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Original article

# Hierarchical structure and importance of patients' reasons for treatment choices in knee and hip osteoarthritis: a concept mapping study

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## Abstract

**Objectives.** To improve patients' use of conservative treatment options of hip and knee OA, in-depth understanding of reasons underlying patients' treatment choices is required. The current study adopted a concept mapping method to thematically structure and prioritize reasons for treatment choice in knee and hip OA from a patients' perspective.

**Methods.** Multiple reasons for treatment choices were previously identified using in-depth interviews. In consensus meetings, experts derived 51 representative reasons from the interviews. Thirty-six patients individually sorted the 51 reasons in two card-sorting tasks: one based on content similarity, and one based on importance of reasons. The individual sortings of the first card-sorting task provided input for a hierarchical cluster analysis (squared Euclidian distances, Ward's method). The importance of the reasons and clusters were examined using descriptive statistics.

**Results.** The hierarchical structure of reasons for treatment choices showed a core distinction between two categories of clusters: barriers [subdivided into context (e.g. the healthcare system) and disadvantages] and outcome (subdivided into treatment and personal life). At the lowest level, 15 clusters were identified of which the clusters Physical functioning, Risks and Prosthesis were considered most important when making a treatment decision for hip or knee OA.

**Conclusion.** Patients' treatment choices in knee and hip OA are guided by contextual barriers, disadvantages of the treatment, outcomes of the treatment and consequences for personal life. The structured overview of reasons can be used to support shared decision-making.

**Key words:** osteoarthritis, hip, knee, concept mapping, decision-making

CLINICAL SCIENCE

**Rheumatology key messages**

- Contextual barriers, disadvantages, outcome expectations and personal life outcomes guide patients' treatment choices in OA.
- The overview of reasons for treatment choices can support patient-centred treatment decisions in OA.

## Introduction

Treatment of knee or hip OA comprises a range of conservative and surgical options such as lifestyle advice, physiotherapy, medication, intra-articular injections and joint arthroplasty [1]. However, patients with knee or hip OA frequently do not receive treatment conforming to the evidence: conservative treatment options are underused [2–4], while surgical treatment options are increasingly

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used [5]. Besides, patients for whom surgical treatment options are not considered appropriate, are not always adequately referred for conservative treatment options [2–4]. Also, patients' opinions, needs, values and preferences, are not sufficiently taken into account in treatment decision-making [6]. This suboptimal assessment of timing and type of treatment, and mismatch with patients' preferences, may lead to dissatisfaction and lower treatment adherence. Ultimately, these inadequacies can result in suboptimal OA care with higher health care costs.

Patients with knee or hip OA and healthcare providers need to decide together which of several treatment modalities fit best with patients' needs and preferences [7]. Decision aids—tools providing information about the treatment options and their outcomes—can support patients and healthcare providers in this shared decision-making process [7, 8]. Decision aids increase knowledge about treatment options, clarify patients' needs and preferences, and help with reaching an informed decision [9–11]. It has been suggested that the use of decision aids can also reduce rates of surgery and health care costs. Patients who make well-informed choices may prefer conservative treatment even when the option of surgery is presented [12], but more research is needed to confirm this notion [10, 13].

Although development of a decision aid in collaboration between both patients and healthcare providers will facilitate implementation [14], only few decision aids used patient input during development [7, 15, 16]. A valid and reliable method to generate and hierarchically structure patients' opinions as input for a decision tool is concept mapping [17–19], a method that can be used to thematically analyse and prioritize reasons for treatment choice from a patients' perspective. Following this method, patients themselves structure the items that are derived from interviews or another source of information in a card-sorting task, after which a statistical technique hierarchically structures these sortings.

The current study is part of a project, in which qualitative and quantitative studies are combined to develop a decision tool for clinical practice. In previous interviews, 24 patients with knee and hip OA [20] and 24 health care providers working in the field of knee and hip OA (unpublished data) offered reasons to choose a treatment modality of knee and hip OA. The aim of the current study was to thematically structure and prioritize these reasons to choose a treatment modality in knee and hip OA from the perspective of patients.

## Method

A concept mapping method [19] was adopted consisting of six steps: preparation consisting of development of the focus of the study and recruitment of patients (step 1); the generation of multiple reasons for treatment choices (step 2); the structuring and prioritizing of reasons in two card-sorting tasks (step 3); the hierarchical clustering of the identified reasons (step 4); the interpretation of the cluster solution (step 5); and the definition of how to use the results of the concept mapping study (step 6). Steps 1–4 will be explained in this section, and the interpretation of clusters (step 5) and utilization of clusters (step 6) will be described in the results and discussion sections.

### Step 1: preparation

*Focus*

In a previous study, 24 patients with knee and hip OA [20] and 24 health care providers working in the field of knee and hip OA (unpublished data) were interviewed about all reasons they might have to choose a treatment modality of knee and hip OA. The reasons identified in the interviews were used as input for the systematic overview of reasons that should be the product of this concept mapping study.

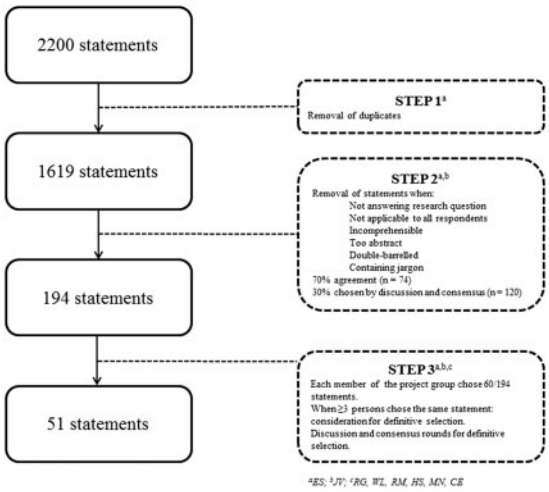
*Recruitment*

Patients for the current study were extracted from patient records of a general practitioner (GP) practice in Lent/Nijmegen, The Netherlands. Eligible patients were: >18 years of age, diagnosed with hip or knee OA by their GP, Dutch speaking, having no visual impairments or reading restrictions. All patients provided informed consent. For each potential patient, the inclusion criteria were assessed by their GP. The Institutional Review Board of the Radboud University Medical Centre, Nijmegen concluded that the Medical Research Involving Human Subjects Act did not apply to this study (protocol number: 2014/325).

### Step 2: reduction of statements

A representative set of statements was derived from the previous interview study by a project group comprising researchers, medical specialists and health professionals (E.S., R.G., W.L., R.M., H.S., M.N., C.E., J.V.). We aimed for a maximum number of 60 statements, because previous studies taught us that this was a workable number [17]. All 2200 statements from the interviews were reduced to a representative set of statements in three steps (Fig. 1). First, unmistakably duplicated statements were removed by the primary researcher (E.S.). Second, two researchers (J.V. and E.S.) assessed the 1619 remaining statements. The variety and representativeness of the set of statements were continuously protected. Criteria for removing statements were: duplication, being not applicable to the target group, incomprehensible wording, too abstract and ambiguous wording. The two researcher reached an agreement for 70% of the statements for inclusion or removal from the set. For the remaining 30%, consensus was reached through discussion. After this second step, 194 statements were left. Third, members of the project group were asked to select independently 60 statements out of 194, following the same rule as described in step 2. Statements chosen by three or more members of the project group (cut-off point arbitrarily chosen) were discussed in consensus meetings with the project group until full agreement was achieved. Furthermore, the wording of the statements—with regard to length and comprehensibility [21]—was discussed in this consensus meeting. The final set comprised

FIG. 1 Flowchart of selection of statements for the card-sorting task

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51 statements. Five co-workers (researchers, physiotherapists and a social worker) pilot-tested the feasibility of the card-sorting task. Furthermore, two patients with knee and hip OA evaluated the final set of statements for its representativeness and comprehensiveness and were asked to propose any additional statement. Minor changes were made in the wording of the statements.

### Step 3: sorting of statements

In this step, patients individually sorted the reasons in two card sorting tasks: one based on content similarity and one on importance. The selected reasons were numbered randomly and printed on separate cards. Each reason started with: Important when making my treatment decision is. . ., followed by one of the reasons. Patients could choose between four different shifts to make the sorting task in the Sint Maartenskliniek. After an extensive explanation, patients had 60 min to complete the first task and 45 min to complete the second task, with a short break of 15 min in between.

The first task was to individually sort the reasons into piles based on similarity of meaning. Patients were asked to label each pile with a personally meaningful, overarching theme. These labels could be used by the researchers to interpret sortings. The following rules applied: (i) all reasons had to be placed on a pile; (ii) each reason could be placed on one pile only; (iii) a minimum of four and a maximum of 10 piles had to be formed; and (v) each pile could contain 2–20 reasons. This procedure assured that participants grouped reasons in a varied number of themes and that participants would not make piles including only a single or few reasons.

The second task was to individually sort the reasons into five categories of importance. The categories varied from 1 (least important to me when making a treatment decision for OA) to 5 (most important to me when making a treatment decision for OA). Reasons had to be equally allocated over five piles (the five categories of importance), four piles containing 10 reasons and one containing 11 reasons. Participants prioritized reasons in this way to force them to think about differences in importance. After the card-sorting task, patients could share their thoughts in a group discussion.

### Step 4: representation of statements

Hierarchical cluster analysis was used to structure the individual card sorts from the first card-sorting task. Cluster analysis is a statistical technique to classify similar objects into clusters [22]. In cluster analysis, the cells of the input proximity matrix comprised the number of times that two reasons were not sorted in the same pile. Squared Euclidean distances were computed between each pair of reasons not sorted on the same pile after which Ward's method was applied to group the most similar reasons in one cluster.

The project group used the outcome of the hierarchical cluster analysis to set the final number of clusters. The main criterion to decide on the number of clusters was that the clusters should reflect distinct components of reasons. The decision on the number of clusters was guided by the dendrogram and the agglomeration schedule produced by the statistical software program showing which reasons were being combined at each stage of the hierarchical clustering process. After deciding on the number of clusters, the contents of both a lower and a higher number of clusters were compared to finally decide on the number of clusters, based on consensus of the project group.

Descriptive statistics (mean, standard deviation, frequency) were computed to analyse the importance of the statements and the clusters (second card-sorting task). Data were analysed with the statistical software package SPSS Statistics version 22 (IBM Corp., Armonk, NY, USA).

## Results

### Demographics

One hundred and eight patients were invited to participate, of which 39 responded positively to the invitation. Thirty-six patients completed the card-sorting tasks. Three invited patients were not able to carry out the tasks due to illness, forgetting the appointment and complexity of the tasks. Table 1 presents demographic and medical characteristics of the sample.

### First card-sorting task (content)

Participants individually sorted the 51 cards with reasons into piles. The mean number of piles was 6.3 (range 4–10). The number of cards per pile varied from 2 to 20. Three patients were excluded in the analysis due to incomplete

**Table 1** Demographic and medical characteristics of 36 patients

| characteristic | |
|---|---|
| Women, n | 26 |
| Age, mean (s.d.) | 65.6 (6.6) |
| Marital status, n[a] | |
| Married or registered partnership | 31 |
| Education, n[a,b] | |
| Primary | 1 |
| Secondary | 26 |
| Tertiary | 8 |
| Working status, n[a] | |
| Retired | 15 |
| Housewife[c] | 9 |
| Working (full time or part time) | 9 |
| Affected joint, n | |
| Knee | 15 |
| Hip | 11 |
| Knee and hip | 10 |
| Symptom duration, mean (s.d.), years | 8.0 (5.6) |
| Treatment history, n[d] | |
| Pain medication | 29 |
| Physiotherapy | 25 |
| Injection | 12 |
| Surgery | 21 |
| Complementary and alternative treatment[e] | 2 |

[a]Missing values: some patients did not fill out this question. [b]Primary: primary education; secondary: vocational education, high school, middle-level applied education; tertiary: university of applied sciences, university; [c]men/female; [d]>1 treatment possible; [e]Homeopathy, glucosamine.

performance of this card-sorting task (>2 statements not allocated to a pile). In total, the participants made 213 piles of which 202 piles were given a label. Patients used different similarity criteria while sorting as shown by their labelling of the piles. Some patients sorted the statements in daily life activities (work, going out, gardening), others sorted the statements to the degree that the statements were personally applicable to them or from a social perspective (meaningful to me, consequences for society, consequences for me personally, beliefs from others). Seventy-five labels were given more than one time by different patients, including labels such as fear, result, costs, important, quality of life, pain, risks and treatment.

### Structured overview of reasons

Hierarchical cluster analyses of the 51 sorted reasons yielded a 15-cluster solution (Fig. 2). Consensus was reached in a discussion meeting with the project group, in which hierarchical structures of 13, 14, 16 and 17 clusters were also considered. Decreasing the number of clusters to 14 would combine the clusters Conformism and Indifference and combine the clusters Autonomy and Suitability. These clusters were too distinct to combine in one cluster, and information would be missed. Increasing the number of clusters to 16 and 17 would separate both the clusters Customized and Evidence-based into two clusters, which did not lead to new, clearly interpretable clusters. The number of reasons per cluster varied from two to six. The reasons were at the highest-order level divided into barriers and outcomes. The cluster barriers comprised context (e.g. the healthcare system) and disadvantages. The cluster outcomes included outcomes of treatment and consequences for personal life. Each of these four clusters included several clusters. Table 2 shows the reasons that were included in the 15 clusters.

### Importance of reasons

Table 2 shows the mean importance ratings of reasons underlying treatment choices. The mean ratings for the 15 clusters ranged from 1.8 (Indifference, s.d. = 0.7) to 3.9 (Physical functioning, s.d. = 0.8). The mean ratings for the 51 individual reasons ranged from 1.6 (Whether I can do the treatment with others, s.d. = 0.8) to 4.4 (Whether I can move more easily as a result of the treatment, s.d. = 1.0). The clusters with the highest mean ratings were physical functioning, prosthesis and risks, the clusters with the lowest mean ratings were indifference, conformism and healthcare system. The standard deviations show that importance ratings differed considerably between individuals.

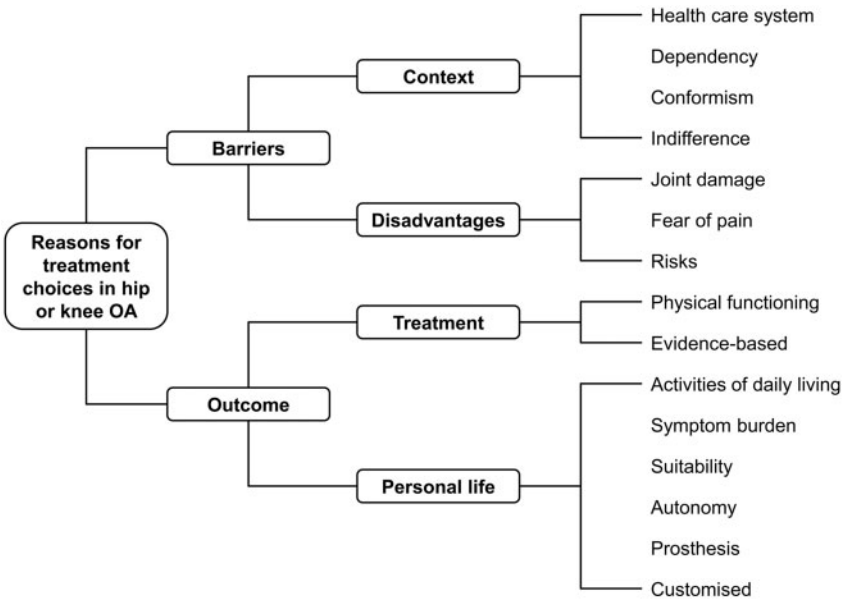
## Discussion

This study examined the hierarchical structure of reasons underlying treatment choices from the perspective of patients with hip or knee OA. Fifteen clusters of reasons were identified that were classified in two broad categories reflecting barriers and treatment outcomes. Physical functioning, Prosthesis and Risks were on average considered to be the most important clusters for patients.

The main differentiation of the cluster solution in barriers and outcomes of the treatment found in our study confirms several economic behavioural theories in which rational choices are based on weighing risks and benefits [23, 24] and social-psychology theories in which perceived benefits and barriers of behaviour play a central role in explaining behaviour (i.e. treatment choices in this study) [25]. Similarly, previous empirical studies have shown that barriers and outcomes are important constructs influencing patients' treatment decisions in OA [26, 27].

With respect to the first main category of clusters, barriers, besides possible disadvantages of treatment (joint damage, pain and risks), also contextual factors play a role in decision-making (i.e. the healthcare system and social environment). As an example, financial constraints can act as a barrier for treatment choices, for example, when specific treatment modalities such as physiotherapy are not (fully) reimbursed by the health insurer [20, 28]. A previous study showed that also diabetes patients may take less medication than prescribed because of financial constraints [29]. Thus, some treatment modalities will not

Fig. 2 Hierarchical structure of reasons for treatment choices in knee and hip OA




be an option for the patient if the barrier cannot be overcome.

The second main category of clusters outcomes comprised treatment outcomes and consequences of a treatment for personal life, which included six clusters of reasons varying from doing household chores and participating in social activities to whether or not the treatment outcome fitted with one's daily life, possibilities and goals. By mentioning these reasons, patients emphasize the importance of patient-centred care, meaning that patients should be involved in treatment decision-making and that the treatment should be individualized [30]. Research has shown that patient-centred care leads to better treatment adherence and health outcomes [30].

Patients, on average, rated some clusters of reasons as more important than others. Potential risks of a treatment were considered important, which confirms that addressing risk beliefs during consultations is needed [26, 27, 31]. For instance, the potentially mistaken belief that physical exercise damages the joint should be discussed [1, 32]. Also the anticipated effects on physical functioning of medication [33], exercising [34] and surgery [35–37] are considered important in this study and in other studies. Furthermore, concerns about the durability of a prosthesis and restrictions in movements with a prosthesis agree with previous findings about decision-making regarding total knee replacement [36]. Other reasons, such as the reasons summarized in the cluster conformism, were rated on average as of little important in our study. This appears to contrast with reviews about other chronic diseases, in which opinions of family, peers and healthcare providers [38, 39] are identified as factors influencing treatment decision-making. It is important to note that a cluster of reasons that is rated less important on average by our sample with OA can for an individual patient be a primary reason to choose or not choose a specific treatment modality.

The encompassing overview of reasons is useful in both research and in shared decision-making. The findings of the current study can be used to develop a survey about preferences for specific treatments in knee and hip OA. This survey can be used to assess treatment beliefs across larger populations and to examine determinants of treatment choices. Besides, a more specific tool can be developed to be used during consultations or to be used online as a decision aid. This tool can help to discover potential barriers for conservative treatment in each patient. In this way it helps to steer the conversation between the health professional and the patient to detect issues that otherwise might be left unspoken. Meanwhile, the results can already be used by healthcare providers in everyday practice. By discussing the mentioned barriers and treatment outcomes when treatment decisions have to be made, healthcare providers will support a shared decision-making process in OA. Our findings warrant also further research on the added value of incorporating contextual barriers and outcomes for personal life in (existing) decision aids [15, 40].

A strength of this study is the combination of qualitative and quantitative methods to organize and represent ideas of a group of patients. It provides a hierarchically structured overview of these ideas from a patients' perspective while minimizing the subjective interpretation of researchers. Our sample size was larger than 30; for card sorting a sample size between 10 and 20 people has been

**Table 2:** Fifteen clusters of reasons underlying patients' treatment choices in hip or knee OA

| Cluster | Label | Mean (s.d.) |
|---|---|---|
| 1 | **Healthcare system [3]** | **2.1 (0.9)** |
| | whether I have to pay (part of) the costs myself | 2.3 (1.4) |
| | whether the treatment brings high costs to society | 2.0 (1.4) |
| | whether the healthcare provider advises the treatment | 1.9 (1.4) |
| 2 | **Dependency [3]** | **2.5 (0.8)** |
| | whether I become dependent on the treatment | 3.2 (1.3) |
| | whether I can become habituated to the treatment | 2.3 (1.1) |
| | whether I am afraid of the treatment | 2.1 (1.2) |
| 3 | **Conformism [3]** | **1.9 (0.8)** |
| | whether I can do the treatment together with others | 1.6 (0.8) |
| | whether more people choose this treatment | 1.7 (1.1) |
| | whether I get a foreign object in my body | 2.2 (1.3) |
| 4 | **Indifference [3]** | **1.8 (0.7)** |
| | whether I think: it can't do any harm to try | 1.6 (1.1) |
| | whether the treatment is pleasant | 1.7 (1.1) |
| | whether I think that osteoarthritis is a fact of life | 1.9 (1.1) |
| 5 | **Joint damage [3]** | **3.4 (0.7)** |
| | whether the treatment will cause me to strain the joint | 3.4 (0.9) |
| | whether I cross my limits by following the treatment | 2.8 (1.1) |
| | whether the joint worsens more quickly as a result of the treatment | 3.9 (1.2) |
| 6 | **Fear of pain [3]** | **2.9 (1.1)** |
| | whether the pain increases as a result of the treatment | 3.0 (1.4) |
| | whether the treatment causes pain | 2.9 (1.3) |
| | whether the treatment is painful | 2.8 (1.3) |
| 7 | **Risks [5]** | **3.7 (0.7)** |
| | whether there are side effects from the treatment | 3.3 (1.2) |
| | whether there are risks with the treatment | 3.8 (1.3) |
| | whether the treatment damages the joints | 3.7 (1.2) |
| | whether there is a risk of infection | 3.9 (0.9) |
| | whether the treatment is harmful for health | 3.8 (1.1) |
| 8 | **Physical functioning [4]** | **3.9 (0.8)** |
| | whether I can move more easily as a result of the treatment | 4.4 (1.0) |
| | whether I can work more easily as a result of the treatment | 3.7 (1.2) |
| | whether the treatment reduces the pain | 4.3 (1.0) |
| | whether I no longer need medication after the treatment | 3.1 (1.4) |
| 9 | **Evidence-based [6]** | **3.6 (0.7)** |
| | whether the treatment is the only option | 3.0 (1.5) |
| | whether the treatment reduces inflammation | 3.8 (1.1) |
| | whether I see quick results with the treatment | 3.5 (1.2) |
| | whether the effect persists for a long time | 3.8 (1.1) |
| | whether the treatment has been shown effective | 3.3 (1.5) |
| | whether the treatment gives good results for someone of my age | 3.9 (1.3) |
| 10 | **Activities of daily living [2]** | **3.3 (1.1)** |
| | whether I can do housework more easily as a result of the treatment | 2.9 (1.4) |
| | whether I can take part again in social activities after the treatment | 3.6 (1.5) |
| 11 | **Symptom burden [3]** | **3.4 (0.8)** |
| | whether I learn to cope better with my symptoms | 3.1 (1.2) |
| | whether the treatment improves my quality of life | 4.0 (1.3) |
| | whether I need help and care after the treatment | 3.0 (1.1) |
| 12 | **Suitability [4]** | **2.4 (0.7)** |
| | whether the treatment requires an active role from me | 2.3 (1.2) |
| | whether the treatment takes much effort | 2.1 (1.8) |
| | whether the treatment is easy to fit in with everyday life | 2.6 (1.2) |
| | whether the treatment is easy to carry out | 2.6 (1.2) |
| 13 | **Autonomy [3]** | **2.5 (0.8)** |
| | whether I can do the treatment where and when I want | 2.2 (1.2) |
| | whether the treatment takes a lot of time | 2.3 (1.2) |
| | whether I can delay an operation | 2.8 (1.6) |

(continued)

TABLE 2: Continued

| Cluster | Label | Mean (S.D.) |
|---|---|---|
| 14 | **Prosthesis [2]** | **3.8** (**1.0**) |
| | whether a prosthesis lasts long | 3.9 (1.1) |
| | whether a prosthesis allows me to move freely | 3.8 (1.1) |
| 15 | **Customized [4]** | **3.2** (**0.7**) |
| | whether the treatment is personalized to what I can do | 3.0 (1.2) |
| | whether the treatment personalized to my goals | 3.0 (1.5) |
| | whether the treatment can be repeated | 3.7 (1.3) |
| | whether the treatment is invasive | 3.2 (1.1) |

The number of reasons included in a cluster is provided in square brackets. For each cluster (in bold) and reason (in regular font) the mean importance rating and S.D. are given. Importance could be graded from 1 (least important) to 5 (most important).

suggested to be a suitable number [19], and 25–30 participants will likely have similar results to those of several hundred participants [41]. Patients were extracted from the patients' records of a GP practice. Because all people living in the Netherlands are registered in a GP practice, our sample seems representative for OA patients. However, generalization of the results across other OA samples can only be made with care, as results may rely on the healthcare system in each country. For instance, reasons regarding the costs of the treatment will be perceived as less or more important in treatment choices depending on the reimbursement of healthcare costs in a specific country. As a limitation of our study, it was noticed that some patients had difficulties with the first task, which required a certain level of abstract reasoning, that is, structuring the reasons into piles with similar meaning. Another limitation of the study is that patients did not participate in the reduction of statements. A project group consisting of researchers and medical specialists conducted this reduction process after which two patients evaluated the final set of statements for its representativeness and comprehensiveness. Furthermore, our results may have been biased by the wording of reasons. For instance, in the cluster Conformism we used the word others instead of words such as family or friends, which may have contributed to a low average importance rating of this cluster. Also, the positive formulation of reasons may unintentionally have influenced respondents to sort them in outcomes clusters instead of barriers clusters.

In conclusion, reasons to choose a specific treatment for knee or hip OA include disadvantages of the treatment, contextual barriers, outcomes of the treatment and consequences for personal life. The identified themes can be used during consultations in clinical practice, in order to support patient-centred treatment decisions. The development of a decision aid including the identified themes may facilitate the implementation of the results of our study. Our findings may contribute to a better allocation of treatment customized to patients' needs and preferences.

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