCUSSIONS

The quality of the care process depends not only on the appropriateness of treatments delivered by health professionals (technical aspects) but also on relational and functional aspects.<sup>37</sup> From our results, several of these aspects were hindered during the OA care process, and this could be one of the possible explanations for why patients with this disease do not reach good levels of health-related outcomes and adherence towards first-line interventions.

As far as the technical aspects are concerned, patients did not receive first-line interventions. As a matter of fact, their care process was mainly based on passive therapies while waiting for surgery, with a scarce prescription of movement, seen not only as dangerous, but even as a possible risk factor for anticipated surgery, and valuable only after joint replacement. However, oral medications have been shown to reach similar effects to exercise therapy for improving functionality and pain relief in OA.<sup>38</sup> Nevertheless, oral medications, and in particular nonsteroidal anti-inflammatory drugs, have potential and well-documented side-effects, such as gastrointestinal toxicity, cardiovascular adverse effects and nephrotoxicity.<sup>39</sup> whereas exercise has been shown to have benefits that go beyond joint health, reducing the risk of developing a wide array of comorbidities and promoting a healthy lifestyle.<sup>40</sup> Moreover, evidence showed that individuals with OA are seeking

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non-pharmacological and non-surgical treatments for their conditions, and they want more information about these treatments, which highlights the likelihood that they might be open to undergoing exercise and physiotherapy interventions if educated on their benefits.<sup>41,42</sup> This was also retrieved in our interviews in which patients understood the importance of being active and saw exercise as a concrete support to their care, something that one can see while doing it, in contrast to medications and supplements that do not immediately show tangible effects.

According to the findings of this paper, there are several aspects that may facilitate or hinder patients' adherence towards physical exercise, and these should be taken into account by clinicians once it is prescribed. Regarding the obstacles, the lack of time and the cost seemed to be the main ones. The former was already known to be one of the more prominent causes of lack of adherence to physical exercise, in general.<sup>43-45</sup> However, preliminary evidence showed that there is a gap between perceived and real lack of time<sup>46</sup> and that is why it is essential to address this issue while educating the patients, to help them reach a good level of awareness of the real-time they can devolve to their own care, and to tailor self-management programmes according to their needs.<sup>47</sup> The latter, on the other hand, has to be tackled at a higher health-policy level. People in lower socioeconomic positions show a higher incidence of OA, more severe symptomatology and tend to experience lower benefits from OA interventions.48,49 However, despite Italy's public healthcare system, none of the participants who were being followed by professionals within the public system reported that exercise was included in their care process. There is a need to establish an effective care pathway for people with OA to implement evidence-based treatments in the care routine employed in the public system, with the aim of reducing the healthcare inequalities faced by those patients who are not able to access alternative private systems.

Another barrier to the implementation of exercise into the patients' self-management routine was their unwillingness to change their habits. This was a shared barrier with the implementation of diet strategies into their care. It is already known that individuals do not engage in health-promoting behaviours, even though these can reduce mortality and contribute to their wellness.<sup>50</sup> However, our findings show that patients were not motivated by their health professionals to follow such treatments. As reported by Hardcastle et al.,<sup>51</sup> there are several strategies that professionals can implement to foster patients' motivation, such as strategies targeting selfefficacy, outcome expectancies, effort and value beliefs, as well as motivational interviewing techniques, and these should be used and implemented for more effective communication. Moreover, as far as the diet is concerned, it was seen by the interviewees as applicable only to reduce weight on the joint. However, patients need to change their diet not only by focussing on losing weight but also because this has the potential to mitigate pro-inflammatory mediators, including cytokines, interleukins, histamine and free radicals that lead to increasing systematic inflammation.52-56 Patients should be made aware of the fundamental role of diet in their care process and should be guided to no longer see it as a liminal treatment.

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The functional aspect can be defined as the basic expectations about how care is delivered, and it comprises, among others, the delivery of effective treatments by trusted professionals and the coordination and continuity of care.<sup>17,37</sup> When considering the former, the interviewees did not perceive that the indications they had received were based on evidence, and this raised a general sense of uncertainty. Uncertainty is a poorly addressed and managed issue in healthcare, which can result in patients' poor or inefficient coping strategies and dysfunctional adaptation to illness, as well as in a conflicting relationship with health professionals.57-59 For what concerns the latter, the interviewees did not perceive the coordination and continuity of care as smooth and clear. In fact, the interviewees felt frustrated and angry, as they did not receive straightforward treatment. This was also powered by the fact that the different health professionals they had met had different and incoherent opinions, and therefore they perceived that indications about the OA decision-making process were based on health professionals' preferences and attitudes.

Patients desire empowerment and are keen to be actively involved in their own care process.<sup>42</sup> If they do not find answers to their questions from a source (e.g., their health professional), they will seek them through other outlets, such as different professionals, acquaintances or the Internet.42,60 This is in line with what was observed in our study, where the sense of uncertainty experienced by the interviewees led them to seek information from different professionals, the Internet and word-of-mouth. However, as pointed out by Chou et al.,42 the patients' necessity to interrogate various sources can indeed stem from the dissatisfaction with the information retrieved from one source, but it can also arouse from the patients' need to gather information from different and complementary sources to receive a tailored and holistic approach. In line with this, there rises a need to create ad hoc resources for people with OA whose content is based on solid evidence and that is tailored to their needs and expectations.

The relational aspect concerns all interactions between patients and health professionals.37 The interviewees felt as if they were not being understood by both their relatives and health professionals, and they found a lack of empathy in the professionals they met. Empathy declines throughout medical formation, especially when it is not trained with specific interventions.61,62 Treatments devoid of empathy spoil the relationship between patients and health providers, and may lead to dissatisfied patients who are in turn discouraged to stick to the recommended interventions, resulting in poor health-related outcomes.<sup>63</sup> An empathetic communication style is a fundamental skill that health professionals need to learn and optimise because it can allow patients to reach good compliance towards treatments and, therefore, better outcomes, A strategy reported by patients for an efficient communication style was the use of metaphor to explain the pathology. Human beings rely on metaphor to understand the world around them. The use of relevant metaphors that tap into the patients' life and experience can ease the creation of a bond of trust between the health professional and the patient. leading to a truly therapeutic alliance,64,65 which is fundamental

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when the care process of patients need a high level of patients' compliance, as in the case of OA.

In particular, this lack of empathy was found during the diagnosis and the prognosis of OA. The individuals interviewed extracted a sense of hopelessness from health professionals' words, which was derived from seeing OA as a pathology with a sealed faith-surgery-and a sign of their ageing process. This was also fostered by the reading of their radiographic findings that physicians found necessary to perform the diagnosis and commented with sentences such as "if I did not know that these x-rays belonged to you, I would think that they belong to someone who is at least 30 years older than you". However, radiographic findings are considered by CPGs, as complementary for the assessment of OA and should be considered only when other diseases are the suspected cause of the symptoms (e.g., infection, cancer, rheumatoid arthritis) or once the surgical intervention has been planned.<sup>8</sup> Besides, there is a weak association between the severity of radiographic findings, pain and disability levels 28,66 and basing clinical decisions on imaging fosters the perception of OA as a wear-and-tear disease, which may, in turn, induce fear-avoidance behaviours.28,67 Finally, promoting surgery as the unique and real solution to OA may demotivate patients to change their life habits, considering the difficulty to follow diet and a physical activity programmes compared to the 'easy way out' of undergoing surgery.

Some limitations of this study need to be underlined. Firstly, the small sample size required to conduct a qualitative study limits the generalisability of the results.<sup>68</sup> Besides, all the interviewees lived in a similar geographical area (i.e., northern Italy), so that it is not possible to conclude that the results of this study may be transferrable to the other Italian regions. However, in Italy, there is a well-known negative gradient gap from North to South when it comes to the efficiency of the healthcare system.<sup>69,70</sup> In light of this, it is possible that this study depicted the best-case scenario that patients with OA may experience. Moreover, the results gathered from this study may not be transferrable to other European countries, such as the ones comprised in the northern areas, due to the geopolitical differences between them.<sup>71</sup> Conversely, they may be more applicable to other Mediterranean countries, considering the similarities in the health professionals' educational needs within the field of rheumatology 71 Secondly, the patients interviewed were at different stages of their care process, and their experience may change during the different stages. However, all patients agree with what emerged during the member checking phase. On the contrary, one of the strengths of this study is that it is the first one that takes into account the whole care process experienced by patients with OA from diagnosis to pre-surgery, highlighting some of the possible pitfalls that both patients and clinicians may encounter, and that can hinder the success of the intervention.

# 5 | CONCLUSIONS

This study highlights potential common themes in the experience of people with OA, with a focus on its care process, which should be taken into account to enhance the quality of it. People with hip and knee OA seem to experience an uncertain care process. In particular, they experienced a lack of clear explanations, a lack of empathy, and a general, negative attitude towards first-line nonsurgical treatments. All those factors underline the importance of providing patients with adequate information through effective communication about the treatment options. By doing so, it will be possible to shift patients' beliefs and improve their awareness of the first-line treatments they should follow. This will enhance patient-centred treatments led by shared decision-making processes with patients, increasing their compliance towards first-line interventions and their skills to take care of their health and healthcare, with positive effects on their health-related outcomes and healthcare costs.

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#### CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

#### AUTHOR CONTRIBUTIONS

Simone Battista made substantial contributions to the conception or design of the work, the acquisition, analysis or interpretation of data. Mattia Manoni made substantial contributions to the conception or design of the work, the acquisition, analysis and interpretation of data. Andrea Dell'Isola made substantial contributions to the conception or design of the work, analysis, and interpretation of data. Mattia Manoni made substantial contributions to the conception or design of the work and interpretation of data. Alvisa Palese made substantial contributions to the design of the work, the acquisition, analysis or interpretation of data. Marco Testa made substantial contributions to the conception and design of the work, the acquisition, analysis or interpretation of data. All authors drafted the work or revised it critically for important intellectual content. All authors approved the version to be published. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

#### ETHICS STATEMENT

Ethics approval was obtained from the Ethics Committee for University Research (CERA: Comitato Etico per la Ricerca di Ateneo), University of Genova (Approval date: 15 June 2020; CERA2020.07). The participants signed informed consent before participation.

#### DATA AVAILABILITY STATEMENT

Data are available upon reasonable request to the corresponding author.

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# SUPPORTING INFORMATION

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# Factors Associated With Adherence to a Supervised Exercise Intervention for Osteoarthritis: Data From the Swedish Osteoarthritis Registry

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**Objective.** To explore how lifestyle and demographic, socioeconomic, and disease-related factors are associated with supervised exercise adherence in an osteoarthritis (OA) management program and the ability of these factors to explain exercise adherence.

**Methods.** A cohort register-based study on participants from the Swedish Osteoarthritis Registry who attended the exercise part of a nationwide Swedish OA management program. We ran a multinomial logistic regression to determine the association of exercise adherence with the abovementioned factors. We calculated their ability to explain exercise adherence with the McFadden R<sup>2</sup>.

**Results.** Our sample comprises 19,750 participants (73% female, mean  $\pm$  SD age 67  $\pm$  8.9 years). Among them, 5,862 (30%) reached a low level of adherence, 3,947 (20%) a medium level, and 9,941 (50%) a high level. After a listwise deletion, the analysis was run on 16,685 participants (85%), with low levels of adherence as the reference category. Some factors were positively associated with high levels of adherence, such as older age (relative risk ratio [RRR] 1.01 [95% confidence interval (95% Cl) 1.01–1.02] per year), and the arthritis-specific self-efficacy (RRR 1.04 [95% Cl 1.02–1.07] per 10-point increase). Others were negatively associated with high levels of adherence, such as female sex (RRR 0.82 [95% Cl 0.75–0.89]), having a medium (RRR 0.89 [95% Cl 0.81–0.98] or a high level of education (RRR 0.84 [95% Cl 0.76–0.94]). Nevertheless, the investigating factors could explain 1% of the variability in exercise adherence (R<sup>2</sup> = 0.012).

**Conclusion.** Despite the associations reported above, the poorly explained variability suggests that strategies based on lifestyle and demographic, socioeconomic, and disease-related factors are unlikely to improve exercise adherence significantly.

# INTRODUCTION

In osteoarthritis (OA), exercise is considered a first-line intervention by international clinical practice guidelines (1,2) due to its ability to improve symptoms and levels of functionality (3,4). Exercise positively affects body weight, lipid metabolism, glycemic control, and systemic inflammation, preventing and treating OA-related chronic diseases (5). Despite these benefits, adherence to exercise in OA is subootimal (6,7).

Adherence is described by the World Health Organization (WHO) as "the extent to which a person's behavior, taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (8). Poor adherence to exercise can severely compromise its long-term effectiveness, limiting its benefits (9). Considering the rising prevalence (10) and economic burden of OA (11), identifying factors associated with exercise adherence is fundamental to creating specific interventions to improve it.

Several elements have been hypothesized to be associated with exercise adherence, including lifestyle and demographic, socioeconomic, and disease-related factors (12–17). However, evidence on this topic arises mainly from other chronic conditions than OA, qualitative studies whose aims are not to generalize knowledge, as well as studies with small samples (12–19).

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# **SIGNIFICANCE & INNOVATIONS**

- Though exercise is a first-line intervention in osteoarthritis (OA), levels of exercise adherence among people with OA are suboptimal. Several elements have been hypothesized to be associated with exercise adherence, including lifestyle and demographic, socioeconomic, and disease-related factors in conditions other than OA.
- Analyzing real-world data from a first-line intervention provided nationwide in Swedish primary care, we found that high levels of adherence were positively associated with increased age, frequent pain, walking difficulties, and higher levels of selfefficacy. Conversely, high levels of adherence were negatively associated with female sex, higher body mass index, and high socioeconomic positions. However, these factors could explain 1% of the exercise variability.
- In OA, strategies based on lifestyle and demographic, socioeconomic, and disease-related factors are unlikely to improve exercise adherence significantly. Therefore, to improve adherence significantly, we need to consider other elements.

Moreover, the WHO has stated that the combination of different factors, rather than a single one, determines adherence (8). In contrast, the abovementioned studies focused primarily on single factors and their measures of mean association with adherence (e.g., odds ratio). Relying just on measures of association corresponds to an abstraction that does not take into account the variability of individual-level effects (20).

Therefore, we aimed to investigate the associations between lifestyle and demographic, socioeconomic, and disease-related factors with adherence to supervised exercise as a part of an OA management program delivered nationwide in Swedish primary care. Furthermore, we aimed to investigate these factors' ability to explain exercise adherence variability.

# MATERIALS AND METHODS

Study design and setting. This study is a cohort registerbased study on individual-level data retrieved from the Swedish Osteoarthritis Registry (SOAR; for data on the OA management program) and the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA) administered by Statistics Sweden (for data on socioeconomic positions). These data sets were merged using personal identity numbers unique to all citizens in Sweden.

SOAR includes data from approximately 195,000 people with OA who attended an OA management program provided nationwide by the Swedish health care system (21,22). This program has already been thoroughly described elsewhere (23,24). Briefly, it is composed of 2 parts: education and exercise. The education part is mandatory, while the exercise part is optional. The education part is based on 3 sessions that revolve around the pathophysiology of the disease and its self-care management. The first 2 sessions are mandatory and held by a physiotherapist. The third is optional and held by a person with OA, trained as an OA communicator. The exercise (optional) part starts with an individual encounter with a physiotherapist to tailor the exercise program to the participants' needs and characteristics. At this point, participants can decide whether to exercise at home or with a physiotherapist. Those who decide to exercise with a physiotherapist are offered the opportunity to attend 12 sessions over 6 to 8 weeks (2 sessions/week) following OA Swedish clinical practice guidelines (25). LISA provides socioeconomic data such as cohabitation, institutionally based education level, employment, income, and residential area (26). The research was conducted in respect of the Declaration of Helsinki and reported following the Strengthening the Reporting of Observational studies in Epidemiology guidelines. Ethical approval was obtained from the Swedish Ethics Committee (Dnr: 2019-02570).

**Population.** The study cohort comprises all the participants in the SOAR with a first registration (baseline) between 2012 and 2015. We included only those who started the exercise group sessions supervised by the physiotherapists after the initial encounter with them. We selected participants with knee or hip OA who were recorded in the SOAR only once.

Variables. The level of adherence to the supervised exercise part, reported in the SOAR, is the dependent variable of this study. This is a predetermined categorical variable recorded by the physiotherapists and stratified on the number of sessions participants attended (low levels of adherence: 1–6 training sessions; medium levels of adherence: 7–9 training sessions; or high levels of adherence: 10–12 sessions). In this study, high levels of adherence represent >80% of the adherence with the recommended interventions (12 sessions) (25), which is typically considered a satisfactory level of adherence (27). The collected independent variables are reported hereafter and divided as demographic and lifestyle characteristics, socioeconomic characteristics, and disease-related characteristics.

**Demographic** and lifestyle characteristics. Participants' demographic and lifestyle characteristics were reported by the participants themselves at the baseline and recorded in the SOAR. These characteristics were assigned sex at birth (binary variable: male/female), age (continuous variable), body mass index (BMI; continuous variable computed from selfreported height and weight), weekly physical activity (continuous variable: hours) that was assessed with the question "How active are you during a regular, typical week?" (21), and health-related quality of life (HRQoL; continuous variable: EuroQoI 5-domain instrument visual analog scale [EQ-5D VAS]). In the EQ-5D VAS, the respondents reported their perceived HRQoL on a VAS scale that scored from 0 (the worst possible) to 100 (the best possible). The EQ-5D VAS is part of the EQ-5D scale (28).

Socioeconomic characteristics. Each socioeconomic position indicator from the year before the enrollment to the SOAR was considered for the analysis. In particular, the following socioeconomic position factors were retrieved and categorized: living alone (binary variable: living alone/living with someone), institutionally based education level (categorical variable: low [primary school: 0–9 years], medium [secondary school up to postsecondary education <3 years: 10–14 years], or high [postsecondary education: ≥15 years]), employment (binary variable: employed/ retired-unemployed), residential area (categorical variable: rural/ suburban/urban) and the net income.

Residential area was classified based on the Swedish Association of Local Authorities and Regions classification of Swedish municipalities. Specifically, rural areas are smaller towns/urban areas and rural municipalities, suburban areas are medium-sized towns (≥40,000 inhabitants) and municipalities near mediumsized towns, and urban areas are large cities (≥200,000 inhabitants) and municipalities near large cities (≥200,000 inhabitants) and municipalities near large cities (29). The individual yearly net income was categorized into quartile sased on the sample income distribution: lowest income quartile (<146,500 Swedish krona (SEKJ), second income quartile (146,501–198,100 SEK), third income quartile (198,101–278,800 SEK), and highest income quartile (>278,800 SEK) (29).

Disease-related characteristics. The physiotherapists recorded the index joint (categorical variable: hip or knee) (21), namely, the joint with OA. They assessed this variable based on the participant's medical history, symptoms, and clinical assessment. In the case of multiple joints with OA, the most symptomatic joint was considered the index joint for the treatment. The participants self-recorded the numbers of painful joints (continuous variable); their desire for surgery (binary variable: yes/no) that was assessed by asking them: "Are your knee/hip symptoms so severe that you wish to undergo surgery?" (21); their pain intensity (ordinal variable: 0-10 on a numeric rating scale [NRS] [30]) in their index joint; their pain frequency (binary variable: infrequent pain [less than every week], frequent pain [almost every day]) that was assessed with the question: "How often do you have pain in your knee/hip" (21); their fear of movement (binary variable: yes/no) that was assessed with the question "Are you afraid your joints will be injured by physical training/activity?"; the Charnley score (categorical variable: A = unilateral hip or knee OA, B = bilateral hip or knee OA, C = multiple joint OA or some other condition) that categorizes people with OA into 3 classes based on the diseases that affect walking ability (31); and arthritis-specific selfefficacy (continuous variable: 10-100, pain and symptoms on the Arthritis Self-Efficacy Scale [ASES], using the Swedish version of the scale) (32). The ASES scale is a reliable instrument that assesses patients' arthritis-specific self-efficacy, namely, their beliefs about their ability to perform a specific task and cope with OA (33). The full version is composed of 3 subscales: 1) selfefficacy pain scale (5 items), 2) function scale (9 items), and 3) other symptoms scale (6 items). Participants indicate to what extent they feel confident they can do the tasks reported in the items from 10 (very uncertain) to 100 (very certain). In the SOAR, only 1) and 3) were adopted and combined as suggested in the scale instruction (33).

Statistical analysis. Descriptive statistics are reported as mean  $\pm$  SD and absolute and percentage frequencies. A multivariable exploratory analysis was performed to identify which independent variables were independently associated with exercise adherence in the SOAR (34). Multivariable exploratory analyses detect patterns and identify relationships between the independent variables and the outcome (34–36).

Since the proportional odds assumption was not met, an ordered logistic regression could not be performed. Hence, we ran a multinomial logistic regression with a listwise deletion (Stata function mlogit) to determine the association between the independent variables and the adherence to exercise. No missing data were reported in the outcome (adherence). Less than 1% of the data on socioeconomic characteristics was missing, primarily due to an error during the data upload process in LISA. Missing data on demographic and lifestyle and disease-related characteristics may be physiotherapists responsible for uploading the data at the local unit. Hence missing data in both registers could be considered missing completely at random, introducing no or minimal bias in our analysis.

The selection of the variables in the model was informed by previous literature on exercise adherence in other chronic pain conditions (12–17) and the evidence for action on adherence by the WHO (8). Then, the variables were clustered in demographic and lifestyle, socioeconomic, and disease-related groups, following the dimensions proposed by the WHO (8). The multicollinearity assumption between continuous variables was tested, and none of the continuous variables was highly correlated. The relative risk ratio (RRR) of being in medium level of adherence or high level of adherence with respect to low level of adherence and 95% confidence intervals (95% CIs) were estimated for each covariate in the model. For the variables HRQoL and arthritis-specific self-efficacy, the RRR is presented as a 10-point change in their scales.

Finally, the ability of the models to explain the variability of exercise adherence was calculated with the McFadden  $R^2$  statistic (Stata function fitstat). McFadden  $R^2$  measures the ability of a model to explain the variance of dependent variables on a convenient 0–100% scale. In particular, this value highlights how much of the variance in the dependent variable (adherence) can be explained by the independent variables collectively. We calculated McFadden  $R^2$  for the model with all variables included (full model).

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Afterward, we excluded 1 set of variables from the model and calculated the difference between McFadden R<sup>2</sup> with the full model. A higher difference would indicate a higher contribution of the variables set into the explanatory power of the full model. The analysis was done through Stata 17.

# RESULTS

Between January 1, 2012 and December 31, 2015, 46,905 people with OA were recorded in the SOAR. However, we excluded 7 participants who had joints other than hip and knee as their first cause of pain, 27,147 who did not perform any supervised exercise sessions, and 1 for attending the program more than once. Hence, 19,750 participants with knee (69%) and hip (31%) OA were included in this study (73% female, mean  $\pm$  SD age 67  $\pm$  8.9 years). Figure 1 shows the participants' selection process. Table 1 presents the characteristics of the entire sample and stratified by the levels of adherence. 3,947 (20%) a medium level, and 9,941 (50%) a high level.

After the listwise deletion, the multinomial logistic regression was run on 16,685 individuals (85%), using low levels of

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adherence as the reference category (Table 2). Overall, excluded participants (n = 3,065) had similar characteristics to the ones included in the analysis (see Supplementary Table 1, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25135). We found that female sex (RRR 1.13 [95% CI 1.02–1.27]), living with someone (RRR 1.21 [95% CI 1.10–1.32]), and an increase of 1 number of joints with OA (RRR 1.06 [95% CI 1.01–1.10]) were positively associated with achieving medium levels of adherence. Conversely, an increase in an hour of weekly physical activity (RRR 0.98 [95% CI 0.96–0.99]), living in an urban area (RRR 0.87 [95% CI 0.78–0.98]), and being employed (RRR 0.82 [95% CI 0.72–0.93]) were negatively associated with achieving medium levels of adherence.

An increase of 1 year in age (RRR 1.01 [95% CI 1.01–1.02]), having frequent pain (RRR 1.13 [95% CI 1.02–1.25]), having walking difficulties (RRR 1.12 [95% CI 1.01–1.24]), and having a 10-point increase on the ASES (RRR 1.04 [95% CI 1.02–1.07]) were positively associated with high levels of adherence. By contrast, female sex (RRR 0.82 [95% CI 0.75–0.89]), an increase of 1 point in BMI (RRR 0.99 [95% CI 0.98–0.99]), living in a suburban (RRR 0.79 [95% CI 0.73–0.86]) or an urban area (RRR 0.78 [95% CI 0.71–0.86]), being employed (RRR 0.71 [95% CI 0.64–0.78]),

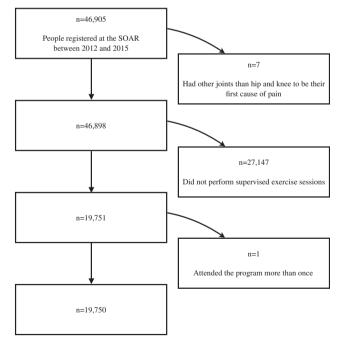


Figure 1. Selection of the study population. SOAR = Swedish Osteoarthritis Registry.

# EXERCISE ADHERENCE IN OSTEOARTHRITIS

# Table 1. Descriptive statistics\*

		Level of adherence		
Variables	Total sample (n = 19,750)	Low (n = 5,862)	Medium (n = 3,947)	High (n = 9,941)
Demographic and lifestyle characteristics				
Assigned sex at birth	n = 19,750	n = 5,862	n = 3,947	n = 9,941
Male	5,421 (27.45)	1,519 (25.91)	925 (23.44)	2,977 (29.95)
Female	14,329 (72.55)	4,343 (74.09)	3,022 (76.65)	6,964 (70.05)
Age	n = 19,750	n = 5,862	n = 3,947	n = 9,941
Mean ± SD	66.86 ± 8.94	65.87 ± 9.39	66.47 ± 9.01	67.60 ± 8.57
Body mass index	n = 19,381	n = 5,735	n = 3,867	n = 9,779
Mean ± SD	27.56 ± 4.76	27.73 ± 4.90	27.75 ± 4.89	27.43 ± 4.63
HRQoL (EQ-5D VAS, 0–100) Mean ± SD	n = 17,933 65.82 ± 19.22	n = 5,317 65.84 ± 19.37	n = 3,592 65.74 ± 19.35	n = 9,024 65.85 ± 19.07
Weekly physical activity, hours	n = 18,050	n = 5,364	n = 3,606	n = 9,080
Mean ± SD	4.11 ± 2.53	4.14 ± 2.53	4.03 ± 2.49	4.13 ± 2.54
Socioeconomic characteristics				
Institutionally based education level	n = 19,699	n = 5,862	n = 3,938	n = 9,918
Low	4,331 (21.99)	1,170 (20.02)	795 (20.19)	2,366 (23.86)
Medium	9,843 (49.97)	2,962 (50.69)	2,007 (50.96)	4,874 (49.14)
High	5,525 (28.05)	1,711 (29.28)	1,136 (28.85)	2,678 (27.00)
Income quartile	n = 19,738	n = 5,858	n = 3,945	n = 9,935
Lowest Second	4,942 (25.04)	1,345 (22.96)	1,022 (25.91)	2,575 (25.92)
Third	4,936 (25.01) 4,929 (24.97)	1,393 (23.78) 1,517 (25.90)	982 (24.89) 976 (24.74)	2,561 (25.78) 2,436 (24.52)
Highest	4,931 (24.98)	1,603 (27.36)	965 (24.46)	2,363 (23.78)
Area of living	n = 19,738	n = 5,858	n = 3,945	n = 9,935
Rural	6,047 (30.64)	1,667 (28.46)	1,180 (29.91)	3,200 (32.21)
Suburban	8,252 (41.81)	2,435 (41.57)	1,708 (43.30)	4,109 (41.36)
Urban	5,439 (27.56)	1,756 (29.98)	1,057 (26.79)	2,626 (26.43)
Employment	n = 19,738	n = 5,858	n = 3,945	n = 9,935
Unemployed	12,244 (62.03)	3,275 (55.91)	2,394 (60.68)	6,575 (66.18)
Employed	7,494 (37.97)	2,583 (44.09)	1,551 (39.32)	3,360 (33.82)
Living alone	n = 19,738	n = 5,858	n = 3,945	n = 9,935
Living alone	7,754 (39.28)	2,411 (41.16)	1,457 (36.93)	3,886 (39.11)
Living with someone	11,984 (60.72)	3,447 (58.84)	2,488 (63.07)	6,049 (60.89)
Disease-related characteristics	40.750	- 5062	- 2047	- 0.044
Worst joint	n = 19,750	n = 5,862	n = 3,947	n = 9,941
Hip Knee	6,049 (30.63) 13,701 (69.37)	1,708 (29.14) 4,154 (70.86)	1,188 (30.10) 2,759 (69.90)	3,153 (31.72) 6,788 (68.28)
Pain intensity (NRS 0–10)	n = 19,686	n = 5,843	n = 3,935	n = 9,908
Mean ± SD	5.25 ± 1.83	5.23 ± 1.85	5.24 ± 1.87	5.26 ± 1.80
Pain frequency	n = 19,700	n = 5,842	n = 3,940	n = 9,918
Infrequent	3,436 (17.44)	1,100 (18.83)	723 (18.35)	1,613 (16.26)
Frequent	16,264 (82.56)	4,742 (81.17)	3,217 (81.65)	8,305 (87.34)
Number of painful joints	n = 19,750	n = 5,862	n = 3,947	n = 9,941
Mean ± SD	1.94 ± 1.29	1.95 ± 1.28	2.00 ± 1.32	1.91 ± 1.27
Charnley score	n = 19,735	n = 5,855	n = 3,946	n = 9,934
A	6,814 (34.53)	2,000 (34.16)	1,340 (33.96)	3,474 (34.97)
В	3,437 (17.42)	1,009 (17.23)	686 (17.38)	1,742 (17.54)
C	9,484 (48.06)	2,946 (48.61)	1,920 (48.66)	4,718 (47.49)
Walking difficulties	n = 19,651	n = 5,835	n = 3,932	n = 9,884
No	3,472 (17.67)	1,105 (18.94)	731 (18.59)	1,636 (16.55)
Yes Foor of movement	16,179 (82.33)	4,730 (81.06)	3,201 (81.41)	8,248 (83.45)
Fear of movement	n = 19,651	n = 5,821	n = 3,928	n = 9,902
No Yes	16,562 (84.28) 3,089 (15.72)	4,871 (83.68) 950 (16.32)	3,303 (84.09) 625 (15.91)	8,388 (84.71) 1,514 (15.29)
Desire for surgery	n = 19,558	n = 5,798	n = 3,906	n = 9,854
No	14,936 (76.37)	4,441 (76.60)	3,017 (77.24)	7,478 (75.89)
Yes	4,622 (23.63)	1,357 (23.40)	889 (22.76)	2,376 (24.11)
ASES pain and symptoms (0–100)	n = 19,149	n = 5,660	n = 3,834	n = 9,655
Mean ± SD	65.54 ± 16.43	65.44 ± 16.54	65.51 ± 16.62	65.61 ± 16.28

\* Values are the number (%) unless indicated otherwise. To calculate the missing values, subtract the number of participants listed in the second column (Total sample) from the total sample size of 19,750. ASES = Arthritis Self-Efficacy Scale; EQ-5D VAS = EuroQol 5-domain instrument visual analog scale; HRQoL = health-related quality of life; NRS = numeric rating scale.

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**Table 2.** Association between exercise adherence and investigated factors  $(n = 16,685)^*$ 

IdCIOIS (II = 10,083)		
Variables	Р	RRR (95% CI for EXP[B])
Medium levels of adherence		
Assigned sex at birth		
Male (base category) Female	- 0.03	
Age	0.03	1.13 (1.02–1.27) 1.00 (0.99–1.01)
Body mass index	0.37	0.99 (0.99–1.01)
HRQoL (EQ-5D VAS, 0-100)†	0.57	0.99 (0.97–1.02)
Weekly physical activity, hours	0.02	0.98 (0.96–0.99)
Institutionally based education level		
Low (base category)	-	-
Medium High	0.88 0.63	0.99 (0.88–1.12) 0.97 (0.84–1.11)
Income quartile	0.05	0.97 (0.84-1.11)
Lowest (base category)	_	-
Second	0.71	0.98 (0.86-1.11)
Third	0.63	0.97 (0.84–1.11)
Highest	0.41	0.94 (0.81–1.09)
Area of living		
Rural (base category) Suburban	- 0.27	- 0.94 (0.85–1.05)
Urban	0.27	0.87 (0.78-0.98)
Employment	0.02	0.07 (0.70 0.50)
Unemployed (base category)	-	-
Employed	<0.01	0.82 (0.72-0.93)
Living alone		
Living alone (base category)	-	-
Living with someone	<0.01	1.21 (1.10–1.32)
Worst joint Hip (base category)	_	_
Knee	0.35	0.95 (0.86-1.05)
Pain intensity (NRS 0–10)	0.49	1.01 (0.98–1.04)
Pain frequency		
Infrequent (base category)	-	-
Frequent	0.80	0.98 (0.87-1.11)
Number of painful joints	0.01	1.06 (1.01–1.10)
Charnley score A (base category)	_	_
B	0.99	_ 0.99 (0.97–1.15)
c	0.13	0.91 (0.81–1.03)
Walking difficulties		(
No (base category)	-	-
Yes	0.93	0.99 (0.88–1.13)
Fear of movement		
No (base category)	- 10	-
Yes Desire for surgery	0.49	1.04 (0.92–1.18)
No (base category)	_	_
Yes	0.26	0.94 (0.83–1.05)
ASES pain and symptoms (0-100) <sup>†</sup>	0.29	1.02 (0.99–1.05)
High levels of adherence		
Assigned sex at birth		
Male (base category)	-	-
Female Age	<0.01 <0.01	0.82 (0.75-0.89) 1.01 (1.01-1.02)
Body mass index	0.01	0.99 (0.98-0.99)
HRQoL (EQ-5D VAS, 0–100)†	0.18	0.98 (0.96–1.01)
Weekly physical activity, hours	0.79	0.99 (0.98–1.01)
Institutionally based education level		
Low (base category)	-	-
Medium	0.02	0.89 (0.81–0.98)

(Continued)

## Table 2. (Cont'd)

Variables	Р	RRR (95% CI for EXP[B])
High	< 0.01	0.84 (0.76-0.94)
Income quartile		
Lowest (base category)	-	-
Second	0.79	1.01 (0.91–1.13)
Third	0.61	1.03 (0.92–1.15)
Highest	0.95	1.00 (0.89–1.14)
Area of living		
Rural (base category)	-	-
Suburban	< 0.01	0.79 (0.73–0.86)
Urban	<0.01	0.78 (0.71–0.86)
Employment		
Unemployed (base category)	-	-
Employed	<0.01	0.71 (0.64–0.78)
Living alone		
Living alone (base category)	-	-
Living with someone	0.29	1.04 (0.97–1.12)
Worst joint		
Hip (base category) Knee	0.03	- 0.92 (0.85-0.99)
Pain intensity (NRS 0–10)	0.03	1.02 (0.85-0.99)
Pain frequency	0.12	1.02 (0.55=1.04)
Infrequent (base category)	_	_
Frequent	0.02	1.13 (1.02-1.25)
Number of painful joints	0.50	1.01 (0.98–1.05)
Charnley score	0.50	1.01 (0.50 1.05)
A (base category)	_	_
В	0.74	1.02 (0.91-1.14)
С	0.11	0.93 (0.84-1.02)
Walking difficulties		,
No (base category)	-	-
Yes	0.03	1.12 (1.01-1.24)
Fear of movement		
No (base category)	-	-
Yes	0.93	1.00 (0.91-1.11)
Desire for surgery		
No (base category)	-	-
Yes	0.44	0.96 (0.88-1.06)
ASES pain and symptoms (0–100)†	<0.01	1.04 (1.02–1.07)

\* Low levels of adherence are the reference. 95% CI = 95% confidence interval; ASES = Arthritis Self-Efficacy Scale; EQ-5D VAS = EuroQol 5-domain instrument visual analog scale; HRQoL = health-related quality of life; NRS = numeric rating scale; RRR = relative risk ratio.

† RRR is reported as an increase of 10 points in the scale.

having a medium (RRR 0.89 [95% CI 0.81–0.98]) or a high level of institutionally based education (RRR 0.84 [95% CI 0.76–0.94]), and having the knee as the worst joint (RRR 0.92 [95% CI 0.85–0.99]) were negatively associated with high levels of adherence.

Finally, the McFadden  $R^2$  of the full model suggested that participants' demographic and lifestyle characteristics, socioeconomic characteristics, and disease-related characteristics can explain approximately 1.2% of the variation in adherence. After we removed participants' demographic and lifestyle characteristics, socioeconomic characteristics, and disease-related characteristics alternatively, there was a difference in the McFadden  $R^2$  with respect to the full model of 0.3%, 0.4%, and 0.2%, respectively. Disease-related characteristics had the most explanatory power, albeit the total explanatory ability of the full model was very small.

# DISCUSSION

This study is the first to try to understand the relationship between demographic and lifestyle, socioeconomic, and diseaserelated factors, with the level of adherence to a face-to-face supervised exercise program for OA in a large sample of participants with this disease. Of the total sample, approximately 30% had low adherence levels, 20% had medium adherence levels, and 50% had high adherence levels. The distribution of adherence levels in our sample is consistent with that of participants in a similar Danish intervention (37) but differs from the distribution observed in an online version of the same intervention, which had a higher proportion of people with high levels of adherence than our sample (38). While several factors were associated with adherence, the full model could explain only 1% of the variability, which suggests that these factors are unlikely to have a tangible impact on adherence.

Regarding demographic and lifestyle factors, female sex was negatively associated with a high level of adherence. Previous evidence has indicated that women (with or without OA) might face societal expectations of household and caregiving responsibilities, experiencing greater difficulty finding time to exercise (39-43). However, in the digital version of this intervention, female sex suggested a positive association with high levels of exercise adherence (38), suggesting that digital interventions may be more convenient for females. Despite these findings, addressing the root causes of these disparities in exercise adherence is crucial, rather than focusing on exercise delivery mode to reduce this sex gap. However, our study only collected information on participants' assigned sex at birth, limiting the generalizability of our results to those individuals who are not cisgender. Therefore, further research is needed to explore the relationship between gender identity, sex, and exercise adherence in individuals with OA. In addition, participants' older age was positively associated with reaching a high level of adherence. Considering how exercise is delivered in this program, our result aligns with previous evidence where older adults adhered more to self-paced rather than moderate-intensity exercise (44). Finally, BMI was negatively associated with reaching high levels of adherence, which is consistent with previous evidence where people with high BMI are less keen on engaging in physical exercise (38,45).

Among the socioeconomic factors, people who lived in an urban or suburban area, were employed, and had medium or high levels of institutionally based education tended to exercise less than their counterparts. Similar results were found in the digital version of this intervention, where lower institutionally based education and living outside the largest Swedish cities were associated with higher adherence (38). These results contrast with the previous literature, where socioeconomic categories typically representing higher socioeconomic positions tended to adhere

more to exercise (46,47). However, it is essential to consider that most of the data on adherence were retrieved from secondary analyses of randomized controlled trials (RCTs) (48). First, these studies were not designed to study adherence. RCTs per se tend to enhance adherence to treatment, which might create an overestimation of the factors related to adherence (49).

Second, in RCTs, people are volunteers who are selected following specific inclusion and exclusion criteria, which may fail to mirror the socioeconomic variability of the underlying population from which the sample is drawn (50). Moreover, we might not have reached the more socioeconomically disadvantaged groups, considering the higher socioeconomic positions of the SOAR sample compared to the general Swedish population (29). Finally, another explanation of this tendency is that people in lower socioeconomic positions seemed exposed to a more detrimental OA-disease burden than their higher counterparts (51). Severe symptoms can act as a motivator and drive exercise adherence (46,52). Those who experience a higher disease burden might be more motivated to follow exercise regimens. This phenomenon was also highlighted in our study when looking at the disease-related factors, as having frequent pain and walking difficulties were associated with high levels of adherence.

Moreover, self-efficacy was associated with exercise adherence, as per previous evidence (53), but with a modest RRR. Self-efficacy is characterized by a curvilinear (U-shaped) relationship between this construct and task accomplishment (54). People with low self-efficacy are likely to doubt their chance to accomplish a task, and those with a high-self efficacy might be characterized by complacency, inadequate preparation, and a focus on achieving task-related targets (54). Therefore, low and high levels of self-efficacy can lead to a similar outcome, namely, low adherence to a task (e.g., exercise). Considering the large cohort of our study, the effect of self-efficacy might be diluted due to the high variety of our population.

However, our model could explain just 1% of the variability, as indicated by the McFadden R<sup>2</sup>. Thus, if we wanted to design an exercise intervention and understand which strategies to adopt to increase adherence, we should accept that demographic and lifestyle, socioeconomic, and disease-related factors are unlikely to improve adherence significantly, considering how little they explain adherence variability. This conclusion is further supported by the limited ability of similar factors to explain exercise adherence in the digital version of the intervention (38). Therefore, other factors should be taken into account.

The SOAR gathers real-world data from >500 different units throughout Sweden, with considerable variability among them. These contexts are characterized by specific contextual factors (e.g., structures' facilities, clinicians' communication style and ability to motivate patients, etc.) that affect people's outcomes via a placebo (or nocebo) response if positively (placebo) or negatively (nocebo) encoded by the brain via the so-called "mindsets" (55). Mindsets are "core assumptions about a domain or category that

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orient individuals to a particular set of attributions, expectations, and goals" (56,57). Preliminary evidence indicated that improving mindsets about exercise increased its adherence (57). Moreover, booster sessions, reminders, and behavioral change techniques can improve exercise adherence by increasing motivation to partake in exercise (58,59). These strategies seem to ground their efficacy on contextual factors as well (e.g., communication with the clinicians, feeling taken care of by them, etc.). Therefore, we can argue that contextual factors and the mindsets responsible for interpreting them are worth exploring in future studies to understand their relationship with exercise adherence.

Some limitations of this study need to be discussed. First, the observational nature of the study does not allow us to establish causality and draw any definitive conclusion on the relationship between exercise adherence and the investigated factors. Second, a few variables were not reported. However, as explained in the methods section, the missingness of our data could be considered to be completely at random, primarily due to an error during the data upload process in the registers, introducing no or minimal bias in our results. However, we recommend interpreting our results cautiously, as we could not verify the reason for the data missingness. Third, our results might not be reliably applied to other forms of exercise (e.g., unsupervised home exercise) due to the specific research question of our study. Finally, physical activity hours, the number of painful joints, and living alone were found to be associated with medium but not high levels of adherence. However, this result may be influenced by chance and could also be attributed to the ad hoc adherence categorization adopted in the SOAR. Bearing in mind the limits of this study, it is worth highlighting that we reported the results of roughly 20,000 people with OA, followed by physiotherapists in the Swedish national health care system who tailored their intervention to patients' needs and characteristics. The size and data quality of our study strengthen its clinical importance and relevance for research.

To conclude, strategies based on demographic and lifestyle, socioeconomic, and disease-related factors are unlikely to improve exercise adherence significantly. Other elements, such as mindsets and contextual factors, need to be investigated. Moreover, as booster sessions, reminders, and behavioral-change techniques seem to improve exercise adherence (58,59), we should also understand how they motivate people to partake in exercise. Considering the complexity of adherence and the types of treatments that have succeeded in improving it so far, there is a call for solutions that go beyond a one-size-fits-all approach, to accept human variability and uncertainty, and to foster tailored interventions for individuals.

#### AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Dr. Testa had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Battista, Kiadaliri, Jönsson, Dell'Isola. Acquisition of data. Battista, Jönsson, Dell'Isola.

Analysis and interpretation of data. Battista, Kiadaliri, Gustafsson, Englund, Testa, Dell'Isola.

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Study 4

Various cultural, sociodemographic, and economic elements can influence osteoarthritis (OA) care. This thesis examines physiotherapists' knowledge of and adherence to OA clinical practice guidelines, the sociodemographic and economic factors of people with OA, and their experience and beliefs about OA care. The investigated cohort of physiotherapists showed knowledge but an inconsistent implementation of OA first-line interventions. The interviewed people with OA experienced an uncertain care process and had a negative attitude towards first-line interventions. Once exploring factors associated with exercise adherence in OA, we found an association with age, sex, socioeconomic status, disease severity, and self-efficacy. However, these factors explained only a small portion of exercise adherence variability. Income inequalities were identified among the outcomes of the participants in an OA first-line intervention. Improving OA care requires bridging the gap between knowledge of and adherence to clinical practice guidelines, empowering individuals with OA through precise explanations and support, further research on exercise adherence factors, and addressing income inequalities.



**SIMONE BATTISTA** is a physiotherapist specialised in Rheumatic and Musculoskeletal Diseases Rehabilitation with a Master's degree in 'Health Professional Rehabilitation Sciences'. Simone Battista is interested in the rehabilitation and management of chronic rheumatic and musculoskeletal diseases and the impact that the socioeconomic, cultural, and psychological factors specific to patients and healthcare professionals can have on the care process of these diseases. His goal is to study and improve the care quality of rheumatic and musculoskeletal conditions, considering the challenges and needs of those with these diseases.



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