# Shared Decision Making in Orthopaedic Surgery

*Implementation of tools and training in clinical practice*

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Met steun van de Nederlandse Orthopaedische Vereniging

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# General Introduction

## BACKGROUND

It was not until the second half of the 20th century that people began to recognise the importance of patient autonomy in medical care. In the past, only the doctor's opinion mattered, but since the end of the last century, patients' wishes and opinions have become more important in decision-making (1). Patient centred care was also seen as a tool to counter unwarranted variation in provided medical care. In the 1980s, Jack Wennberg first wrote about practice variation, which is driven by healthcare providers and could not be explained by patients' illness, preferences or medical needs. Shared decision-making would allow patients' preferences and values to determine the right use of health care (2).

As evidence-based medicine became increasingly important in the second half of the 20$^{th}$ century, guidelines were formulated in accordance with scientific developments. Physicians were expected to comply with these directives (3). Unfortunately, the guidelines were not always suitable for decision-making at the individual patient level. For example, certain patient populations might have been disregarded or excluded from the relevant data on the basis of characteristics such as gender or race (4-6). True evidence-based medicine is not merely about using evidence from randomized controlled trials; it is much more complex. It combines the latest scientific evidence and the clinical judgement of the healthcare professional with patient values and preferences (9).

Patient-centred care concerns the whole spectrum of care in which shared decision-making (SDM) is a pivotal element. Patient-centred care requires that the care process considers the health needs and wishes of the individual (7). These considerations are then integrated with scientific evidence to provide optimal medical treatment (8). SDM is more than simply informed consent: it is a model for clinician-patient communication that lies between the paternalistic model and the informed model of medical decision making. In the paternalistic model, clinicians decide what is best for the patient. In the informed model, the clinician's sole role is to provide information and the patient decides on the course of treatment (10). SDM can best be described as a collaborative process in which a clinician works together with a patient to reach a decision about care. A review article by Bomhof-Roordink et al. on SDM models describes seven core behavioural components for SDM that have all been well accepted in the literature (see table 1) (11). Interventions that aim at enhancing SDM address these components in the training of clinicians to improve SDM communication (12).

In addition to interventions directed towards the communication skills of clinicians, research into the effectiveness of patient decision aids (ptDAs) is a major part of SDM research (13). PtDAs are tools that support SDM. They are designed to complement, rather than replace, consultation with a clinician (14). The International Patient

Decision Aids Standards (IPDAS) Collaboration is a group of researchers who designed an evidence-based framework that can be used in the development of ptDAs (15). They define ptDAs as tools that help people become involved in decision-making by explicitly identifying a treatment choice that needs to be made, providing information about the options and outcomes, and by clarifying personal values (16). When we focus on SDM interventions in orthopaedic surgery, most studies use a ptDA as the intervention to improve SDM (17).

| Table 1. Key components of shared decision-making models, Bomhof-Roordink et al. (11) | |
|---|---|
| **1** | Creating patient awareness that a decision must be made |
| **2** | Tailoring information to the patient's needs and capabilities |
| **3** | Learning about the patient |
| **4** | Exploring patient preferences |
| **5** | Describing treatment options |
| **6** | Deliberating about the most appropriate treatment |
| **7** | Making the decision |

## SHARED DECISION-MAKING IN ORTHOPAEDIC SURGERY

Certain situations may warrant bypassing or limiting shared decision-making (SDM), such as time-sensitive trauma care, but SDM is usually indicated in the field of orthopaedic surgery (17). Many orthopaedic treatment decisions, such as for hip or knee osteoarthritis, can be described as preference-sensitive (18). This means that there is often no single 'best' treatment option available. SDM is very well suited for these situations in which there is equipoise between care options, and treatment decisions are very much dependent on individual patient preferences and needs (19). SDM helps patients to be more aware of what matters most to them (14, 20). Multiple studies have shown that when patients are involved in decision making, risk perception is more accurate, patient knowledge increases and patient satisfaction improves (14, 21-24).

Moreover, SDM can play an influential role in reducing overuse and costs in healthcare. The literature indicates that SDM helps to cut down on unnecessary procedures such as inappropriate diagnostical tests and surgical interventions (14, 25, 26). A cost-effectiveness study in total joint replacement surgery showed that an SDM intervention helped to curtail rates of surgery while still achieving similar health outcomes (27). In that study, the patients were given a ptDA and the clinicians subsequently received a preference report that contained information on patient knowledge, values, preferred treatment choice, and decisional conflict (28). The impact of SDM on cost-effectiveness may be far-reaching since orthopaedic care forms a great burden on national health

costs, and given today's aging population, the annual number of joint arthroplasty procedures is likely to increase rapidly (29).

Most patients report a preference for SDM instead of having a passive or fully autonomous role in decision-making (30-32). Clinicians also express positive attitudes towards SDM (33). The beneficial effects of SDM make it the preferred decision model in most situations, and healthcare authorities have declared SDM indispensable in orthopaedic decision-making (17, 29). Despite the focus on SDM by both policymakers and scientists, SDM in actual clinical practice is often lacking (34-37). Literature on SDM in orthopaedic surgery is limited, but suggestions for improvement have been identified (38, 39). There is a growing body of literature on barriers to successful SDM implementation (40-43). An umbrella review study categorised barriers at different levels in five themes: patient factors, health-professional factors, organisational factors, patient-clinician relationship factors, and factors related to information provision (40). Lack of information sharing, particularly about patients' conditions, treatment options and outcomes, is the most commonly identified barrier to SDM (40). Future programmes can take current barriers and facilitators to SDM into account in order to increase the use of SDM in orthopaedic care.

## ACCESSIBLE AND COMPREHENSIBLE PATIENT INFORMATION

To enable SDM it is essential to provide accessible and understandable medical information (7). From research, we know that 40 to 80% of the medical information provided by care providers is immediately forgotten by the patient (44). As patient information is a prerequisite to SDM (40), alternative methods should be found to adequately inform patients.

Governments are increasingly requiring healthcare providers to make electronic medical records directly accessible to patients to improve information provision (45, 46). By means of these accessible health records, patients can read their medical information, and they may receive test results, including radiology reports. Recently, a review study by Benjamins et al. showed that patient-accessible electronic health records may improve patient-centred care (47). These systems help to empower patients, inform them about their health and involve them in their care process (47). Although these patient information systems can cause a powershift towards the patient, multiple studies have pointed out that patients do not understand everything they read (48-50). In these studies, patients remark that their understanding is sometimes hampered by the use of medical terms and jargon. To illustrate, the word 'tear' refers to a signal abnormality or defect. In radiology reports, this term is frequently used to describe degenerative and often physiological processes of aging. A patient with no

knowledge of the medial use of the word ‘tear’ will likely interpret it colloquially and assume that it means damage and needs repair (51). A study about the use of words by patients with chronic low back pain disclosed that the term ‘tear’ was associated with poor perceived prognosis (52).

It is possible that terms like these can cause patient distress. Patient distress is characterized by feelings of anxiety, sadness, frustration, and helplessness (53). Research in the field of lung cancer has revealed that patient distress is associated with higher perceived risk of complications and could therefore influence decision-making (54). Studies indicate that more than half of American adults have limited health literacy, although patients with high literacy may misinterpret some common medical jargon (55, 56). For patient-accessible electronic health records, the use of language that can easily be understood by laypeople is recommended (49) along with words that do not unnecessarily distress patients. By doing so, it can support SDM while serving as a valuable addition to the consultation with the doctor (57).

## SHARED DECISION-MAKING BEHAVIOUR OF CLINICIANS

### Communication model

Clinicians play a central role in the decision-making process. In order to effectively participate in SDM, the clinician who ‘knows best’ needs to become the clinician who stimulates the patient to actively participate in the decision process, who listens to the patient, and reaches a shared medical decision tailored to what matters to the patient. Different communication models for SDM have been developed (56-58). The *three-talk model* was first published in 2012 by Elwyn et al. It is a widely cited standard for decision-making in clinical practice (58). *Team talk* focuses on the importance of informing the patient that a medical choice must be made and that SDM is the preferred method. The desired role of the patient in the decision-making process is explored and goals for decision-making are set. *Option talk* refers to the process of elaborating on different options with their advantages and disadvantages. *Decision talk* describes the task of making decisions that reflect the informed preferences of the patient, guided by the experience of the clinician. Although this last model consists of clear steps and is brief, in actual practice, the decision conversation during consultation is far more complex and does not necessarily follow these steps (59). Nevertheless, the *three-talk model* is useful for communication training and as a guideline in clinical practice since the elements of this model are the core components of SDM (60).

## Shared decision-making behaviour in clinical practice

When clinicians are asked about their decision-making style, they say they adopt SDM in most cases and express positive attitudes towards its use (61, 62). However, when SDM is measured with observational tools, actual patient involvement in decisions is often limited (61, 63). It seems that clinicians have misconceptions about what SDM entails and they overestimate their level of SDM behaviour (41, 61, 63). Physicians identify several barriers to their use of SDM, including limited consultation time, lack of effective instruments to support SDM, and patient characteristics (64). Patient characteristics such as limited health literacy and anxiety are important obstacles to effective SDM (65, 66). Patient anxiety may cause the patient to prefer leaving the decision-making to the clinician and with that it can influence the level of SDM (67). Although a substantial number of patients suffer from some degree of anxiety (68), research is limited about the effect of patient anxiety on SDM in consultations.

## Shared decision-making behaviour of residents

Little is known about differences between residents in training and orthopaedic surgeons in SDM communication. This information is relevant, as attitudes and educational needs may differ between these groups and educational programmes need to be tailored appropriately. During medical school, undergraduates are trained in communication skills and SDM is increasingly incorporated in educational programmes, although these developments seems limited to high-income countries (55). Nevertheless, studies suggest that residents have decreased empathic communication skills compared to young medical students (69, 70). In the field of surgery, preferences for SDM seems to be related to their years of experience: surgeons with less experience are more likely to exclude patients from the decision-making process (71). Van der Horst et al. showed in their survey study that residents had a more negative attitude towards SDM compared to their teachers (72). The authors hypothesized that these negative attitudes may be caused by lack of structural SDM communication training in residency programmes, and called for more SDM education (72). General practitioner residents expressed a need for training in SDM knowledge and skills with practical exercises, and that they would profit from longitudinal and integrated training (73). Currently, literature is scant on programmes that successfully increase the use of SDM by residents. It is imperative that this group is included in future SDM interventions.

## Theoretical framework to explain behaviour

To explain behaviour, for example the SDM behaviour of clinicians, various studies have used the Theory of Planned Behaviour (TPB) as theoretical framework (74). The key component in the TPB model is intention; it is the main driver for actual behaviour (74, 75). Behavioural intention is determined by three independent variables. Firstly,

*attitude*, which is the degree to which a person evaluates the behaviour in question as positive or negative. Secondly, *subjective norms*, which refer to a person's beliefs about whether peers and people of importance think that he or she should engage in the behaviour. Thirdly, *perceived behavioural control*, that is the perceived ability to perform a behaviour and to deal with anticipated obstacles (74). A review article of twenty studies that used the TPB to assess clinicians' SDM behaviour found that these three variables were highly predictive of both the intention to use SDM and the actual SDM behaviour (75). Of these three variables, subjective norm was the strongest determinant for intention in SDM behaviour. Thus, clinicians' SDM behaviours are most influenced by the opinions and behaviours of key others, such as patients, colleagues, or mentors. A possible explanation for this finding is that SDM is a direct social behaviour between the clinician and the patient (75). As mentioned earlier, there is some evidence that SDM is influenced by patient behaviour with psychosocial factors such as patient anxiety and emotional distress hampering the level of SDM participation (76, 77). Another explanation for the greater relevance of subjective norm is that there is currently a strong social movement in favour of patient-centred care (75, 78, 79), and clinicians may be influenced by role models or senior doctors doing this.

## INTERVENTIONS TO IMPROVE SHARED DECISION-MAKING

### Interventions to improve clinicians' behaviour

In general, interventions are more successful in changing clinicians' behaviour when they are based on a theoretical framework (80, 81). As previously indicated, the Theory of Planned Behaviour (TPB) can be used to explain behaviour as well as to design interventions aimed at changing behaviour (82). Interventions based on this theory aim to change behavioural beliefs and attitudes, subjective norms and/or perceived behavioural control. Thus, a successful intervention for SDM should enhance beliefs about positive outcomes, diminish apprehensions about negative outcomes, raise the perception that important others approve of the behaviour, increase skills or knowledge to perform the behaviour, lower barriers and/or generate facilitators.

The first step in designing an intervention programme with the TPB as theoretical framework is analysing current behaviour. Such analysis permits the above-mentioned elements to be explored and the results is used to determine the focus of the intervention (83, 84). Interventions based on the TPB have proven to be effective (84). A review study from Steinmetz et al. confirmed the effectiveness of TPB-based interventions, with a mean effect size of 0.50 for behavioural change. The Steinmetz review included studies with a wide variety of conditions, but most often these interventions aimed at changing lifestyle behaviour, for example condom use, eating vegetables, or stimulating weight

loss (84). At present, there are to our best knowledge no SDM intervention studies using the TPB theoretical framework in the field of orthopaedics. Since behaviour change is more effective when a theoretical framework is used, it seems promising to incorporate such a theory into SDM intervention programmes.

It remains a challenge to improve clinician's SDM communication. There is currently no solid evidence that behavioural interventions for clinicians have an effect on the level of SDM (12). Research about clinicians communication interventions in general illustrate that training programmes are more effective if they include practical and clinic-oriented elements, such as the use of simulated patients and education in the actual clinical setting (85). When interventions engage the participation of both clinicians and patients together, it seems to be more effective at improving SDM when compared to interventions that are aimed solely at the doctor or at the patient (20, 86). Despite its obvious relevance, no studies have been conducted in the field of orthopaedics in which the SDM intervention focuses on both the doctor and the patient.

## Patient decision aids

Most SDM interventions tested in orthopaedic surgery concerned decision aids (87, 88). Although some decision aids can be used by both patients and clinicians (e.g., option grids) (89), decision aids are mostly directed towards the patient. Patients use these tools at home or in the waiting area. These patient-directed decision aids (ptDAs) come in different formats, the most common being leaflets, videos, and web-based interactive tools (90, 91). These tools aim to involve patients in the decision-making process. They explain that a health decision must be made, provide information about the disease and treatment options, and encourage patients to consider which treatment option is most appropriate for them in light of their own personal values. PtDAs are designed to complement, rather than replace, consultation with the clinician (92). Extensive evidence supports the benefit of these tools (13, 93). A Cochrane review study found that patients who used a ptDA were better informed, had more realistic risk perceptions, had increased knowledge about disease and treatment options, and were more clear about their values relevant to the decision (13). In hip and knee osteoarthritis, evidence supporting the use of these tools is growing, and a recent randomized controlled trial showed reduced decisional conflict and higher patient satisfaction amongst patients who used a ptDA (94).

Although governments explicitly recommend the use of SDM in healthcare, successful implementation of ptDAs in daily clinics remains challenging (95). Multiple barriers to and facilitators for ptDA implementation have been identified by implementation studies (96). Using this literature, a recent review study from Joseph-Williams et al. evaluated how ptDAs can be implemented successfully (97). Recommended strategies include co-production between a ptDA developer and local stakeholders (e.g., the clinic and

caregivers) taking local needs into account, training the entire team, preparing patients to engage in SDM, and creating ownership of ptDA implementation with senior-level staff members. These components can be used as a practical guide for local implementation and overcoming barriers to ptDA implementation (97).

## AIM AND OUTLINE OF THIS THESIS

Regrettably, SDM is not widely employed in orthopaedic practice, despite evidence of its favourable impact on medical care (17, 36, 37, 61, 98-100). Literature on the effect of SDM behaviour in orthopaedic consultations is scarce. This emphasises the need to investigate SDM interventions to improve orthopaedic uptake. Understanding why SDM uptake is hampered is crucial to addressing these shortcomings and designing effective SDM programmes for clinicians and patients.

Electronic health reports have been made increasingly accessible for patients (46). At the same time, we know that psychological factors, for instance anxiety after patients read information they do not fully understand, influence patients' risk perception (54). The possible solution to this dilemma is to ensure that the health reports are comprehensible to patients while reducing unnecessary distress. These goals are compatible with SDM, which by its very nature involves informing patients and improving their understanding of their medical situation and treatment options.

Before designing an SDM training programme, it is imperative to gain information on the current SDM behaviour of clinicians. Following a theoretical framework, the Theory of Planned Behaviour, this information can then be used to build a well-founded training programme (83). Since residents tend to have more negative attitudes towards SDM (72), it is particularly important to address this group in SDM training programmes. Although combined interventions (e.g., directed at both the clinician and the patient) are advocated (20, 101), most interventions comprise a decision aid directed solely to the patient (17). To increase the level of SDM in orthopaedic care, it would be advisable to develop a training programme which is directed toward both the clinician and the patient (102).

Based on the above-mentioned gaps and needs around SDM in orthopaedic clinical practice, we formulated research questions and described the research outline:

1. **What is the current level of observed SDM and does patient anxiety influence the level of SDM?**

Using a prospective study design, we investigated the level of SDM in the setting of an orthopaedic clinic. Using audio recordings, we measured the observed level of SDM with a validated instrument. The psychosocial factors patient anxiety, catastrophizing, and

symptoms of depression were measured using questionnaires. The relation between the level of SDM and these psychosocial factors was analysed using regression analyses (**chapter 2**).

2. **Is patient distress and understandability of patient information improved when accessible health reports are adjusted to be more patient-friendly?**

Radiology reports were reworded to an eighth-grade reading level and words were used that were least distressing. Enrolled patients read the reworded reports and the original ones. After reading these reports, patients' emotional response and understanding was measured (**chapter 3**).

3. **What are the reported levels of attitude, subjective norms, and perceived behaviour control with regard to SDM behaviour, and do these differ for residents and orthopaedic surgeons?**

We performed a survey study amongst orthopaedic surgeons and residents to explore current SDM. We used the Theory of Planned Behaviour for this questionnaire to explain the behaviour. The questionnaire measured the reported levels of intention, attitude, subjective norms, and perceived behaviour control. With this data we were able to compare the perceived SDM behaviour of orthopaedic surgeons and residents (**chapter 4**).

4. **Is the level of SDM increased by a multifaceted intervention, addressing both patients and clinicians?**

Based on the results of the survey study, we developed a theory-based intervention programme to improve SDM. The intervention was multifaceted. It consisted of a multi-session communication programme for clinicians and a decision aid for patients. The programme was implemented in the setting of hip and knee osteoarthritis care. We tested the intervention using a pre- and post-intervention study design (**chapter 5**).

5. **What hampers successful implementation of a patient decision aid in orthopaedic care?**

With a mixed method process evaluation, we investigated patient factors associated with accepting versus declining the use of the ptDA, patients' reasons for declining the ptDA and clinicians' perceived barriers and facilitators for its use (**chapter 6**).


**Figure 1.** Overview of the following chapters

**Table 2:** Overview of purpose, design, data sources and analyses of the studies

| | Chapters | | | | |
|---|---|---|---|---|---|
| | **2** | **3** | **4** | **5** | **6** |
| **Title** | Informed shared decision-making and patient satisfaction | Does rewording MRI^ reports improve patient understanding and emotional response to a clinical report? | Barriers experienced in shared decision-making behaviour of orthopaedic surgery residents compared with surgeons | Disappointing evaluation of a shared decision-making intervention for residents and orthopaedic surgeons | Implementation of a decision aid for hip and knee osteoarthritis in orthopaedics – a mixed methods process evaluation |
| **Aim of the study** | To measure levels of SDM~ and satisfaction. To determine influence of psychosocial factors on SDM in orthopaedics | To determine if rewording patient-accessible report improves understanding and reduces distress | To gain insight into SDM by measuring elements of TPB * | To evaluate a SDM intervention in orthopaedic hip and knee osteoarthritis care | To evaluate factors associated with use and declining of a ptDA, reasons for declining the tool and clinicians' perceived barriers and facilitators for use |
| **Design** | Prospective cohort study | Observational cross-sectional study | Survey study | Pre- and post-intervention | Retrospective (quantitative) and interview study (qualitative) |
| **Data** | Questionnaires and audio recordings | After reading the report, patients' emotional response (distress) and understanding was measured | Questionnaires on elements of TPB: intention, attitudes, subjective norms, and perceived behavioural control | Questionnaire data on SDM, and satisfaction. Secondary data about physicians' attitude and knowledge, and uptake of the ptDA | PROM† data to compare group that used ptDA with group that rejected the use. Interview data from staff surgeons and residents |
| **Analyses** | Coding of the audio recording for level of SDM. Regression analyses to predict SDM and satisfaction | Comparing group that reads the original report vs group that reads reworded report | Testing of the questionnaire validity. Regression analyses to predict SDM behaviour | Comparing cohorts pre- and post-intervention | Comparing the group that uses the ptDA with the group that declined the use. Coding of interviews and qualitative analysis |

~ SDM: shared decision-making, * TPB: Theory of Planned Behaviour, † PROM: patient reported outcome measure, ^ MRI: Magnetic resonance imaging

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# Informed shared decision making and patient satisfaction

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## ABSTRACT

**Background:** Evidence suggests that when patients have a role in medical decisions they are more satisfied with their health care.

**Objective**: To assess predictors of patient satisfaction, ratings of the provider's Informed Shared Decision Making (ISDM), and disability among patients with orthopaedic pain complaints.

**Research Design:** We enrolled 130 patients with non-traumatic pain conditions of the upper extremity. Medical encounters were audio recorded and coded by 2 independent coders, to evaluate the 8 ISDM elements and total ISDM. We used bivariate and multivariable analyses to answer the study questions.

**Measures:** The participants completed: the Princess Margaret Hospital Patient Satisfaction with their Doctor Questionnaire (PMH-PSQ-MD) to measure satisfaction; Disabilities of Arm Shoulder and Hand questionnaire (DASH); Patient Health Questionnaire-9 (PHQ-9) to measure depression; Whiteley index to assess heightened illness concerns and Pain Catastrophizing Scale (PCS) to assess pain coping.

**Results***:* Less health anxiety, female sex, the ISDM element *Identify choice*, and any specific diagnosis determined 22% of the variation of PMH-PSQ-MD score. Less health anxiety and unemployed unable to work compared to full-time working status were associated with better shared decision-making. Catastrophic thinking, female sex, symptoms of depression and any specific diagnosis were associated with greater disability. Catastrophic thinking and symptoms of depression were the greatest contributors to the variation in disability.

**Conclusions***:* Psychological factors are the strongest determinants of patient satisfaction, surgeon proficiency in providing ISDM, and upper-extremity disability. Health anxiety is most important in patient satisfaction and ISDM, while depression and catastrophizing are most important in disability.

# INTRODUCTION

Informed shared decision making (ISDM) is the process by which a physician and informed patient make a shared medical decision taking into account the preferences and values of the patient (1). ISDM may be particularly important when it comes to preference-sensitive conditions, such as discretionary surgeries. These types of medical decisions require a balance of understanding the patient's needs, desires and lifestyle on one hand, with the risks, benefits and potential outcomes of surgery. Because the surgery is not required, the patient must perceive sufficient benefit to outweigh the inherent risks (2). Orthopaedic surgeons increasingly use ISDM, but opportunities for improvement were identified in prior studies (3, 4). In particular, the patient's role in decision-making and the patient's understanding of the disease merit more discussion in the medical encounter (3).

A handful of prior studies show that when patients have a role in medical decisions, they are more satisfied with their health care (5, 6). While a few studies indicate that some patients prefer the doctor to take the lead in decision-making (5), others found that informed patients tend to participate more active in their care, and have greater compliance (6).

Models for scoring of ISDM include a rating of both the provider (on developing partnership; ascertaining the beliefs and preferences of the patient; providing complete and explicit information; and making a shared decision) as well as the medical encounter (on partnership, expressed information and role preferences, explicit dialogue and shared discussed decision making) (1, 7).

This study aimed to assess: 1) the level of ISDM in an orthopaedic medical setting; 2) predictors of ISDM; 3) predictors of satisfaction and 4) predictors of hand specific disability.

## Patients and methods

We included new adult patients with a non-traumatic condition of the upper extremity. Per IRB request, we excluded pregnant patients and those who did not speak English. All patients were enrolled between December 2009 and May 2012. Medical encounters with hand surgeons were audio recorded to evaluate the components of informed shared decision-making (ISDM). Informed consent for participation in the study and audio recording of the medical encounter was obtained before enrollment.

One hundred and forty-nine patients that met the inclusion criteria were invited to participate. Four patients declined and 145 patients were enrolled in the study. Audio recording failed in 7 patients; 5 subjects were enrolled and then discovered to have a traumatic condition; 1 patient was enrolled and then discovered to be a returning patient; 1 patient decided he did not want to be recorded and withdrew; and one patient

had cognitive difficulty attempting to complete the questionnaires and was therefore withdrawn. These 15 patients were excluded, leaving 130 patients in the study.

There were 62 men and 68 women (52%), with a mean age (±SD) of 52 ± 16 (range, 18 to 91 years). Most patients were married, worked full-time and did not smoke. (Table 1) The diagnoses were collected from the surgical visit note from the patients' medical record (Table 2).

The patients were seen by one of five different orthopaedic providers within the practice. Most of the patients were seen by doctor A (86 patients) or doctor B (26 patients).

## Evaluation

Three sets of two independent trained researchers that were not involved in the patients' care, listened to the audio recordings of the visits and coded the encounters using the ISDM coding scale until 90% agreement was observed (7). Then one of the set of two coders continued coding the recordings. In other studies using similar audio recording techniques to analyze doctor-patient interaction, inter-coder reliability was high and ranged between 85 and 91% (8, 9).

The Princess Margaret Hospital Satisfaction With Doctor Questionnaire (PMH-PSQ-MD) was used to measure patients' satisfaction with the encounter with the hand specialist (10). This questionnaire was completed after the recording and the encounter with the hand surgeon. This questionnaire is an outpatient satisfaction questionnaire specific to the patients physician interaction that was developed and validated for use with oncologic patients (10). The questionnaire contains 29 Likert scale questions ranging from 1 (strongly agree) to 4 (strongly disagree). A higher score on this questionnaire, corresponds to a situation when patients were more satisfied with the doctor – patient interaction (10, 11). We also noted whether a patient was seen by an orthopaedic resident or fellow first, before the specialist. In 6 patients this was not registered. Five subjects missed more than 25% of this questionnaire, which made the questionnaire invalid and we used group mean imputation to complete these values. One patient declined to complete the questionnaire appropriately. We imputed the group mean for this patient as well. We proved that this correction did not have an effect on the final result by doing the same analysis without these 6 patients. There were 17 missing questions in 12 subjects (with a maximum of 3 questions missed for one subject). We imputed the mean of the patients' other questions to complete these missing values.

We used the ISDM coding scale as described by Towle et al., a validated measure to assess informed shared decision making (ISDM) (7). The measure assessed competencies that physicians should pursue for informed shared decision making, and delivered a total score as well as subscores (7). Individual medical encounters were audio recorded with permission from patients. The doctors were aware that ISDM would be scored, but did not know the specific criteria by which they were being measured.

**Table 1 Patient demographics (n=130)**

| Variable | | Mean | SD | Range |
|---|---|---|---|---|
| Age (years) | | 52 | 16 | 18-91 |
| Patient Self-rating of Health | | 2.9 | 2.0 | 0-9 |
| Education (years) | | 16 | 2.8 | 8-22 |
| | | **Number** | **%** | |
| Sex | | | | |
| | Male | 62 | 48 | |
| | Female | 68 | 52 | |
| Other pain conditions | | | | |
| | Yes | 62 | 48 | |
| | No | 66 | 52 | |
| | Missing | 2 | | |
| Smoking | | | | |
| | Yes | 11 | 8 | |
| | No | 119 | 92 | |
| Marital status | | | | |
| | Single | 36 | 28 | |
| | Living with partner | 9 | 6.9 | |
| | Married | 65 | 50 | |
| | Separated/Divorced | 11 | 8.5 | |
| | Widowed | 9 | 6.9 | |
| Working status | | | | |
| | Full-time | 60 | 46 | |
| | Part-time | 16 | 12 | |
| | Homemaker | 5 | 3.8 | |
| | Retired | 25 | 19 | |
| | Unemployed- able to work | 4 | 3.1 | |
| | Unemployed- unable to work | 11 | 8.5 | |
| | Workers compensation | 1 | 0.8 | |
| | Student | 8 | 6.2 | |
| Diagnoses | | | | |
| | Non-specific arm pain | 27 | 21 | |
| | Osteoarthritis | 23 | 18 | |
| | Ganglion/cyst | 17 | 13 | |
| | Epicondylitis | 14 | 11 | |
| | Carpal tunnel syndrome | 12 | 9.2 | |
| | Trigger finger | 12 | 9.2 | |
| | Dupuytren’s disease | 11 | 8.5 | |
| | Other | 14 | 11 | |

| Table 2 Primary variables (n=130) | | | |
|---|---|---|---|
| **Questionnaires** | **Mean** | **SD** | **Range** |
| *DASH | 24 | 19 | 0-88 |
| ^PHQ-9 | 3.1 | 4.3 | 0-22 |
| †PCS | 8.7 | 9.4 | 0-39 |
| Whiteley Index | 25 | 10 | 14-65 |
| ∞PMH-PSQ-MD | 106 | 12 | 67-116 |
| °ISDM | 19 | 3.6 | 10-27 |

*DASH = Disabilities of the Arm, Shoulder and Hand

^PHQ = Patient Health Questionnaire

†PCS = Pain Catastrophizing Scale

∞PMH-PSQ-MD = The Princess Margaret Hospital Patient Satisfaction with Doctor Questionnaire

°ISDM coding score = Total score of ISDM competencies during medical encounter

We used the following competencies with questions: *Identify choice*, *Establish role of decision-making*, *Information preference*, *Present evidence*, *Ascertain ideas, concerns and expectations*, *Develop partnership*, *Negotiate decisions* and *Agree on an action plan* (7) (Table 2). Each of the 8 competences were assessed with two questions (16 questions in total). The competences were scored on a validated and reliable coding sheet (7). Each question was scored with 0 when the element was absent in the medical encounter, 1 when the element was only briefly/partially mentioned or 2 points when the element was discussed. The total score of all competencies ranged from 0 to 32. A higher ISDM coding score indicates a greater level of informed shared decision making. We categorized the total score in following four groups: none if the total score was 0, low for scores ranging 1 to 12, moderate for scores between 13 to 24 and high for scores ranging 25 to 32. The strongest and the weakest ISDM competencies were listed for each encounter.

The patients also completed the Disabilities of the Arm, Shoulder and Hand (DASH) questionnaire to measure arm specific disability (12), the Patient Health Questionnaire-9 (PHQ-9) for depressive symptoms (13), the Pain Catastrophizing Scale (PCS) to measure catastrophic thinking (a misconception of nociception) (14) and the Whiteley index to measure heightened illness concern (hypochondriasis) (15). For more details on these questionnaires we refer to earlier work (16, 17).

We assessed the patients' self-rating of health, with an ordinal scale, rated from 0 to 10, with zero being as healthy as can be and 10 as unhealthy as can be. We had two missing values for this question and used group mean imputation to deal with these missing variables.

Two patients did not complete the pain score, and we used group mean imputation. When there were unanswered questions in the questionnaires we imputed the mean of the other questions for these unanswered questions.

Except for the PMH-PSQ-MD, the patients completed all questionnaires before the encounter with the surgeon.



## Statistical Analysis

Power analysis for the primary null hypothesis, with a medium correlation (effect size of 0.3) with alpha = 0.05, revealed that 130 patients would provide 90% power for regression analysis with effect size f squared = 0.15 with 3 main predictors. We calculated means and standard deviations for continuous variables, and frequencies for categorical variables. Based on our sample size, we chose to use parametric tests.

To evaluate the association between continuous parameters with the dependent outcome measures (PMH-PSQ-MD, DASH and ISDM total and subscales) we used Pearson's correlations. Independent samples T-tests were used for dichotomous parameters and one-way ANOVA for categorical parameters. All parameters which were significant or had $p<0.10$ in the bivariate analysis, were entered in a stepwise backwards multivariable linear regression analysis.

Our response variables were PMH-PSQ-MD, ISDM and DASH. We did 3 regression analysis for the dependent outcome measures PMH-PSQ-MD, ISDM and DASH. When the ISDM score was significant we entered the total score in the regression rather than the individual elements. The study was designed to evaluate PCS and PHQ-9 as predictors for the dependent outcome measures (PMH-PSQ-MD, ISDM and DASH).

We used coding with dummy variables for the analysis for the influence of doctor, diagnoses and work status.

## RESULTS

The mean PMH-PSQ-MD was 106. The total ISDM was moderate with a score of 19 (range 10 to 27). One of the 3 surgeons had a much lower score on ISDM compared to the other 2, although this did not reach statistical significance. We did not analyze if years of experience of a surgeon was a predictor for satisfaction, that could be a topic of interest for a future study. The total score on DASH score was 24 points (range 0 to 88), which is higher compared to the normal scores in the United States in a healthy population(18). (Table 2) Doctors scored highest on the ISDM element *Action plan* and lowest on *Information preference* (Table 3).

**Table 3 Informed Shared Decision Making (ISDM) coding outcomes (n=130)**

| ISDM category | Number of patients | | | | Strongest | Weakest |
|---|---|---|---|---|---|---|
| | 0 (none) | 1 (partly) | 2 (yes) | Mean total score | Numbers | Numbers |
| A (Indentify choice) | | | | | | |
| 1. It is clear that there may be more than one possible management choice? | 4 | 24 | 105 | | | |
| 2. Are the choices presented without bias? | 11 | 33 | 86 | A: 3.4 | 73 | 4 |
| B (Establish role of decision-making) | | | | | | |
| 3. Does the doctor establish the patient's preference for involvement in decisions? | 87 | 34 | 9 | | | |
| 4. Does the doctor find out if the patient would like others involved in the decision? | 118 | 8 | 4 | B: 0.5 | 2 | 91 |
| C (Information preference) | | | | | | |
| 5. Does the doctor ask the patient about the form in which she/he would like to receive information? | 124 | 6 | 0 | | | |
| 6. Does the doctor ask the patient about how much information she/he would like? | 106 | 22 | 2 | C: 0.3 | 3 | 111 |
| D (Present evidence) | | | | | | |
| 7. Does the doctor present/direct the patient to evidence? | 1 | 16 | 113 | | | |
| 8. Does the doctor direct the patient to sources of information that are consistent with the information preferences of the patient? | 109 | 14 | 7 | D: 2.1 | 9 | 1 |
| E (Ascertain ideas, concerns and expectations) | | | | | | |
| 9. Does the doctor ask if the patient has any questions about the treatment choices? | 12 | 43 | 75 | | | |
| 10. Does the doctor ask the patient for his/her thoughts about the choices under consideration? | 18 | 34 | 78 | E: 3.0 | 53 | 3 |
| F (Develop partnership) | | | | | | |
| 11. Is the patient encouraged to be involved in decision? | 17 | 27 | 86 | | | |
| 12. Does the doctor encourage the patient to take some responsibility for their treatment and/or health care? | 2 | 22 | 106 | F:3.3 | 68 | 1 |
| G (Negotiate decisions) | | | | | | |
| 13. Do both the doctor and the patient contribute to the decision? | 10 | 48 | 72 | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| 14. Does the doctor provide opportunities for the patient to voice disagreement? | 1 | 12 | 117 | G: 3.4 | 69 | 1 |
| H (Agree on an action plan) | | | | | | |
| 15. Does the doctor seek the patient's input on the action plan? | 10 | 35 | 85 | | | |
| 16. Is it clear who does what by when? | 90 | 9 | 121 | H: 3.5 | 76 | 1 |

Strongest = the number of times these categories are the strongest elements of the medical encounters

Weakest = the number of times these categories are the weakest elements of the medical encounters

Numbers = multiple strongest and weakest elements are possible



After the bivariate analysis, the following variables met the criteria for inclusion in the regression with PMH-PSQ-MD score as outcome: Whiteley Index (health anxiety), female sex, having been seen by a fellow first, any specific diagnosis (i.e. not nonspecific pain), the ISDM element *Identify choice*, age and PCS (catastrophic thinking). (Table 4) The final regression model included Whiteley index ( health anxiety), female sex, the ISDM element *Identify choice*, and any specific diagnosis, and explained 22% of the PMH-PSQ-MD score (adjusted $R^2$=0.22, p<0.001). Table 5 presents results of regression including percent variance explained by each significant predictor; Whiteley index explained most of the variance (6.6%)( of the individual predictors.

The bivariate analysis revealed a significantly inverse correlation of ISDM with Whiteley score (health anxiety) and working status; education, smoking and PCS (catastrophic thinking) satisfied the criteria for entry into the multivariable analysis (p<0.10). The best model retained the Whiteley Index and working status (unemployed unable to work compared to full-time; full-time was associated with a higher ISDM), and accounted for 11% of the variation in the total ISDM scores (adjusted $R^2$=0.11, p<0.001), of which Whitely index explained 3.1% variance and work 5.6%. (Table 5)

The following variables were inserted in the regression for the DASH score: Patient self- rating of health, education, ISDM score, PCS (catastrophic thinking), PHQ ( depressive symptoms), Whiteley Index (health anxiety), smoking, working status, diagnoses and female sex. We entered the entire ISDM in the regression, rather than the individual elements of the ISDM. PCS, PHQ, female sex and any specific diagnosis remained in the model, which accounted for 55% of the variation in DASH scores (adjusted $R^2$=0.55, p<0.001). Table 5 shows details of regression including percent variance explained by each predictor. PCS explained most of the variance, 12%.

**Table 4 Bivariate analysis (n=130)**

| | ∞PMH-PSQ-MD | | °ISDM | | *DASH | |
|---|---|---|---|---|---|---|
| **Pearson's correlation** | **r** | **p** | **r** | **p** | **r** | **p** |
| Age | 0.15 | 0.081 | 0.047 | NS | 0.067 | NS |
| Patient self | -0.035 | NS | -0.11 | NS | 0.32 | <0.001 |
| rating of health | 0.036 | NS | 0.17 | 0.061 | -0.27 | 0.002 |
| Education | 0.046 | NS | X | X | -0.20 | 0.023 |
| °ISDM | X | X | 0.046 | NS | -0.058 | NS |
| ∞PMH-PSQ-MD | -0.17 | 0.051 | -0.15 | 0.086 | 0.66 | <0.001 |
| †PCS | -0.10 | NS | -0.12 | NS | 0.64 | <0.001 |
| ^PHQ | -0.28 | 0.001 | -0.25 | 0.004 | 0.40 | <0.001 |
| Whiteley Index | | | | | | |
| **T-test** | **T** | **p** | **T** | **p** | **T** | **p** |
| Gender | 2.2 | 0.033 | | NS | 1.9 | 0.065 |
| Smoking | | NS | -2.0 | 0.050 | 2.3 | 0.021 |
| Fellow | 3.5 | 0.006 | | NS | | NS |
| **One-way ANOVA** | **F** | **p** | **F** | **p** | **F** | **p** |
| °ISDM Score Category | 0.58 | NS | X | X | 2.0 | NS |
| Working status | 1.5 | NS | 2.5 | 0.019 | 3.1 | 0.005 |
| Marital status | 2.0 | NS | 1.2 | NS | 0.66 | NS |
| Doctor | 0.62 | NS | 0.71 | NS | 0.78 | NS |
| Diagnoses | 2.7 | 0.012 | 1.7 | NS | 2.5 | 0.017 |
| A: *Identify choice* | 2.8 | 0.030 | X | X | 0.41 | NS |
| B: *Establish role of decision making* | 1.0 | NS | X | X | 2.4 | 0.052 |
| C: *Information preference* | 0.7 | NS | X | X | 1.6 | NS |
| D: *Present evidence* | 2.0 | NS | X | X | 0.98 | NS |
| E: *Ideas, concerns and expectations* | 1.4 | NS | X | X | 1.4 | NS |
| F: *Develop partnership* | 0.14 | NS | X | X | 1.6 | NS |
| G: *Negotiate decisions* | 1.1 | NS | X | X | 2.7 | 0.046 |
| H: *Agree on an action plan* | 0.12 | NS | X | X | 0.96 | NS |

∞PMH-PSQ-MD = Princess Margaret Hospital Satisfaction with Doctor questionnaire

°ISDM = Informed Shared Decision Making coding

*DASH = Disabilities of the Arm, Shoulder and Hand

†PCS = Pain Catastrophizing Scale

^PHQ = Patient Health Questionnaire

**Table 5 Multivariable analysis N = 130**

| PMH-PSQ-MD | | | | ISDM | | | | DASH | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **Model** | **‡Adjusted $R^2$** | **p** | **•partial R-squared** | **Model** | **‡Adjusted $R^2$** | **p** | **•partial R-squared** | **Model** | **‡Adjusted $R^2$** | **p** | **•partial R-squared** |
| | 0.22 | <0.001 | | | 0.11 | <0.001 | | | 0.55 | <0.001 | |
| Whiteley index | | 0.001 | 0.066 | Whiteley index | | | | PCS | | <0.001 | 0.12 |
| Female sex | | 0.040 | 0.026 | Work status | | 0.037 | 0.031 | PHQ | | <0.001 | 0.060 |
| Identify choice (ISDM) Score of 0 compared to 4 | | 0.024 | 0.031 | Unemployed unable to work compared to full-time | | 0.005 | 0.056 | Female sex | | 0.090 | 0.010 |
| Having a specific diagnosis | | | | | | | | Having a specific diagnosis | | 0.002 | |
| Trigger finger compared to NSAP | | 0.024 | 0.031 | | | | | OA compared to NSAP | | 0.077 | 0.033 |
| Dupuytren's disease compared to NSAP | | 0.066 | 0.021 | | | | | Trigger finger compared to NSAP | | 0.052 | 0.011 |
| Ganglion/cyst compared to ¤NSAP | | 0.020 | 0.034 | | | | | Dupuytren's disease compared to NSAP | | 0.044 | 0.013 |
| Epicondylitis compared to NSAP | | 0.017 | 0.035 | | | | | CTS compared to NSAP | | 0.010 | 0.014 |
| Other compared to NSAP | | 0.007 | 0.045 | | | | | Epicondylitis compared to NSAP | | 0.059 | 0.024 |
| CTS compared to NSAP | | 0.002 | 0.061 | | | | | Other compared to NSAP | | 0.002 | 0.013 |

PMH-PSQ-MD = Princess Margaret Hospital Satisfaction with Doctor questionnaire, ISDM = Informed Shared Decision Making coding, DASH = Disabilities of the Arm, Shoulder and Hand, NSAP = Non Specific Arm Pain, CTS = Carpal Tunnel Syndrome, ‡percentage of the overall variability in the dependent variable explained or accounted for by the independent variables in the model , ‡Part R-squared: the individual contribution of each variable to the adjusted $R^2$, PHQ = Patient Health Questionnaire, PCS = Pain Catastrophizing Scale.

# DISCUSSION

This study showed that overall orthopaedic surgeons in a hand clinic practice ISDM at a moderate level. The fact that there was a relatively high range of ISDM ratings with one surgeon having much lower scores compare to the other 2, suggests opportunities for surgeons to improve their delivery of ISDM. Although these differences were not statistically significant in this study, those differences could reach significance with a larger sample.

We found that health anxiety as measured by the Whitely Index was a significant predictor of both patient satisfaction and ISDM. These patients may be the most dissatisfied and difficult to treat. This represents a window of opportunity for treatment; by referring patients to efficacious psychosocial treatments to decrease their health anxiety, ratings of both satisfaction and ISDM may improve. In addition, surgeons may need extra patience and time in working with these patients, as to improve their ISDM. This certainly reflects daily practice and reemphasizes the need for expert and well-practiced communication strategies with patients that have greater distress.

Although a higher score on the element *Identify choice* of the ISDM was associated with greater patient satisfaction, this explained a smaller percentage of variance compared to health anxiety. This shows that health anxiety is a more important predictor than ISDM. Having a specific diagnoses also explained more variance compared to ISDM identity choice. Previous research has identified a strong association between nonspecific, idiopathic diagnoses and increased health concerns (17, 19) . This suggests that patients' diagnoses (nonspecific vs discrete) and health concerns may also be more important than ISDM in determining level of satisfaction with medical care. This is an important point with strong implications for surgeons, given the emphasis of increasing patients' satisfaction ratings at the hospital level.

Secondly and consistent with our previous point, we found that variation in ISDM was determined by health anxiety and differences in working status, although this explained only 11% of the variation. In other words, when patients have greater concern about their illness, the surgeons did less well on the ISDM rating. This suggests that surgeons' ability to practice shared decision making decreases as patients' heightened illness concerns increase. Thirdly, consistent with prior studies (20, 21), arm specific disability was strongly determined by catastrophic thinking, symptoms of depression and specific diagnoses, but not by ISDM. Catastrophic thinking and depression are more important than health anxiety in reports of disability.

The finding that a specific diagnosis was associated with greater disability runs counter to prior research that identified unexpectedly high disability with nonspecific arm pains (22). We speculate that this is due to the fact that that the patients in this cohort with a specific diagnosis had higher levels of depression than the patients with

non-specific arm pain (mean PHQ 3.5 vs. 1.5), which is atypical and inconsistent with prior reports (19).

Our finding that a higher score on the element *Identify choice* of the ISDM influences patient satisfaction is consistent with other studies (6, 23). Also in line with earlier findings, the providers in this study used ISDM to a moderate level, but the elements *Establish role of decision-making* (where the doctor assesses the patient's preference for involvement in decision making, and finds out if the patient would like to have others involved in the decision) and *Information preference* (where the doctor asks the patient about the form in which she/he would like to receive information, and how much information the patient would like to receive) show room for improvement (3, 4). *Identify choice* was the only element of the ISDM related to satisfaction, indicating the importance of providing patients various treatment options.

ISDM is particularly important when it concerns debatable diagnoses with no standard treatment (4, 24). Nonspecific arm pain is diagnosed in the absence of objectively measurable pathophysiology (22, 25). We found that patients with nonspecific arm pain had less disability and lower satisfaction with the healthcare provided compared to patients with a specific diagnosis. Surgeons' received lower ISDM scores with these patients. This suggests either that surgeons are less equipped in dealing with patients who have heightened illness concerns and nonspecific puzzling conditions or that they have fewer options for patients to consider (although diagnosis was not in the final model predicting ISDM), or both. Psychosocial interventions such as Cognitive Behavioral Therapy (CBT) provide effective treatment for heightened illness concerns (26, 27) and help decrease pain and disability in patients with nonspecific pain (28-30). CBT might improve both patient specific outcomes of pain and disability, as well as overall patient satisfaction and ISDM.

There were several limitations to this study. We only enrolled non-traumatic, English speaking patients, so our results are not generalizable to all patients visiting a hand surgeon. We deliberately excluded traumatic patients since it has been suggested that patients may prefer a slightly more paternalistic approach to decision making when they are injured (5). Six patients did not complete the questions concerning satisfaction with the surgeon, and we used mean imputation for their scores in order to limit bias (31, 32). Other than the 6 patients with missing data for the satisfaction, the percentage of missing data was very low. We did not correlate years if years of experience of the surgeon correlated positive or negative with the amount of ISDM or satisfaction. Also, we did not analyse if using more ISDM takes more time or not in a first encounter with a hand surgeon. In addition, we have no information if higher initial ISDM scores have any influence on disability in follow-up visits. The findings of this study apply primarily to the practice styles of three surgeons, and might not be externally valid.

The finding that ISDM is important in the variation of satisfaction supports the use of decision aids (4). Decision aids are tools used to inform the patient and to facilitate shared decision-making. They are not yet used in daily practice but studies have shown that they might be effective when treating low back pain and hip fractures (33, 34). This study and earlier studies showed (3, 4) opportunities for presenting clear information about diagnoses and options, and emphasizing the role of the patient in decision-making both of which are well-addressed by decision aids.

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3

# Does Rewording MRI Reports Improve Patient Understanding and Emotional Response to a Clinical Report?

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## ABSTRACT

**Background:** Diagnostic MRI reports can be distressing for patients with limited health literacy. Humans tend to prepare for the worst--particularly when we are in pain—and words like “tear” can make us feel damaged and in need of repair. Research on words used in provider-patient interactions have demonstrated a strong impact on response to treatment and coping strategies, but the literature on this remains relatively sparse.

**Questions/purposes:** The aim of this observational cross-sectional study is to determine whether rewording of MRI reports in understandable, more dispassionate language will result in better patient ratings of emotional response, satisfaction, usefulness, and understanding. Furthermore, we wanted to find out which type of report patients would choose to receive.

**Methods:** One hundred patients visiting an orthopaedic hand and upper extremity outpatient office for reasons unrelated to the presented MRI report were enrolled. Four MRI reports, concerning upper extremity conditions, were reworded to an eighth-grade reading level and with the use of neutral descriptive words and the most optimistic interpretations based on current best evidence. After reading each report, emotional response was measured using the Self-Assessment Manikin (SAM). Subjects also completed questions about satisfaction, usefulness, and understanding of the report.

**Results:** According to the results of the SAM questionnaire, the reworded MRI report resulted in significantly higher pleasure and dominance scores and lower arousal scores. The mean satisfaction, usefulness, and understanding scores of the reworded report were significantly higher compared with the original reports. Seventy percent of the patients preferred the reworded report over the original reports.

**Conclusions:** Emotional response, satisfaction, usefulness, and understanding were all superior in MRI reports reworded for lower reading level and optimal emotional valence and optimism. Given that patients increasingly have access to their medical record and diagnostic reports, attention to health literacy and psychological aspects of the report may help optimize health and patient satisfaction.

## INTRODUCTION

Patients often read their medical records, and they may receive test reports, including radiology reports, in the mail. In general, these documents are written in medical jargon that is intended for documentation and for use by other medical professionals. Studies indicate that more than half of American adults have limited health literacy (1-3). Even medically sophisticated patients may misinterpret some common medical jargon. Limited understanding and misinterpretation may affect health and patient satisfaction (2). A Cochrane review showed that when providing patient-centered care, a model in which communication of health information is a key element, patients are more satisfied (4). This underlines the pivotal role of patient information that is tailored to patients' need and understanding.

Research on words used in provider-patient interactions demonstrate a strong impact on response to treatment and coping strategies (5-10). To illustrate, the word "tear" refers to a signal abnormality or defect. In radiology reports, this term is commonly used to describe degenerative and often benign conditions of aging. A patient with no knowledge of the professional use of the word tear will likely interpret it colloquially and assume that they have damage in need of repair (11). A study about the use of words by patients with chronic low back pain showed that the term "tear" was associated with poor perceived prognosis (12). It is possible that this term might increase the chances that patients choose operative treatment. A few studies have demonstrated that incomprehensible and incomplete written information is associated with negative emotions and confusion (9,13).

We sought to determine whether MRI reports that are rewritten to be understandable by a reader with an eighth-grade reading level, and that the use neutral descriptive words and the most optimistic interpretations based on current best evidence will be better received by patients. Specifically, our primary study hypothesis was that the original and the reworded MRI reports would have comparable emotional valence. Valence is a term used by psychologists to refer to an object or event's inherent attractiveness or aversiveness (i.e. the quality that determines the emotional response). Our secondary hypotheses were that patient satisfaction, understanding, and perceived usefulness also would be comparable. Our third hypothesis was that equal numbers of patients would prefer the original or the reworded report.

## PATIENTS AND METHODS

Using an institutional review board-approved protocol, we enrolled patients visiting the orthopaedic hand and upper extremity outpatient office for this observational

cross-sectional study. Pregnant patients and those who could not speak English were excluded, as mandated by the institutional review board. All patients were enrolled between May 2012 and July 2012.

We enrolled 102 patients, but two patients did not complete the questionnaire resulting in a study cohort of 100 patients. Of the 100 patients enrolled, 59 were women and 41 men. The mean (± SD) age was 51 ± 16 years (range, 21-80 years), the level of education was 15 ± 2.9 years (range, 4-24 years), and the majority of the patients worked full time (Table 1).

A list of all shoulder, elbow, wrist, and hand MRIs ordered in the year 2011 was obtained from the radiology service. From this list, the first four MRI reports (one each shoulder, elbow, wrist, and hand) in chronological order were selected with the following inclusion and exclusion criteria: (1) adult patient; (2) pain as the primary indication for the MRI; and (3) no malignancy presented or suspected. This resulted in reports about lateral epicondylitis (one), rotator cuff tendinopathy (two), trapeziometacarpal arthritis (three), and extensor carpi ulnaris tendinopathy (four) (see supplement I for example of reports).

The original reports were reworded to the recommended reading level for effective health education of below the eighth-grade level (14). This is easily checked using tools in Microsoft Word (Redmond, CA). It's straightforward to explain medical things in simple, everyday language; although it's not something we are accustomed to doing. We used neutral descriptive words and the most optimistic interpretation based on current best evidence. For instance, words such as "tear" were replaced by more descriptive and accurate words such as hole, signal change, or defect. We also used analogies (e.g., gray hair, bald spot) where appropriate. It was emphasized that the reports are simulated reports unrelated to their problem.

## Evaluation

Each patient was presented with a report either on the shoulder, the elbow, the wrist, or the hand irrespective of their reason for coming to the doctor. We were interested in the emotional content of the reports as judged by people not directly impacted by the reports. The original (A) and the reworded (B) report about the same condition were presented to the patient. We alternated the order of presentation, in order to avoid bias. After reading each report, patients completed a questionnaire concerning their satisfaction with the presented report, usefulness of the presented contend, the ability to understand the report, and their emotional valence using the Self-Assessment Manikin (SAM) (6).

Patients' satisfaction with each report was assessed using an 11-point Likert scale question: "On a scale between 0 meaning completely unsatisfied and 10 meaning completely satisfied, how would you feel to receive this report?" Two more questions were completed about the usefulness and understanding using 11-point Likert scale questions. Higher scores indicated greater usefulness and more understanding.

**Table 1. Patient demographics (n = 100)**

| Demographics | Mean | SD | Range |
|---|---|---|---|
| Age (years) | 51 | 16 | 21-80 |
| Education | 15 | 2.9 | 4-24 |
| | Number | Percent | |
| Sex | | | |
| Men | 41 | 59 | |
| Women | 59 | 59 | |
| Ethnicity | | | |
| Hispanic or Latino | 7 | 7 | |
| Not Hispanic or Latino | 93 | 93 | |
| Race | | | |
| White | 82 | 82 | |
| Black or African American | 3 | 3 | |
| Asian | 5 | 5 | |
| American Indian or Alaskan Native | 1 | 1 | |
| More than one race | 3 | 3 | |
| Other or unknown | 6 | 6 | |
| Work status | | | |
| Working full-time | 49 | 49 | |
| Working part-time | 10 | 10 | |
| Homemaker | 5 | 5 | |
| Retired | 19 | 19 | |
| Unemployed, able to work | 6 | 6 | |
| Unemployed, unable to work | 8 | 8 | |
| Workers' compensation | 2 | 2 | |
| Currently on sick leave | 1 | 1 | |
| Household income (USD) | | | |
| 0-10.000 | 7 | 7 | |
| 10,000-30,000 | 12 | 12 | |
| 30,000-50,000 | 8 | 8 | |
| 50,000-80,000 | 19 | 19 | |
| 80,000-120,000 | 18 | 18 | |
| 120,000-200,000 | 12 | 12 | |
| +200,000 | 3 | 3 | |
| N/A | 21 | 21 | |

After each report, the SAM was obtained. The SAM is an affective rating system developed to study emotion (6). The SAM is a validated and reliable affective rating system tool for pleasure, arousal, and dominance (meaning control over the situation as opposed to feeling helpless) (6, 15). Patients were requested to rate their emotional dimension pleasure from faces that range from happy (low score) to frowning (high score). Patients stated their arousal by selecting from an excited/worried (low score) face to a relaxed face (high score). The dominance dimension ranged from a small figure (no control; low score) to a large figure (full control; high score). For analyses, we scored the outcome of this questionnaire, ranging from 1 to 9 points. Additionally, after reading both reports, patients were asked which report they preferred.

### Statistics

According to a power analysis, 82 patients provide 80% power to detect a difference between MRI reports of 30% of a standard deviation in values for a specific type of emotional response with alpha set at 0.05. We enrolled 100 patients to have 25 patients for each report. We calculated means and SDs for continuous variables and frequencies for categorical variables. We used the nonparametric Mann-Whitney tests to compare the independent variables when not normally distributed. For the variables that were normally distributed, we used independent-samples t-tests.

We had one missing value for the question about satisfaction and one missing value for the SAM dimension pleasure. We imputed the mean to complete these values.

## RESULTS

### Emotional Valence of the Reports

Subjects felt more pleasant, calm, and in control when reading the reworded compared to the original reports. The pleasure score (mean ± SD) of all the original MRI reports was lower (4.6 ± 2.1) compared with the reworded reports (5.8 ± 2, $p < 0.001$). The arousal score (mean ± SD) of all the original reports was higher (4.1 ± 2.5) compared with the reworded reports (2.9 ± 1.8, $p < 0.001$). The dominance score (mean ± SD) of all the original reports was lower (4.4 ± 2.3) compared with the reworded reports (5.8 ± 2.2, $p < 0.001$) (Table 2).

Analyzing the 4 different reports for differences by specific disease (acknowledging limited power), we found differences more for the tendinopathies than the arthropathy. The pleasure score was higher for report reworded rotator cuff tendinopathy report compared with the original ($p = 0.001$). The arousal score was greater for the original lateral epicondylitis and ECU tendinopathy reports compared with the reworded reports ($p = 0.01$ and $p = 0.04$). The dominance score was greater for reworded rotator cuff tendinopathy report compared with the original ($p < 0.001$) (Table 3).

**Table 2. Bivariate analysis: SAM questionnaire**

| *Emotional response* | Report | Frequency | Mean | SD | p value |
|---|---|---|---|---|---|
| Pleasure | | | | | |
| | Original | 100 | 4.6 | 2.1 | < 0.001 |
| | Reworded | 100 | 5.8 | 2 | |
| Arousal | | | | | |
| | Original | 100 | 4.1 | 2.5 | < 0.001 |
| | Reworded | 100 | 2.9 | 1.8 | |
| Dominancy | | | | | |
| | Original | 100 | 4.4 | 2.3 | < 0.001 |
| | Reworded | 100 | 5.8 | 2.2 | |

**Table 3. Bivariate analysis: SAM questionnaire subreports**

| Emotional response | Subreport | Frequency | Mean | SD | p value |
|---|---|---|---|---|---|
| Pleasure | | | | | |
| | 1A | 25 | 4.3 | 2.2 | 0.05 |
| | 1B | 25 | 5.4 | 2 | |
| | 2A | 25 | 4.2 | 18 | 0.001 |
| | 2B | 25 | 6.4 | 2 | |
| | 3A | 25 | 5.5 | 2.3 | 0.31 |
| | 3B | 25 | 6.1 | 1.8 | |
| | 4A | 25 | 4.4 | 2.6 | 0.12 |
| | 4B | 25 | 5.4 | 2.4 | |
| Arousal | | | | | |
| | 1A | 25 | 5.2 | 2.3 | 0.01 |
| | 1B | 25 | 3.6 | 1.7 | |
| | 2A | 25 | 4.2 | 2.5 | 0.12 |
| | 2B | 25 | 3.2 | 1.8 | |
| | 3A | 25 | 3.3 | 2.3 | 0.37 |
| | 3B | 25 | 2.7 | 1.9 | |
| | 4A | 25 | 3.7 | 2.5 | 0.04 |
| | 4B | 25 | 2.3 | 1.6 | |
| Dominancy | | | | | |
| | 1A | 25 | 4.4 | 2.4 | 0.05 |
| | 1B | 25 | 5.7 | 2 | |
| | 2A | 25 | 4 | 1.9 | < 0.001 |
| | 2B | 25 | 6.4 | 1.8 | |
| | 3A | 25 | 5.2 | 2.6 | 0.37 |
| | 3B | 25 | 5.8 | 2.6 | |
| | 4A | 25 | 4.2 | 2.5 | 0.07 |
| | 4B | 25 | 5.4 | 2.3 | |

Reports 1A, 2A, 3A, and 4A are original reports. Reports 1B, 2B, 3B, and 4B are reworded reports;

## Satisfaction, Usefulness, and Understanding of the Reports

Subjects found the reworded reports more satisfying, useful, and understandable than the original reports. The satisfaction score (mean ± SD) of all the original MRI reports was lower (5.1 ± 3.3) compared with the reworded reports (7.1 ± 2.8, $p < 0.001$). The usefulness score of all the original reports (mean ± SD) was lower (4.8 ± 3.5) compared with the reworded reports (7.1 ± 2.9, $p < 0.001$). The understanding score (mean ± SD) of all the original reports was lower (4.2 ± 2.3) compared with the reworded report (8.1 ± 2.6, $p < 0.001$) (Table 4).

**Table 4. Bivariate analysis: satisfaction, usefulness, and understanding**

| Parameter | Report | Frequency | Mean | SD | p value |
|---|---|---|---|---|---|
| Satisfaction | | | | | |
| | Original | 100 | 5.1 | 3.3 | < 0.001 |
| | Reworded | 100 | 7.1 | 2.8 | |
| Uswvefulness | | | | | |
| | Original | 100 | 4.8 | 3.5 | < 0.001 |
| | Reworded | 100 | 7.1 | 2.9 | |
| Understanding | | | | | |
| | Original | 100 | 4.2 | 2.3 | < 0.001 |
| | Reworded | 100 | 8.1 | 2.6 | |

Of the four subreports, the satisfaction score was higher for the original rotator cuff tendinopathy report than the original ($p < 0.001$). The usefulness score of the reworded tennis elbow, rotator cuff, and trapeziometacarpal arthrosis reports was higher than the original reports ($p = 0.012$, $p < 0.001$, and $p = 0.024$, respectively). The understanding score was greater in all the four reworded subreports (Table 5).

## Preferred Report

Seventy of 100 patients preferred the reworded MRI reports (Table 6). Within each of four subreports, the reworded report was preferred by more patients (Table 7).

As an supplement, a table with the association of demographical parameters with the emotional response on the reports could be found (supplement II).

**Table 5. Bivariate analysis: satisfaction, usefulness, and understanding. subreports**

| Parameter | Subreport | Frequency | Mean | SD | p value |
|---|---|---|---|---|---|
| Satisfaction | | | | | |
| | 1A | 25 | 5.4 | 2.9 | 0.25 |
| | 1B | 25 | 7.3 | 2 | |
| | 2A | 25 | 4.9 | 3.2 | < 0.001 |
| | 2B | 25 | 8.2 | 2 | |
| | 3A | 25 | 5.9 | 3.4 | 0.12 |
| | 3B | 25 | 7.4 | 2.8 | |
| | 4A | 25 | 4.4 | 3.6 | 0.19 |
| | 4B | 25 | 5.6 | 3.7 | |
| Usefulness | | | | | |
| | 1A | 25 | 5.7 | 2.9 | 0.012 |
| | 1B | 25 | 7.5 | 2 | |
| | 2A | 25 | 4.4 | 3.4 | < 0.001 |
| | 2B | 25 | 8.1 | 2.4 | |
| | 3A | 25 | 5.2 | 4 | 0.024 |
| | 3B | 25 | 7.7 | 2.4 | |
| | 4A | 25 | 4 | 3.7 | 0.28 |
| | 4B | 25 | 5.2 | 3.6 | |
| Understanding | | | | | |
| | 1A | 25 | 5.2 | 2.4 | 0.004 |
| | 1B | 25 | 7.9 | 2.3 | |
| | 2A | 25 | 3.6 | 3.1 | < 0.001 |
| | 2B | 25 | 9 | 1.6 | |
| | 3A | 25 | 4.7 | 4 | < 0.001 |
| | 3B | 25 | 8.7 | 2.2 | |
| | 4A | 25 | 3.2 | 3 | 0.001 |
| | 4B | 25 | 6.8 | 3.6 | |

Reports 1A, 2A, 3A, and 4A are original reports. Reports 1B, 2B, 3B, and 4B are reworded reports.

**Table 6. Preferred report**

| Report | Number | Total | Percentage |
|---|---|---|---|
| Original | 30 | | 30 |
| Reworded | 70 | 100 | 70 |

**Table 7. Preferred subreports**

| Subreport | Number | Total | Percentage of subreport |
|---|---|---|---|
| 1A | 7 | | 28 |
| 1B | 18 | 25 | 72 |
| 2A | 4 | | 16 |
| 2B | 21 | 25 | 84 |
| 3A | 9 | | 36 |
| 3B | 16 | 25 | 64 |
| 4A | 10 | | 40 |
| 4B | 15 | 25 | 60 |

## DISCUSSION

Diagnostic reports can be distressing, perhaps more so for patients with limited health literacy (2,9,13). The aim of this study was to determine whether rewording of MRI reports results in better patient ratings of emotional valence, satisfaction, usefulness, and understanding. Furthermore, we wanted to find out whether the neutrally worded MRI reports rewritten at the eighth-grade reading level would be preferred by patients. Subjects felt more pleasant, calm, and in control on average after reading MRI reports reworded for readability and optimism. They also rated the reworded reports as more satisfying, useful, and understandable on average. Most patients preferred the reworded report over the original report.

These data should be interpreted in light of the fact that subjects were reading an MRI report that was unrelated to their problem and they may have a different emotional response if the report was their own. This was done for practical reasons and as pilot work to establish the merit of the concept given that a study of patients with each specific disease undergoing MRI would take much longer to complete. On a positive note, the subjects questioned were patients in a patient-provider setting and could envision receiving such a report. Other than the consistent approach of our team we did not control for the degree to which the report was modified. The reliability of rules for formatting reports or modifying existing reports could be the focus of future research. Measuring emotion is difficult, but the SAM questionnaire is a widely used and reliable method for capturing affective effects of information on people (6). Our subgroup analysis for different anatomical sites was secondary, underpowered, and hypothesis-generating at best. The MRI reports used in this study were limited to upper extremity and hand orthopaedic conditions and did not encompass other regions and conditions

of the human body. The reports did not include malignancies or dangerous conditions; hence, we cannot generalize it to these conditions. We only had two uncompleted answers for which we imputed the mean. This is an accepted way to address missing values and two missing entries is a very low number (7).

These data suggest an advantage to including a summary of the report directed to the patient that is easy to understand and as optimistic as possible. This may encourage and reinforce optimal coping strategies, because distressing or confusing material may reinforce the natural human tendency to prepare for the worst, which psychologists call catastrophic thinking (10). In addition, more satisfying patient information has been shown to reduce malpractice (8). Understandable information allows the patient to be more involved with their medical care, which is associated with greater adherence to provider recommendations and better health outcomes (16).

The improved emotions and satisfaction of subjects reading reworded reports might translate to better overall satisfaction with care. Satisfaction with care can be at odds with good medical care and the example of opioid prescription has been used to highlight this recently (17,18). Diagnostic reports with simple, accurate, dispassionate and even optimistic wording can set providers up for more satisfying discussions of how to optimize health (ability to depend on one's body) and help limit less satisfying conversations about "why we aren't going to fix that tear they found in my elbow/shoulder/wrist".

Among the 30% (30 of 100) subjects that preferred the original report, some commented that "the original report was more detailed" and some said the reworded report looked "too simple." Others mentioned they preferred the original report because they want to unravel it with the help of the internet or their physician. We would argue that the technical information can be reported dispassionately and descriptively (eg, signal change, defect) more or less as it is now and that a less technical, more readable, and optimistic rewording of the interpretation portion of the report might be no less complete or less accurate. This combination might satisfy all patient interests. Any type of report will always benefit from discussion with a health care professional. Further research is needed to determine how best to word reports to provide correct and optimistic medical information with enough details yet still be understandable and without causing unnecessary distress.

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# SUPPLEMENTS

## Supplement 1. Original and reworded reports rotator cuff

Original report:

Findings:

Rotator cuff: There is subtotal articular sided tear of the distal supraspinatus tendon with delaminating component and proximal retraction of articular sided fibers up to 2 cm from the greater tuberosity. Full thickness tendon perforation may be present. The tear extends inferiorly into the infraspinatus, which remains mostly intact at the greater tuberosity attachment site. There is subscapularis tendinopathy without full thickness tear. The teres minor is intact. The rotator cuff muscle bulk is intact.

Glenoid labrum and biceps tendon: Just proximal to the biceps tendon groove, there is fusiform enlargement of the biceps tendon with signal increase suggesting longitudinal tear. The extracapsular biceps tendon remains within the groove. There is degenerative tearing of the superior and anterior labrum. There is a small joint effusion.

AC joint: There are hypertrophic degenerative changes of the acromioclavicular joint. There is trace fluid in the subacromial bursa.

AC joint: There are hypertrophic degenerative changes of the acromioclavicular joint. There is trace fluid in the subacromial bursa.

Articular Cartilage: The articular cartilage is of normal thickness. No focal defects are seen.

Bone: There is subchondral cyst formation in the humeral head.

Impression:

Subtotal articular surface tear of the distal supraspinatus tendon with delaminating component and proximal retraction of articular sided fibers up to 2 cm from the greater tuberosity. The tear extends posteriorly into the infraspinatus which remains mostly intact at the greater tuberosity attachment site.

Prominent bicipital tendinosis with longitudinal partial tear just proximal to the bicipital groove.

Hypertrophic degenerative changes of the acromioclavicular joint.

Rewritten report:

Findings:

Rotator cuff: There is signal change consistent with tendinopathy involving the entire supraspinatus tendon and part of the infraspinatus and subscapularis tendons consistent with age. There is thinning of the supraspinatus. The muscles are healthy.

Glenoid labrum and biceps tendon: Enlargement and signal changes in the biceps tendon consistent with rotator cuff tendinopathy as expected at this age. There is a small amount of superior and anterior labral changes, a small subchondral cyst in the humeral head, and a small amount of fluid in the joint suggestive of very mild glenohumeral

arthrosis consistent with age. The articular cartilage is of normal thickness and without defect.
AC joint: Arthritis consistent with age.
Impression:
Expected age-related changes including:

1. Rotator cuff/biceps tendinopathy with some thinning in the supraspinatus, but no defect and healthy muscle.
2. Moderate arthritis of the acromioclavicular joint.
3. Very mild arthritis of the glenohumeral joint.

## Supplement 2: Original and reworded report lateral epicondylitis.

Original report:
Findings:
There is a skin marker over the lateral humeral epicondyle. There is severe thickening of the common extensor tendon insertion consistent with tendinosis, and a superimposed partial tear measuring 5 mm. There is prominence of the adjacent joint capsule raising the question of concurrent partial tear of the radial collateral ligament.
The remaining ligaments and tendons are normal in configuration and signal intensity.
The ulnar nerve is in the groove. Bones and bone marrow are unremarkable.
Impression:
Tendinosis and partial tear of the common extensor tendon at the insertion on the lateral humeral epicondyle.
Reworded report:
Findings:
Thickening and signal changes of the origins of the common extensor tendon and radial collateral ligament origin consistent with tendinopathy. The remaining ligaments, tendons, bones and nerves are normal.
Impression:
Findings consistent with lateral epicondylitis.

4

# Experienced barriers in shared decision making behaviour of orthopaedic surgery residents compared to orthopaedic surgeons

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## ABSTRACT

**Background:** In shared decision making (SDM) the physicians encourage the patient to participate in decision making. The theory of planned behaviour describes that behaviour is dependent of the intention. Subsequently, intention is explained by attitude, subjective norm and perceived behaviour control. This theory is used to explain behaviour. In orthopaedics little is known about current SDM behaviour and how to promote this.

**Objective:** To get insight into SDM behaviour of orthopaedic residents and supervisors by measuring levels of intention, attitude, subjective norm and perceived behaviour control. Furthermore we want to determine the predictors of intention for SDM behaviour.

**Method:** A questionnaire survey study was conducted among orthopaedic surgeons and residents working in the care of hip and knee osteoarthritis to determine their intentions, attitudes, subjective norms and perceived behavioural control regarding SDM. Of the 385 addressed physicians, 71 residents and 64 orthopaedic surgeons participated.

**Results:** Positive intentions were seen towards SDM. Intention for SDM behaviour was explained by attitude, subjective norm and perceived behaviour control, with perceived behaviour control having the strongest association. In residents, intention to engage in SDM was more hampered by a lower level of perceived behavioural control than in surgeons.

**Conclusion:** Physicians express willingness to perform SDM and consider SDM as favourable in the orthopaedic clinic. Implementation of SDM is mainly hampered by experienced barriers they cannot control. Findings underline the importance of incorporating shared decision making in the curriculum of post graduates. Possibilities must be explored for efficient SDM implementation to overcome perceived barriers.

## INTRODUCTION

There is a strong patient participation movement (1). Patient participation in clinical decision making is embodied in the concept of shared decision making (SDM), in which the patient and physician share responsibility in the clinical decision making process (1-3). To improve shared decision making, clinicians increasingly use supporting programs (4), such as the Ask 3 Questions campaign and patient decision aids (5, 6). However, some authors warn against the implementation of patient decision aids without appropriate education for physicians, because this might lead to the use of patient decision aids without coaching patients in the decision making process, or even to patients feeling abandoned with decision making responsibilities (4). Little is known about current SDM behaviour of physicians and how to promote this (3).

To explain behaviour in relation to health outcomes, various studies have used the theory of planned behaviour (TPB) (7). The theory was also used in designing theory-based interventions to change clinicians behaviour (8). The key component in the TPB model is behavioural intention, which is related to actual behaviour (7, 9). Behavioural intention is determined by three independent variables: 1. attitude, i.e. the degree to which a person has a favourable or unfavourable evaluation of the behaviour of interest, 2. subjective norm, i.e. a person's beliefs about whether peers and people of importance think he or she should engage in the behaviour, and 3. perceived behaviour control, i.e. the perceived ability to perform a behaviour and to deal with anticipated obstacles (7).

In 2014, a review article on 20 studies that used the TPB to assess SDM behaviour in health professionals observed that these three variables predicted intention for SDM or actual SDM behaviour (9). Although there was large variance, the intention to engage in SDM was most strongly associated with subjective norm. A possible explanation for this finding is that SDM is a direct social interaction between physician and patient and hence its favourable or unfavourable outcome is perceived to be highly dependent on issues that are not under the physician's control, such as the patients' competencies and contextual barriers and facilitators (9). Another explanation for subjective norm being dominant is that there is currently a strong social movement in favour of patient-centred care (9).

Apparently, intention for performing SDM varies between settings and disciplines. The extent to which physicians use SDM in practice is influenced by individual and organisational factors (8,10-12). For instance, qualitative research on the care of patients with herniated back pain showed that physician had negative attitudes towards shared decision making. Physicians found it important to express their own views on the available treatment options and were afraid that SDM would result in a choice of treatment they did not consider appropriate (12). Besides negative attitudes, other

important barriers for physicians to perform SDM are organisational obstacles, such as lack of time (13).

Little is known about differences in SDM behaviour between orthopaedic surgery residents (i.e. physician participating in training program for a medical speciality) and orthopaedic surgeons. This information is relevant since attitudes and educational needs may differ between these groups and educational programs need to be tailored towards these needs. A Swiss study showed that residents had more negative attitudes toward SDM than their teachers (14). The authors speculated that these negative attitudes might be caused by the lack of structural SDM communication education in residency programs (13) and they pleaded for more SDM education in residency programs (14).

The aim of this study was to get insight into SDM behaviour of orthopaedic residents and their supervisors in order to be able to improve the design of post-graduate educational programs on SDM. Therefore we assessed the levels of intention, attitude, subjective norm and perceived behavioural control of Dutch orthopaedic surgeons and residents concerning SDM in the daily care of patients with hip or knee osteoarthritis.

## METHOD

### Study design

We performed a survey study among an unselected group of all Dutch orthopaedic surgeons and orthopaedic surgery residents who treat patients with hip and knee osteoarthritis. We obtained approval from the Medical Ethical Committee (study number 16-N-195).

### Population and procedure

We invited orthopaedic surgeons (staff physicians) and residents for orthopaedic surgery who are working in the care of patient with hip and knee osteoarthritis in the Netherlands. We received the contact information of these physicians from the Dutch Orthopaedic Association. We addressed the physicians by email, and two reminders were sent after the first invitation to complete the survey. Informed consent was given before filling in the questionnaire. The questionnaire contained 36 questions and it took participating physicians 10 to 15 minutes to complete this electronically.

### Responder analysis

We performed an analysis of the non-responders. We knew the professional role of the physicians that did not respond to our survey study. The distribution of the professional roles of the non-responders did not differ significantly from that of the participating

physicians, with 56% of the non-responders being residents and 44% orthopaedic surgeons. No other variables were recorded about non-responding physicians.

## Measurement

We developed a questionnaire to measure intention and the determinants of intention for SDM. The questionnaire was based on a manual for developing TPB questionnaires (15). To our knowledge no validated questionnaire is published to determine SDM behaviour according to the TPB of physicians working in orthopaedics. Our questionnaire contained questions about behavioural intention and about the three main elements of intention; attitude, subjective norm and perceived behaviour control.

From literature, we selected factors for attitudes, subjective norm and perceived behaviour control, associated with shared decision making behaviour (8, 10, 16-18). All listed authors were consulted and a selection from these factors for the final items of the questionnaire was made. For attitude, six items were constructed, for subjective norm five and for perceived behaviour control seven. Items consist of two subitems. The first subitem is the selected attitude, subjective norm factor or factors of perceived behaviour control. With the second subitem, the participant stated how important or relevant the specific first subitem is. More specific, the first subitem on attitude is about the selected beliefs or attitudes on shared decision making. The second subitem is about the corresponding positive of negative judgements about these attitudes. For subjective norm, the first subitem scores the beliefs on shared decision making behaviour of other people or groups. Secondly, the influence of these people or groups on the participant's behaviour is scored. For perceived behaviour control the first subitem scores the perceived barriers and facilitating factors for performing SDM, and the second subitem scores the control of the participant on these factors. Answers are given on a 7-point Likert scale with consistent direction. For scoring the items, the first subitem is multiplied with the second, and the root of this score gives the final score. Scores range from 1 to 7, with a high score representing high intention, positive attitude, high subjective norm or high perceived behaviour control (see supplement for the questions measuring attitude, subjective norm and perceived behaviour control). Demographic data were collected with questions regarding age, professional role (resident or orthopaedic surgeon), type of hospital (academic or peripheral hospital) and gender.

We pilot-tested the questionnaire with three orthopaedic residents and two orthopaedic surgeons, who were not part of the research team, to ensure usability and to identify need for clarification, which led to some small adjustments to the questionnaire.

## Analysis

The manual we used to develop the questionnaire advised a sample size of 80 participants based on an effect size of 0.3 (15) points on the questionnaire. The population of our interest consists of 395 persons, so we expected that this sample size would be achieved.

We tested the internal reliability of the questionnaire. We calculated Cronbach's alpha for the three dimensions. The Cronbach's alpha of attitude subscale was 0.87, of subjective norm 0.55 and of perceived behaviour control 0.84. No questions were deleted after this analysis, because this would not have increased the Cronbach's alpha value.

The main outcome measures were not normally distributed at final evaluation and therefore we used non-parametric tests for our analyses. We reported baseline characteristics of the participating physicians. We performed an non-responder analysis with the variables we had of the physicians not responding. For the sums of the scores for attitude, subjective norm and perceived behaviour control, we calculated mean scores and for the question about intention we used a median as a measure of centre. We tested the differences between orthopaedic surgeons and residents in the scores of the dimensions of the TPB with the Mann Whitney *U* test. Age was transformed from an ordinal variable (7 age groups) to a dichotomous variable. Cut-off point was 35 years of age, with the younger group having 67 percent of the participants, and in the older group 33 percent. In the bivariate analyses we calculated how attitude, subjective norm and perceived behaviour control were correlated with intention, using Spearman's rho correlations. All parameters with a p-value lower than 0.10 in the bivariate analysis were entered into multivariate linear regression analysis, with intention as the dependent outcome. We used the enter method in our regression analyses. We assessed multicollinearity in the model using the variance inflation factor (VIF). The VIF was found to be satisfactory (mean VIF = 1.66).

# RESULTS

Between April 2017 and June 2017 we sent out the survey to 395 physicians, 46% of whom were orthopaedic surgeons and 54% were residents. Of these, 135 (34%) completed the questionnaire. Most physicians were aged between 31 and 35 (47%) and were male (84%). Of the responders, 48% were orthopaedic surgeons and 52% were residents.

## Outcome measures (table 1):

Both residents and orthopaedic surgeons scored high on intention for SDM behaviour, with a median of 6.0 on the 7-point Likert scale questionnaire (see table 1).

**Table I. Scores questionnaire TPB of residents and orthopaedic surgeons (n=135)**

| | Total group (n=135) | Residents (n=71) | Orthopaedic surgeons (n=64) | |
|---|---|---|---|---|
| | **Mean** | **Mean (SD)** | **Mean (SD)** | **p-value** |
| Intention of physicians to use SDM in practice | 6 | 6 | 6 | 0.1 |
| *How important do you find the attitudes below and are these attitudes accomplished through SDM?* | | | | |
| The patient is informed about important benefits and disadvantages of different treatment options | 5.9 | 5.8 (0.9) | 6.0 (1.0) | 0.2 |
| The background and relevant situation of the patient is discussed | 5.7 | 5.5 (0.8) | 5.8 (0.9) | 0.1 |
| The opinion and wishes of the patient are discussed during the treatment process | 5.9 | 5.8 (0.7) | 6.0 (0.8) | 0.048 |
| The decision for treatment is made together with the patient | 5.9 | 5.9 (0.7) | 5.9 (1.1) | NS |
| The patient is satisfied with the care process | 5.9 | 5.8 (0.9) | 5.9 (0.9) | NS |
| The patient is involved in the treatment process | 5.8 | 5.7 (0.7) | 6.0 (0.8) | 0.1 |
| The treatment chosen is appropriate for the specific patient | 5.8 | 5.8 (0.8) | 5.8 (1.2) | NS |
| **Total score Attitude** | **5.9** | **5.7 (0.6)** | **5.9 (0.7)** | **0.055** |
| *Subjective norm; how important is the opinion of these persons or social groups and do they advise you to do SDM?* | | | | |
| Colleagues | 5.2 | 5.2 (1.0) | 5.2 (1.1) | NS |
| Local residency training program director | 5.3 | 5.5 (1.0) | 5.0 (1.5) | 0.1 |
| Insurers | 2.6 | 2.3 (1.0) | 3.0 (1.3) | 0.002 |
| Patients | 5.0 | 4.9 (0.9) | 5.0 (1.1) | NS |
| Health policy makers (e.g. national orthopaedic society, ministry of health) | 3.9 | 3.7 (1.3) | 4.1 (1.4) | 0.08 |
| **Total score Subjective Norm** | **4.6** | **4.5 (0.7)** | **4.7 (0.7)** | **NS** |
| *Perceived behavioural control* | | | | |
| I am convinced that I can share decision making in the clinic | 5.9 | 5.8 (1.0) | 6.0 (1.0) | NS |
| I have control about the level of SDM that is accomplished in the clinic | 5.7 | 5.5 (1.0) | 5.8 (1.2) | 0.02 |
| I can perform SDM without extending the duration of the consultation | 3.6 | 3.3 (1.1) | 3.9 (1.5) | 0.036 |
| Time constraints are an important issue in SDM | | | | |
| Knowledge about SDM is important in order to perform SDM | 5.4 | 5.2 (1.0) | 5.5 (1.0) | 0.027 |
| My knowledge about SDM is sufficient | | | | |
| Communication skills are important for SDM | | | | |
| My communication skills required for SDM are sufficient | 6.1 | 5.9 (0.7) | 6.3 (0.7) | 0.006 |
| Patient motivation is important for SDM | | | | |
| In general the patient's knowledge, intelligence and understanding needed for SDM is sufficient | 3.7 | 3.7 (0.9) | 4.2 (1.0) | 0.046 |
| Patient's knowledge, intelligence and understanding are important for SDM | | | | |
| **Total Behavioural Control** | **5.3** | **5.2 (0.6)** | **5.5 (0.7)** | **0.021** |

Of the three items of the TPB, attitude showed the highest scores with a total score of 5.9. Although residents had a lower mean total score, there were no significant differences in the scores between residents and orthopaedic surgeons.

For subjective norm, the total score was 4.6. This was the lowest score of the three sub-dimension. Of the factors of subjective norm, physicians viewed the opinion of the local residency training program director as most important. Low scores were given for the influence of health policy makers and insurers. Compared with residents, orthopaedic surgeons reported to be significantly more influenced by insurers in their SDM behaviour.

For perceived behaviour control, the total mean score was 5.3. The scores for physician's knowledge about SDM and communication skills needed for SDM were high among residents and orthopaedic surgeons, and low scores were given for perceived control on time and on patient knowledge, intelligence and understanding. Residents scored significantly lower on perceived behaviour control than orthopaedic surgeons. Items on this dimension that received lower scores from residents were the level of control about SDM, time constraints, communication skills important for SDM and the item patient knowledge, intelligence and understanding.

Furthermore we saw that physicians with an age above 35 years had a higher total score of attitude (p=0.036). No significant differences were seen between scores of male and female physicians. Also, type of hospital (academic or non-academic) was not associated with different scores for the items of the theory of planned behaviour.

## Bivariate and Multivariable Analysis (table 2 and 3)

In the bivariate analyses, attitude, subjective norm and perceived behaviour control were correlated with intention for SDM behaviour (see table 2). Of the three determinants, the one most strongly associated with intention for SDM behaviour was perceived behaviour control. The determinant that was least associated with intention for SDM behaviour was subjective norm.

**Table II. Bivariate analysis: association with intention for SDM behaviour**

| Spearman's rho | Correlation | p-value |
|---|---|---|
| Attitude | 0.45 | <0.001 |
| Subjective norm | 0.28 | 0.001 |
| Perceived behaviour control | 0.53 | <0.001 |

The variables that satisfied the criteria for entry in the multivariate analyses were higher attitude, higher subjective norm, higher perceived behaviour control and orthopaedic surgeon (professional role). Entry of these variables resulted in a model that explained 27% of the variation in the intention scores ($R^2$ 0.27, $p < 0.001$) (table 3).

**Table III. Regression coefficients and 95% confidence intervals of the intention for SDM behaviour**

| Coefficients | b (95%CI) | Standard error | p-value |
|---|---|---|---|
| Attitude | 0.233 (-0.068, 0.534) | 0.152 | 0.129 |
| Subjective norm | -0.002 (-0.276, 0.271) | 0.138 | 0.986 |
| Perceived behaviour control | 0.604 (0.291, 0,917) | 0.158 | <0.001 |
| Professional role | 0.081 (-0.228, 0.390) | 0.156 | 0.607 |

# DISCUSSION

The aim of this study was to get insight into intention of Shared Decision Making (SDM) behaviour of orthopaedic residents and their supervisors in the care of patients with hip and knee osteoarthritis. This study shows that orthopaedic surgeons and residents in general express positive attitudes toward SDM in the care of hip and knee osteoarthritis patients. Lower scores were seen for perceived behaviour control and subjective norm. As expected according to the Theory of Planned Behaviour (TPB), the intention to engage in SDM was associated with attitude, subjective norm and perceived behaviour control. Intention for SDM behaviour was most strongly associated with perceived behaviour control. The variation in scores of intention for SDM behaviour was explained for 27% by higher attitude, higher subjective norm, higher perceived behaviour control and having a professional role as orthopaedic surgeon.

Residents felt significantly less in control about factors influencing their SDM behaviour. Although mean scores of physician knowledge and skills relevant for SDM were high in all physicians, residents were less confident that they possessed the communication skills needed to perform SDM, and they rated their knowledge about SDM lower than orthopaedic surgeons did. This is a relevant finding since patient communication and even shared decision making are increasingly implemented in medical education programs recent years. It is therefore to be questioned what the effect is of these pre-graduation programs. Additionally, the clinical experience orthopaedic surgeons have might be important in the control physicians experience in this behaviour.

External factors outside of the physician's perceived control contributed to the low score in perceived behaviour control. This resonates with other research findings in which physicians experience many barriers from external factors when implementing SDM (8, 12). In a review study by Légaré and colleagues, the most important obstacles to implementing SDM mentioned by physicians were time constraints, characteristics of the patient and clinical context (8).

One of the external factors pointed out by physicians was that patients had limited capabilities to participate in the decision making process. This is in line with a study by Van der Horst and colleagues (14). In this study residents were more negative about

the ability of patients to participate in decision making than their teachers. (19, 20, 36). This perspective could partly be explained by physicians' interpretation of the concept of SDM. In SDM, the patient does not need to have medical expertise but needs to give information about his or her background, situation and preferences relevant for the medical decision. This in itself may be a challenge for some patients, but with coaching from the physician, most patients are keen to do this (21). Even when patients have low health literacy, the level of SDM can be improved successfully by SDM interventions (22).

Another important perceived obstacle is the extra time needed for shared decision making. In 2014, a review study investigated the effects of interventions to improve the adoption of SDM by healthcare professionals and reported no difference in duration of consultation after implementation of these interventions (3), although it must be noted that most of the reviewed studies had no effect on the level of SDM. A Cochrane review on implementing decision aids reported a median increase on the duration of consultations of 2.6 minutes (23). Little is known about the, possibly positive, effects of shared decision making on the total duration of health care provision, for instance on the number of follow-up visits to the outpatient clinic.

In our study we found high levels of attitude and competencies for SDM of physicians. Previous research on actual SDM behaviour in orthopaedics showed that there is much room for improvement. (25, 25). The difference in positive scores of physicians about SDM in our study and the actual (relative low) levels of SDM in the orthopaedic clinic could be explained by the reason that physicians may overestimate their SDM competencies and may be unconsciously incompetent in this behaviour. This reasoning is supported by a review study of Pollard and colleagues from 2014 (26), which describes five studies that compared self-reported attitudes about SDM with actual SDM behaviour. In most of these studies the actual decision making behaviour appeared to be rather paternalistic, while most physicians had positive attitudes toward SDM (26).

As mentioned, our study explained 27% of the intention of SDM behaviour. This means that most of the variation in intention is explained by other factors that were not included in our study. The level of variation in intention that was explained by the determinants of the TPB is in line with the results of other research. In the review study of Thompson-Leduc about SDM behaviour explained by the TPB, the predictability of the variance of intention varied, with $R^2$ values ranging from 15% to 88% (9). Other mentioned factors explaining intention for SDM behaviour are self-efficacy (27,28) and moral and professional norms (9,29-31). In our study, the strongest predictor for SDM intention was perceived behavioural control, a finding which is not in line with the review of Thomas Leduc (9).

As this study relied on self-reported scores, it is susceptible to cognitive bias and socially desirable answers (26, 32). When attitude is measured in interviews or focus

groups, more salient beliefs and attitudes on SDM are being reported, (12, 33) and attitude was found to be not as high as in our study.

We used closed-ended items to measure the complicated construct of shared decision making based on the TPB. Our questionnaire was designed with the help of the manual developed by Francis and colleagues in 2004 (15). According to this manual, closed-ended items are constructed by first executing a qualitative study which elicits commonly held beliefs about intention, attitude, subjective norm and perceived behaviour control. For SDM, extensive research is already available. Therefore, we did not execute this step and based our items of the TBP on current literature.

In our study we had a response rate of 34%, which is comparable to other survey studies using email approach (34). We approached the whole population of interest by email. For this we used the email database of the Dutch orthopaedic society, which might not have been completely up to date. Selection bias might have occurred as physicians with a positive attitude toward SDM might have been more inclined to participate in our survey.

A ceiling effect was seen in the questionnaire with high median and mean scores for intention, attitude and perceived behaviour control.

This study indicates that the intention to perform shared decision making is high. Since intention is corelated to actual behaviour (7, 9, 29) this gives us indirect information about clinical behaviour of physicians in the care of hip and knee osteoarthritis. In our study, intention for SDM is predicted by the three dimensions of the theory of planned behaviour, with perceived behavioural control having the most influence. Our findings imply that a shift towards positive attitudes about SDM has taken place in physicians in orthopaedics, but on the other hand they, and especially residents, experience barriers and difficulties that hamper implementation of SDM. The differences in perceived behavioural control between orthopaedic surgeons and residents underline the importance of incorporating shared decision making in the curriculum of medical student and post graduates. Students and residents should be taught what SDM entails and what the impact is of shared decision making. Furthermore, they must be aware of the different possibilities for efficient SDM implementation to overcome perceived barriers. Information about current predictors of SDM behaviour amongst physicians working in the care of patients with hip and knee osteoarthritis is valuable and necessary for developing programs that aim to improve SDM behaviour as depicted by the theory of planned behaviour (35).

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5

# Disappointing evaluation of a shared decision-making intervention for residents and orthopaedic surgeons

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## ABSTRACT

**Objective:** To evaluate a shared decision-making (SDM) intervention in orthopaedic hip and knee osteoarthritis care.

**Method:** Using a pre- post intervention design study, we tested an intervention, that included a decision aid for patients (ptDA) and a SDM training course for residents in training and orthopaedic surgeons. The theory of planned behaviour was used for intervention development. Primary outcomes included patient reported decisional conflict, SDM, and satisfaction. Secondary outcomes were physicians' attitude and knowledge, and uptake of the ptDA.

**Results:** 317 patients were included. The intervention improved physicians' knowledge about SDM but had no effect on the primary outcomes. 19 eligible patients used the ptDA (17%). SDM was higher for middle educated patients compared to lower educated (mean difference 9.91, p = 0.004 ), patients who saw surgeons instead of residents (mean difference 5.46, p = 0.044) and when surgery was chosen and desired by patients compared to situations where surgery was desired but not chosen (mean difference 15.39, p = 0.036).

**Conclusion:** Our multifaceted intervention did not improve SDM and ptDA uptake was low.

**Practice Implications:** In orthopaedic hip and knee osteoarthritic care other ways should be explored to successful implement SDM. Since residents received lower SDM scores, special focus should go to this group.

# INTRODUCTION

In recent years patient centred care has gained importance in healthcare (1,2). A pivotal element of patient centred care is shared decision-making (SDM), in which a healthcare choice is made by the patient and the healthcare professional together (3). Healthcare authorities in the Netherlands and internationally declared SDM as a key element in the care of patients with hip and knee osteoarthritis (2,4). SDM supports the process of choosing the best treatment for an individual patient taking into account their preferences and context (2). For example, for some patients with end stage hip osteoarthritis surgery may not be the right option because of low demand physical functioning. SDM is associated with higher levels of patient knowledge about the disease, treatment options and related treatment risks (7). Moreover, SDM helps patients to be more aware of what matters most to them (8,9). Research in the field of urology and surgical oncology showed that patients are less likely to choose elective surgical procedures when SDM interventions are implemented (9). Because of the preference sensitive nature of this decision, and the high load and impact of joint replacement surgery, it is important to develop interventions to support SDM in this context and evaluate their clinical implementation (2,10).



Multiple SDM related studies have been conducted in orthopaedic surgery (10,11). A patient decision aid (ptDA) is a commonly used example of a SDM intervention. PtDA's aim to specify the decision that needs to be made, inform patients about the medical problem and treatment options, and help patients to clarify their values and preferences relevant to the treatment options (12). These tools are increasingly used in clinical practice and solid evidence shows that they are associated with better informed patients and decreased levels of patient reported decisional conflict (11). Also, physician directed interventions exist as training programmes to improve physician communication skills relevant for SDM (7). Previous research illustrates that these training programmes are more effective if they include active and practice-oriented elements, such as the use of simulated patients and education in the actual clinical setting (13). Interventions targeting both doctors and patients, are more effective than SDM interventions that are solely aimed at the doctor or the patient (7). Although relevant in orthopaedics, none of the published studies focused on patients and physicians, and research about such combined intervention might give insight for SDM efforts in the care of hip and knee osteoarthritis.

In general, interventions are more successful in changing clinicians' behaviour when they are based on a conceptual framework (14). The theory of planned behaviour emphasizes that human behaviour is governed not only by personal attitudes, but also by social pressures and sense of control (15). This theory is often used in research and has successfully predicted behaviour of healthcare professionals (e.g. SDM) in

previous studies (16). A recent conducted study showed that orthopaedic surgeons and residents, in general express positive attitudes toward SDM in the care of hip and knee osteoartritis (17). However, they experienced little control on the level of SDM and were hampered by factors like time constraints, insufficient education about SDM and lack of available instruments to support the SDM process (17). These results are of value in the development of SDM interventions.

In this study, we evaluated the effect of a multifaceted SDM programme for hip and knee osteoarthritis on patient reported decisional conflict, levels of SDM, patient satisfaction (primary outcomes) and physicians' attitudes and knowledge about SDM (secondary outcomes).

## METHODS

### Setting of the study

The study was conducted between August 2017 and March 2020 in an Orthopaedic Department of a large training hospital in the Netherlands.

### Design of the intervention

The intervention was based on the theory of planned behaviour (TPB) (18). According to this theory intention is the best predictor of behaviour. Intention in turn is a function of attitude, subjective norm and perceived behavioural control. Recently these elements were investigated for SDM behaviour in the care of hip and knee osteoarthritis (17) and, as recommended for the development of TPB-based interventions (15,19), we used this information to develop our intervention. Goals of the intervention were to enhance clinician's knowledge about SDM, to train and practice SDM communication skills, and to provide education about tools to facilitate and advance SDM. In addition, an existing ptDA on hip and knee osteoarthritis was made available as part of the intervention. Altogether, the intervention was multifaceted and consisted of an e-learning module and a communication training for the physicians working in orthopaedics and the implementation of ptDA's for patients (see Box 1). During the study we recorded the uptake of these different intervention elements.

#### *E-learning for physicians*

Prior to the training physicians participated in an e-learning module. This e-learning was developed by the Fontys University of Applied Sciences in collaboration with the Academical Medical Centre of Amsterdam in the Netherlands (20). This e-learning module focuses on increasing knowledge about SDM and gives practical lessons on how to implement SDM in clinical practice.

| **Box 1: Elements SDM intervention Hip and Knee osteoarthritis** | |
|---|---|
| Interventions for Physician | E-learning<br>- Knowledge lessons about SDM<br>- Lessons for clinical practice, communication model |
| | Communication training<br>- Two sessions of two hours<br>- Clinical exercise with SDM Talk model<br>- SDM communication training with role play exercises<br>- Lessons about ptDA's and how to implement them |
| Intervention for Patient | Decision aids<br>- Information about disease<br>- Information about treatment options, with pros and cons<br>- Patient knowledge test<br>- Value clarification<br>- Verification of decisional readiness |



### *Communication training for physicians*

The communication training consisted of two sessions of each two hours. The training was executed by a resident in training in collaboration with an external SDM expert. The first training provided information about SDM. Beliefs and attitudes about SDM were discussed and (mis)conceptions about SDM were reviewed. The SDM Talk model of Elwyn et al (21) was explained and practiced using role playing with patient vignettes. The second session evaluated how acquired skills were implemented in the clinic by the participating physicians and experiences were shared. Further, ptDA's were discussed, and a variety of tools was reviewed. Finally, consultation skills were practiced with role playing, with the focus on how to implement ptDA's. At least, a part of the staff was highly motivated for the SDM training, as the training was initiated by one of the senior orthopaedic surgeons, the residency programme director.

### *Implementation of decision aids for patients*

Two ptDA's on hip and knee osteoarthritis were made available. These web based ptDA's were developed by the company Patient Plus (22,23). The online ptDA's were developed by patients and physicians according to the International Patient Decision Aids Standards (IPDAS) (24). At that time, the participating hospital rolled out ptDA's in the care of other specialties, but not yet orthopaedics.

## Participants

### *Physicians*

The SDM training was directed at orthopaedic surgeons and residents working at the Orthopaedic Department. All staff surgeons (10) and residents (9) involved in hip and knee osteoarthritis care participated in the training.

### *Patients*

Adult patients referred by a general practitioner, who were suffering from hip or knee osteoarthritis were included. Patients who were unable to give informed consent and non-Dutch speaking or illiterate patients were excluded.

## Design of the study

For this study we used a pre- post intervention design. When physicians completed the training and after implementation of the ptDA, enroled patients comprised the intervention group. Patients who were enroled before these interventions started comprised the control group. This study design removes potential contamination between the different groups and is therefore commonly used for evaluating educational interventions (16). We obtained approval from the Medical Ethnical Committee (METC Zuyd – number: 16-N-195) and from the Dutch Organization for Medical Education (NVMO).

## Procedure

Eligible patients were informed by a physician or research nurse, were asked to read the information letter and signed the informed consent form if they agreed to participate. After complete enrolment of the control group, the intervention started. If there was an indication for surgery, the trained physicians proposed the use of the ptDA during consultation. So, the ptDA was not offered if surgery was not considered as a treatment option. The tool was presented to the patient after the different treatment options were discussed, prior to making the decision. Discussed treatment options included watchful waiting, pain medication, physiotherapy and joint infiltration. If indicated, non-conservative options were proposed by the surgeon involving joint replacement surgery. If patients opted to use the ptDA, they were provided a web address and login. Patients went through the ptDA in their own environment (e.g. at home) and a follow-up appointment was scheduled to review the ptDA and to make a final treatment decision. This follow-up appointment took place at the outpatient clinic or via telephone. If eligible patients chose not to use the ptDA the reason was recorded in order to obtain insight in barriers for usage.

## Outcome measures

Outcome measures were completed after the treatment decision was made.

### *Background measures*

Background measures included gender, age and the International Standard Classification of Education (ISCED) for the level of education (25). Patients were asked about their preferred treatment choice, final treatment decision, and we asked patients

which sources of information about their complaint they used prior to consultation (e.g. friends, websites, and pamphlets).

Patient activation was measured using the Patient Activation Measure (PAM) to assess patients' knowledge and confidence in self-management concerning health problems (26,27). Knee and hip pathology related physical functioning was measured with the short versions of the Hip and Knee disability and Osteoarthritis Outcome Scores (28,29) (see table 1).

**Table 1. Patient reported outcome measures - questionnaires**

| | Items | Summary score | High score means |
|---|---|---|---|
| ***Background measures*** | | | |
| Patient Activation Measure (PAM) | 13 items. Likert scales : 0 (totally disagree) to 4 (totally agree) and 'non applicable' | Total score. Scores were converted to 0-100 scale. | More patient activation |
| Hip disability and Osteoarthritis Outcome Score short form (HOOS-PS) | 5 items. Likert scales: 0 (no difficulty) – 5 (very hard) | Total score. Scores were converted to 0-100 scale | Better physical functioning |
| Knee disability and Osteoarthritis Outcome Score short form (KOOS-PS) | 7 items. Likert scales: 0 (no difficulty) – 5 (very hard) | Total score. Scores were converted to 0-100 scale. | Better physical functioning |
| ***Primary outcome measures*** | | | |
| 9-item Shared Decision-Making Questionnaire (SDM-Q-9) | 9 items. Likert Scale: 0 (totally disagree) to 6 (totally agree) | Total scores. Scores were converted to 0-100 scale | High level of SDM |
| Decisional Conflict Scale | 16 items. Likert scales: 0 (Strongly agree) to 4 (Strongly disagree) | Total scores. Scores were converted to 0-100 scale | High decisional conflict |

### *Primary outcome measures*

Experienced quality of the decision was measured with the Decisional Conflict Scale (DCS) (30,31). The DCS is a validated 16 item questionnaire with 5-point Likert response scale. It measures: 1) healthcare consumers' uncertainty in making a health-related decision; 2) the factors contributing to the uncertainty; and 3) healthcare consumers' perceived effective decision-making. The total score was used as outcome measure. This questionnaire is validated for Dutch use by Koedoot et al. in 2001 (31).

Perceived quality of the decision process was measured with the 9-Item Shared Decision-Making Questionnaire (SDM-Q-9) which is validated in Dutch (32) (see table 1). A visual analogue scale from 0 to 10 measured patient satisfaction, with 0 indication least satisfaction and 10 maximal satisfaction with received care.

### *Secondary outcome measures*

*Knowledge and attitude questionnaire physicians*

Participating physicians completed a validated questionnaire assessing SDM attitude and knowledge prior and after the training (33). The questionnaire was developed for medical students and we adapted it for clinician's without revising the content. Scores ranged from 0 to 18 and 0 to 15 for attitude and knowledge respectively.

*Use of Patient Decision Aid*

As mentioned, the uptake of the ptDA's was recorded and used as a process measure. If patients opted not to use the tool, reported reasons were recorded by the physician. These records provided us information about barriers for use of the ptDA's.

## Statistical analyses

Descriptive statistics were used to report the baseline characteristics of the different groups. We found that the distribution of primary outcome measures was skewed, so we used non-parametric tests. The Mann-Whitney U-test was used to compare continuous measures between the different groups. We used the Kruskal-Wallis test to report the association of categorical variables with the primary outcome measures. Variables that were significant or had $p<0.10$ in the bivariate analyses were selected for the regression analyses of the primary outcome measures. Since we were interested in the variable intervention as possible predictor for the primary outcome measures we included this as well in the regression models. The regression analyses were done on two levels namely the physician and the patient level and intraclass-correlation scores (ICC) were calculated. In the models we checked for collinearity and adjusted the model for this. The software programme Stata (v14) was used for the analyses.

Level of education was measured in 8 groups according to the ISCED classification (25). We recoded it into three groups, low education (primary, basic and lower secondary education), medium education (upper secondary and post-secondary non-tertiary education) and high education (bachelors, masters and higher) in line with international guidelines (25). For regression analyses we used dummy coding and low education was used as reference group.

A categorical variable was created to indicate whether the chosen treatment corresponded with the desired treatment. Four value options for this variable were possible: 1) conservative treatment preferred, conservative treatment chosen, 2) conservative treatment preferred, surgical treatment chosen, 3) surgical treatment preferred, surgical treatment chosen, and 4) surgical treatment preferred, conservative treatment chosen. For regression analyses we used dummy coding with the latter variable (4) as a reference.

We used mean imputation when in questionnaires less that 25 percent was missing for a patient (34,35). We imputed values for 13, 14, 18, and 8 patients for the SDM-Q9, DCS, HOOS and KOOS respectively. After imputation of the values the total scores were calculated of different questionnaires.

Our calculation of the sample size was based on previous research that investigated an intervention for patients with hip or knee osteoarthritis to promote SDM (36). With a difference of 5.8 points on the DCS (SD 16.6 of the control group and SD 14.9 of the intervention group) the power analysis for the primary objective (null hypothesis) revealed that 121 patients in each group would provide 80% power with a 0.050 two-sided significance level. With a drop out loss of 10% the sample would be 133 patients in each group. Sample size calculation was done with the programme G-Power (37).



## RESULTS

### Baseline results

Overall, 317 patients participated in our study, 142 in the control group and 175 in the intervention group. Mean age was 70 years, around half (51%) were woman and almost 40 percent lower educated. The most common diagnosis was knee osteoarthritis (58%) and the most common treatment was surgery (61%). Prior to the consultation, patients obtained information about their hip or knee complaint most often from friends and family (47% of the patients) followed by the internet (27%) or pamphlets (15%).

The control and intervention group differed in age with a mean of 71 years for the control group and 68 years for the intervention group (p= 0.011). The number of patients who preferred surgical treatment but received non-surgical treatment was larger in the intervention group compared to the control group (8 vs 2%, p=0.039). Other baseline characteristics did not differ for the two groups (see table 2 and 3).

### Primary outcome measures

*Bivariate analyses*

No significant differences were seen between the control and intervention group for the primary outcome measures (decisional conflict, level of SDM and patient satisfaction) (see table 3).

Compared to residents, patients who consulted orthopaedic surgeons had higher SDM scores (74.80, vs 80.20, p=0.035) and higher patient satisfaction scores (7.80 vs 8.40, p=0.036). When patients preferred surgical treatment but received non-surgical treatment, SDM scores (66.27, SD=23.89) and patient satisfaction were lower (7.50, SD=1.87) and decisional conflict higher (35.20, SD=23.04) compared to situations of concordance between preferred and chosen treatment, and if patients preferred non-

surgical treatment but surgery was chosen eventually. Furthermore, patients with knee osteoarthritis were less satisfied and experienced higher decisional conflict than patients with hip osteoarthritis (see table 4).

**Table 2. Descriptives categorical variables, control and intervention group**

| | Control group (n=142) | | Intervention group (n=175) | | |
|---|---|---|---|---|---|
| | Number | % | Number | % | p value |
| Sex | | | | | NS |
| Male | 70 | 49.3 | 87 | 50.29 | |
| Female | 72 | 51.7 | 88 | 49.71 | |
| Diagnose | | | | | NS |
| Hip osteoarthritis | 63 | 44.37 | 70 | 40 | |
| Knee osteoarthritis | 79 | 55.63 | 105 | 60 | |
| Job function physician | | | | | NS |
| Orthopaedic surgeon | 112 | 21.13 | 49 | 28 | |
| Resident in training | 30 | 78.87 | 126 | 126 | |
| Patient information leaflet | | | | | NS |
| Yes | 20 | 14.08 | 28 | 16 | |
| No | 122 | 85.92 | 147 | 84 | |
| Patient information internet | | | | | NS |
| Yes | 39 | 27.46 | 48 | 27.43 | |
| No | 103 | 72.54 | 127 | 72.57 | |
| Patient information family / friends | | | | | NS |
| Yes | 61 | 42.96 | 87 | 49.71 | |
| No | 81 | 57.04 | 88 | 50.29 | |
| Treatment | | | | | NS |
| Non-surgical | 62 | 43.66 | 65 | 37.14 | |
| Surgical | 80 | 56.34 | 110 | 62.86 | |
| Desired treatment | | | | | NS |
| Non-surgical | 59 | 42.45 | 63 | 36.42 | |
| Surgical | 80 | 57.55 | 110 | 63.58 | |
| Concordance between preferred and chosen treatment | | | | | **0.039** |
| Surgical treatment preferred, non-surgical was chosen | 3 | 2.21 | 14 | 8.14 | |
| Non-surgical was preferred, surgical was chosen | 3 | 2.21 | 3 | 1.74 | |
| Non-surgical was preferred, non-surgical was chosen | 53 | 38.97 | 50 | 29.07 | |
| Surgical was preferred, surgical was chosen | 77 | 56.62 | 105 | 61.05 | |
| Level of education patient | | | | | NS |
| Lower | 56 | 39.44 | 70 | 40 | |
| Middle | 27 | 19.01 | 27 | 15.43 | |
| Higher | 59 | 41.55 | 78 | 44.57 | |

**Table 3. Descriptives continuous variables, control and intervention group**

| | Control group (n=142) | | | Intervention group (n=175) | | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Range | Mean | SD | Range | Z | p |
| Age (years) | 71 | 8.28 | 48-89 | 68 | 8.69 | 46-90 | 2.536 | **0.011** |
| Patient Satisfaction | 8.464 | 1.638 | 2-10 | 8.14 | 1.72 | 1-10 | 1.913 | 0.056 |
| Decisional Conflict Scale (DCS) | 19.91 | 20.37 | 0-100 | 21.04 | 16.8 | 0-100 | -1.208 | NS |
| Shared decision-making (SDM-Q-9) | 82.04 | 16.69 | 26-100 | 76.26 | 21.66 | 11-100 | 1956 | 0.053 |
| Patient Activation Measure (PAM) | 86.7 | 11.59 | 0-100 | 84.98 | 13.15 | 0-100 | 1.003 | NS |
| Physical functioning score | | | | | | | | |
| Hip (HOOS-ps) | 45.87 | 23.62 | 0-100 | 48.65 | 22.08 | 0-100 | -0.542 | NS |
| Knee (KOOS-ps) | 47.38 | 21.25 | 0-100 | 48.37 | 17.01 | 0-90 | -0.217 | NS |



### *Multivariate analyses (table 5)*

Multivariate analyses were performed to explain the relations of the included variables on the primary outcome measures.

Variables included in the model for decisional conflict (DCS) were intervention, diagnosis, knee function score, patient activation, and concordance between treatment and preferred treatment. Concordance between desired and chosen therapy was the most important predictor for less decisional conflict, especially when surgical treatment was chosen. Furthermore, patients with higher patient activation scores reported lower decisional conflict. The ICC was 0.006 using 298 observations (patients) and 19 groups (physicians).

Variables included in the regression model for SDM (SDM-Q-9) were intervention, level of education, function of the physician (resident or staff surgeon), patient activation and concordance between treatment and preferred treatment. Significant predictor for lower levels of SDM was middle level education (compared with lower education). Further, SDM scores were higher for surgeons than for residents, and for patients with higher patient activation scores. The ICC was 0.014 using 291 observations (patients) and 19 groups (physicians).

Variables included in the model for patient satisfaction were intervention, diagnosis, function of the physician, patient activation and concordance between treatment and preferred treatment. None of the variables predicted patient satisfaction. The ICC was $1.71\ 10^{-19}$ using 282 observations (patients) and 19 groups (physicians).

## Secondary outcome measures

### *Participation training and effect on physicians' knowledge and attitudes.*

As mentioned earlier, 19 physicians participated the communication training. Fourteen physicians also completed the e-learning, which took them 15 to 30 minutes to go through.

**Table 4 Correlations with primary outcome measures**

| | DCS | | | SDM-Q-9 | | | Satisfaction | | |
|---|---|---|---|---|---|---|---|---|---|
| | mean (SD) | z | p | mean (SD) | z | p | mean (SD) | z | p |
| Sex | | -1.080 | NS | | 1.052 | 0.29 | | -0.077 | NS |
| Male | 21.27 (17.91) | | | 77.45 (20.72) | | | 8.25 (1.76) | | |
| Female | 19.79 (19.02) | | | 80.25 (18.74) | | | 8.28 (1.62) | | |
| Diagnose | | -1.947 | 0.05 | | 1.105 | 0.269 | | 3.580 | **<0.001** |
| Hip osteoartritis | 18.73 (18.56) | | | 80.39 (18.94) | | | 8.65 (1.46) | | |
| Knee osteoartritis | 21.88 (18.22) | | | 77.73 (20.34) | | | 8.00 (1.79) | | |
| Job function of physician | | 0.435 | NS | | -2.101 | **0.035** | | -2.096 | **0.036** |
| Orthopaedic surgeon | 20.25 (18.26) | | | 80.22 (19.16) | | | 8.40 (1.58) | | |
| Resident in training | 21.38 (19.13) | | | 74.76 (21.11) | | | 7.82 (1.94) | | |
| Patient information leaflet | | -0.189 | NS | | -0.294 | NS | | 0.881 | NS |
| Yes | 19.91 (15.70) | | | 79.56 (19.40) | | | 8.11 (1.65) | | |
| No | 20.64 (18.91) | | | 78.69 (19.98) | | | 8.29 (1.70) | | |
| Patient information internet | | 1.644 | 0.1 | | 1.521 | 0.128 | | 0.868 | NS |
| Yes | 17.57 (16.334 | | | 76.45 (19.70) | | | 8.06 (1.89) | | |
| No | 21.68 (19.13) | | | 79.79 (19.79) | | | 8.25 (1.61) | | |
| Patient information family / friends | | 0.425 | NS | | -1.237 | NS | | -0.081 | NS |
| Yes | 19.28 (15.89) | | | 80.15 (19.38) | | | 8.25 (1.72) | | |
| No | 21.70 (20.55) | | | 77.95 (20.14) | | | 8.28 (1.67) | | |
| Patient information decision aid | | -0.439 | NS | | 0.034 | NS | | 0.446 | NS |
| Yes | 20.38 (15.59 | | | 79.37 (19.63) | | | 8.10 (1.46) | | |
| No | 20.58 (18.80) | | | 78.54 (19.85) | | | 8.27 (1.72) | | |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| Treatment | | 4.736 | **<0.001** | | -3.697 | **<0.001** | | -3.600 | **<0.001** |
| Non-surgical | 26.75 (20.24) | | | 73.55 (21.35) | | | 7.70 (2.02) | | |
| Surgical | 16.46 (15.98) | | | 82.33 (17.89) | | | 8.62 (1.33) | | |
| | mean (SD) | $Chi^2$ | p | mean (SD) | $Chi^2$ | p | mean (SD) | $Chi^2$ | p |
| Concordance between preferred and chosen treatment | | 25.410 | **<0.001** | | 14.81 | **0.002** | | 13.061 | **0.004** |
| Surgical preferred non-surgical was chosen | 35.20 (23.04) | | | 66.27 (23.89) | | | 7.50 (1.87) | | |
| Non-surgical was preferred surgical was chosen | 17.70 (9.09) | | | 87.19 (12.71) | | | 8.8 (1.44) | | |
| Non-surgical was preferred non-surgical was chosen | 25.59 (19.75) | | | 74.64 (20.98) | | | 7.72 (2.10) | | |
| Surgical was preferred surgical was chosen | 16.37 (16.21) | | | 82.06 (18.05) | | | 8.62 (1.33) | | |
| Level of education patients | | 1.013 | NS | | 9.349 | **0.009** | | 0.718 | NS |
| Lower | 20.63 (16.01) | | | 76.47 (18.95) | | | 8.20 (1.71) | | |
| Middle | 19.84 (21.40) | | | 85.38 (16.29) | | | 8.38 (1.7) | | |
| Higher | 20.70 (19.53) | | | 78.57 (21.31) | | | 8.28 (1.68) | | |

**Table 5 Regression Primary Outcome Measures**

| *Decisional Conflict Score* | **Coeff** | **Std Err** | **z** | **p** | **95% CI Interval** | |
|---|---|---|---|---|---|---|
| Intervention | 0.789 | 1.865 | 0.42 | 0.672 | -2.867 | 4.445 |
| Diagnosis | 1.262 | 1.900 | 0.77 | 0.442 | -2.262 | 5.187 |
| Concordance between preferred and chosen treatment ~ | | | | | | |
| Non-surgical was preferred, sugical was chosen | -13.170 | 7.480 | -1.76 | 0.078 | -27.832 | 1.490 |
| Non-surgical was preferred, non-surgical was chosen | -8.882 | 4.233 | -2.10 | **0.036** | -17.179 | -0.584 |
| Surgical was preferred, surgical was chosen | -16.501 | 4.127 | -4.00 | **<0.001** | -24.590 | -8.411 |
| Knee function score (KOOS-ps) | 0.073 | 0.047 | 1.55 | 0.122 | -0.019 | 0.166 |
| Patient Activation Measure (PAM) | -0.549 | 0.072 | -7.58 | **<0.001** | -0.691 | -0.407 |
| *Shared Decision-Making Questionnaire* | | | | | | |
| Intervention | -3.776 | 2.262 | -1.67 | 0.095 | -8.211 | 0.659 |
| Level of education patients* | | | | | | |
| Middle | 9.293 | 3.160 | 2.94 | **0.003** | 3.099 | 15.487 |
| High | 2.526 | 2.340 | 1.08 | 0.280 | -2.059 | 7.112 |
| Job function of physician | 4.586 | 2.767 | 1.66 | 0.098 | -0.838 | 10.011 |
| Concordance between preferred and chosen treatment ~ | | | | | | |
| Non-surgical was preferred, sugical was chosen | 16.046 | 8.792 | 1.83 | 0.068 | -1.186 | 33.279 |
| Non-surgical was preferred, non-surgical was chosen | 5.527 | 4.994 | 1.11 | 0.268 | -4.261 | 15.316 |
| Surgical was preferred, surgical was chosen | 11.940 | 4.809 | 2.48 | **0.013** | 2.514 | 21.365 |
| Patient Activation Measure (PAM) | 0.162 | 0.085 | 1.91 | 0.056 | -0.004 | 0.329 |
| *Patient Satisfaction* | | | | | | |
| Intervention | -0.281 | 0.194 | -1.44 | 0.149 | -0.662 | 0.100 |
| Diagnosis | -0.312 | 0.203 | -1.54 | 0.123 | -0.710 | 0.085 |
| Job function of physician | 0.437 | 0.229 | 1.91 | 0.056 | -0.011 | 0.886 |
| Concordance between preferred and chosen treatment ~ | | | | | | |
| Non-surgical was preferred, sugical was chosen | 0.865 | 0.844 | 1.02 | 0.305 | -0.798 | 2.520 |
| Non-surgical was preferred, non-surgical was chosen | -0.054 | 0.477 | -0.11 | 0.909 | -0.991 | 0.881 |
| Surgical was preferred, surgical was chosen | 0.655 | 0.468 | 1.40 | 0.161 | -0.261 | 1.573 |
| Patient Activation Measure (PAM) | 0.012 | 0.007 | 1.62 | 0.105 | -0.003 | 0.027 |

* reference group: low education

~ reference group: surgical treatent preferred, non-surgical was chosen.

Physicians mean knowledge scores were significantly higher after training 12.70 (SD=1.70) versus before training 10.0 (SD=1.87) (95% CI: -2.85 to -0.39). No significant difference was seen in attitude scores (after training 13.47, SD=2.06 compared to before training 14.06, SD=1.88).

### *Use of patient decision aid*

The ptDA was used by 19 out of 110 eligible patients (17%). There were no differences in SDM, decisional conflict or satisfaction between patients who used and patients who did not use the ptDA. Reasons why a ptDA was not used were recorded for 46 of the 110 patients. For 36 patients (78%) physicians indicated that it was clear for the patient what the best treatment option was, they had sufficient information, felt ready to make the decision and did not want to use the tool. Five patients (11%) reported that they did not want to slow down the treatment process by using the ptDA. Five patients (11%) did not have a computer or cell phone required to access the ptDA.



## DISCUSSION AND CONCLUSION

### Discussion

Despite an increase in physician's SDM knowledge after the training, the intervention did not result in improved decisional conflict, patient reported SDM or patient satisfaction. Uptake of the ptDA's was low. Hip an knee osteoarthritis patients reported little decisional conflict, high levels of SDM and high satisfaction rates compared to scores found in literature (38-40).

Several reasons could be proposed for the fact that the intervention had no effect on the primary outcome measures.

First, hip and knee osteoarthritis care is partly done by general practitioners (GP). Generally, GP's can accurately diagnose hip or knee osteoarthritis. Following the stepped care pathway which is implemented, non-operative treatment is discussed and advised first by the GP (41). If this step is taken and complains aggravate, more invasive treatment options will be considered, and patients are referred to a secondary care clinic. So, discussing treatment options and decision-making steps may have already partly taken place with the GP. Patients who are referred to the orthopaedic clinic tend to lean more towards surgical treatment options (42), as is seen in our group, with non-surgical treatment viewed as the least preferred option for these patients. Because of this, an intervention in the setting of secondary care clinic could potentially be less effective. This may also explain why scores on SDM, decisional conflict and satisfaction were highest for patients receiving surgical instead of conservative treatment.

Second, uptake of the ptDA by patients was low. Often patients expressed a strong preference for surgery, they felt it was the only right option for them and they did not want the ptDA in addition to the conversation with the physician. In previous research orthopaedic physicians mentioned that the lack of good conservative treatment options for moderate to severe osteoarthritis was a barrier for conservative treatment selection (43). This makes surgery the default option in these situations and alternatives seem not

suited as definitive treatment according to physicians. This reasoning poses a barrier for physicians to use a ptDA.

Third, the SDM measures we used might not be sensitive enough to detect differences in SDM because of a ceiling effect. Generally, patients were very satisfied and scored high on reported SDM with little room for improvement. There was a strong positive correlation between patient reported SDM and patient satisfaction, and these satisfied patients might have given more (socially desired) positive answers in the SDM questionnaire. In literature patient reported SDM poorly correlates with the OPTION scale, a measure that scores observed SDM and which is seen as a more objective measure for SDM, and the association of patient reported SDM (SDM-Q-9) with patient satisfaction is frequently seen (32,44,45).

Previous work on ptDA's used in primary care setting suggests that patients' health history is better known to GP's and they are often better able to align treatment choices with personal values of their patients (46-48). On the other hand, specialist working in hospitals are better informed about relevant treatment options and outcome of therapy. In oncology care, patients valued the involvement of their GP in treatment decisions greatly (49) and efforts are made to include the GP in decision-making (50). Initiatives to connect primary and secondary care could optimise decision-making for patients with hip and knee osteoarthritis. Recently, initiatives are employed to implement specialised orthopaedic care in primary care setting (51). In doing so, orthopaedic decision-making could benefit from the patient-oriented GP setting and the specialized knowledge of the orthopaedic caregiver. Also, ptDA's could be implemented in GP care setting since care partly takes place in this line of care.

Previous literature indicates that residents in training show less positive attitudes toward SDM compared to more senior physicians (17,52). A survey study in the Netherlands showed that residents expressed a stronger preference for a paternalistic role compared to specialists (53), and preference for SDM roles seem to be related to clinical years of experience (54). In our study both patient reported SDM and patient satisfaction were lower in the resident group. Interventions should therefore include residents and incorporate their attitudes and misconceptions about SDM and perceived barriers to its implementation. Yet it is not evident what type of intervention would work best for this group.

Previous research mainly investigated the effect of stand-alone ptDA's in the care of hip and/or knee osteoarthritis. For SDM interventions it is advised to focus on both patient and physician (7), and to the best of our knowledge, this is the first study in literature that studied such combined intervention in orthopaedic care. Another strength of our intervention, is that we used a theoretical framework, the theory of planned behaviour, to develop our training as is advised in literature (14). In line with

this theory, SDM behaviour of physicians in orthopaedics was studied first (17) and we used this information in the intervention development.

The study we conducted has several limitations. One of the limitations of our study is the non-randomised design (a pre- post intervention study). The design we used prevents contamination between the different groups (16,55). Because of this design, confounding factors could have changed over time during the study period, although no changes in hip and knee osteoarthritis care were observed. Second, it must be mentioned that patients reported their preferred treatment after the medical decision was made. So reported pre-clinical preferred treatment could have been influenced by conversation with the physician and final treatment decision. Third, in our sample size calculation we didn't take into account the multilevel analyses we performed. Because of this the study might be underpowered. But since intraclass-correlation scores were low (below 0.05) the variance in the scores is probably not explained at group level (physicians) making multilevel analyses less relevant (56).



## Conclusion

Although physicians showed to have more knowledge about SDM after the training, this elaborate multi-faceted intervention programme did not have any effect on the SDM outcomes we measured. Patient decision aid uptake was remarkably low and patients felt it was not necessary in the decision-making process. They had a strong desire for surgery and outcomes were most beneficial if this treatment was chosen eventually. Furthermore, it must be noted that patients reported lower scores on SDM and satisfaction if they consulted a resident instead of a more experienced orthopaedic surgeon.

## Practice implications

In order to improve uptake of a ptDA in clinical setting, future research should investigate why only a few patients valued the ptDA, and why so many considered surgery the only real option. Furthermore, collaborations with first line caregivers such as GPs should be explored in the care of hip and knee osteoarthritis. Special efforts should go towards training residents since they perform less well on SDM and seem to have less positive attitudes towards it.

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6

# Implementation of a decision aid for hip and knee osteoarthritis in orthopaedics – a mixed methods process evaluation

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## ABSTRACT

**Background:** In orthopaedics, use of patient decision aids (ptDAs) is limited. With a mixed method process evaluation we investigated patient factors associated with accepting versus declining the use of the ptDA, patients' reasons for declining the ptDA and clinicians' perceived barriers and facilitators for its use.

**Methods:** Patients with an indication for joint replacement surgery (n=153) completed questionnaires measuring demographics, physical functioning, quality of life (EQ-5D-3L) and a VAS pain score at one time point. Subsequently, their clinician offered them the relevant ptDA. Using a retrospective design, we compared patients who used the ptDA (59%) with patients who declined (41%) on all these measures as well as the chosen treatment. If use of the ptDA was declined, patients' reasons were recorded by their clinician and analysed (n=46). To evaluate the experiences of clinicians (n=5), semi-structured interviews were conducted and thematically analysed. Also clinicians who didn't used the ptDA substantially (less than 10 time) were interviewed (n=3).

**Results:** Compared with patients who used the ptDA, patients who declined the use had higher VAS pain scores (7.2 vs 6.2, $p<0.001$), reported significant worse quality of life (on 4/6 EQ-5D-3L subscales), and were less likely to receive non-surgical treatment (4% vs 28%, $p<0.001$). Of the patients who declined to use the ptDA, 46% said they had enough information and felt ready to make a decision without the ptDA. The interviews revealed that clinicians considered the ptDAs most useful for newly diagnosed patients who had not received previous treatment.

**Conclusion:** These results suggest that the uptake of a ptDA may be improved if it is introduced in the early disease stages of hip and knee osteoarthritis.

# BACKGROUND

Shared decision-making (SDM) is a collaborative process in which a clinician works together with a patient to reach a decision about care (1). A patient decision aid (ptDA) is complementary to the consultation and supports SDM. In short, these tools aim to inform patients about treatment options and encourage them to consider which treatment option is most appropriate for them. Extensive evidence supports the benefits of these tools (2,3). A recent review study of randomized controlled trials that evaluated ptDAs for patients considering elective surgery, including hip and knee arthroplasty surgery, showed that these tools reduced decisional conflict, increased knowledge of disease and treatment, improved decision-making preparedness, and enhanced decision quality (4). Although governments explicitly recommend the use of SDM in healthcare, successful implementation of SDM, including ptDA's, remains challenging (5-7). In orthopaedics, implementation studies are sparse and, although orthopaedic surgeons have positive attitudes towards SDM (8), actual implementation of ptDAs in clinical care is limited (9). A cross-sectional survey study of patients undergoing total hip or knee arthroplasty, found that less than half of patients reported that non-surgical options or the risks of surgery during were discussed during the decision-making process (10). Another study that used observational measures to score informed decision-making, reported comparable deficits, with discussion of pros and cons and elicitation of patient preferences occurring less than half the time during orthopaedic consultations (11). Little is known on ptDA uptake in orthopaedic clinical care. Stacey and colleagues conducted a survey study, to determine the subsequent use of PtDAs in daily practice following published randomised controlled trials in a variety of clinical settings. They found that only 44% of PtDA study authors reported some level of use in everyday clinical practice after their study (12).

A review of patient barriers to SDM identified lack of patients' knowledge and a power imbalance in the doctor–patient relationship as key issues (13). In this context, the term 'power' pertains to patients' perceived level of influence in the decision-making process, including patients' self-efficacy in decision-making and confidence in their knowledge and ability to make a decision. Patient information, for example from ptDA's and pamphlets, are helpful in providing facts about diseases and treatment options, thereby increasing patient knowledge. However, if the power imbalance is not addressed, it has the potential to become a barrier to SDM (13). Training clinicians in SDM skills is likely to empower patients and to encourage them to participate in the decision-making process and the care process as a whole (14).

A recognized physician barrier to SDM is lack of time (15). A Cochrane review found that consultations took 2.6 minutes longer when a ptDA was used (2). Other barriers to implementation include lack of applicability due to patient characteristics or the clinical

situation (16). Consequently, clinicians often neglect SDM in actual clinical practice, because they feel that the situation is not appropriate.

Recommendations to improve uptake were made in a recent rapid review study on the effectiveness of strategies for ptDA implementation in routine clinical settings (17). These recommendations included co-production between the ptDA developer and end users (e.g., clinician, patient and carers), taking account of local needs, training the whole team, preparing patients to engage in SDM, and creating ownership of ptDA implementation by senior staff.

In a previously published article, we described the implementation of a programme to improve SDM in orthopaedic care and reported that only 17% of the participating patients with hip and knee osteoarthritis used the ptDA that was routinely offered as part of the programme.[18] This programme included a comprehensive training in SDM and ptDAs use, and most of the recommended measures for successful implementation of PtDAs (17) were adopted. These findings raise the question of why ptDA uptake had been so low. In the current study, we aim to explore why the use of ptDA was limited. The work could contribute to the existing literature on barriers to ptDA use, by providing a practical example of the obstacles faced when implementation is done in a specific clinical setting, namely the orthopaedic care for hip and knee osteoarthritis patients. We investigated clinicians' perceived barriers and facilitators to ptDA use, patients' reasons for declining the ptDA, and patient factors associated with ptDA use and decline.

## METHOD

### Design

This study is a process evaluation following the multifaceted SDM intervention described previously (18). Consecutive hip and knee osteoarthritis patients who met the inclusion criterion were offered the use of a ptDA and were asked to participate in the study. The treating clinicians determined whether patients met the inclusion criteria. A mixed method study was employed to evaluate implementation of the ptDAs. Using a retrospective design, we compared the demographics and clinical outcome of patients who used the ptDA with a group of patients who declined. If use of the ptDA was declined, patients' reasons were recorded by their clinician. To evaluate the experiences of clinicians, semi-structured interviews were conducted.

### Population

#### *Patients*

Inclusion criteria for the study were in line with the criteria for ptDA use. Eligible patients were adults, who had been newly referred with hip or knee osteoarthritis, for whom a

surgical intervention (joint replacement surgery) was an appropriate option as judged by their orthopaedic clinician. Between August 2019 and March 2020, orthopaedic clinicians offered the ptDA to all adult patients who met these criteria. We provided paper forms for the surgeons to indicate which patients were given the ptDA and which were not, and for what reason. Medical ethical approval was obtained from the regional Medical Ethnical Board (METC Z, nr 16-N-195).

***Clinicians***

As part of the SDM intervention (18), 19 clinicians from a large Dutch training hospital received training in SDM and ptDA use. This group consisted of 8 orthopaedic surgeons, 8 residents in training and 3 physician assistants. Of this group, 12 clinicians were involved in hip and/or knee osteoarthritis care. Clinicians who used the ptDA substantially (more than 10 times) were interviewed to evaluate the ptDAs used (see figure 1). Additional brief interviews were undertaken with three clinicians who did not use the ptDAs substantially (less than 10 times), in order to understand why they did not use the tool. The invitations to be interviewed were sent by email.



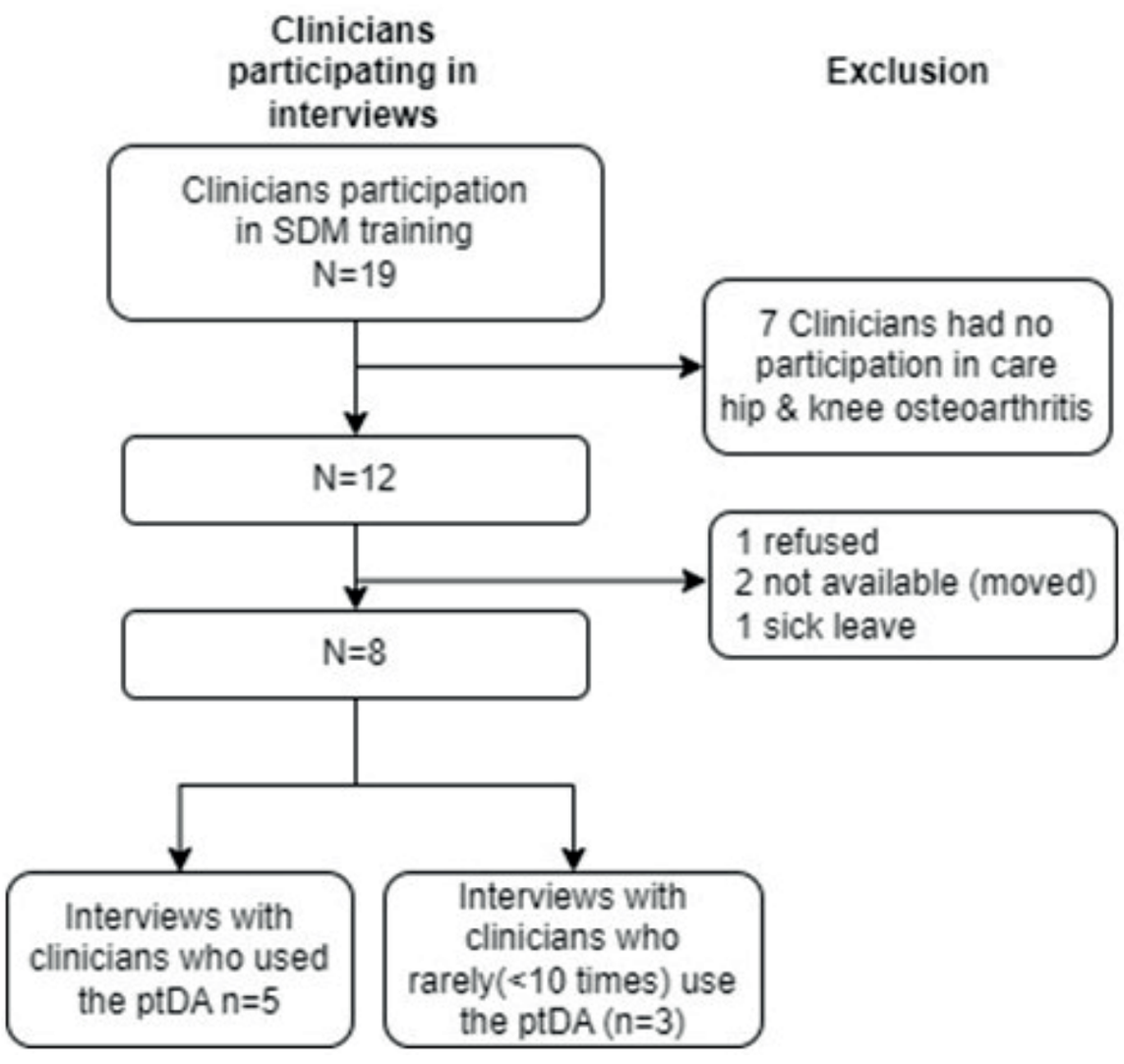


**Figure 6.1**: Flowchart of participating clinicians in interviews

## The patient decision aids

The hip and knee ptDAs were designed in accordance with International Decision Aids Standards (IPDAS criteria) (19). The web-based ptDAs contained five different elements: information, comparison of treatment options, summary of important points, patient preferences, and questions to verify patient knowledge. The information in the ptDA was provided in colloquial language. The Easy Reading Foundation (in Dutch: *Stichting*

*Makkelijk Lezen*) assessed the text used in the ptDAs and provided a certificate confirming that the text was easy for lay people to understand (20). The implemented ptDAs are described in detail in previous literature (21).

### *Implementation strategy*

The implementation of the ptDA was tailored to the specific needs and context of the orthopaedic clinic as described in the parent study (18). Prior to implementation, all clinicians and outpatient clinic staff were trained. The training consisted of a one-hour e-learning session and a face-to-face training. The training was divided into two sessions of two hours each, and was led by two trainers with experience in SDM: one general physician who is an SDM expert and one resident in orthopaedic surgery. To enhance practical skills, clinicians were trained in SDM communication and ptDA use through role-play exercises. A senior orthopaedic surgeon (and head of the residency programme) championed the implementation of the ptDAs.

Patients who met the inclusion criteria and who gave informed consent to participate in the study were invited to use the ptDA. This was done at the first visit before the decision was made. Patients who were willing to use the ptDA were provided a personal access code and an information leaflet so that they could go through the web-based ptDA at home. After two weeks, a telephone consultation with a clinician took place to review the ptDA and to make a treatment decision.

## Data collection and analyses

Comparison of clinical outcome measures of decision aid users and non-users

Prior to the first consult, patients completed the following questionnaires: the Western Ontario and McMaster Osteoarthritis Index (WOMAC), the Oxford Knee Score and Oxford Hip score, Pain Visual Analogue Score, and the EQ-5D-3L (see table 1). In the participating hospitals, the EQ-5D-3L was routinely used as a patient reported outcome measure (PROM). Therefore, we choose to use this questionnaire, instead of the EQ-5D-5L, in order to increase feasibility and reduce the administrative burden on the participating patients. The questionnaires were completed at one time point.

For the analysis of this quantitative data we used independent samples t-test and chi-square tests to analyse this normally distributed dataset. Since the cell count was low for the categorical variable non-operative treatment in the ptDA decliner group, we also used Fisher's Exact Test to assess the association with the categorical variable intervention (ptDA use or ptDA decline). Stata software was used for the statistical analyses (StataCorp, v14).

**Table 1. Patient reported outcome measures**

| *Measure* | Items | Summary score | High score means |
|---|---|---|---|
| Western Ontario and McMaster Osteoarthritis Index (WOMAC) (22) | 24 items. Likert scale: 0 (none) – 4 (very much). | Total score. Scores were converted to 0-100 scale. | Better physical functioning with less stiffness and pain. |
| The Oxford Knee Score and Oxford Hip score (23,24) | 12 items. Likert scale: 1 (not at all) – 5 (very much). | Total score with a range from 12 to 60. | More pain and physical impairment. |
| Pain Visual Analogue Score (VAS) | 1 item. Visual analogue scale 0 to 10. | Score from 0 to 10. | More pain. |
| EuroQol 5D (EQ-5D-3L) (25) | 5 multiple choice questions. One VAS question about perceived health status. | The 5 multiple choice items are scored on a 1-3 scale. The VAS question for health status has scores ranging from 0 to 100. | For the multiple choice questions, it indicates worse health quality of life. For the VAS question, higher scores indicate better perceived health status. |



### *Reasons why patients declined to use the ptDA*

Clinicians were asked to record which patient accepted and which declined ptDA use, on a paper based form. When patients declined to use the ptDA, clinicians briefly noted the patient-reported reasons but did not conduct in-depth interviews to explore underlying thoughts or beliefs.

For the analysis, these handwritten reports were digitised and evaluated using content analysis. Three members of the research team read the reports and through discussion identified four categories of reasons for declining (as described in the Results section). Two authors then assigned each of the reported reasons to one of the four categories. Because the detail in the stated reasons was limited and there were only four categories, this was a straightforward process and the two coders were in full agreement.

### *Interviews with clinicians*

The junior researcher who conducted the interviews with the clinicians was a medical student (author initials JW). Although she had some experience in SDM research, she was unfamiliar with qualitative interviewing for research purposes and was therefore trained and supervised by an experienced senior researcher (author initials JJ). To ensure her independence, JW confirmed that she had never met any of the clinicians prior to the interview. Further, she declared that she held no preconceived notions about, or prejudices towards, the way in which the clinicians handled the SDM process with patients. The interviews were semi-structured and we used a brief topic guide that was developed by the whole research team. The online or telephone interviews explored clinicians' experiences with ptDA implementation and perceived barriers and facilitators for its use. The interviews ranged between 15 and 25 minutes during which only the interviewed clinicians and the researcher were present. Notes were taken during the

interviews and audio recordings were made and transcribed afterwards. No interviews were repeated, and the transcripts were not returned to the interviewed clinician for comment or correction. Moreover, the participating clinicians did not provide feedback on the findings.

At a later phase, separate interviews were done with three other clinicians who did not use the ptDA substantially, in order to find out why they did not use the tool. These brief interviews were done by telephone and have been analysed separately. A summary of each interview is provided in the results section.

To analyse the interviews, transcripts and notes were studied using framework analysis.(26) The analysis was undertaken primarily by three of the four authors of the study: JW, JB and JJ, who hold the credentials of B.Sc., MD and PhD, respectively. Author JW started by reviewing the interviews and developing a list of themes and topics using an inductive perspective. Those themes, along with the interview schedule (deductive approach), formed the basis of the coding framework. Two additional authors (JJ and JB) reviewed the coding framework, and changes were discussed and made accordingly. Once the coding framework was agreed, author JW coded all interviews. Author JJ double-coded a sub-set of interviews. Coding similarities and differences between authors were discussed and changes were made to the themes when deemed necessary. Data saturation was assessed by the whole team, and after five interviews, we had a clear picture of the clinicians' experiences of ptDA use. The COREQ checklist, a criteria list for reporting qualitative research (27), was used for reporting the analysis of the interviews (see supplement 2).

## RESULTS

### Comparison of clinical outcome measures of decision aid users and non-users

In total, a group of 153 patients met the inclusion criteria and were invited to use a ptDA. Of this group, 91 patients used the ptDA and 62 patients declined. The mean age was 70 years and 60% (n= 92) was female; 54% (n=82) was diagnosed with hip osteoarthritis and 46% (n=69) with knee osteoarthritis. These characteristics did not differ significantly between the ptDA users and non-users. Patients who used a ptDA chose a conservative treatment in 28% (n=25) of the cases, compared to 4% (n=2) of the non-users ($p<0.001$). PtDA users had a VAS pain score of 6.2 compared to a score of 7.2 for the non-users ($p<0.001$). Quality of life was significantly worse in the group who declined the ptDA, on 4 of the 6 EQ-5D subscales, with worse scores for self-care (1.48 vs 1.26; p=0.008), usual activities (2.02 vs 1.77; p=0.004), pain and discomfort (2.39 vs 2.18; p=0.042), and health status (49.31 vs 60.79; $p<0.001$). The disability related to hip osteoarthritis (WOMAC and Oxford questionnaires) did not differ between the two groups (see table 2).

**Table 2. Characteristics for ptDA users and ptDA decliners**

| | | Decision aid | | Standard care | | *p-value* |
|---|---|---|---|---|---|---|
| | | n | % | n | % | |
| Gender | | | | | | |
| | Female | 53 | 42 | 39 | 63 | 0.25 |
| | Male | 38 | 58 | 23 | 37 | |
| Diagnosis | | | | | | |
| | Hip osteoarthritis | 47 | 52 | 35 | 58 | 0.19 |
| | Knee osteoarthritis | 44 | 48 | 25 | 42 | |
| Treatment | | | | | | |
| | Operative | 65 | 72 | 52 | 96 | <0.001 |
| | Non-operative | 25 | 28 | 2 | 4 | |
| | | mean | SD | mean | SD | *p-value* |
| Age | | 69.15 | 12.50 | 71.28 | 8.92 | 0.22 |
| VAS | | 6.19 | 1.96 | 7.22 | 1.27 | <0.001 |
| Oxford score | | 36.72 | 8.83 | 35.86 | 9.21 | 0.57 |
| WOMAC score | | 48.17 | 23.29 | 48.06 | 23.8 | 0.25 |
| EQ-5D-3L | | | | | | |
| | Mobility | 1.93 | 0.25 | 1.98 | 0.29 | 0.27 |
| | Self-care | 1.26 | 0.46 | 1.48 | 0.54 | 0.008 |
| | Usual activities | 1.77 | 0.49 | 2.02 | 0.47 | 0.004 |
| | Pain/Discomfort | 2.18 | 0.63 | 2.39 | 0.62 | 0.042 |
| | Anxiety/Depression | 1.24 | 0.48 | 1.41 | 0.56 | 0.78 |
| | Health Status | 60.79 | 16.81 | 49.31 | 16.24 | <0.001 |

## Reasons why patients declined to use the ptDA

Of the 62 ptDA non-users, 46 patients (39%) reported why they declined to use the tool. The main reason for declining the ptDA was that they felt they did not need it because they were sufficiently informed about their disease and the treatment options (46%, 21/46). For example, these patients had already received extensive information from their general practitioner (GP), or had undergone hip or knee replacement surgery previously. In addition, patients (33%, 15/46) indicated that they had no desire for information regardless of their existing level of knowledge about the disease and treatment options. Another reason given was that the use of a ptDA required an extra consult and the patients did not want to delay the treatment process (11%, 5/46). Finally, some patients (11%, 5/46) were not able to use the digital ptDA due to insufficient digital skills (digital illiteracy) or because they did not have a smartphone or computer (see figure 2).

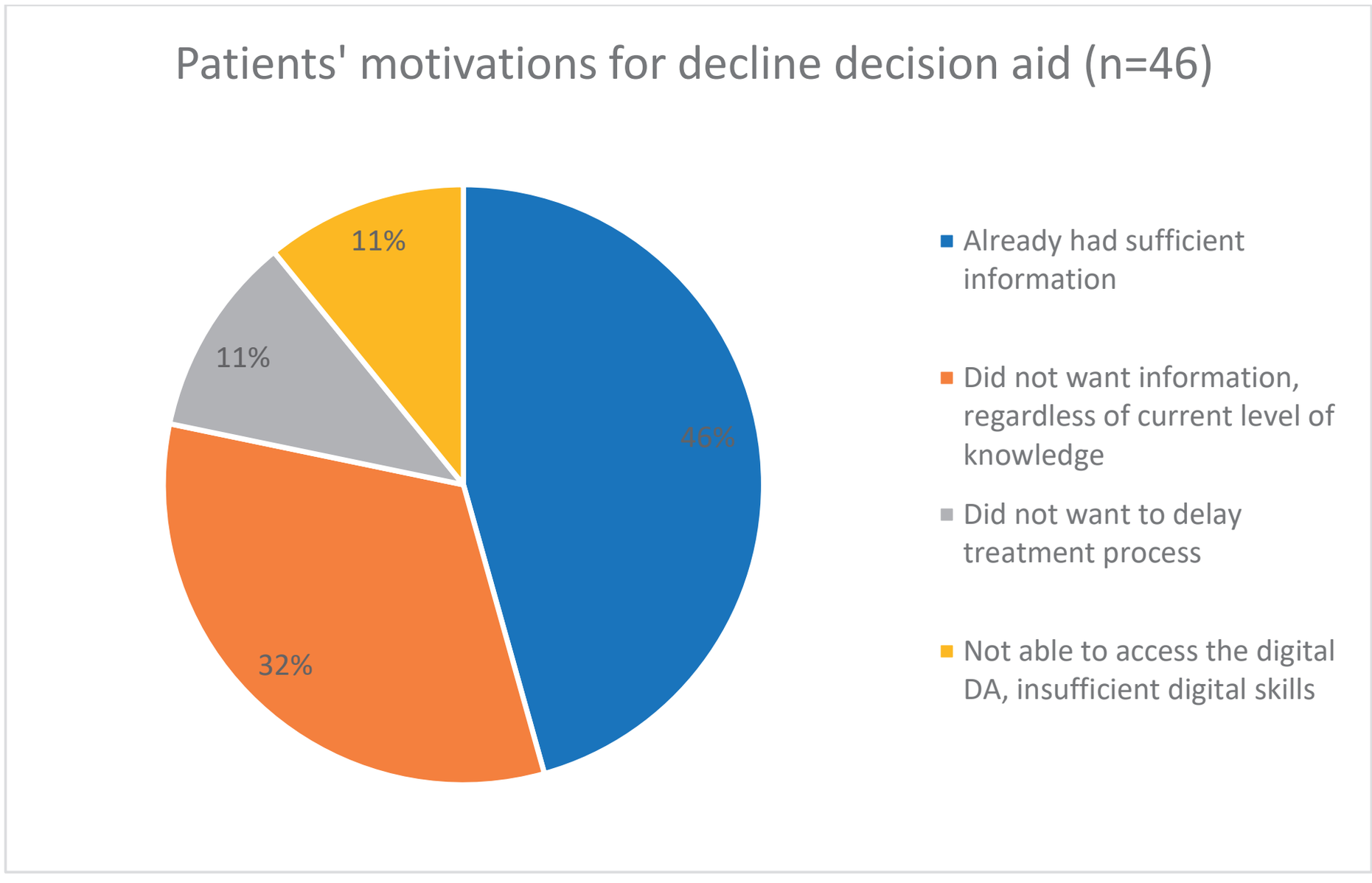


**Figure 6.2***:* Pie chart on patients' motivation for declining the decision aid.

## Interviews with clinicians

Nine clinicians reported substantial use of the ptDA (at least 10 times). Three clinicians rarely used the ptDA and a summary of their reasons for non-use is given at the end of this paragraph. Of the nine clinicians who used the ptDAs, two clinicians were not available for the interviews because they worked in other hospitals at the time of the interviews. One clinician was unavailable because of sick leave. One refused to be interviewed, due to time constraints. We interviewed five clinicians to evaluate the ptDAs that were implemented: three orthopaedic surgeons, one orthopaedic resident and a physician assistant. The clinicians who were interviewed had a mean age of 46 years (range 38 to 63 years) and mean clinical experience of 21 years (range 12 to 39 years). All interviewed clinicians were male. Data saturation was reached after five interviews with no new themes emerging. The central themes derived from the interviews were *Benefits of ptDA use, Barriers to ptDA use,* and *Timing of the ptDA in the care process* (see supplement 1 for quotes supporting the major themes and minor themes).

### *Benefits of patient decision aid use*

*Information provision*

Four out of five clinicians indicated that the ptDA was a helpful addition to the conversation. The clinicians noticed that patients were better informed and had more specific questions after going over the ptDA.

*The ptDA was found most useful for a subgroup of patients*

Most clinicians (4 out of 5) observed that the usefulness of the ptDA depended on what stage of care the individual patient was in. It was found to be particularly useful for recently diagnosed patients, who were overwhelmed by the diagnosis, as it provided often new information about the pros and cons of different treatment options. Another group of patients who were perceived to especially benefit from the ptDA were those who were unsure about which treatment was best for them. According to the clinicians, these patients valued the ptDA because it allowed them to take the time they needed to absorb all the information and consider different treatment options.

One of the clinicians mentioned that he found the ptDA useful for patients who had not deliberated on different treatment options well enough. The clinician felt that these patients needed information and time to consider different treatment options, as they were not yet ready to make an informed decision. The ptDA encouraged these patients to consider the different treatment options and to avoid making a hasty or uninformed decision.



*Helpful in time constrained clinic*

One clinician stated that the tool was helpful in a time deficient clinic. The provision of information is one of the tasks a clinician. As the ptDA provides information, this clinician perceived the tool as supporting the consultation process and thus reducing his workload.

***Barriers to the use of patient decision aids***

The majority of clinicians (4 out of 5) pointed out that the tool was often considered to be superfluous by a particular group of patients. Clinicians described this group of patients as those who were already fully aware of the diagnosis and had been treated by their GP or by a physiotherapist. They often came to the hospital with a clear request for surgery, and felt sufficiently informed about different treatment options. There is a significant number of patients with this background in the orthopaedic clinic. Clinicians observed that when the ptDA was offered to these patients, they did not think it was necessary, and the patients often declined to use it.

*Delays to care process*

Patients often expressed concern that the ptDA would delay the care process. This is because the decision to use a ptDA requires a second meeting to be scheduled for final decision-making, after the patients had been given the opportunity to complete the ptDA at home. Patients often felt ready to make a treatment decision at their initial meeting and therefore declined to use the tool in order to avoid treatment delay.

*Concerns about the concept of patient decision aid*

One surgeon pointed out that making the ptDA mandatory could result in less interaction between the orthopaedic surgeon and the patient. He was concerned that the ptDA might reduce the need for doctor–patient communication and thus replace the consultation.

*Digital literacy*

Although clinicians reported that most patients were able to use the web-based online ptDA, three out of five clinicians remarked that some patients had no smartphone, computer, or the skills needed to access the web-based tool.

***Timing of patient decision aid use in care process***

*Requisites for patient decision aid use*

Most of the clinicians pointed to the importance of having a confirmed diagnosis before using a ptDA. Therefore, implementation of this the tool in primary care was not found appropriate, as orthopaedic expertise and diagnostics were perceived to be lacking in that setting. Another consideration expressed was that the ptDA was found to be only suitable for patients eligible for a surgical treatment, because it contained information about surgical treatment options. The clinicians were concerned that patients who had no indication for surgery might mistakenly be led by the ptDA to believe that surgery was an option for them. They proposed that patients should be eligible for surgery as a condition of receiving the ptDA.

*Early care process*

The clinicians commented that uptake of the ptDA might be improved if it was used at an early stage of the disease when all treatments are optional. Following on with that idea, one clinician mentioned that implementation in primary care might improve uptake of the ptDA, conflicting to the views of other clinicians who considered implementation in primary care inappropriate (see above).

***Summary of interviews with clinicians who used the ptDAs***

All in all, most clinicians were positive about the use of the ptDA and found it to be a helpful addition to the conversation with patients. The ptDA was perceived to be especially useful for newly diagnosed patients and for patients who were uncertain about the right treatment. For these patients, the ptDA was considered an excellent tool, as it gave them time to consider treatment options at home. However, the clinicians pointed out that the ptDA was not suitable for all patients. As an example, they cited patients with more advanced osteoarthritis, who commonly have a clear preference for surgery. These patients found the ptDA to be unnecessary and the cause of needless delay. Digital illiteracy was considered a barrier for a small group of patients. Regarding

the timing of the ptDA dissemination, the clinicians were in agreement that it is preferable to distribute it at an early stage of the disease, but only after a diagnosis had been established.

### *Interviews with clinicians who didn't use the ptDAs substantially*

We had brief additional interviews with clinicians (n=3) who did not use the ptDA substantially, in order to understand their reasonings. Two of them were male and one clinician was a female. Age ranged between 45 and 63 years of age. The first clinician expressed a desire to be in control of the whole decision-making process. That clinician was concerned that patients who used a ptDA outside of the clinician's office, would be less likely to choose a treatment that coincided with the clinician's studied opinion. The second clinician reported that use of the ptDA was not feasible because of time constraints. The third clinician thought that the decision-making process was too complex for a ptDA to be of assistance. That clinician pointed out that the conversation with the patient is the single most important modality in the decision-making process. Time constraints along with a dislike of administration and new tasks also played a role in not using the ptDA.



## DISCUSSION

This research study is a follow-up study to a published paper in which we tested and implemented a programme to improve the use of SDM in the orthopaedic care setting (18). In that article, we reported that only 17% of the patients with hip and knee osteoarthritis used a ptDA.[18] In the current study, we used qualitative and quantitative analyses to assess perceived barriers and facilitators for the implementation of ptDAs in hip and knee osteoarthritis.

We found that patients who used the tool were more likely to choose conservative treatment over surgery. This ptDA group reported less pain and a better quality of life. Patients who declined the use of a ptDA reported having sufficient information to make a decision and had frequently received prior, conservative treatment. Patients with more severe complaints were more likely to want surgery for their hip or knee complaint and less often felt the need for a ptDA. These patients commonly perceived surgery as the only suitable treatment option and therefore considered a ptDA to be superfluous. Other studies pointed out that surgery is often seen as the default treatment for severe osteoarthritis (28) and this is a barrier to the use of ptDAs. Similarly, surgeons have confidence in their surgical treatment and generally consider joint replacement as the only solution for advanced hip or knee osteoarthritis (29). Although hip joint replacement surgery is especially successful in terms of patient satisfaction (30), the

dissatisfaction rate after total knee arthroplasty still ranges between 15% and 25% (31). A ptDA stimulates patients to consider all treatment options instead of just focusing on the surgical solution. Consequently, the tool has the potential to produce more realistic expectations (32).

The interviews revealed that clinicians generally found the ptDA to be useful. It provides additional information to patients and, in their experience, patients asked more specific questions after completing it. The tool was found to be most helpful for recently diagnosed patients who had little knowledge of the diagnosis and treatment options. The ptDA was least helpful for patients who felt well-informed enough to make a decision at the first consultation. The interviews revealed that patients who declined the tool had often been treated conservatively and had previously discussed treatment options with their GP or physiotherapist. Although these patients often believed themselves to be sufficiently informed to make a treatment decision, we know from previous research that patients often are unaware of their misconceptions, and their treatment preferences may be based on limited knowledge (33). In a study about Parkinson's disease, most patients thought they were well-informed, but only 41% was aware of the different treatment options (34). We know that patients who are better informed make different treatment choices (14). Therefore, clinicians should not assume that their patients have adequate knowledge of disease and treatment options. They should strive to verify this to ensure that patients do indeed make informed decisions.

When considering ways to improve the uptake of the ptDA, it seems logical to implement the ptDA in the early stages of hip or knee osteoarthritis. The primary care setting would appear to be opportune for introduction of the ptDA, as newly diagnosed patients who have not exhausted all treatment options tend to be more inclined to use the tool. However, when asked about alternative implementation approaches, the interviewed clinicians did not believe it was appropriate for GPs to discuss the ptDA with their patients. The clinicians felt that a diagnosis needed to be made first, before considering treatment options, and in their view, a confirmed diagnosis can only be made by an orthopaedic clinician. In addition, they did not think it was right for the GP to discuss the options for surgical treatment in detail when going through the PtDA. These beliefs need to be addressed in order to improve ptDA use in orthopaedic care. Recently, initiatives have been taken to implement specialised orthopaedic care in the primary care setting in order to reduce referral rates from primary care to the orthopaedic clinic in the hospital (35). This arrangement allows orthopaedic clinicians to make a diagnosis in the primary care setting. This may address the concerns of the clinicians and with that the disease-specific ptDA can be distributed to patients at an early phase of hip or knee osteoarthritis care. This scenario could have a positive effect on the uptake of ptDAs.

## Limitations

Patients who were eligible to use the ptDA were invited to participate in the study. A decline to use the ptDA was also recorded. Although the clinicians confirmed that they had invited all eligible patients for ptDA use, we did not collect data on this. it is possible that some eligible patients were overlooked due to the nature of clinical practice. For example, patients with very severe complaints of advanced osteoarthritis may have been scheduled directly for surgery at short notice, without considering a ptDA. However, the number of such incidents is estimate to be small, as consecutive patients were invited to use the ptDA and the burden on patients was low as the questionnaires obtained were part of the hospital's PROM's set. Patients' reasons for declining the ptDA were collected and written down on special forms by the clinicians. This could have introduced bias and elicited socially desired responses from patients. On the other hand, this information was important for clinicians, as it enabled them to check if the patient had correctly understood the options and the aim of the PtDA. The clinicians limited themselves to simply noting the reason for declining the ptDA; they did not conduct in-depth interviews with the patients to explore underlying thoughts or beliefs. Another limitation of our study is the relatively small sample size for the interviews obtained. However, we interviewed the majority of the clinicians who were involved in the care of hip and knee osteoarthritis and participated in the SDM programme (8 out of 12 clinicians). We believe that saturation had been reached after the interviews and were able to derive a central and shared message from these interviews. In addition, our findings from the interviews were supported by reasons given by patients for declining the ptDA and by the data from the questionnaires.



## Conclusion

Findings suggest that the ptDA is most suitable for patients with a recent diagnosis and less advanced disease and symptoms. Implementation of the tool earlier in the illness trajectory might be more appropriate, provided that the patients have a confirmed diagnosis. More research is needed to determine the optimal setting, timing, and target population for the ptDA for hip and knee osteoarthritis. Our study highlights the importance of considering context including patient characteristics when implementing ptDAs.

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# SUPPLEMENTS

## Supplement 1: Quotes of clinicians during interviews.

| **Benefits of patient decision aid use** |
|---|
| Information provision<br>*"In the beginning, when it was just implemented, I pushed a bit, but then some people thought it was provided to dissuade them from surgery. But in general patients were positive about the decision aid and found it added value. Patients had more specific questions after going through the decision aid and they seemed to be better informed. ' ID 2 orthopedic resident*<br><br>For certain groups of patients who need more information<br>*"I think the decision aid is useful for people who didn't know what the diagnosis implied and how severe their hip condition is. Sometimes a patient is overwhelmed by the new diagnosis of severe joint osteoarthritis and the possibility of hip or knee arthroplasty surgery. These patients need time to think things through and decision aids are particularly valuable for them." ID 2 orthopedic resident*<br><br>*"The tool is very useful for the patients who are in doubt, who have not yet undergone therapy and who, despite severe osteoarthritis, are uncertain about next steps." ID 3 orthopedic surgeon*<br><br>Helpful in a time constrained clinic<br>*"A consultation takes a maximum of fifteen minutes, including the patient arrival, history, physical examination, assessment of the x-ray, and then we have to explain all treatment options.... Yes, then a decision aid is useful, a real added value, I think, because of the time pressure." ID 1 orthopedic surgeon* |
| **Barrier to patient decision aid use** |
| Decision aid is often felt unnecessary<br>*"Yesterday I had a patient in the outpatient clinic who said: "I've been in pain for a year, I know my hip is worn out, I've had physiotherapy and painkillers but they don't work, so I'm coming here for a new hip." I can oblige him to go over the decision aid, but then he calls me back an hour later to say he still wants surgery as treatment. There are also patients who had a knee or hip prosthesis before, (…) they are also sure of what they want. For these patients the tool seems less appropriate and they decline to use it." ID 4 physician assistant*<br><br>*"On the other hand, you have patients who have been treated by their GP for years for diagnosed hip osteoarthritis and they come to the specialist and say: "I can't walk anymore, I have too much pain, can I have surgery?" Those people have already made their choice with the help of their GP or physiotherapist. There must be a very good reason for us not to do it. These patients are often well-informed and a decision aid is felt to be unnecessary. ID 2 orthopedic resident*<br><br>*"It is not uncommon for patients to decline to use the tool, they say it's clear and they've made up their mind. These patients know what they want and they want to be on the surgery list (…)". ID 1 orthopedic surgeon*<br><br>*"I don't want it to be compulsory (…) There are many people for whom it is really clear, for example, for patients who have had joint replacement surgery before on the other side and now have the same symptoms with severe osteoarthritis on the x-ray. These patients already know what they want, they have experience, and they know what surgical treatment entails. I think these people should not be forced to use such tool." ID 1 orthopedic surgeon*<br><br>Delays to care process<br>*" (…) Many people think that it (the ptDA) delays the whole process and that they have to wait even longer because of it." ID 5 orthopedic surgeon* |

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| Concerns about the concept of patient decision aid<br>*"I can see it being good for providing information, but sometimes it is interpreted as a substitute for talking with the clinician. I think that people are looking for a good conversation with the doctor. To use tools that select patients with an automated process for surgery is wrong. I think that, by definition this is not the purpose of these tools. The surgeon must remain in control…." ID 3 orthopedic surgeon*<br><br>Digital literacy<br>*"And there is a small group for whom it's technically difficult. They don't have a computer, they don't know how it works, they think it's all a hassle." ID 5 orthopedic surgeon* |
| **Timing of the patient decision aid in the care process** |
| Requisite for patient decision aid use<br>*"I think above all, it is important that the orthopedic surgeon makes a confirmed diagnosis and then determines if the patient is a candidate for surgery. A firm diagnosis is a prerequisite for decision aid use. " ID 4 physician assistant*<br><br>*"So I do think you have to get a diagnosis first. Then treatment possibilities are discussed with the clinician. Patients also need to be able to choose between different treatment options, such as joint replacement and joint infiltration as a therapy. Only then can the patient go through a decision aid." ID 1 orthopedic surgeon*<br><br>Implementation in an early phase of care<br>*"What I'm saying is that you should use the tool early in the process, preferably in primary care. You need a correct diagnosis but if you implement it early, people can be well-informed about all the options, including surgery if things get worse." ID 4 physician assistant* |

## Supplement 2: COREQ checklist.

| COREQ item | Page | Text in manuscript / description |
|---|---|---|
| 1. Inter viewer/facilitator | 8 | The junior researcher who obtained the interviews was a medical student (author initials JW) |
| 2 Credentials | 9 | who hold the credentials of B.Sc., MD and PhD, respectively. |
| 3 Occupation | 8 | was a medical student |
| 4 Gender | n/a | |
| 5 Experience and training | 8 | …., she was unfamiliar with interviewing for qualitative research purposes and was therefore trained and supervised by an experienced senior researcher. |
| 6. Relationship established | 8 | ...she declared that she had never met any of the clinicians prior to the interview. |
| 7 Participant knowledge of the interviewer | 8 | JW confirmed that she had never met any of the clinicians prior to the interview. |
| 8 Interviewer characteristics | 8 | Further, she declared that she held no preconceived notions about, or prejudices towards, the way in which the clinicians handled the SDM process with patients |
| 9 Methodological orientation and Theory | 9 | The transcripts and notes were analysed using framework analysis |
| 10 Sampling | 5 | Consecutive hip and knee osteoarthritis patients who met the inclusion criteria were offered to use a ptDA and were asked to participated in the study. |
| 11. Method of approach | 6 | The invitation to be interviewed was sent by email. |
| 12. Sample size | 6 | As part of the SDM intervention,15 19 clinicians from a large Dutch training hospital received training in SDM and ptDA use. This group consisted of 8 orthopedic surgeons, 8 residents in training and 3 physician assistants. Of this group, 12 clinicians were involved in hip and/or knee osteoarthritis care. Clinicians who used the ptDA substantially (more than 10 times) were interviewed to evaluate the ptDAs used (see figure 1). Additional brief interviews were undertaken with three clinicians who did not use the ptDAs substantially (less than 10 times), in order to understand why they did not use the tool. The invitation to be interviewed was sent by email. |
| 13. Non-participation | 11 | Two clinicians were not available for the interviews because they worked in other hospitals at the time of the interviews. One clinicians was not available because of sick leave. One refused to be interviewed, because of time constraint. |
| 14. Setting of data collection | 9 | The online or telephone interviews explored clinicians' experiences with ptDA implementation and perceived barriers and facilitators for its use |
| 15 Presence of nonparticipants | 9-10 | Only the interviewed clinician and the researcher were present during the interviews. |

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| 16 Description of sample | 11 and 14 | - The clinicians that were interviewed had a mean age of 46 years (range 38 to 63 years) and the mean clinical experience was 21 years (range 12 to 39 years).<br>- All interviewed clinicians were male. We had brief additional interviews with clinicians (n=3) who did not use the ptDA substantially, in order to understand their reasonings. Two of them were male and one clinician was a female. Age ranged between 45 and 64 years of age. |
| 17. Interview guide | | • What were your experiences with ptDA use?<br>• Is the ptDA helpful for decision making?<br>• Were patients better informed when they used the ptDA?<br>• Were patients more involved in the care process after they used a ptDA?<br>• What barriers exist for ptDA implementation?<br>• Was it easy to use the ptDA or burdensome, why?<br>• Did the staff – nurses had resistance against the use of the ptDA?<br>• For which situations is ptDA most suited, and when is it less useful?<br>• Which patient group benefits most from ptDA use?<br>• For which patient group was the ptDA least useful?<br>• What is the best timing for ptDA use in the care process?<br>• Was it easy for patients to use the ptDA or did digital literacy prevent use?<br>• How can uptake of the ptDA be increased?<br>• Should all patients use the ptDA?<br>• Did you often think the ptDA was not useful, why?<br>• Did you offer the ptDA always when eligible?<br>• Are patients in the need of more information?<br>· What do you like most of using the ptDA? |
| 18 Repeat interviews | 9 | No repeat interviews were executed… |
| 19. Audio/visual recording | 9 | Interviews were audio recorded and transcribed… |
| 20 Field notes | 9 | Notes were taken during the interviews and audio recordings were made and transcribed afterwards. |
| 21 Duration | 9 | The interviews ranged between 15 and 25 minutes. |
| 22. Data saturation | 9 | Data saturation was discussed with the whole team and after five interviews we had a clear picture of the clinicians' experiences of ptDA use |
| 23 Transcripts returned | 9 | ….. and the transcripts were not returned to the interviewed clinician for comment and/or correction |
| 24. Number of data coders | 9 | Once the coding framework was agreed upon, author JW coded all interviews. Author JJ double-coded a sub-set of interviews. |
| 25. Description of the coding tree | | n/a |

| | | |
|---|---|---|
| 26. Derivation of themes | 9 | The transcripts and notes were analysed using framework analysis. Author JW started by reviewing the interviews and developing a list of themes and topics using an inductive perspective. Those themes, along with the interview schedule (deductive approach), formed the basis of the coding framework. Two additional authors (JJ and JB) reviewed the coding framework, and changes were discussed and made accordingly. Once the coding framework was agreed upon, author JW coded all interviews. Author JJ double-coded a sub-set of interviews. Coding similarities and differences between authors were discussed and changes were made to the themes when deemed necessary. |
| 27. Software | | n/a |
| 28 Participant checking | 9 | Also, the participants did not provide feedback on the findings. |
| 29. Quotations presented | 27 – 30 | The quotes of the clinicians were provided as a supplement.. These quotes were ordered so they illustrate the different themes. ID's of the different clinicians were provided. |
| 30. Data and findings consistent | 18 | Our findings from the interviews were supported by the patients' reasons for declining the ptDA and by the data from the questionnaires. |
| 31. Clarity of major themes | 11-14 | Major themes were described. |
| 32. Clarity of minor themes | 11-14 | Minor themes (subthemes) were described. |

7

# General discussion

Shared decision-making (SDM) is considered the preferred model of decision-making by patients, clinicians, and health policymakers (1). Despite the extensive evidence of its benefits, SDM is not commonly employed in orthopaedic practice (2-5). This highlights the importance of the development and evaluation of an SDM intervention aimed at increasing the uptake of SDM in routine orthopaedic care.

Before designing an SDM training programme, we obtained information about current SDM behaviour as recommended by the Theory of Planned Behaviour (6, 7). With this information, a well-founded, theory-based intervention could be built.

In addition to designing an SDM intervention, we wished to improve the quality of patient information necessary for decision-making. As accessible electronic health records become more widely used (8, 9), we must ensure that the information in these systems can be easily understood by patients while limiting any unnecessary distress. Achieving this goal would support SDM since accessible and comprehensible information for patients is a requisite for SDM.



The primary objective of this thesis was to develop an SDM intervention based on the Theory of Planned Behaviour, focused on both the clinician and the patient. The intervention aimed at clinicians consisted of a communication training; for patients, an decision aid (10) was used. The interventions were implemented in the orthopaedic clinic and evaluated afterwards.

**The goals of this thesis were:**

1. To measure the current level of SDM and investigate the influence of patient factors on SDM in orthopaedic care.
2. To make accessible digital patient information easier to understand while minimising patient distress.
3. To explore current SDM behaviour of orthopaedic surgeons and residents in the care of hip and knee osteoarthritis.
4. To develop and implement a multifaceted, theory-based intervention programme to improve SDM in the care of hip and knee osteoarthritis.
5. To evaluate the implementation process of a patient decision aid in the care of hip and knee osteoarthritis.

These research aims have been addressed in the previous chapters of this thesis. The main findings and discussion points are summarised below. In the final section of this chapter, the SDM behaviour of residents is discussed in greater detail.

# MEASURING THE LEVEL OF SDM IN ORTHOPAEDIC CONSULTATIONS

## Different elements of SDM discussed in consultations

In **chapter 2**, we used an SDM measurement tool that is based on a competency framework developed by Towle and Godolphin (11) to explore the extent of SDM in orthopaedic consultations. Audiotapes of orthopaedic consultations were obtained to score observed SDM according to the eight competencies described in that framework. Those competencies are: *Develop partnership, Information preference, Establish role of decision-making, Ascertain concerns and expectations of the patient, Identify choices and current evidence, Discuss treatment options and impact on patient, Negotiate decision,* and *Agree on an action plan* (11). We sought to investigate the relationship between the level of observed SDM and patient factors such as health anxiety, coping, and depression. We found that clinicians varied in their competencies and the extent to which they used SDM. Clinicians were least likely to discuss patients' preferred role (establish or review the patient's preferences for role in decision-making) and information preference (establish or review the patient's preferences for information, such as amount or format). These findings are consistent with previous findings in literature. A review that included studies using a measurement tool to score observed SDM, the OPTION-5 questionnaire, across a range of clinical contexts, found that clinicians paid little attention to patients' preferred role and their preferred method of receiving information (12). The preferred role is not the same for all patients (13-15) and a review of oncology trials found that the median percentage of patients preferring an active, shared or passive role in decision-making was 25%, 46%, and 27%, respectively (15). A mismatch between the desired role and the actual role is common, underlining the need to explore if and how the patient wants to be involved (16). Healthcare providers should explain to patients that a decision needs to be made and, although SDM is preferred, the patient can point out what role they wish to play in the decision-making process. When exploring their preferred role, we need to explain to patients what SDM entails, as limited understanding of SDM can deter patients. Patients are more likely to prefer a passive role in decision-making if they believe that SDM leaves them alone in the process with no guidance from a clinician (16). We should prepare patients for this process prior to the consultation (17). e-Health applications may be able to help with this. Patients are increasingly invited to use applications that inform them about treatment (18). Applications such as the Patient Journey App (19), which is frequently used in the Netherlands, can potentially be employed before the consultation. With this App, patients can learn about SDM and the relevance of participating in the decision-making process. They can then have the time to consider their preferences about their role in the decision-making process, the format used, and amount of medical information presented. Provided that this information is discussed

with the clinician during the consultation, this helps putting the patient's preferences on the table. This could improve patient-doctor communication and enhance SDM.

### The influence of patient anxiety on the level of SDM

In chapter 2, we also investigated the relationship between patient factors, such as health anxiety, coping, and depression, to the level of SDM. We found that health anxiety predicted lower levels of observed SDM in consultations. Specifically, the level of SDM was curtailed when patients expressed higher levels of anxiety to the orthopaedic clinician. This finding is useful in understanding what factors contribute to the likelihood of an individual being involved in treatment decisions, and currently little is known about psychological factors in relation to the occurrence of SDM (20). When explaining treatment options to patients, we know that clinicians face a dilemma between raising awareness, for example of the risks of surgery, and increasing anxiety (21). Indeed, a possible explanation for the findings in our study could be that to avoid patient anxiety, clinicians limit their communications about risk and take a more leading role. Contrary to such expectations, however, a Cochrane review of ptDAs found that extensive patient information and communication about risks did not increase anxiety in patients (22). When dealing with patients who demonstrate high levels of anxiety, we know that it is important to validate and reassure them while gently challenging any unrealistic beliefs or concerns they may have (23). Our research has shown that SDM tends to be lower in consultations with anxious patients. This knowledge may be of value as this group of patients should not be left out of SDM. Knowledge of our findings should be imparted to clinicians who are being trained on SDM.

## MAKING ELECTRONIC HEALTH RECORDS MORE ACCESSIBLE TO PATIENTS

In **chapter 3** of this thesis, we describe a study in which we aimed to improve the understandability of radiology reports that are accessible for patient through digital portals. This study was implemented in recognition of the spread of information systems that allow patients to view their own medical records (9, 24). Governments require hospitals to make these systems available to patients to improve patient-centred care (8, 25). In a recent Dutch survey study, 80% of the medical specialists reported that their hospital had a portal for patient-accessible health information (26).

Potentially, these systems improve patients' medical understanding and participation in care, although the evidence for this is weak according to a 2021 Cochrane review (27). In principle, allowing patients to access their personal health information opens up the possibility of improved communication between patients and clinicians, because

the level of information is more evenly distributed, and the patient's knowledge gap is diminished. This enables patients to be more aware of their medical situation and to explore treatment options that are most suitable to them (28). Greater knowledge also helps them to prepare for clinical visits and decision-making (29). A qualitative study showed that patients felt that having access to their records improved their participation in their medical care (30).

Unfortunately, information in medical records is often challenging for patients to fully understand (30-33). It is important for effective SDM to ensure that medical information is intelligible to lay persons. To further our insight into this aspect of SDM, we revised radiology reports to make them more comprehensible to non-medical persons. These rewritten reports were perceived by patients as easier to understand compared to the original reports. Furthermore, the patients felt more pleasant, calm and in control when reading the rewritten reports. We concluded that the rewritten reports were less distressing compared to the original ones.

Patient distress and anxiety may influence SDM. In chapter 2 we described that lower levels of SDM were seen in consultations with patient that had more health anxiety. Also, from the field of lung cancer research we know that distress alters risk perception; and distressed patients feel more pessimistic about the future than if they were less worried and upset (34). Although the population in this last study is different from the population in this thesis, it seems important to provide patients with information that is not only understandable but also reduces unnecessary distress. A Dutch survey study asked clinicians and patients about their experiences with accessible medical records at a major university hospital (35). The system they used enabled real-time access by patients to their reports, so these patients were often able to read radiology reports before they spoke to their clinicians. This had certain benefits, in that patients who read their report at home seemed better prepared and asked more focused questions during the consultation. However, care providers also reported some negative experiences, particularly with patients who received a unexpected new finding. Most of these negative experiences with real-time access were due to the inability to interpret the results of the tests. Clinicians pointed out that this caused unnecessary anxiety and fear in patients (35). In cases of real-time access, patients should be made aware of the potential for misunderstanding, as the context and explanation of medical jargon otherwise provided by the clinician is missing.

As we showed in our research study, adapting medical information to accommodate patient understanding could help limit the potential for misconception. It is not clear how best to organise this in the clinical setting, what level of detail is best without losing information, and who should rewrite the reports. It seems most logical for the radiologist to provide a rewritten report at the same time as the original report. Alternatively, a trained and/or supervised radiology lab worker may be tasked with rewriting the report

based on the original. Since manpower is problematic in healthcare (36), we should also explore the role of artificial intelligence applications and find out if these systems could help with rewriting. In a recent exploratory case study, five radiologists were asked to assess the quality of radiology reports simplified by ChatGPT (37). In general, the simplified reports were found to be correct and complete, but errors were frequent. The study concluded that AI systems have great potential, but further development is needed. Currently there's considerable debate regarding the desirability of providing real-time access, and clinicians appear hesitant about it (26, 31, 35). With the rapid and certain advance of digital patient portals, we need to find ways to facilitate patient access and understanding. For now, the central role of the clinician remains vital.

## SDM BEHAVIOUR OF CLINICIANS



In **chapter 4**, we gained insight into the SDM behaviour of orthopaedic clinicians. We used the Theory of Planned Behaviour (TPB) to explain the SDM behaviour of residents in training and staff surgeons working in orthopaedics. With this theory, behaviour can be predicted by attitude (the person's positive or negative evaluation of the behaviour), subjective norms (the perceived social pressure or expectations to perform or not perform the behaviour), and perceived behaviour control (the perceived ease or difficulty of performing the behaviour) (38). In our study, we found that, of the TPB elements, clinicians scored highest on attitude. This means they valued SDM as something positive in the care of patients with hip and knee osteoarthritis. This finding is consistent with other literature showing that attitudes towards SDM are mostly positive (39-41). Although this is a positive finding, a discrepancy is seen between the positive attitudes expressed towards SDM and the actual SDM behaviour in the consultation as objectively determined by observational measures (2, 3, 42, 43). As the Theory of Planned Behaviour points out, actual behaviour is not dictated solely by attitude. We found that the clinicians' intention to engage in SDM was lower when they perceived less control over their behaviour in implementing SDM and this forms an important barrier to SDM behaviour.

Our study indicated that, according to the clinicians, effective SDM behaviour was limited by patient health literacy. They felt that SDM was often hindered by patients lacking the knowledge and skills to participate in the decision-making process. In fact, the perception that patients not always have the skills to participate in decision-making is frequently mentioned by clinicians as barrier to SDM (44, 45). SDM is known to be more challenging for patients with limited health literacy and is associated with patients taking a passive role in decision-making (32, 46). At the same time, patients with limited health literacy still want to be involved in decision-making. A recent study

in orthopaedics observed that there was no correlation between health literacy and patient preference for involvement in decision-making (47). Patients with limited health literacy should not be excluded from SDM but they may need more preparation and a supportive clinician (48).

Time constraints were identified as another important barrier to perceived behaviour control in our study. Clinicians indicated that they were hampered in their SDM behaviour because they simply did not have enough time to put SDM into practice. They felt they had no control over this aspect. In the SDM literature, time constraints are often mentioned as an impediment (49, 50). There is some research about the way in which SDM affects the length of consultations (51, 52). A Cochrane review showed that consultations were on average 2.6 minutes longer when a ptDA was used (53). Little is known about the impact of SDM on time in the long run. For example, by involving patients in the decision-making process, clinicians may be able to identify and address concerns or misconceptions earlier, potentially reducing the need for additional visits, phone calls or interventions down the line. A study by Wilson and colleagues showed that SDM in asthma care resulted fewer asthma-related medical visits compared to the usual, although the time per consult was extended (54). Future research should investigate the effect of SDM on follow-up consultations and care consumption to provide a more nuanced picture of the time investment of SDM communication in consultations.

## DEVELOPMENT OF AN INTERVENTION TO IMPROVE SDM IN ORTHOPAEDIC CARE

As described in **chapter 5**, we developed a multifaceted theory-based intervention programme with an emphasis on improving perceived behavioural control and reducing barriers to SDM. The results from our study on SDM behaviour of clinicians (chapters 4) were used to build this intervention program. It is important to develop interventions that are based on a theoretical framework (55) and the TBP is often used in behavioural science (6, 38). We used this theory in the development of the SDM programme. The breadth of barriers to SDM suggests that multidimensional interventions are needed, targeting patients and health care professionals (1, 56). Combined interventions that target both the clinician and the patient have been shown to be promising for improving SDM (57, 58) and we designed interventions directed at both of these groups.

To increase clinicians' knowledge of SDM, they were asked to complete an e-learning tool ahead of the two session training course. The training course that was implemented focused on communication skills relevant to SDM in the care of patients with hip and knee osteoarthritis. In addition, clinicians were trained in the use a ptDA in clinical care. For the patient intervention, we sought to improve patient information and participation

in decision-making by using an existing web-based ptDA for hip and knee osteoarthritis. These ptDAs were certified as easy to read for lay people and previously implemented in hospitals across the Netherlands (10, 59). In our intervention, patients with hip and knee osteoarthritis who were eligible for surgery were offered the ptDA by a trained surgeon or orthopaedic resident.

We found no significant differences between the pre- and post-intervention groups on the primary outcome measures, the level of SDM (SDM-Q-9) (60, 61), decisional conflict (Decisional Conflict Scale) (62, 63), and patient satisfaction. The ptDA was not mandatory as part of the intervention, and only 17% of eligible patients agreed to use it. The limited use of this tool might explain why SDM did not increase in our multifaceted intervention study.

The communication training for clinicians had a clear positive effect on the clinicians' knowledge of SDM. There is some evidence in the literature of the benefits of behavioural interventions on clinicians' levels of SDM, but the certainty of this evidence is low. A Cochrane review on this topic found many errors in the methodological design of the studies, and often poor reporting of results (64). In fibromyalgia care, a training programme for clinicians was tested using a randomised controlled trial design (65). Several similarities can be found between this study and the study that we conducted. Both studies combined a patient-directed intervention, consisting of a ptDA combined with an SDM training programme for clinicians. The main difference is that the training in our study was shorter. The clinicians in our study completed an e-learning and participated in a two-session training of 2 hours each. The clinicians in the fibromyalgia study participated in 12 training sessions. The fibromyalgia study did find that the quality of doctor-patient interaction – their primary outcome measure – significantly improved in the intervention group compared to the control group. In a qualitative study by Bachus and colleagues, residents in training were interviewed about their needs for SDM education. The residents believed that repeated attention to SDM over a longer period of time was necessary for effective learning (66). Following the above studies, changing clinician behaviour may require a longitudinal training programme to ensure continued attention to SDM skills in clinical practice.

As lengthy training sessions can also have the adverse effect of reducing clinician uptake, we should be looking for time-efficient programmes as well. Recent research showed that SDM interventions that incorporate reflexivity have more positive effects than those that do not (67). Reflexivity is a form of learning based on reflection on one's own experiences (68). In a Norwegian RCT that tested an SDM training programme, the clinicians had to reflect on their own consultations by evaluating video recordings (69). This intervention programme was shown to be effective and the observed SDM increased until the final follow-up three months after the training. Interestingly, this training programme took up only 2.5 hours of the clinician's time. Due to its success,

it is now being rolled out more widely in Norway (70). In our training programme, we asked clinicians to reflect in-between the two training sessions on their own progress and obstacles in clinical practice concerning learned SDM skills. However, reflexivity was not extensively used in our training programme. Future communication training programmes may include this form of learning, as current research showed that it seems to be successful in changing clinicians' behaviour (67).

## EVALUATION OF THE SDM PROGRAMME

In **chapter 6**, we evaluated the implementation of the SDM programme. The goal was to investigate patient factors associated with accepting versus declining the use of the ptDA, along with patients' reasons for declining the ptDA and clinicians' perceived barriers to and facilitators for its use. We used a mixed method design and retrospectively compared patient factors of ptDA users with non-users. When patients declined the use of a ptDA, their reasons were reported and analysed. We also conducted interviews with participating clinicians to explore their experiences of the ptDA, which were qualitatively analysed. We found that, compared to patients who used the ptDA, patients who declined ptDA use had higher pain scores, significantly worse quality of life (on 4 out of 6 EQ-5D subscales), and were less likely to receive non-surgical treatment. In other words, patients who declined to use a ptDA had more severe symptoms of hip and knee osteoarthritis.

The many patients in our study who declined the use of the ptDA reported that they felt informed enough to make a decision and therefore did not want to use the tool. These patients pointed out that they had little choice, as they had often received conservative treatment before and believed that surgery was the only correct treatment for them. Additionally, patients who had been treated in primary care, for example by a physiotherapist or general practitioner, were more prone to decline the ptDA. From the literature, we know that both patients and clinicians resist non-surgical treatment in hip and knee osteoarthritis, especially when the complaints are as severe as in our study (71). Several studies suggest that the uptake of non-surgical treatment could be improved (72). Stepped care is being promoted to ensure that the least intensive intervention is tried, and that more invasive treatments are only used if necessary (73). Many patients in our study indicated that surgery was the only right option for them. However, conservative treatment option are not always tried by patients and a study pointed out that the different treatment steps were insufficiently utilized in the Dutch care of osteoarthritis (74). Hofstede and colleagues conducted a survey among patients and clinicians in the Netherlands to explore barriers and facilitators in non-surgical treatment in osteoarthritis care (71). Clinicians in their study pointed out that patients

with more advanced osteoarthritis often responded well to surgery and they felt this was the right option for their patients in most cases. These findings are consistent with the results of our study. SDM may be side-lined by such beliefs and non-surgical treatment is not considered a valid option. Both patients and clinicians may think there is only one available option, rather than a clear *preference-sensitive choice* as is often the case in osteoarthritis conditions (75). Although hip joint replacement surgery, in particular, is very successful in terms of patient satisfaction (76), the dissatisfaction rate after total knee arthroplasty still ranges between 15% and 25% (77). Surgery therefore might not be the right treatment for all patients. Some patients who think surgery is the only option, may do better with a non-surgical treatment option.

From the interviews with the clinicians, it was clear that they often had the same thoughts about the ptDA use as patients. They considered the ptDA to be superfluous for a significant group of patients, for example, those patients who had undergone extensive conservative care. These clinicians' beliefs may play a role in the limited uptake of the ptDA, as they believe that only a subset of clinicians can benefit from the ptDA. Although these clinicians might believe that patients are sufficiently informed to make a treatment decision, patients might have misconceptions and limited knowledge. Therefore, clinicians should not assume that their patients have adequate knowledge of disease and treatment options.

When considering ways to improve the uptake of the ptDA it seems important to take the context of the patient into account. Following the results of our study, it makes sense to introduce it in the early stages of hip or knee osteoarthritis. Primary care might be the appropriate setting for implementing the ptDA, as newly diagnosed patients seem more inclined to use the tool. However, the clinicians in our study insisted that a confirmed diagnosis was prerequisite to the use of the ptDA and questioned whether a GP could make such a diagnosis. This concern is not supported by the current literature, and hip and knee osteoarthritis is considered a clinical diagnosis that can be made in first-line care according to UK and Dutch guidelines (78, 79). In addition, the clinicians in our study felt it was inappropriate for GPs to discuss surgical treatment options in detail, as the orthopaedic surgeon is responsible for a correct diagnosis when considering surgery and is answerable for controlling the indication for surgery in hip and knee osteoarthritis. Recently, initiatives have been taken to implement specialised orthopaedic care in primary care settings to reduce referral rates (80). This situation allows the orthopaedic surgeon to discuss surgery as one of the options for the patient in primary care. Moreover, patients in this setting are more likely to be in the early stages of hip or knee osteoarthritis, and, as indicated in our study, more likely to use a ptDA. The primary care setting and collaboration with an orthopaedic surgeon may therefore be the right context for implementation of ptDAs.

# RESIDENTS AND SDM BEHAVIOUR

## Residents experience more barriers to SDM behaviour

In the intervention study (chapter 5), we found that patients who saw residents in training during consultations, experienced less SDM. These patients were also less satisfied than patients who saw staff surgeons. These findings could be partly explained by the fact that residents encounter more barriers to SDM compared to more experienced surgeons, as was found in our survey study (chapter 4). Time limitations form a serious obstacle for the residents, and we know from the literature that young doctors experience more time constraints compared to senior clinicians (81, 82). As they are less experienced, clinical tasks seem to take up the young doctor's time and they experience high levels of stress during residency (83). In a Dutch focus group study, orthopaedic and surgical residents indicated that they were too busy with clinical work to devote time to improving their communication skills (84). This is in line with findings from a systematic review exploring the barriers to and facilitators for SDM implementation in hospitals (85). The study concluded that experience is essential for the confidence and awareness of clinicians' own clinical skills and limitations, and that these competencies were considered to be facilitators for SDM. In a study by Driever and colleagues, twelve residents from various specialties were interviewed to explore how they make decisions with patients (86). The residents in the Driever study reported that they were less aware of the different treatment options that would be appropriate for a specific patient, and they were more likely to choose the option they knew from the guidelines or one that was recommended by current evidence. They observed that as they gained experience, they felt more confident in discussing different options with patients and involving them in the decision-making process (86). Thus, clinical experience and knowledge seems to play an important role in SDM behaviour. This should be recognized when training residents. However, residents in orthopedic surgeons should be trained in SDM knowledge and behaviour so that they can use their clinical skills to discuss different treatment options and their implications with the individual patient.

## The integration of SDM in evidence-based medicine education for residents

Ideally, residents should be trained to understand that practicing evidence-based medicine (EMB) is not only about following the most recent scientific evidence, but also about considering the patients' preferences and circumstances (87). In a Dutch interview study, young clinicians saw it as their primary responsibility to make the right diagnosis and decide on the best treatment for patients based on scientific evidence. The residents described this as EBM. Less emphasis was placed on the patient's perspectives and desires (86). These beliefs and attitudes of residents could be addressed in training

programmes that prioritise patient perspectives and preferences in consultations. In our training programme, we briefly addressed the concept of EBM as set out by Hoffmann and colleagues (87).

The literature shows that training programmes often fail to address EBM as an integrated concept. EBM and SDM are seen as two different themes for which separate training courses are provided (88). For effective integration, guidelines and training courses should combine the two. This will help residents realise that these are not two separate entities.

Current clinical guidelines start to advocate unified SDM/EBM thinking, as emphasis is placed on the importance of patient preference and perspectives. For example, the Dutch guidelines on proximal femur fractures advise using SDM to choose between internal fixation and hip arthroplasty when treating dislocated femoral neck fractures (89). Such recommendations promote SDM by encouraging residents to consider the patient's perspective as part of the treatment options recommended by the guidelines. Notwithstanding such advances in incorporating SDM in patient care, greater improvement still is possible. A Dutch study explored clinical practice guidelines in oncology, and used qualitative methods to evaluate the presentation of preference-sensitive decisions and recommendations. They found that the Dutch guidelines were not neutral in presentation and not all available treatment options were addressed (90). Thus, there is still work to be done to integrate SDM and evidence based medical knowledge into both clinical guidelines and clinician education to facilitate optimal patient care.



## STRENGTHS AND LIMITATIONS

One of the strengths of this thesis is that we have used a theoretical framework, the Theory of Planned Behaviour, in various chapters of this thesis. In chapter 4, we explored current SDM behaviour using this theoretical framework, and this information was used to build a well-founded theory based training, as described in chapter 5.

A variety of data sources have been used in this thesis. In chapter 2 we used audio-recordings for an observational SDM measurement tool and in chapter 5 different patients reported outcome measures for SDM were analysed. With this, a rich overview is provided of SDM in orthopaedic care. In the evaluation study, described in chapter 6, we used three sources of data to reflect on the implementation of the ptDAs. Using both qualitative and quantitative analyses to analyse this data, the conclusion was reinforced from different perspectives.

Another strength of this thesis is that we used a multifaceted intervention (chapter 5), targeting both clinicians and patients. The clinicians' intervention consisted of

e-learning and communication training, and patients were offered a ptDA. Such combined interventions are recommended in the literature and, to our knowledge, this is the first study to investigate this in orthopaedic care.

One of the limitations is that we used a non-randomized study design to test our intervention (chapter 5). Although a randomised control trial would be superior to eliminate many biases, there would have been a chance of contamination between the trained clinicians and the untrained clinicians when using that study design. We also found it impractical to train half the orthopaedic staff first rather than all at once. This is why we decided for the pre- post intervention design in our intervention study.

In the evaluation study (chapter 6), eight interviews were conducted with clinicians to assess their experiences with the implemented ptDA. Although we were able to derive a central and shared message from these interviews this number of clinicians is relatively small and can be seen as a limitation.

In the evaluation study (chapter 6) we compared patients who declined the ptDA with patients who used this tool. We tested a subset of clinicians who said that when indicated, they offered the tool. Although the clinicians confirmed that they had invited all eligible patients for ptDA use, we did not collect data on this, and it is possible that some eligible patients were overlooked due to the nature of clinical practice. For example, patients with very severe complaints of advanced osteoarthritis may have been scheduled directly for surgery at short notice, without considering a ptDA. The lack of clear insight into how patients were asked to use a PtDA is a limitation and unknown factors could have influenced ptDA uptake.

## CONCLUSION

Especially residents mentioned to struggle with SDM because of limited patient health literacy but also because of time constraints in the busy orthopedic clinic. They may best be taught that their evidence-based clinical practice should be integrated with patient centred decision-making for optimal patient care.

We know that patients want to be involved (41, 91, 92) but they may struggle with understanding and distress when they absorb medical reports that are available accessible digital portals. Re-writing radiology reports showed to improve patient comprehension while reducing anxiety. Future research could be done to investigate whether rewriting reports is of value and whether it is feasible in clinical practice. Until we know more on this, the role of the clinician in explaining and interpreting medical information to the patient remains central.

Improving SDM behaviour in clinical practise remains struggling and a multidimensional intervention program that was tested did not show any improvement

in the level of SDM and patient satisfaction in the orthopaedic care for hip and knee osteoarthritis patients. In order to change clinicians' behaviour a more lengthy program may be needed that is embedded in clinical practice.

Overall, uptake of the ptDA was low and the tool was considered most appropriate for recently diagnosed patients or those with less advanced disease and symptoms. Our study highlights the importance of considering the context, including patient characteristics, when implementing ptDAs. Further research is needed to determine the optimal setting, timing and target population for the ptDA in hip and knee osteoarthritis.

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# Impact paragraph

## OBJECTIVE OF THE THESIS

For many orthopaedic conditions, SDM is recommended by clinical guidelines to promote patient centred communication and to ensure that the decision is in line with the patient's preferences and needs (1-5). The use of SDM interventions, such as patient decision aids (ptDAs), has been shown to improve SDM, patient satisfaction and in some cases, reduce surgery rates (6-8). However, SDM is not widely used in the management of hip and knee osteoarthritis (9, 10). It is therefore important to develop interventions that aim to improve SDM in the care of hip and knee osteoarthritis. The objectives of this thesis were to investigate current SDM, to optimise the preconditions for SDM by improving the comprehension of patient information, to develop a multifaceted intervention and to conduct an evaluation study to learn from the implementation of the intervention in clinical practice.

## BRIEF SUMMARY OF RELEVANT FINDINGS

In the setting of an outpatient orthopedic clinic, we measured SDM using an observational measurement tool (11). We found that the preferred role of the patients in the decision-making process was not often discussed. Also, clinicians infrequently reviewed the patient's preferences for information, such as the desired amount or format of information. When patients had a higher level of health anxiety, this predicted a lower level of observed SDM.

To improve patient information that is used in digital accessible portals, we rewrote radiology reports. We showed that, compared to reading the original report, these rewritten reports resulted in more patient comprehension and reduced patient distress.

To explore the current SDM behaviours of orthopaedic surgeons and residents, a survey study was conducted. These clinicians reported that their SDM behaviour was mainly hindered by factors beyond their control, such as patients' health literacy and time constraints. We used this information to build a well-founded training program.

A training program was developed for clinicians to improve SDM behaviour and at the same time an ptDA was implemented in the clinical care for hip and knee osteoarthritis. The intervention study pointed out that this program did not improve SDM.

In the intervention study, the uptake of the ptDA was only 17% and the evaluation study showed us that patients with more advanced osteoarthritis were less likely to use this tool.

## TARGET GROUPS

The work of this thesis enriches the literature on SDM research. In addition, specific groups, involved in the management of hip and knee osteoarthritis, may benefit from the results.

### Patients

As a patient, it is good to be aware of the barriers to SDM. We found that in orthopedic consultations relatively little attention was given to the patients' preferred decision making role. There was also little discussion on how patients would like to receive information. As the adage 'it takes two to tango' still applies to SDM (12), patients can be empowered to proactively address these elements during consultations with their clinician. To stimulate this patient behaviour, we should encourage them to be involved in SDM. In the General Discussion of this thesis, we suggested that patients could be informed digitally prior to the orthopedic consultation. This could be done through digital applications, which are increasingly being used to guide patients through the treatment process. These applications could be used to inform patients on the relevance of SDM prior to decision-making. As we found that the patient's role in decision-making and information preference were the least discussed, emphasis should be placed on these elements of SDM. This allows patients to be more aware of these lacking items and gives them a shared responsibility to point out their preferred decision-making role and how they want to receive medical information.

### Clinicians

Clinicians could be made aware that there is too little discussion of certain SDM components in clinical consultations, in particular the favoured decision making role of the patients and their preferred method of receiving information. They could benefit from the knowledge that, when seeing a patient with heightened health anxiety, clinicians tend to reduce SDM behaviour. Residents in particular could learn from our findings, as they experienced more barriers to SDM behaviours and had lower SDM scores in the intervention study compared to more experienced surgeons. Reaching orthopaedic clinicians is a challenge. Clinicians are generally unaware of their shortcomings in SDM and appear to be unconsciously incompetent in this behaviour (13). There is also a lack of interventions that have successfully improved clinician behaviour in current literature. This makes it difficult to specify how we should use our findings to improve current SDM behaviour. SDM training could best be integrated throughout the whole residency program as longitudinal learning and integration in clinical practice could be more effective in changing behaviour (14-17). We could also train orthopaedic

clinicians in the use of ptDAs. These tools should be seen as a common adjunct to their consultation as they showed to be effective in increasing SDM (18).

## Educators

Educators and teachers can learn from the results of this thesis in multiple ways. We found that this multifaceted intervention did not result in improved levels of SDM. At present, it remains unclear how doctors' SDM performance can best be improved. In our programme, reflexivity as a learning method was not given any particular focus. Recent literature shows that this form of learning is effective, and we advise educators to incorporate this form of learning more elaborately (19). Especially residents could be addressed in SDM training, as we showed that they felt more hampered in SDM behaviour and had lower SDM scores when measured with patient reported outcome measures. Learning programmes could help to improve SDM skills, with education in medical school and during postgraduate training, providing ongoing attention to SDM. When residents are taught on SDM this training should integrated with education on evidence-based medicine, as the two should not be seen separately. Residents must know that optimal medical care is achieved by the integrating of a patient-centred approach with the latest medical evidence (20).

## Healthcare policy makers

Nowadays, many hospitals offer digital online portals through which patients can access their medical information. In some hospitals patients are able to access medical reports real-time, without delay, meaning that the read their reports often prior to consultation. There is some debate about the desirability of providing real-time access, and clinicians in particular are concerned that medical reports will be misunderstood and distressing for patients (21, 22). There is support for these concerns, and therefore, our findings on the effect of rewriting radiology reports are relevant. When thinking about ways to improve this information, rewriting radiology reports could be considered when using real-time access. More research is needed before this can be implemented in clinical care. Nevertheless, health policy makers should be aware of the potentials of rewriting information, as accessible digital information becomes increasingly important.

In our evaluation study on the implementation of the ptDA, we found that a number of reason are given for the low take-up of the tool. We showed that the context is important when implementation of a ptDA is considered. The uptake in an orthopaedic clinic was when patients had advanced complaints and had previously undergone conservative therapy for of hip and knee osteoarthritis. The interviewed clinicians suggested that uptake could be improved if the ptDA was used earlier in the course of the disease. Given the longitudinal nature of many patients' relationships with their GPs, conversations about treatment options and expectations could take into account a broader and more

nuanced health history. Implementation of ptDA as part of the SDM processes in primary care settings could improve SDM more effectively. Although this should be examined in future research, this could be relevant for healthcare policy makers when considering ptDA implementation in the care of hip and knee osteoarthritis.

## ACTIVITY

The work of this thesis has been presented at multiple national and international conferences. The audience included SDM experts, educators and clinicians working in the field of orthopaedics. In addition to disseminating findings in this setting, I also emphasise the importance of the findings in orthopaedic practice. As an orthopaedic clinician, I am part of many medical decisions, and the work of the thesis will have an impact on orthopaedic care through me. Decision-making in hand surgery, my field of expertise, can be challenging. The likelihood of the patient having the condition in question, the probability of the operation being successful, and the risk of complications are all examples of uncertainties that are faced. Therefore SDM is very important. Because of my clinical experience and knowledge on SDM I can be an advocate for SDM in orthopaedics. We are constantly training young doctors and medical students. This allows me to act as an SDM educator for medical students and residents. In the hospital I work, the University Hospital of Leuven, Patient Centred Care is made a top priority recently for the upcoming years. As part of this, I am involved in committees that aims to improve SDM across the hospital. The knowledge of the results of this thesis can be of great value in this role.

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# English Summary

Despite the evidence that shared decision-making (SDM) has beneficial effects on patients' risk perceptions, knowledge and satisfaction, it is not widely adopted in orthopaedic practice (1, 2). To stimulate the practise of SDM, we designed a multifaceted programme to improve the level of SDM in the care of hip and knee osteoarthritis. We used a theoretical framework, the Theory of Planned Behaviour, to design our intervention (3, 4). First we explored current SDM in orthopedic care. With that information a well-founded training program was built to improve SDM (see figure 9.1).

Barriers for SDM could be identified at different levels: patient factors, health-professional factors, organisational factors, patient-clinician relationship factors, and factors related to information provision (5). Lack of information for patients, particularly about the patients' conditions, treatment options and outcomes, is known as an important identified barrier to SDM (5). Digital information systems are becoming more widespread and they aim to inform patients about their current medical situation by providing access through online portals (6). This information is not always easy to understand for patients and reading these reports could be distressing for patients (7-9). In this thesis we aimed to make these reports better understandable and less distressing for lay persons, so it could support decision-making.


**Figure 9.1:** Overview of the following chapters.

As mentioned, we developed a theory based SDM programme in the care of hip and knee osteoarthritis and this was tested in a pre- post-intervention design study. The intervention programme consisted of a training course for clinicians and a decision aid for patients (ptDA). At last, we conducted a study with the aim to evaluate on the implementation of this programme, with a particular focus on the uptake of the ptDA in daily clinical care.

Below we summarise how each chapter addressed the research questions.

***What is the current level of observed SDM and does patient anxiety influence the level of SDM?***

In **Chapter 2,** a prospective cohort study was performed in which we measured the current level of SDM in the setting of an outpatient orthopedic clinic. We aimed to examine the predictors for observed SDM and patient satisfaction and measured psychological factors such as symptoms of depression, health anxiety and pain catastrophizing as determinants. Audio recordings of 130 consultations were used to score the SDM. For this we used a validated tool that scored SDM behaviour according to eight competencies

(10). The competencies used are *Develop partnership, Information preference, Establish role of decision-making, Ascertain concerns and expectations of the patient, Identify choices and current evidence, Discuss treatment options and impact on patient, Negotiate decision,* and *Agree on an action plan* (10). Patients satisfaction was measured using a visual analogue scale, with possible scores ranging from 0 to 10. The results showed that the highest mean SDM was observed for the competence *Agree on action plan*, meaning the ability to discuss an action plan and complete arrangements for follow-up. The lowest score was observed for the *Role of decision-making (*establish or review the patient's preferences for role in decision-making) and *Information preference* (establish or review the patient's preferences for information, such as amount or format). The SDM element *Identify choice* (clarification that there are a range of treatment options that will be presented in an unbiased manner) was associated with higher patient satisfaction. The findings suggests that patients are more satisfied when all available treatment options are neutrally discussed. We found that less SDM was observed in consultations where patients expressed higher levels of health anxiety ($r = 0.25$, $p = 0.004$). In the regression analyses, health anxiety was found to be a predictor for both lower patient satisfaction and lower SDM.

Conclusion:

- The SDM competences *Role of decision making* and *Information preference* were least discussed in an
- outpatient orthopedic clinic.
- Patients were more satisfied when the different treatment options were discussed
- When patients had elevated health anxiety less SDM was observed and patients were less satisfied.

***Is patient distress and understandability of patient information improved when accessible health reports are adjusted to more patient-friendly?***

**Chapter 3** describes a cross-sectional study that determined the effect of rewriting radiology reports on patients' perceived comprehension, understanding, usefulness and distress. Accessible electronic health records are increasingly used and it is important to investigate how this information can be optimised in order to support decision-making. In our study we rewrote MRI reports to an eighth-grade reading level and with the use of neutral descriptive words and the most optimistic interpretations based on current best evidence. One hundred patients read both the original and rewritten report. The rewritten reports resulted in better understanding (8.1 vs 4.2, $p < 0.001$, range 0-11) and higher perceived usefulness (7.1 vs 4.8, $p < 0.001$, range 0-11) compared to the original reports. Also, significantly less distress was reported by the patients when they read the reworded reports compared to the original reports.

Conclusion:

- When radiology reports were rewritten for lay people, they are less likely to be distressing when compared to the original reports.
- When using information in digitally accessible portals, rewritten reports may improve comprehension

***What are the reported levels of attitude, subjective norm and perceived behaviour control with regard to SDM behaviour and do these differ for residents and orthopedic surgeons?***

**Chapter 4** explored current SDM behaviour of clinicians. The Theory of Planned Behaviour (TPB) was used to explain current behaviour. According to the TBP, behaviour is determined by attitude (the person's positive or negative evaluation of the behaviour), subjective norm (the perceived social pressure or expectations to perform or not perform the behaviour) and perceived behaviour control (the perceived ease or difficulty of performing the behaviour) (11). A survey was set out that was developed using a manual for constructing questionnaires based on the TPB (12). The questionnaire was completed by 71 orthopedic residents and 64 orthopedic surgeons in the Netherlands. We assessed attitudes, subjective norms and perceived behavioural control in relation to SDM behaviour. We found that these three elements were determinators for SDM behaviour ($R^2 = 0.27$, $p < 0.001$) and perceived behaviour control was the most important predictor (b = 0.604, 95% CI: 0.291 to 0.917). The mean perceived behavioural control score of residents was significantly lower compared to the score of staff surgeons.

Conclusion:

- Of the different TPB items, perceived behaviour control was found the most important predictor of SDM behaviour.
- Residents felt less control over SDM behaviour (low perceived behaviour control) compared to orthopedic surgeon
- This information can be used to build a intervention program for SDM based on the TPB as theoretical construct.
- Residents should be addressed in future SDM training program since they express less control over SDM behaviour.

***Is the level of SDM increased by a multifaceted intervention, addressing both patients and clinicians?***

We developed a multifaceted intervention that aimed to improve SDM in the care of hip and knee osteoarthritis **(Chapter 5)**. The intervention was based on the TPB and we used the information obtained in the previous chapter on SDM behaviour. The

intervention consisted of a training course for clinicians and a decision aid for the patients (ptDA) (13). The clinicians' training course consisted of 2 sessions of 2 hours and was preceded by an e-learning (14). All participating clinicians were trained to increase SDM knowledge and communication skills. During consultations, patients were offered to use a ptDA if surgery was one of the possible treatment options. Using a pre- and post-intervention design, we tested the effectiveness of this programme. The primary outcome measures were the levels of SDM (SDM-Q-9), decisional conflict (Decisional Conflict Scale) and patients satisfaction (visual analogue scale). Secondary outcome measures were clinician attitudes and knowledge of SDM and uptake of the ptDA. In total, 317 patients were included in the study. We found no effect of the intervention programme on the primary outcome measures. Physicians mean knowledge scores were significantly higher after the training compared to before training (12.7 compared to 10.0, 95% CI: -2.85 to -0.39). We found that the uptake of the ptDA was low with only 17% of the eligible patients using the tool. SDM was higher for middle educated patients compared to lower educated (mean difference 9.91, p=0.004), patients who saw surgeons instead of residents (mean difference 5.46, p=0.044) and when surgery was chosen and desired by patients compared to situations where surgery was desired but not chosen (mean difference 15.39, p=0.036).

Conclusion:

- Our multifaceted intervention had no effect on SDM, decisional conflict and on patient satisfaction.
- Clinicians' knowledge about SDM increased after the training.
- Most patients wanted surgery and were most satisfied when this treatment was finally chosen. By seeing surgery as the only good option, the decision is not fully preference sensitive for these patients.
- Patients were less satisfied and expressed lower levels of SDM when they consulted residents in training.
- The uptake of the ptDA was low.

***What hampers successful implementation of a patient decision aid?***

In the final chapter **(Chapter 6)** we evaluated the implementation of the ptDAs that were used in the previous chapter. We used a mixed method approach to investigate clinicians' perceived barriers and facilitators to ptDA use, patients' reasons for declining the ptDA, and patient factors associated with ptDA use and decline. Compared with patients who used the ptDA, patients who declined the use had higher pain visual analogue scores (7.2 vs 6.2, p<0.001), reported significant worse quality of life (on 4/6 EQ-5D-3L subscales), and were less likely to receive non-surgical treatment (4% vs 28%, p<0.001). Of the patients who declined to use the ptDA, 46% indicated to have enough information and

felt ready to make a decision without the ptDA. Interviewed clinicians found the ptDA to be less suitable for patients with more advanced symptoms and who had undergone prior treatment in primary care. The clinicians considered the ptDAs most useful for newly diagnosed patients who had not received previous treatment. The GP setting was seen as promising for ptDA implementation, but some clinicians expressed concerns that contradicted this suggestion. They questioned whether a confirmed diagnosis could be made in primary care and they did not think it was appropriate for a GP to discuss surgical treatment options when going through the PtDA. In order to increase uptake of ptDA these beliefs need to be addressed.

Conclusion:

- The ptDA was found to be more suitable for patients with a recent diagnosis and less advanced disease and symptoms.
- Implementation of the tool earlier in the illness trajectory was found to be more appropriate, provided that the patients have a confirmed diagnosis.
- Our study pointed out that the context of the patient and patient characteristics could be taken into account when a ptDA is implemented.

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# Nederlandse Samenvatting

Ondanks het bewijs dat Shared Decision-Making[1] (SDM) gunstige effecten heeft op de risicoperceptie, kennis en tevredenheid van patiënten, wordt het niet op grote schaal toegepast in de orthopedische praktijk (1, 2). Om het gebruik van SDM te stimuleren, hebben we een interventie programma ontwikkeld en beschreven in dit proefschrift. We hebben een theoretisch kader gebruikt, de Theory of Planned Behaviour, om de interventie te ontwerpen (3, 4). We hebben eerst het huidige gebruik van SDM in de orthopedische zorg in kaart gebracht. Met die informatie is vervolgens een goed onderbouwd trainingsprogramma ontwikkeld welke als doel had de mate van SDM in de zorg voor heup- en knieartrose te vergroten (zie figuur 9.1). De literatuur laat zien dat barrières voor het plaatsvinden van SDM op verschillende niveaus worden geïdentificeerd: patiëntfactoren, gezondheidsprofessionele factoren, organisatorische factoren, patiënt-arts relatie factoren en factoren met betrekking tot informatievoorziening (5). Beperkingen in het delen van informatie, met name over de diagnose, behandelopties en prognose, is een belangrijk tekort in huidig SDM gedrag, en gebrek aan tijd wordt gezien als een oorzaak (5). Online digitale patiëntdossier worden steeds meer gebruikt en hebben als doel patiënten te informeren over hun huidige medische situatie (6). Informatie op deze portals is niet altijd gemakkelijk te begrijpen voor patiënten en het lezen van deze rapporten kan verontrustend zijn (7-9). In dit proefschrift hebben we geprobeerd om deze rapporten begrijpelijker en minder verontrustend te maken, zodat deze patiëntinformatie ondersteunend kan zijn bij de besluitvorming.


**Figuur 9.1.** Overzicht van de verschillende hoofdstukken

Het primaire doel was het testen van een SDM interventie in de zorg voor heup- en knieartrose. Het programma bestond uit een training voor clinici en een keuzehulp voor patiënten (ptDA[2]). Vervolgens hebben we een vervolgonderzoek uitgevoerd met de ambitie de implementatie van dit SDM programma te evalueren, met speciale aandacht voor de toepassing van de ptDA in de dagelijkse klinische zorg.

Hieronder vindt u de verschillende hoofdstukken waarin antwoord wordt gegeven op de opgestelde onderzoeksvragen.

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1 In het Nederlands wordt de term gedeelde samen beslissen of gedeelde besluitvorming gebruikt. Aangezien *Shared Decision Making* in de Nederlandse taal ook een bekend en veelgebruikte term is zullen wij deze hanteren in de Nederlandse samenvatting.

2 Engelse term voor keuzehulp is *patient decision aid*, wat wordt afgekort als ptDA. Wij gebruikten in deze samenvatting de afkorting ptDA voor keuzehulp.

***Wat is het huidige niveau van SDM en beïnvloeden patient factoren zoals ziekteangst het niveau van SDM?***

In **hoofdstuk 2** werd een prospectieve cohortstudie uitgevoerd waarin we het huidige niveau van SDM hebben gemeten in de setting van een orthopedische polikliniek. Wij hebben onderzocht of psychologische factoren zoals symptomen van depressie, gezondheidsangst en catastrofale pijn, determinanten zijn voor SDM. Voor het meten van de SDM zijn audio-opnamen van 130 consulten gebruikt. Hiervoor hebben we een gevalideerde tool gebruikt die SDM gedrag scoorde op basis van acht competenties (10). De gebruikte competenties zijn *Partnerschap met patient aangaan*, *Rol in besluitvorming vaststellen*, *Informatievoorkeur bespreken*, *Verwachtingen en wensen van de patiënt bespreken, Identificeer keuzeopties voor behandeling, Discussie voeren over de keuzes en impact hiervan op patiënt*, *Komen tot een gezamenlijke beslissing,* en *Akkoord gaan met een actieplan* (10). De tevredenheid van de patiënten werd gemeten met behulp van een visueel analoge schaal, met score mogelijkheden tussen een range van 0 tot 10. De resultaten toonden aan dat de hoogste gemiddelde score werd waargenomen voor de SDM competentie *Akkoord gaan met een actieplan* (het bespreken van een actieplan en vervolgafspraken maken). De laagste scores werden waargenomen voor *Rol in besluitvorming* (het vaststellen en beoordelen van de voorkeurs rol van de patient in het besluitproces) en *Informatievoorkeur* (bespreken van de voorkeur van informatie, zoals hoeveelheid en manier van informatie overdracht). Het waarnemen van het SDM element *Identificeer keuze* (uitleggen, zonder bias, dat er meerdere behandelopties zijn) ging gepaard met een hogere patiënttevredenheid. De bevindingen suggereren dat patiënten meer tevreden zijn wanneer alle beschikbare behandelingsopties neutraal worden besproken. Er werd minder SDM werd waargenomen in consultaties waarbij patiënten meer gezondheidsangst uitten ($r=0.25$, $p=0.004$). In de regressieanalyses bleek gezondheidsangst een voorspeller te zijn van zowel een lagere patiënttevredenheid als lagere SDM.

Conclusie**:**

- De SDM competenties *Rol van besluitvorming* en *Informatievoorkeur* werden het minst waargenomen.
- Er was een grotere patient tevredenheid wanneer verschillende behandelopties werden besproken.
- In consultaties met patienten die meer ziekte angst hadden, werd minder SDM waargenomen en die patienten waren tevens minder tevreden.

***Zijn radiologie verslagen beter begrijpelijk en minder verontrustend voor patienten als deze worden herschreven?***

**Hoofdstuk 3** beschrijft het onderzoek waarin we radiologieverslagen hebben herschreven met het doel om deze beter begrijpelijk en minder verontrustend te maken voor patienten. In ons onderzoek hebben we MRI verslagen herschreven naar een leesniveau van groep acht en we hebben neutrale beschrijvende woorden en optimistische interpretaties gebruikt, gebaseerd op wetenschappelijke literatuur. Honderd patiënten hebben zowel het originele als het herschreven verslag gelezen. De herschreven verslagen resulteerden in een beter begrip (8.1 vs. 4.2, p <0.001, range 0-11) en een hogere bruikbaarheid (7.1 vs. 4.8, p <0.001, range 0-11) bij vergeleken met de originele verslagen. Ook waren de herschreven verslagen significant minder verontrustend voor patienten in vergelijking met de originele verslagen.

Conclusie:

- Wanneer radiologieverslagen werden herschreven naar meer patient vriendelijk, dan waren ze minder verontrustend in vergelijking met de oorspronkelijke verslagen.
- Herschreven radiologie verslagen waren beter begrijpelijk voor patienten dan de originele verslagen.

***Wat zijn de gerapporteerde niveaus van attitude, subjectieve norm en ervaren controle met betrekking tot SDM gedrag van arts-assistenten en orthopedisch chirurgen?***

**Hoofdstuk 4** onderzocht het huidige SDM gedrag van clinici. De Theory of Planned Behaviour (TPB) werd gebruikt om het huidige gedrag te verklaren. Volgens de TPB wordt gedrag bepaald door attitude (de positieve of negatieve evaluatie van het gedrag door de persoon), subjectieve norm (de waargenomen sociale druk of verwachtingen om het gedrag wel of niet uit te voeren) en ervaren gedragscontrole (het ervaren gemak of de moeilijkheid om het gedrag uit te voeren) (11). Er werd een enquête uitgezet die was opgesteld met behulp van een handleiding voor het maken van TPB vragenlijsten (12). De vragenlijst werd ingevuld door 71 arts-assistenten en 64 orthopedisch chirurgen in Nederland. We beoordeelden de attitude, subjectieve norm en ervaren gedragscontrole in relatie tot SDM gedrag. We vonden dat deze drie elementen bepalend waren voor SDM gedrag (R2=0.27, p<0.001). Ervaren gedragscontrole was de belangrijkste voorspeller (b=0.604, 95% BI:0.291 tot 0.917) en de gemiddelde score voor ervaren gedragscontrole van arts-assistenten was significant lager dan de score van orthopedisch chirurgen.

Conclusie:

- Van de verschillende TPB items bleek ervaren gedragscontrole de belangrijkste voorspeller van SDM gedrag.

- Arts-assistenten ervaarden minder controle over SDM-gedrag in vergelijking met orthopedisch chirurgen.
- De resultaten van dit onderzoek kan worden gebruikt om een interventieprogramma voor SDM te ontwikkelen met TPB als theoretisch construct.
- In toekomstige SDM trainingsprogramma's moet aandacht worden besteed aan het SDM gedrag van arts-assistenten, omdat zij aangeven minder controle te hebben over SDM-gedrag dan orthopedisch chirurgen.

***Wordt het niveau van SDM verhoogd door een SDM interventie programma, welke zowel aan patiënten als artsen gericht is?***

We hebben een interventie programma ontwikkeld die als doel had om de mate van SDM in de zorg voor heup- en knieartrose te vergroten (**hoofdstuk 5**). De interventie was gebaseerd op de TPB en we hebben de informatie uit het vorige hoofdstuk gebruikt bij de ontwikkeling. De interventie bestond uit een training voor artsen en keuzehulpen voor de patiënten (ptDAs) (13). De training bestond uit twee sessies van twee uur en werd voorafgegaan door een e-learning (14). Alle deelnemende artsen werden getraind om hun kennis en communicatieve vaardigheden ten aanzien van SDM te verbeteren. Tijdens consultaties werd een ptDA werd aangeboden als een operatie een van de mogelijke behandelingsopties was. Het betrof een pre- post interventie design studieopzet. De primaire uitkomstmaten waren SDM (gemeten met de SDM-Q-9 en Decisional Conflict Scale) en patiënttevredenheid (visueel analoge schaal). Secundaire uitkomstmaten waren de attitude en kennis van artsen ten aanzien van SDM en de mate van gebruik van de ptDA's door patienten. In totaal werden 317 patiënten in het onderzoek opgenomen. We vonden geen significant verschil in de primaire uitkomstmaten tussen de interventie groep en de controle groep. De gemiddelde kennisscore van artsen was significant hoger na de training vergeleken met vóór de training (12.70 versus 10.0 punten, 95% BI: -2.85 tot 0.39). Het gebruik van de ptDA was laag, en slechts 17% van de in aanmerking komende patiënten gebruikte een ptDA. De mate van SDM, gemeten met de SDM-Q-9, was hoger bij patiënten met een middelbare opleiding in vergelijking met laagopgeleide patiënten (verschil 9.91, p=0.004), bij patiënten die chirurgen bezochten in plaats van arts-assistenten (verschil 5.46, p=0.044) en wanneer een operatie door patiënten werd gekozen en gewenst, vergeleken met situaties waarin een operatie was gewenst maar niet gekozen (verschil 15.39, p=0.036).

Conclusie:

- Ons interventie programma had geen effect op de mate van SDM en geen effect op patiënttevredenheid.
- Kennis over SDM was na de training beter dan voor de artsen communicatie training

- De meeste patiënten wilden een operatie en ze waren het meest tevreden als uiteindelijk voor deze behandeling werd gekozen.
- Als patienten arts-assistenten consulteerde waren ze minder tevreden en gaven ze aan dat de mate van SDM lager was.
- Het gebruik van de ptDA was beperkt en slechts 17% van de in aanmerking komende patiënten gebruikte deze tool.

***Wat waren de belemmerende factoren voor een succesvolle implementatie van de keuzehulpmiddelen?***

In het laatste hoofdstuk (**hoofdstuk 6**) hebben we de implementatie van de ptDA's, die in het vorig hoofdstuk zijn gebruikt, geëvalueerd. We hebben een *mixed-method* benadering gebruikt om de volgende zaken te onderzoeken: (1) barrières en bevorderende factoren van ptDA-gebruik, (2) redenen van patiënten om ptDA-gebruik af te slaan en (3) patiëntfactoren die geassocieerd waren met het gebruik of afslaan van de ptDA. In vergelijking met patiënten die de ptDA gebruikten, hadden patiënten die bedankte voor het gebruik meer pijn (VAS pijn van 7.2 versus 6.2, $p<0.001$), een slechtere kwaliteit van leven (op 4/6 EQ-5D-3L-subschalen) en werd er vaker een chirurgische behandeling gekozen (4% versus 28%, $p<0.001$). Van de patiënten die ptDA gebruik afsloegen, gaf 46% aan over voldoende informatie te beschikken en klaar te zijn om een beslissing te nemen zonder de ptDA. De geïnterviewde artsen vonden de ptDA minder geschikt voor patiënten met gevorderde artrose en voor patienten die reeds een behandeling in de eerste lijn hadden ondergaan. De artsen waren van mening dat de ptDA het nuttigst was voor nieuw gediagnosticeerde patiënten die nog geen eerdere behandeling hadden ondergaan. De huisartssetting werd gezien als veelbelovend voor de implementatie van ptDA, maar sommige artsen uitten hun bezorgdheid die deze suggestie tegensprak. Ze vroegen zich af of er in de eerstelijnszorg een bevestigde diagnose kon worden gesteld en vonden het niet gepast dat een huisarts chirurgische behandelingsopties besprak tijdens het doorlopen van de PtDA. Om de acceptatie van ptDA te vergroten, moeten deze zorgen van orthopeden worden geadresseerd.

Conclusie:

- De ptDA werd geschikt bevonden voor patiënten met een recente diagnose en minder geschikt voor patiënten met gevorderde heup- of knieartrose.
- Implementatie van de keuzehulp eerder in het ziekteproces kan mogelijk resulteren in een uitgebreider gebruik van deze tool.
- Uit ons onderzoek is gebleken dat bij de implementatie van een ptDA rekening dient te worden gehouden met de context en kenmerken van de patiënt.

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# Biography

Jeroen Bossen was born on 30 November 1985 in Bergen, the Netherlands. He is the youngest son of Johan and Bertie and brother of Daniël. After finishing secondary school at the Vrije School in Bergen and travelling for half a year, he started medical school at the Vrije Universiteit Amsterdam in 2006. During his final year he completed a 6 month research fellowship in Boston, USA (supervisor: dr. David Ring). In 2013 Jeroen graduated and started working as a junior orthopedic resident at the Onze Lieve Vrouwe Gasthuis in Amsterdam. He soon moved to the south of the Netherlands and began working as a junior resident in general surgery at Atrium MC Heerlen.

In 2015 he started his specialist training in orthopaedics at the Zuyderland MC in Heerlen (supervisor: dr. M.N. Sosef). In 2016 he continued his residency at the University Hospital Maastricht (supervisor: dr. H. Staal).

During his residency, he continued the work on shared decision making that he had started in Boston, and developed the ambition to further improve his research skills and to obtain a PhD. In 2017, the first plans for a PhD programme were made with prof. dr. Heyligers and prof. dr. Erik Driessen from the School of Health Professions Education in Maastricht. A collaboration with prof. dr. Trudy van der Weijden and dr. Jesse Janssen (Family Medicine, CAPHRI) was soon established.

In 2017 Jeroen continued his orthopedic residency at the Zuyderland MC in Heerlen (supervisors: prof. dr. Ide Heyligers and dr. Edwin Jansen) and completed his specialist training in March 2021.

In May 2021 he started a fellowship in hip surgery at the UZ Leuven, Belgium (supervisor: dr. Ghijselings). This was followed by a fellowship in hand, wrist and elbow surgery (supervisors: Prof. dr. Degreef and dr. van Nuffel) in November 2021. In February 2023 he started as a consultant orthopaedic surgeon with a strong focus on hand, wrist and elbow surgery at the UZ Leuven. He lives with his girlfriend Melline Somers and they recently moved to Herent, Belgium.