

Building ground for didactics in a patient decision aid for hip osteoarthritis. Exploring patient-related barriers and facilitators towards shared decision-making

Espen Andreas Brembo^{a,b,*}, Hilde Eide^a, Mirjam Lauritzen^c, Sandra van Dulmen^{a,d,e}, Jürgen Kasper^f

^a Science Centre Health and Technology, University of South-Eastern Norway, Papirbredden - Drammen kunnskapspark Grønland 58, 3045 Drammen, Norway

^b Department of Behavioral Sciences in Medicine, University of Oslo, Domus Medica, Sognsvannsveien 9, 0372 Oslo, Norway

^c Centre for Shared Decision Making, University Hospital of North Norway, Hansine Hansens veg 67, 9019 Tromsø, Norway

^d Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, the Netherlands

^e Nivel (Netherlands Institute for Health Services Research), Otterstraat 118-124, 3513 CR, Utrecht, the Netherlands

^f Department of Nursing and Health Promotion, Oslo Metropolitan University, Pilestredet 46, 0167 Oslo, Norway

ARTICLE INFO

Article history:

Received 25 June 2019

Received in revised form 31 January 2020

Accepted 3 February 2020

Keywords:

Osteoarthritis

Patient preference

Practice improvement

Shared decision-making

Patient decision aids

Theory of planned behavior

Qualitative research

ABSTRACT

Objective: The aim of the present study was to explore patient-related barriers and facilitators towards shared decision-making (SDM) during routine orthopedic outpatient consultations as part of the process of developing a patient decision aid (PDA) for patients with hip osteoarthritis (OA).

Methods: Consultations comprising nineteen hip OA patients referred to an orthopedic surgeon for treatment decision-making were observed, audio recorded and transcribed. Iterative thematic analysis proceeded, based on a taxonomy of generic patient-related barriers towards SDM grounded in the Theory of Planned Behavior (TPB).

Results: A targeted taxonomy provided a structured overview of 26 factors influencing hip OA patients' intention to engage in SDM. Patients' perceived ability to change the agenda of the visit emerged as seminal factor and was added to the generic taxonomy.

Conclusion: Using a TPB-based taxonomy, we were able to identify and structure generic and context specific SDM barriers. Addressing patients' communication self-efficacy should be included as didactic feature in PDAs.

Practice implications: PDAs for hip OA should be designed for the broad spectrum of decision-making support needs occurring throughout the continuum of the disease. The provided taxonomy may contribute as guidance within implementation strategies that aim to support patients' intentions to engage in SDM.

© 2020 The Author(s). Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

1. Introduction

Worldwide, osteoarthritis (OA) represents a major cause of chronic musculoskeletal pain and physical disability [1]. Decision-making in OA treatment requires active involvement of patients for many reasons. Due to the poor association between radiographic evidence and the individual experience of symptoms [2], the patients' burden of living with this disease is difficult to consider

from the physician's viewpoint alone. Treatment options for hip OA range from education, physical therapy, pacing of activities, weight reduction and pharmacological treatment to invasive surgery involving total hip replacement (THR) [3–5]. With regard to their impact on lifestyle, and in particular the potentially long timeframes within which such decisions can be made, all of them are considered sensitive to individual preferences [6,7]. Decisions pertinent to the different phases of the hip OA continuum [8] should therefore predominantly rely on patient preferences, rather than recommendations from medical guidelines alone. A major challenge is, however, the identification and optimal timing of appropriate decisions [9,10], and how to adopt communication strategies that promote informed choice [11].

Shared decision-making (SDM) is a method for structuring the process where clinicians and patients share the best available

* Corresponding author at: University of South-Eastern Norway, Post Box 7053, 3007 Drammen, Norway.

E-mail addresses: Espen.Andreas.Brembo@usn.no (E.A. Brembo), Hilde.Eide@usn.no (H. Eide), Mirjam.Lauritzen@unn.no (M. Lauritzen), S.vanDulmen@nivel.nl (S. van Dulmen), Jurgen.Kasper@oslomet.no (J. Kasper).

evidence on the likely benefits and harms of each option, and where they negotiate how those options fit the patient's preferences [12]. Makoul and Clayman describe nine essential elements that must be present for patients and providers to engage in the process of SDM [13]. Table 1 shows six steps derived from the Multifocal Approach to Sharing in SDM (MAPPIN'SDM, items 1–6) [14], which has been proven as the measurement instrument that best covers the nine essential SDM elements [15].

Many steps have been taken to implement SDM internationally, but there is still an evident gap between aspiration and daily clinical practice [16]. The most cited barriers health care providers experience include 1) time constraints, 2) lack of agreement with the applicability of SDM to the patient, or 3) to the clinical situation [17,18]. Patients' capacity to participate in SDM depends on two key factors: *knowledge* and *power* [19]. Knowledge refers to treatment options, and about personal values and preferences. Power refers to the patients' perceived capacity to influence the decision-making process. Reviewing the current evidence, there is a lack of studies that exclusively explore decision-making for patients with hip OA.

This study contributes to the development of a patient decision aid (PDA) to support hip OA treatment decisions guided by the Decision Aid Factory (DAfactory) [20]. The DAfactory is an overarching concept providing guidelines to develop and implement SDM in the clinical practice; amongst which a detailed guide to develop PDAs complying with The International Patient Decision Aid Standards (IPDAS) Collaboration [21] and applying the Theory of Planned Behavior (TPB) [22] in the design of didactics tailored to particular patient groups. No empirical studies have yet described and reported findings from this new and innovative theory-based method.

The aim of the present study was to explore barriers and facilitators influencing hip OA patients' capacity and opportunities to engage actively in SDM. A secondary aim was to determine the utility of the observation method provided by the DAfactory. Two research questions were addressed: 1) How are patients involved in decisions related to treatment of hip OA? 2) Which patient-related factors facilitate or impede SDM in hip OA?

2. Material and methods

2.1. Design and setting

The study had an observational design allowing for theory driven in-depth investigation of real OA decision-making

Table 1
Six SDM steps according to the MAPPIN'SDM observer instrument.

1. Defining problem	Draw attention to a concrete problem as one that requires a decision-making process
2. Key message	Indicate that from a medical point of view there is more than one way to deal with the problem and clarify why it is up to the patient to weigh up possible consequences
3. Discussing options	Discuss the pros and cons of the different options, including "doing nothing" when applicable
4. Expectations and worries	Explore expectations (preferences) and concerns (fears) about how to manage the concrete problem
5. Indicate decision	Selection of an informed and preference based option, including deferment when applicable
6. Follow-up arrangements	Arrangements about how to implement the decision and how to evaluate it

Applies to all steps: Ensure mutual understanding and adapt communication strategy accordingly throughout the conversation.

processes taking place at an orthopedic outpatient clinic. The chosen method intended to support ecological validity by capturing the immediate communication challenges patients with hip OA experience during short outpatient consultations. A guiding principle was to get as close and direct insight into the ongoing communication as possible, without affecting it by potentially invasive presence.

2.2. Participants and data collection

We intended to observe and audio record about 20 outpatient consultations with orthopedic surgeons and cognitively unimpaired patients considering a decision for primary hip OA with more than one treatment option. In cooperation with an orthopedic outpatient clinic at a Norwegian local hospital, we approached eligible participants by attaching an information and consent letter to the scheduled appointment letter. A consecutive sampling procedure followed until the required sample size was achieved.

Data were obtained through direct observation by the main researcher (EAB) and audio recording. At the time of data collection, EAB had theoretical and scientific knowledge about SDM and underwent comprehensive observation training and supervision by JK, who is an experienced SDM researcher and trainer. We conducted two preparatory observation sessions to become familiar with the observation guide and calibrate the observational lens. Direct observation enabled insight into structural features and the non-verbal events, whereas audio recording allowed for subsequent comprehensive qualitative data analysis. Information about patients' age and sex was collected as well as extent of surgeons' previous communication training in SDM.

2.3. Description of observation method and analysis

2.3.1. Observation

An observation guide included instructions about how to tune in and reveal relevant events. Each observation session was guided rigorously by using imagination of an *ideal* SDM process as a sensory corridor. This would entail that the communication strategies applied concurred with essential SDM elements [13], and at a practical skills level, the six SDM steps [14]. The observer sought identification with the patient and made field notes based on projections occurring from this state as data material for further analysis. Recognition of relevant events results from continuous comparison of the ideal with the actual process and identification of either divergence or accordance. Events are utterances or any other kind of communicative behaviors, including lack of behavior where it would have been appropriate. In order to relate in-depth observation through the patient's perspective, the consultations were described according to typical structural consultation features (e.g. diagnosis and assessment, negotiation of alternatives and making a treatment decision) and the extent and manner of the patient's involvement in decision-making.

2.3.2. Taxonomy of barriers to SDM

We applied a taxonomy of a priori categories representing generic patient-related barriers towards SDM as basis for a combined deductive and inductive analytic approach to identify and structure distinctive events. This classification is based on corresponding observation sessions as part of DAfactory PDA developments in other clinical contexts. The taxonomy is structured according to the following three TPB constructs, proposed to determine an individual's intention (i.e., an indication of a person's readiness) to perform a particular behavior [22].

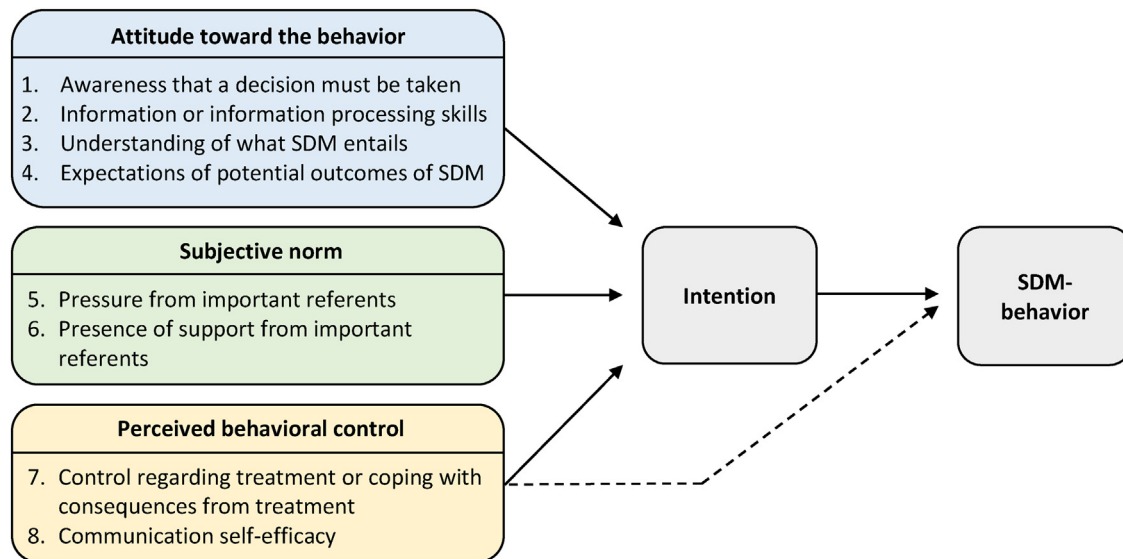


Fig. 1. Modified Theory of Planned Behavior diagram, including the main categories of the taxonomy of patient-related barriers/facilitators towards SDM-behavior.

- 1) Attitude toward performing the behavior: the degree to which a person has a favorable or unfavorable evaluation or appraisal of the behavior.
- 2) Subjective norm: the perceived social pressure to perform or not to perform the behavior.
- 3) Perceived behavioral control: the perceived ease or difficulty of performing the behavior, assumed to reflect past experience as well as anticipated impediments and obstacles.

Moreover, the generic taxonomy is organized across three abstraction levels; the level of the three TPB constructs, the level of subcategories providing abstracted groups of beliefs and the level of amalgamated empirical descriptions. Fig. 1 displays a modified TPB-model including eight main level a priori categories.

2.3.3. Qualitative analysis

The data was analyzed by two researchers (EAB and JK) using an iterative thematic approach inspired by template analysis (TA) [23]. This involved repeated shifting between deductive and inductive approaches. TA allows for the definition of 'a priori' codes, represented by the generic taxonomy in this study. NVivo11 qualitative data analysis software was used for data management [24]. Any divergence regarding recognition and allocation of essential events was resolved by discourse. The analysis consisted of three main steps:

Step 1: The audio recordings were transcribed soon after the observation sessions. Field notes and memory recall were used to identify potentially important sequences of events. These events were carefully interpreted and thematically labeled in accordance with the main and subcategory levels of the generic taxonomy.

Step 2: Through iterative processes, additional events were identified by determining applicability of existing categories of the generic taxonomy. Amalgamated empirical examples relevant to hip OA patients were constructed, leading towards a targeted TPB taxonomy representing barriers specific for hip OA patients.

Step 3: A refinement process intended to determine if any new elements were applicable and lastly, to confirm the final taxonomy.

2.4. Ethical considerations

The Norwegian Centre for Research Data approved the study. The study complies with the ethical standards and principles

stated in the Helsinki declaration [25]. All participants received both written and oral information about the study and patients gave informed written consent.

3. Results

3.1. Patient characteristics and decision outcomes

Of the 20 patients approached, 12 women and 7 men agreed to participate. The youngest was 40, the oldest 84 years old. The consultations took place on two different days, and lasted an average of 22 min (range 11–40). Two male surgeons were involved and had not received any previous SDM communication skills training. Nine patients ended up with the decision to undergo THR. The remaining patients were either scheduled for follow-up after further diagnostic interventions ($n = 3$), considered medically unfit for surgery ($n = 1$) or advised to postpone surgery by optimizing conservative treatment ($n = 6$). Table 2 summarizes patient characteristics and decision outcomes.

3.2. Structural features of the consultations

The consultations had similar content and followed a logical structure arising from the given context, which included consideration of the patients' allocation within the disease continuum, and the specific nature of OA (Fig. 2). Notably, each outpatient consultation was merely representing one sequence within a comprehensive and longitudinal decision-making process, which over time potentially involves several consultations with different health professionals (HPs).

The surgeons seemed to regard their task more or less explicitly to (just) considering the medical indication for prosthetic surgery. As illustrated in Fig. 2, this *diagnostic* decision-making proceeded simultaneously with the more implicit *treatment* decision-making process, which is concerned with reaching the most optimal treatment decision.

In our sample, phase one is predominantly used to confirm an OA diagnosis and to discuss its individual manifestation with regards to ADL and quality of life. This happened by consideration of available information in the referral document, X-rays, history taking and a focused clinical assessment.

Table 2
Patient characteristics and decision-making outcomes.

ID	Age	Gender	Decision-making outcomes
1	40-44	Male	Postpone THR. Follow-up in six months. Physiotherapy, weight loss and increase dose of Etoricoxib.
2	80-84	Female	Not medically fit for THR. Increase pain medication.
3	50-54	Female	Accepted for THR and placed in the queue. Weight loss and smoking cessation.
4	75-79	Female	Postpone THR. Follow-up in six months after lumbar MRI scan. Continue with physiotherapy.
5	80-84	Female	Postpone THR. Follow-up in three months, continue physical therapy and start Etoricoxib.
6	65-69	Male	Accepted for THR and placed in the queue.
7	75-79	Female	Accepted for THR and placed in the queue. Smoking cessation.
8	70-74	Female	Accepted for THR and placed in the queue. Smoking cessation.
9	65-69	Female	Postpone THR. Follow-up in three months after MRI scan. Cortisone injection for trochanter bursitis.
10	75-79	Female	Accepted and agreed time for THR. Postoperative physiotherapy.
11	65-69	Female	Accepted and agreed time for THR. Smoking cessation.
12	60-64	Male	Accepted for THR and placed in the queue. Weight loss.
13	60-64	Female	Rejected for THR. Follow-up after hip MRI scan.
14	70-74	Male	Postpone THR. Follow-up in six months. Cortisone injection for trochanter bursitis.
15	70-74	Female	Patient do not prefer THR. Treatment as usual.
16	55-59	Male	Rejected for THR. Follow-up of back-pain after lumbar MRI scan.
17	55-59	Female	Accepted for THR and placed in the queue. Preoperative physical exercise.
18	50-54	Male	Accepted for THR and placed in the queue.
19	55-59	Male	Rejected for THR. Follow-up by general practitioner.

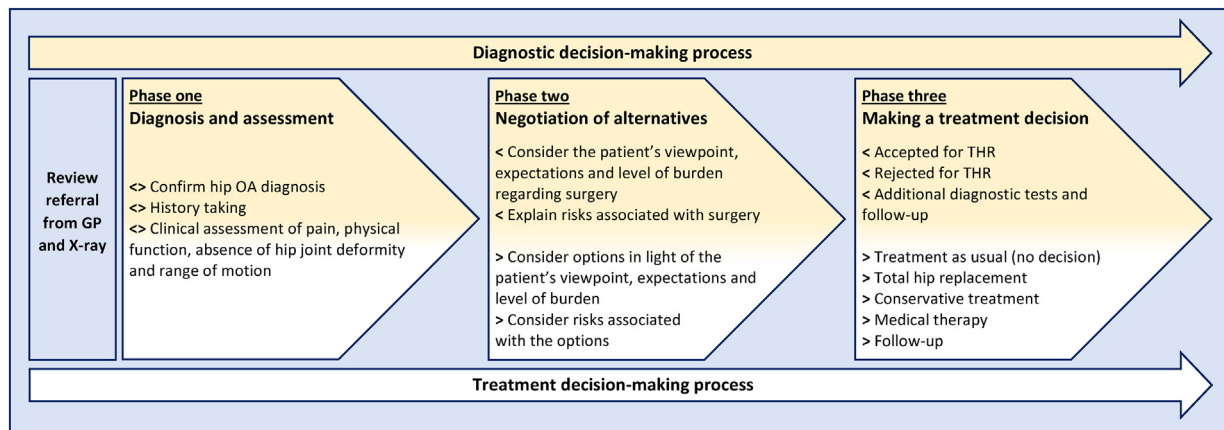


Fig. 2. Overview of the typical course of an orthopedic outpatient hip OA consultation, demonstrating two overlapping decision-making processes.

In phase two, information about the surgical option was in most cases given priority. Depending on individual characteristics, engagement and arguments from both parties varied. In case of suspicion of other possible reasons for the troublesome symptoms, the surgeons challenged the patient's motivation for surgery by putting more emphasis on explaining the associated risks. If the medical indication seemed clear, the surgeons prioritized encouragement of the patient by emphasizing possible benefits. Mutual engagement in critical negotiation of benefits and harms appeared influenced by varying attitudes on the patients' side.

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

3.3. Facilitators and barriers towards SDM

We identified 25 of the 31 subcategories of the generic taxonomy and included one additional barrier relating to patients' communication self-efficacy (marked with bold). This barrier occurs for most patients in this sample given the situation that two communication processes happen simultaneously as described in

the previous section. The latter barrier was included in the revised version of the generic taxonomy yielding 32 subcategories (Table 3).

3.3.1. Patients' attitudes towards SDM-behavior

This theme reflects patients' awareness of options and that a decision must be made, possession of relevant knowledge, information and information processing skills, understanding of what SDM entails in practice, and expectations of potential outcomes of SDM. We identified 14 of the 18 factors relating to this category, and provided amalgamated empirical examples. A common notion was that patients seemed uninformed about OA and the available choices. This was based on the tendency of pursuing a passive role, implying an understanding that their contribution into the decision-making process was primarily to answer the surgeons' questions. In addition, their primary agenda for the visit was hardly ever disclosed directly by the patients. In these cases, the patients tended to follow the surgeon's lead. This apparent absence of initial talk about personal goals, and how they may relate to the available choices, seemed to limit patients' opportunities for active involvement. Previous experience with orthopedic consultations and a history of rejection for surgery seemed to influence patients' attitudes and facilitate involvement. A female patient (P3) had prepared for the consultation by bringing documentation from previous specialist and primary care visits.

Table 3
Revised DAfactory taxonomy of patient-related barriers towards SDM.

L1: Main categories	L2: Abstracted groups of beliefs	L3: Amalgamated empirical examples	L1: Main categories	L2: Abstracted groups of beliefs	L3: Amalgamated empirical examples
1. Awareness that a decision must be made	Being aware of available treatment options	My only concern is to receive treatment for my pain	5. Pressure from important referents	Having excessive trust on others opinions/advice	I believe that the surgeon can decide what is best for me
	Expecting that the decision is already made by the doctor	Nothing I mean or say can influence whether or not I receive hip replacement		Feeling of responsibility for significant others	My employer expects me to return to work in April. I need an operation before that.
	Expecting my predetermined decision to be final	I am convinced that the only solution for my problem is to replace my hip		Being unfamiliar or uncomfortable with taking an active role in the decision-making process	My doctor tells me what to do, and I usually agree with his decisions.
	Future-oriented focus (avoid any personal uncertainties that might arise in the decision-making process)	My focus is what I can expect after undergoing total hip replacement		Assuming that the doctor take one's personal needs into account and makes the optimal decision	I believe that the surgeon knows what it most important for me
	<i>Unreadiness to make a decision (including to defer treatment decision) or avoiding negotiations of a decision</i>			<i>Avoiding conflicts or other social consequences</i>	
2. Information and cognitive processing skills	Being uninformed and/or lacking necessary knowledge	I don't know much about osteoarthritis or which treatment alternatives exist	6. Presence of support from important referents	Lacking social support in the decision-making process (impacts motivation/self-efficacy)	It would help to bring someone to the consultation so that I would remember what to ask the surgeon
	Having difficulties to understand the information (e.g. medical jargon)	It is sometimes difficult to understand what the surgeon means when he talks so quickly		Experiencing conflicting opinions among health professionals	I have been to several doctors and they all have different opinions about what treatment I should receive.
	Having difficulties to perceive the information (e.g. present emotions are blocking)	I am so excited about whether or not I receive the operation that I do not perceive what the doctor says		<i>Lacking communication with important referents about to the forthcoming decision</i>	
	Having difficulties to evaluate the information (e.g. too much information)	It is difficult to concentrate when the surgeon both talks and asks questions while doing physical examinations			
3. Understanding of what SDM entails in practice	Expectation of a passive role in the decision-making process	My contribution into the decision-making process is to answer questions.	7. Control regarding treatment or coping with consequences from treatment	Being uncertain around possible challenges or demands of treatment options	I do not believe that I can stop smoking or lose enough weight
	Expectation of a traditional doctor-patient relationship: the patient disclose personal information and the doctor makes the decision	I am here because I want an operation – I want to move on with my life. However, I do not have the authority to make this decision. It is the doctor's responsibility		Being uncertain around possible challenges or demands of the consequences of treatment	I am afraid what it actually entails to put a prosthesis into my body
	<i>Understanding of the doctor as specialist, but patient makes the decision</i>				
4. Expectations of potential outcomes of SDM	Relying heavily on the opinions of the doctor over own preferences and values	I don't really believe my views matter when it comes to deciding which treatment is best	8. Communication self-efficacy	Feeling of shame (self-image, lack of knowledge)	I know that I should have done more to lose weight
	Frustration about others expectations of being actively involved in the decision-making process	I just want my doctor to decide what I should do		Having low self-confidence	I don't think my concerns are important enough to discuss with the orthopedic surgeon
	Strong conviction with regards to prognosis	I do whatever it takes to get rid of this pain		Belief whether the outpatient setting is a suitable arena to discuss/disclose personal feelings and concerns	The surgeon does not have time to listen to my concerns, so I keep them for myself.
	Expectation of not being entitled of control over own health-situation	I am anxious and I need the surgeon to tell me what to do			
	<i>Having concern of being self-responsible for any negative treatment outcomes</i> <i>Assuming that all treatment options are equally effective</i>			Feeling of being disempowered in changing the agenda	My main concern is that I want to discuss which of the available treatment options fits best to me in my current situation

Main categories 1–4 represent attitude toward the behavior, 5–6 subjective norms and 7–8 perceived behavioral control. Level 1 and level 2 categories are generic, whereas the empirical examples at the third abstraction level are context specific. *Element not identified in this clinical context (italics). New element of the generic taxonomy (bold).*

From the very start, she was standing upright and engaged actively during the initial history taking, and her agenda was explicitly stated.

O: *What do you think is the solution for your problem?*

P: *To replace my hip!*

O: *And you are convinced about that?*

P: *Mm, yes!*

From this point, the surgeon worked with the patient to make her understand the increased risks associated with smoking and obesity. However, this did not change the patient's motivation to undergo surgery, as she argued that previous surgeries had been successful despite smoking and that other overweight people in her social network had undergone hip surgery. With regard to the taxonomy, this illustrates a patient expecting a predetermined decision to be final. Furthermore, the proceeding dialogue shows signs of strong conviction concerning prognosis, which in turn may reveal unawareness of what an SDM process could gain. The patient seems to pursue whatever pain-relieving treatment, and combined with a conviction that surgery is the only option that may help her to achieve this, she may block out any information or arguments that may challenge this conviction.

3.3.2. Subjective norms influencing SDM-behavior

This theme reflects the presence or absence of influence from significant others on the decision-making process. Six of the eight generic barriers were identified. The surgeon's professional judgment about the surgical indication was directive for the overall decision-making process, and many of the patients seemed to trust this judgment uncritically. Excessive trust or uncritical acceptance of the surgeons' advice may lead to passive behavior, mask patients' preferences, prevent informed decision-making, and thus act as a barrier towards SDM. The following example illustrates this finding. A male patient (P1) in his forties was told by the surgeon at the very beginning of the consultation that surgery was out of the picture, even before eliciting the patient's agenda for the visit.

O: *There are some signs of wear and tear on the pictures [P: Yes]. But there isn't . . . there is still some cartilage left [Yes]. And that . . . that is a good thing—right? [Yes] You are simply too young for a hip replacement [P: Yes, yes . . .].*

Here, and in the following, the patient appeared to accept the judgment of the surgeon without attempts to challenge his arguments or conviction.

Another example (P10) illustrates how the surgeon's initial judgment directly influenced the treatment decision-making process. Alternatives to surgery were practically ruled out, and the following information exchange circled around the surgical procedure and what to expect in terms of pain and physical function outcomes (i.e. not balanced against the potential benefit of non-surgical options).

O: *It is . . . when we replace your hip joint- because that is the appropriate procedure for you now [P: Ok, mhm?]. It has progressed so much [P: Mhm], that there is nothing to do to fix it . . . we simply have to put in a prosthesis [P: Yes]. Right? I can almost say that even before doing any examinations.*

Three patients had a family member present during the consultation. This seemed to facilitate more discussions and deliberations around treatment alternatives.

O: *I think that we should proceed with this plan, and then we can arrange a follow-up with a control [P: Mhm..]. Then we will see how it goes [P: Yes].*

Family member: *Yes, but I want to mention one thing.. I mean, you are very keen to spend time at the cabin during the summer [P: Yes].. and it is not easy for you to get up there- to stay there.. [P: No,*

it isn't]. So, as long as you have the cabin and want to stay there, it is . . .

P: *What are you thinking?*

Family member: *I think that you have this pain and trouble walking, and to get around.. that makes it difficult for you to spend time there.. and that is something you really want to do – to stay there.. [P: Yes..] So, that is something that is part of the overall consideration (Family member, P5).*

Given this apparent facilitating effect, the absence of a third person who provides important perspectives relevant to the treatment decision-making process may act as a barrier towards SDM.

3.3.3. Perceived behavioral control influencing SDM-behavior

This theme represents patients' perceived control regarding treatment or coping with the consequences from treatment, and communication self-efficacy. We added one barrier at the subcategory level of the generic taxonomy, and provided corresponding empirical descriptions of a total of six factors. Treatment for hip OA usually requires life-style changes. A request by others to engage in behavior change-dependent treatment may cause emotional and cognitive distress and consequently influence their perceived control beliefs in communication with a medical specialist. Feelings of uncertainty, fear, shame or low confidence relating to previous management attempts are likely to influence own ability or readiness to raise such personal and potential sensitive issues.

The patient's ultimate concern and reason to seek advice from an orthopedic surgeon is to determine the optimal treatment option. The following example shows a female patient (P17) with two previous orthopedic outpatient evaluations. The patient was clearly upset about how her condition affects her daily life.

P: *It is really bad atmosphere at our house, because I simply lose control when this pain comes [O: Yes?]. And that bothers me! But if it turns out that there is nothing to do to improve my situation- then I just have to accept it, and I'll have to find ways to live with it . . .*

O: *We have discussed this on the basis that it might be a weak indication to support a decision for surgery – because that is what the other (orthopedic surgeons) have decided. However, it is not clear yet whether we arrive at the same conclusion [P: Right, we will see!]. We'll see, and maybe there are other things that can help. But now our concern is to determine if you should undergo surgery. There are of course several other things that might help you [P: And that is exactly?]. Well . . . physiotherapy is one option, but also other things that maybe your GP is just as good as me to consider . . . but what I have to find out is the question of hip prosthesis [P: Mhm]. If that is a smart thing to do . . . [P: Yes].*

In this example, the patient responded to the surgeon's statement that there might be other helpful treatment options by asking what specific treatment he means. The surgeon briefly mentioned physiotherapy as alternative to surgery, but at the same time indicated that his responsibility was mainly to determine an indication for surgery. No details about potential benefits or harms of non-surgical options were provided. Given this situation, the patient may feel disempowered in changing the agenda to claim balanced information about all possibilities that may help her problem.

4. Discussion and conclusion

4.1. Discussion

This qualitative study of decision-making in orthopedic outpatient consultations yields important findings both with

regard to research methods in the field of decision support and to the particular needs of patients with hip OA. It is the first study describing the DAfactory method purposed to adapt didactics in PDAs to specific patient groups. Using SDM as a theoretical lens, this observation-based method proved useful to identify prominent factors affecting patients' involvement into treatment decision-making. Moreover, applying TPB to structure these factors affirmed the existing generic taxonomy and refined a hip OA specific taxonomy used to inform development of patient narratives (videos with patient stories) in a PDA published recently at the Norwegian e-health platform www.helsenorge.no/samvalg.

A salient focus in the consultations concerned the *diagnostic* decision where the surgeon makes up judgments about the medical indication for prosthetic surgery. Communication around this question, however, blurred the underlying decision-making process concerning the benefits and harms of all available treatment options. As the first decision represents a pivotal medical judgment from the surgeon's side, the latter guides the patient's agenda, and is the appropriate one for an SDM process. Through the apparent overlap of two decision-making processes, patient involvement appeared primarily related to the diagnostic consideration rather than the corresponding treatment decision-making process, which accordingly presented as more implicit. Nevertheless, some of the observed features of the ongoing communication were corresponding to essential SDM elements [13], but as seen from the patients' point of view, it might be challenging to realize when personal goals and preferences are appropriate to raise.

Because hip OA has a long lasting disease continuum, treatment decision-making is occurring at multiple time-points and with different people involved. Analysis of consultations in the secondary care setting therefore had to take into account that true SDM is longitudinal in nature. An advanced stage referral might for example have implied that the surgical option was the only remaining realistic alternative to consider. Hence, the chosen descriptive rather than judging analytical approach appeared to be a strength of this study.

There are important limitations to consider such as, in particular, issues related to the chosen design and transferability of the findings. The current study includes only nineteen participants situated in one context with two orthopedic surgeons. There is a need for further validation of the findings in other settings and by using adjuvant methods. Furthermore, as one researcher performed the direct observations only, observer bias might have influenced the findings. The procedures during data collection and analysis, including audio recording, analysis by a second coder, discussions in the research group and the theoretical guidance have, however, improved the reliability of the study.

Patients' opportunities and capacity to become active participants in treatment decision-making is affected by several interrelated factors – the patient [19], the HPs [26] and the organization/system [27]. In terms of implementation of SDM through tailored PDAs, there are arguments to target each of them. However, this study is based on the assumption of the patient being a *shared decision-maker* and from this viewpoint investigates particular barriers patients encounter in their attempts to actively engage in treatment decisions. This approach seems to be coherent with the SDM conceptual idea of the autonomous patient. With regard to implementation of SDM, it is not yet clear whether approaching the HPs or the patients is more efficient. It is likely that combined approaches targeting both are most promising [28]. We also know that strategies focusing on the patient can work effectively, such as the three-question method [29,30]. Furthermore, people exposed to PDAs feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision-making and more accurate risk perceptions [31].

4.2. Conclusion

The patients in this study were involved quite actively in the ongoing communication, but more concerning the possible indication for surgery, and less about careful deliberations of benefit and harms associated with other available alternatives. We found that hip OA patients face similar barriers towards SDM as those previously identified in other patient groups. Yet, OA patients seem to find it particularly challenging to engage actively in treatment decision-making when consultations are framed around diagnostic decisions. The observation method proved feasible to identify patient-related barriers towards SDM.

4.3. Practice implications

The current study has contributed to the development of a web-based PDA for hip OA decisions aimed at supporting SDM across the hip OA continuum [8]. Other developers of decision support tools can adopt the methods used to inform the development of PDAs. Moreover, the taxonomy of SDM barriers published in this study can be useful for other SDM implementation strategies.

Author contributions

EAB: study design, data collection, transcription, data analysis and interpretation, drafting and editing the article. HE: study design, interpretation of data and critical revision of the article for intellectual content. ML and SvD: critical revision of the article for intellectual content. JK: study design, data analysis and interpretation, and critical revision of the article for intellectual content. All authors read and approved the final draft.

Funding

The University of South-Eastern Norway funded this research.

Declaration of Competing Interest

None.

Acknowledgements

We warmly thank the nineteen patients and the two surgeons for participating in this study. We also thank the secretary at the orthopedic outpatient clinic for help with recruitment processes.

References

- [1] T. Vos, A.D. Flaxman, M. Naghavi, R. Lozano, C. Michaud, M. Ezzati, et al., Years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010, *Lancet* 380 (2012) 2163–2196, doi:[http://dx.doi.org/10.1016/S0140-6736\(12\)61729-2](http://dx.doi.org/10.1016/S0140-6736(12)61729-2).
- [2] A. Litwic, M.H. Edwards, E.M. Dennison, C. Cooper, Epidemiology and burden of osteoarthritis, *Br. Med. Bull.* 105 (2013) 185–199, doi:<http://dx.doi.org/10.1093/bmb/lds038>.
- [3] NICE, Osteoarthritis: Care and Management in Adults. Clinical Guideline [CG177], (2014) . (Accessed 10 December 2019) <https://www.nice.org.uk/guidance/cg177>.
- [4] W. Zhang, R.W. Moskowitz, G. Nuki, S. Abramson, R.D. Altman, N. Arden, et al., OARSI recommendations for the management of hip and knee osteoarthritis, Part II: OARSI evidence-based, expert consensus guidelines, *Osteoarthr. Cartil.* 16 (2008) 137–162, doi:<http://dx.doi.org/10.1016/j.joca.2007.12.013>.
- [5] L. Fernandes, K.B. Hagen, J.W.J. Bijlsma, O. Andreassen, P. Christensen, P.G. Conaghan, et al., EULAR recommendations for the non-pharmacological core management of hip and knee osteoarthritis, *Ann. Rheum. Dis.* 72 (2013) 1125–1135, doi:<http://dx.doi.org/10.1136/annrheumdis-2012-202745>.
- [6] S. Watt, Clinical decision-making in the context of chronic illness, *Health Expect.* 3 (2000) 6–16, doi:<http://dx.doi.org/10.1046/j.1369-6513.2000.00076.x>.
- [7] V.M. Montori, A. Gafni, C. Charles, A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the

- case of diabetes, *Health Expect.* 9 (2006) 25–36, doi:<http://dx.doi.org/10.1111/j.1369-7625.2006.00359.x>.
- [8] E.A. Brembo, H. Kapstad, T. Eide, L. Månsson, S. Van Dulmen, H. Eide, Patient information and emotional needs across the hip osteoarthritis continuum: a qualitative study, *BMC Health Serv. Res.* 16 (2016) 1–15, doi:<http://dx.doi.org/10.1186/s12913-016-1342-5>.
- [9] P.R. Fortin, J.R. Penrod, A.E. Clarke, Y. St Pierre, L. Joseph, P. Belisle, et al., Timing of total joint replacement affects clinical outcomes among patients with osteoarthritis of the hip or knee, *Arthritis Rheum.* 46 (2002), doi:<http://dx.doi.org/10.1002/art.10631>.
- [10] P.R. Fortin, A.E. Clarke, L. Joseph, M.H. Liang, M. Tanzer, D. Ferland, et al., Outcomes of total hip and knee replacement: preoperative functional status predicts outcomes at six months after surgery, *Arthritis Rheum.* 42 (1999) 1722–1728, doi:[http://dx.doi.org/10.1002/1529-0131\(199908\)42:8<1722::AID-ANR22>3.0.CO;2-R](http://dx.doi.org/10.1002/1529-0131(199908)42:8<1722::AID-ANR22>3.0.CO;2-R).
- [11] W. Levinson, P. Hudak, A.C. Tricco, A systematic review of surgeon–patient communication: strengths and opportunities for improvement, *Patient Educ. Couns.* 93 (2013) 3–17, doi:<http://dx.doi.org/10.1016/j.pec.2013.03.023>.
- [12] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, et al., Shared decision making: a model for clinical practice, *J. Gen. Intern. Med.* 27 (2012) 1361–1367, doi:<http://dx.doi.org/10.1007/s11606-012-2077-6>.
- [13] G. Makoul, M.L. Clayman, An integrative model of shared decision making in medical encounters, *Patient Educ. Couns.* 60 (2006) 301–312, doi:<http://dx.doi.org/10.1016/j.pec.2005.06.010>.
- [14] S. Kienlin, M. Kristiansen, E. Ofstad, K. Liethmann, F. Geiger, P. Joranger, et al., Validation of the Norwegian version of MAPPIN'SDM, an observation-based instrument to measure shared decision-making in clinical encounters, *Patient Educ. Couns.* 100 (2017) 534–541, doi:<http://dx.doi.org/10.1016/j.pec.2016.10.023>.
- [15] N. Bouniols, B. Leclere, L. Moret, Evaluating the quality of shared decision making during the patient–carer encounter: a systematic review of tools, *BMC Res. Notes* 9 (2016) 382, doi:<http://dx.doi.org/10.1186/s13104-016-2164-6>.
- [16] M. Härter, N. Moumjid, J. Cornuz, G. Elwyn, T. van der Weijden, Shared decision making in 2017: International accomplishments in policy, research and implementation, *Zeitschrift für Evidenz Fortbildung und Qualität im Gesundheitswesen* 123–124 (2017) 1–5, doi:<http://dx.doi.org/10.1016/j.zefq.2017.05.024>.
- [17] K. Gravel, F. Légaré, I.D. Graham, Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions, *Implement. Sci.* 1 (2006), doi:<http://dx.doi.org/10.1186/1748-5908-1-16>.
- [18] F. Legare, S. Ratté, K. Gravel, I.D. Graham, Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions, *Patient Educ. Couns.* 73 (2008) 526–535, doi:<http://dx.doi.org/10.1016/j.pec.2008.07.018>.
- [19] N. Joseph-Williams, G. Elwyn, A. Edwards, Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making, *Patient Educ. Couns.* 94 (2014) 291–309, doi:<http://dx.doi.org/10.1016/j.pec.2013.10.031>.
- [20] J. Kasper, A.R. Lager, M. Rumpsfeld, S. Kienlin, K.H. Smestad, T. Bråthen, et al., Status report from Norway: implementation of patient involvement in Norwegian health care, *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen* 123–124 (2017) 75–80, doi:<http://dx.doi.org/10.1016/j.zefq.2017.05.015>.
- [21] International Patient Decision Aids Standards (IPDAS) Collaboration, (2019) . (Accessed 10 December 2019) <http://ipdas.ohri.ca/>.
- [22] I. Ajzen, The theory of planned behavior, *Organ. Behav. Hum. Decis. Process.* 50 (1991), doi:[http://dx.doi.org/10.1016/0749-5978\(91\)90020-t](http://dx.doi.org/10.1016/0749-5978(91)90020-t).
- [23] B.F. Crabtree, W.L. Miller, Using codes and code manuals. A template organizing style of interpretation, in: B.F. Crabtree, W.L. Miller (Eds.), *Doing Qualitative Research*, Sage Publications, Thousand Oaks, California, 1999, pp. 163–177.
- [24] NVivo Qualitative Data Analysis Software, QSR International Pty Ltd. Version 11, 2015.
- [25] Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. (2013) . (Accessed 10 December 2019) <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
- [26] P. Thompson-Leduc, M.L. Clayman, S. Turcotte, F. Legare, Shared decision-making behaviours in health professionals: a systematic review of studies based on the Theory of Planned Behaviour, *Health Expect.* 18 (2015) 754–774, doi:<http://dx.doi.org/10.1111/hex.12176>.
- [27] I. Scholl, A. LaRussa, P. Hahlweg, S. Kobrin, G. Elwyn, Organizational- and system-level characteristics that influence implementation of shared decision-making and strategies to address them – a scoping review, *Implement. Sci.* 13 (2018) 40, doi:<http://dx.doi.org/10.1186/s13012-018-0731-z>.
- [28] F. Legare, S. Turcotte, D. Stacey, S. Ratté, J. Kryworuchko, I.D. Graham, Patients' perceptions of sharing in decisions: a systematic review of interventions to enhance shared decision making in routine clinical practice, *Patient* 5 (2012) 1–19, doi:<http://dx.doi.org/10.2165/11592180-000000000-00000>.
- [29] H.L. Shepherd, A. Barratt, A. Jones, D. Bateson, K. Carey, L.J. Trevena, et al., Can consumers learn to ask three questions to improve shared decision making? A feasibility study of the ASK (AskShareKnow) Patient–Clinician Communication Model((R)) intervention in a primary health-care setting, *Health Expect.* 19 (2016) 1160–1168, doi:<http://dx.doi.org/10.1111/hex.12409>.
- [30] H.L. Shepherd, A. Barratt, L.J. Trevena, K. McGeechan, K. Carey, R.M. Epstein, et al., Three questions that patients can ask to improve the quality of information physicians give about treatment options: a cross-over trial, *Patient Educ. Couns.* 84 (2011) 379–385, doi:<http://dx.doi.org/10.1016/j.pec.2011.07.022>.
- [31] D. Stacey, F. Légaré, K. Lewis, M.J. Barry, C.L. Bennett, K.B. Eden, et al., Decision aids for people facing health treatment or screening decisions, *Cochrane Database Syst. Rev.* (4) (2017), doi:<http://dx.doi.org/10.1002/14651858.CD001431.pub5>.