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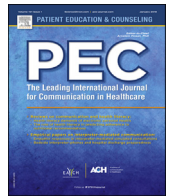
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What makes a patient ready for Shared Decision Making? A qualitative study

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ABSTRACT

Objectives: Shared decision making (SDM) requires an active role from patients, which might be difficult for some. We aimed to identify what patients need to be ready (i.e., well-equipped and enabled) to participate in SDM about treatment, and what patient- and decision-related characteristics may influence readiness.

Methods: We conducted semi-structured interviews with patients and professionals (physicians, nurses, general practitioners, and researchers). Interviews were analyzed inductively.

Results: We identified five elements of patient readiness: 1) understanding of and attitude towards SDM, 2) health literacy, 3) skills in communicating and claiming space, 4) self-awareness, and 5) consideration skills. We identified 10 characteristics that may influence elements of readiness: 1) age, 2) cultural background, 3) educational background, 4) close relationships, 5) mental illness, 6) emotional distress, 7) acceptance of diagnosis, 8) clinician-patient relationship, 9) decision type, and 10) time.

Conclusions: We identified a wide range of elements that may constitute patient readiness for SDM. Readiness might vary between and within patients. This variation may result from differences in patient- and decision-related characteristics.

Practice implications: Clinicians should be aware that not all patients may be ready for SDM at a given moment and may need support to enhance their readiness.

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1. Introduction

Patients with long-term conditions often face preference-sensitive decisions about their treatment, for which their opinion is essential [1–4]. Shared decision making (SDM) is often considered to be the preferred model to involve patients in this process [5], but it is still not implemented routinely in healthcare [6,7]. When patients face preference-sensitive decisions, clinicians have an important role in realizing SDM, but so do patients [8–13]. However, patients may not always feel that they are able to participate in the decision-making process [14,15].

Multiple patient behaviors, both within and outside of consultations, have been described to be part of SDM [8–13]. Patients ask questions [9,10,12,13], and express their preferences [9–11,13], thoughts, feelings, values [9,11], and understanding of

information [11,13]. Patients describe symptoms, listen to clinicians, and answer questions honestly [13]. Patients consider treatment alternatives [9–11], consult others [9,13], and consider the needs of significant others [13]. Patients also access or search for information themselves [9,13], and need to deal with uncertainty or risks [13]. Finally, patients and clinicians build consensus about the preferred treatment [10,11], or patients decide, or ask clinicians to make the decision for them [9]. Patients may need support to fulfill these tasks, but support needs might depend on patient preferences and patient- or decision-related characteristics, and may thus vary over time [9].

As is clear from the above, patients may need to perform a wide variety of behaviors for SDM to occur. This might be difficult for some patients and the lack of SDM may partly arise from patients not yet feeling well-equipped and enabled, i.e., ready, to become involved in SDM. In order to understand how patients can be best supported to be ready for SDM, we first need to understand what patient readiness for SDM entails. Previous research has identified barriers and facilitators of SDM from the perspective of patients, which showed that patients need knowledge of their illness and values, and to experience power [14]. With this qualitative study we aimed to add to this research by focusing on what skills and

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abilities patients need to have to be ready to participate in SDM about treatment, over and above attitudes and knowledge. We therefore sought the perspectives of patients, clinicians, and decision-making and communication researchers. Patients have knowledge of their skills, needs, and experiences with SDM. Clinicians have the medical expertise and experience of discussing decisions with patients. Finally, researchers have insights based on the study of how decision processes unfold, and how individual, decisional, and contextual elements can benefit these. Participants in decision processes may not necessarily be aware of such influences and effects, and these perspectives therefore complement each other. The aim of this study was to assess what patient readiness for SDM entails, and what patient- or decision-related characteristics may influence readiness.

2. Methods

2.1. Design

In this qualitative study we conducted exploratory semi-structured in-depth interviews with patients and professionals. The study is reported according to the checklist of the Consolidated criteria for REporting Qualitative research (COREQ [16]). The Medical Ethical Committee of the Leiden University Medical Center (LUMC) offered exemption for ethical approval of the study protocol (P17.121), as this was not required under Dutch Law.

2.2. Recruitment

2.2.1. Patients

Patients were recruited at the LUMC. Patients were eligible if they: 1) had been diagnosed with cancer or chronic disease; 2) had had a decision consultation in the past six months (i.e., during the consultation a decision to start, stop, change, or forego treatment was discussed); and 3) were ≥ 18 years old. Patients were excluded if they were not able to speak Dutch.

We used purposive sampling to recruit patients. Four physicians at the LUMC, specialized in oncology, cardiovascular disease, endocrinology, or geriatrics, agreed to recruit participants. They were asked to inform at least four eligible patients about the study. We asked them to make efforts to recruit patients with a balance of age and educational backgrounds. Patients were informed about the study during a consultation. Patients who were interested received a participant information leaflet, an informed consent form, a questionnaire, an image summarizing the SDM concept to use during the interview (Appendix A), a reply form to be returned to the researchers, and a return envelope. We then either contacted patients by phone (if they had agreed to this during the

consultation) or patients contacted us themselves by email or phone, or by returning the reply form. We would then answer any questions they had, and schedule an appointment if they agreed to participate.

2.2.2. Professionals

Professionals were recruited through convenience sampling by contacting professionals from our (inter-)national network and through snowballing. Physicians and nurses were eligible if they were specialized in or worked with patients with cancer, cardiovascular disease, or diabetes. Researchers were eligible if their research was focused on healthcare communication or SDM. There were no additional inclusion criteria for general practitioners.

2.3. Data collection

Interviews were face-to-face (for patients at the hospital or their home, for professionals at their workplace) or by telephone, depending on their preference. Informed consent forms were obtained from all patients, verbal consent was obtained from all professionals. Participants could withdraw from the study at any time without being asked to state their reasons for withdrawal.

Interviews were conducted by a female researcher (SK) or research assistant (ND), who were both trained and experienced in conducting interviews. The interviews were conducted according to an interview scheme (Appendix B). During the interviews we used the term 'making decisions together' ('samen beslissen'), which is an easier term to describe SDM in Dutch [9]. The interviewer gave a description of what we believe SDM involves and the behaviors it might require from the clinician and patient [5,9], which were summarized on paper (Appendix A). Patients were then interviewed according to the topic guide (Box 1). The research team developed the topic guide with the aim to identify what makes that a patient is or is not ready for SDM at a given time. We used open-ended questions to allow participants to freely express their ideas. We also compiled a list of potential additional questions to elicit more in-depth responses (Appendix C).

The topic guide was pilot-tested in the first two participants (both researchers). The research team then thoroughly discussed the transcripts. No major changes were made to the topic guide, and these interviews were included in the analysis. New topics that emerged from field notes or during the analysis were used as input for subsequent interviews, and were added to the list of additional questions (Appendix C). We started by interviewing professionals, used their input for the patient interviews, and then interviewed more professionals using the input of the patients. We aimed to include 15 patients and 18 professionals, or until data saturation

Box 1. Topic guide.

1. Patients and doctors sometimes say that 'making decisions together' can sometimes be difficult for patients. Why do you think that 'making decisions together' is sometimes difficult for patients?
2. What makes that 'making decisions together' is sometimes difficult for patients?
3. What could make that 'making decisions together' would be easier for patients? What must the patient be able to do to 'making decisions together' with a doctor or a nurse?
4. What would make that a patient is ready for 'making decisions together'?
5. What else is needed for them?
6. What do you think could be done to make it more likely that patients can participate in 'making decisions together'?
7. Why would that work?
8. Is there anything patients can do to make "making decisions together" more likely to happen?
9. What?
10. Why would that work?

Box 2. Self-developed question about distress.

A while ago a decision was made about your treatment. If you think back to this time period, how emotional was this for you back then?

- ☐ Not at all
☐ A little
☐ Somewhat
☐ Quite
☐ Very much

had been reached. When no new ideas emerged in three successive interviews, regardless of participant group, we concluded that data saturation had been reached.

We wanted to find out if we had variety in our patient group with regard to how stressful they had experienced treatment decision making. Prior to the interview, we asked patients to fill out a self-developed question on paper to ask them about how much distress they had experienced (Box 2). Patients were also asked about their education level at the start of the interview, which was categorized as low (primary or lower secondary education), intermediate (upper secondary or post-secondary non-tertiary education), or high (short cycle tertiary education or university) [17].

2.4. Analyses

All interviews were audio-recorded and transcribed verbatim. Transcripts were analyzed based on the Grounded Theory approach [18]. Two coders who were trained and experienced in qualitative data analysis (SK and ND) started by independently coding the transcripts. During the coding process the coders frequently met (usually after one or two transcripts had been coded) and compared their coding until consensus was reached. A code list was developed inductively, which was used for all subsequent interviews. Codes were added or renamed whenever coders agreed that this was needed. After the first 14 interviews had been coded and discussed, the coders showed few coding discrepancies. One coder coded the final 17 transcripts, which was checked by the second coder, and disagreements were resolved in consensus meetings. The final coding was entered in Atlas.ti version 7.5.18. We did not perform a member check, which participants could have experienced as threatening [19]. We also did not ask participants for feedback on the findings, as even more time had passed since they had faced the decision.

Parallel to the open coding process, a preliminary categorization of the codes was developed (i.e., axial coding). The categorization was revised after all interviews had been completed. SK identified categories by clustering relating concepts based on code names. ND checked the categories, after which they discussed the category names and content. SK then looked at the full set of underlying data fragments of each code to see whether each data fragment indeed fitted with the code name, and the code fitted within the assigned category. This was discussed with ND. At this stage, some data fragments were assigned a different code, and some codes were renamed, removed, or added. Where needed, categories were regrouped or renamed in consensus. The final step was selective coding, where SK assigned all categories to a higher order category and a distinction was made between elements that constitute readiness, and characteristics that influence the elements of readiness. These categories were thoroughly discussed within the research team, and after adjustments a final categorization was developed in consensus.

Table 1

Patient characteristics (n = 15).

Characteristic	Value
Age (Md, range)	69; 38 – 92
Female (n)	11
Diagnosis (n)	
- Cancer	7
- Cardiovascular disease	7
- Diabetes	1
Marital status (n)	
- Married/cohabiting	10
- Relationship, not cohabiting	1
- Widowed	2
- Divorced	1
- Single	1
Education level (n)	
- Low	6
- Intermediate	3
- High	6
Experienced emotional distress during the decision (n = 14; n)	
- Not at all	2
- A little	4
- Somewhat	4
- Quite	2
- Very	2

3. Results

3.1. Participants

In total, we conducted 31 interviews between February 2017 and May 2019. We received informed consent from 17 patients, of whom 15 were interviewed (Table 1). One patient declined participation after receiving treatment, the other due to lack of time. Included patients had varying educational backgrounds and had experienced varying levels of emotional distress during the decision-making process. We interviewed 16 professionals (Table 2). During some interviews a family member (patients) or coworker (professionals) was present.

3.2. Elements of patient readiness

We identified five elements of patient readiness for SDM. The complete coding structure can be found in Appendix D.

3.2.1. Understanding of and attitude towards SDM

Some patients were not used to being involved in SDM.

Patient (female, cancer, low education level): “I find it difficult because until now you are used [to it] that the physician with all his wisdom and his education makes the decision for you.”

Both patients and professionals described that patients sometimes have paternalistic expectations and may feel inferior to physicians. This may make it less likely that patients will express their opinions and questions, and it might decrease their motivation for participation.

When asked what could make that a patient is ready for SDM, it was suggested that patients need to understand why they need to give their opinion, and why they should agree with the decision. Clinicians added that patients need to understand the SDM process.

3.2.2. Health literacy

When patients are involved in SDM they often receive a lot of new information which they need to absorb and understand. Multiple patients, both with low and high education levels, experienced this as overwhelming. Participants felt that it helps if

Table 2
Professional characteristics (n = 16).

Profession	n	Female (n)	Age (Md; range)
Physician	6	3	42 (37 – 53)
- Oncology	3		
- Endocrinology	1		
- Geriatrics	1		
- Cardiology	1		
Nurse	3	2	55 (44 – 61)
- Oncology	2		
- Cardiology	1		
General practitioner	2	1	48.5 (44 – 53)
Researcher	5	5	^a

^a not collected.

patients have basic knowledge of health and illness, and understand the concept of risks. A researcher stated (female):

“So it is often suddenly about a treatment in relation to risks, chances, etcetera, while ultimately they lack that basic understanding of those terms that, yes, they actually need to be able to fully understand all those treatment options.”

In addition, it was suggested that patients need to take ownership of the process by also searching for more information themselves.

Patient (male, cardiovascular disease, high education level): *“So dealing with what is wrong with you. And not to say: well the doctor will know. But also inform yourself.”*

However, one patient with a low education level (female, cancer) believed that searching for information should not be necessary when patients receive good information from their clinician.

3.2.3. Skills in communicating and claiming space

Patients often have questions, which they need to be able to formulate and dare to ask. It was discussed that patients also need to be able to verbalize their thoughts, and express their feelings, values, opinions, and needs. In addition, they also need to be able to claim the space to express themselves. This might be easier for patients who are assertive.

Patient (female, cancer, intermediate education level): *“I think it is easier if the patient is a bit assertive. Because then he dares to say more things. He dares to ask his dumb questions, so to speak.”*

Patients might find it difficult to ask questions when they are confronted with new information. One patient (male,

cardiovascular disease, high education level) said that he is not able to ask a good question if he has not first studied the information himself. This illustrates that in order to ask questions, patients first need to have had the ability and time to study and absorb information.

3.2.4. Self-awareness

In order to contribute to the decision-making process, patients may need to be aware of their goals and what they value.

Physician (male, cardiology): *“People should be well aware of well, I am here now and what do I want in the coming years. What do I still want to do, how do I want to live. I absolutely don't want that. You must have that realization, I think, if you want to make a decision to undergo something.”*

Clinicians also suggested that it can help if patients are aware of what they need.

Physician (male, oncology): *“... that they are at least aware of whether or not they want to know and what it can mean for them.”*

3.2.5. Consideration skills

Patients need to consider the different options and need to be able to oversee their consequences. They may have to relate to different possible future scenarios, which some participants said can be difficult.

Patient (female, cardiovascular disease, low education level): *“That people maybe don't oversee the consequences of certain decisions. That that is too confusing for them or too difficult for them or [that they] are too afraid of that to decide themselves. To decide that if I choose this then it has that consequence, and if I choose that then that has that consequence. You need to be able to oversee that.”*

3.3. Patient- and decision-related characteristics

We identified multiple patient- and decision-related characteristics that may influence the identified elements of patient readiness (Table 3).

3.3.1. Age

Participants believed that older patients might find it more difficult to participate in SDM. They said that older patients are often used to a paternalistic decision style and might experience more difficulties with absorbing information, which may inhibit them from expressing themselves.

Table 3
Participants' views on the influence of characteristics on elements of patient readiness.

Characteristics	Elements of patient readiness				
	Understanding of and attitude towards SDM	Health literacy	Skills in communicating and claiming space	Self-awareness	Consideration skills
Higher age	+/-	-	-		
Non-Western cultural background	-		-		
Higher education level	+	+	+/-		+
Close relationships		+	+/-	+	+/-
Mental illness				-	-
Emotional distress	-	-	-	+	+/-
Acceptance of diagnosis		+	+		
Good clinician-patient relationship	+/-	+	+		
More complex decision					-
Time		+	+		+

+ = suggested positive effect; - = suggested negative effect; x = suggested that characteristic has no effect; if cell is empty, none of the participants mentioned a possible effect.

Patient (male, cardiovascular disease, high education level): *"I definitely think that [. . .] the elderly have more difficulties with [being assertive]."*

However, one researcher mentioned that young adults may also struggle with SDM as they have been used to their parents being present during consultations and deciding for them.

3.3.2. Cultural background

Several professionals believed that patients with a non-western cultural background might find it more difficult to participate in SDM than patients with a western background. They may experience cultural differences and language barriers that may complicate SDM.

Physician (male, cardiology): *" . . . sometimes also cultural. 'Oh well, the doctor knows it better, so it is good whatever you decide'. That is difficult . . . "*

3.3.3. Educational background

Medical information might be more difficult to understand for patients with a lower compared to a higher educational background. It was stated that it might be more difficult for these patients to apply information to their own situation, to speak with physicians on the same level, and to oversee consequences. They may also be less motivated and less assertive.

Physician (female, geriatrics): *" . . . the second step is, you have the information [. . .] then it is still difficult to apply it to yourself. Because there are still dry figures and the patient has to imagine various scenarios. And that is, people with a higher education do that better, than [those with] lower education. So education plays a role."*

However, some professionals indicated that a low education level is not an insurmountable barrier. As one physician (female, oncology) said, it is key that patients express themselves and they should be able to do this regardless of education level.

3.3.4. Close relationships

Both patients and professionals thought that patients may be more ready for SDM if they have someone in their lives who can be involved in the decision-making process. Having someone present during the consultation can help with absorbing and remembering information, especially when patients feel tired or distressed.

Patient (female, cancer, low education level): *"I had my son and my daughter with me and that was . . . If I would have been alone it would have been different. Then I would not have remembered anything."*

Having someone else present may also help with communicating with clinicians. However, it could also inhibit patients from saying everything they want.

If patients can discuss the decision at home with someone who knows them well, this might help patients to get better insight into what they value and help them consider the options. The involvement of others can have a negative effect when patients give the other's emotions precedence over their own. This may especially be the case in older patients, such as when a patient accepts further treatment for the sake of others.

3.3.5. Mental illness

A few professionals mentioned that mental illness might make it more difficult for patients to be aware of what they value,

consider the options, and oversee the decision and its consequences.

General practitioner (male): *"With people with depression [. . .], for that patient group it is more difficult to make a decision, because [. . .] it quickly becomes too much. And they can't decide because they can't see the forest for the trees."*

3.3.6. Emotional distress

Patients may experience emotional distress when they face a treatment decision. Participants believed that this might make it more difficult to understand and remember information, to communicate with clinicians, to consider the options, and to feel motivated for SDM.

Researcher (female): *" . . . that people who are [. . .] being confronted with a life-threatening or serious condition such as cancer, that at that moment, even though they are, for example, very highly educated, they are still low health literate, because they are simply overwhelmed by fears and other emotions that prevent them from absorbing information properly at that moment."*

However, as both some clinicians as well as a patient stated, emotions can also help patients in making decisions, as it can help them determining what is important to them.

3.3.7. Acceptance of diagnosis

Both physicians and patients believed that patients need to accept their diagnosis, as being in denial may prevent patients from absorbing information, searching for information themselves, and expressing themselves.

Patient (female, cancer, high education level): *"So they are in a sort of denial and if you have this problem, denial, you can't give an opinion."*

3.3.8. Clinician-patient relationship

Participants thought that not having a good relationship with their clinician might result in patients being less likely to absorb information, expressing themselves, and asking questions. This may especially be the case if they do not like or feel intimidated by the clinician. Having the same clinician throughout the process might help patients and clinicians in building a good relationship.

Patients are more likely to be open and honest with clinicians if they trust them. However, patients' motivation to participate in SDM may be lower if they fully trust clinicians to make the right decisions for them.

3.3.9. Decision type

It was believed that SDM can be more complicated when there are many different options with a lot of uncertainty, and when decisions cannot be revisited. It might also be more difficult when the disease is serious or even life-threatening. These types of decision situations may increase patients' emotional distress. One patient (male, diabetes, low education level) compared the decision he had faced about switching diabetes treatment to the decision his mother had faced about cancer treatment:

"[when you have cancer] then you are suddenly talking about your life in the short term. [. . .] Then the choices are a bit heavier."

3.3.10. Time

Having sufficient time was considered important. For example, time to process information, to develop a relationship with

clinicians, and to consider the options. Experiencing time pressure may inhibit patients from communicating and sufficiently considering the options. Patients may especially experience time pressure when their disease is progressive.

4. Discussion and conclusion

4.1. Discussion

This study gives a concise overview of what might make that patients are ready for SDM about treatment. Our study adds to the previously described concept of *individual capacity to participate in SDM* [14], by also identifying a range of skills that patients may need to be ready for SDM. First, patients need to have knowledge about the disease and decision [14,20,21], but also need to be able to absorb and understand the information. This is in line with research suggesting that lower health literacy may be related to limited patient participation [22]. Second, it is important that patients are aware of their own values [14] and needs. Third, patients also need to be aware of their role in SDM [14,21,23]. Fourth, patients need to have the ability to communicate their opinions, concerns, and questions [20,23,24]. Patients need to dare to do this and claim the space to express themselves. Fifth, patients need to be able to consider their options, a key feature of SDM [5,25]. We identified all these as separate elements of readiness, but they appear related to each other. For example, patients who are better able to understand information, may then also be better able to ask questions and to consider the options. This shows that patient readiness is a multifaceted concept of which the elements are interrelated. The identified set of elements may however not be exhaustive. For example, our participants did not mention self-efficacy, which in previous research was found to be needed for patients to feel capable to participate [14]. Higher self-efficacy may potentially also be part of what makes that patients are ready for SDM.

Patient readiness for SDM is not a given, nor is it a psychological trait. A key feature is that it may vary over time as a result of fluctuations in patient- and decision-related characteristics, and interactions between these characteristics. For example, facing a decision about a potentially life-threatening disease with many different options may cause patients to experience emotional distress, to struggle with accepting their diagnosis, and to experience time pressure. This may in turn negatively affect various elements of readiness. This insight shows that support needs may vary across patients and situations. For some patients support may need to focus on one or more of the *elements*, while for other patients, or at other times, support may need to focus on patient- or decision-related *characteristics*.

We interviewed a heterogeneous group of participants. Professionals and patients overall had similar views on what constitutes readiness. However, patients added more nuance to certain topics by giving detailed descriptions of their experiences (e.g., feeling overwhelmed by information), whereas professionals reflected more thoroughly on aspects such as understanding of the SDM process. Professionals also discussed more characteristics that may influence readiness.

4.1.1. Strengths and limitations

A strength of our study is that we collected a wide range of views from different parties that are involved in SDM. We interviewed professionals from different backgrounds and patients differing in diagnoses, ages, education levels, and distress levels at the time of decision making, allowing for a mix in experiences and expertise. Another strength is that we first gave a description of SDM and specifically stated the role of both clinicians and patients, to trigger participants to think about what might make SDM

difficult for patients. Our explorative interview method allowed participants to convey their viewpoints without restrictions. We also used input from earlier interviews in subsequent interviews to allow participants to reflect on ideas brought up by other participants.

Our study also has limitations. We do not know how many patients were informed about the study and declined participation, and for what reasons. Furthermore, we included patients who had faced a treatment decision in the past six months. Patients may not fully remember how they felt and what they needed at that time.

4.2. Conclusion

A wide variety of elements make that patients may or may not be ready for SDM at a given time. Our study adds to the current body of research by identifying specific skills and abilities that patients may need to participate in SDM, as well as identifying a wide range of characteristics that may influence readiness. Not every patient will be ready for SDM, which does not preclude SDM but points to a need for better support or preparation. Not all patients will need support in all areas of readiness, nor will individual patients need the same support in all situations. For some patients support might need to focus on actionable characteristics such as emotional distress, instead of on the elements itself. The list of identified elements and characteristics may not be exhaustive and further research is needed to further clarify the concept. Furthermore, more research is needed to understand how readiness may change over time, especially in decisions that are complex and stressful, and how patients can be supported to become increasingly ready.

4.3. Practice implications

Even though clinicians have a central role in making SDM happen, we should also pay attention to the role of patients. It is important that clinicians are aware that not all patients may be ready for SDM about treatment when they face the decision, and patients may need support to increase readiness. Support should not only focus on the elements of readiness, but also on the patient- and decision-related characteristics that may affect readiness. For example, this could mean that patients who have difficulty understanding information may not only benefit from being given information that is easier to understand, but also from attention to emotional distress and from being given time to process their diagnosis.

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CRediT authorship contribution statement

Sascha M. Keij: Methodology, Project administration, Investigation, Data curation, Formal analysis, Writing - original draft, Writing - review & editing. **Nanny van Duijn-Bakker:** Investigation, Data curation, Formal analysis, Writing - review & editing. **Anne M. Stiggelbout:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing - review & editing. **Arwen H. Pieterse:** Conceptualization, Funding acquisition, Methodology, Project administration, Supervision, Writing - review & editing.

Declaration of Competing Interest

The authors report no declarations of interest.

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I confirm all personal identifiers have been removed or disguised so the persons described are not identifiable and cannot be identified through the details of the story.

Appendices A–D. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2020.08.031>.

References

- [1] T. Xiong, R.M. Turner, Y. Wei, D.E. Neal, G. Lyrtzopoulos, J.P. Higgins, Comparative efficacy and safety of treatments for localised prostate cancer: an application of network meta-analysis, *BMJ open* 4 (2014) e004285.
- [2] J. van de Haterd, H. Voogdt-Pruis, I. Raats, R. van den Brink, H. van Veenendaal, Preference-sensitive decisions of patients with metastatic breast cancer: The need for decision support, *Patient Exp. J* 3 (2016) 50–56.
- [3] G. Elwyn, D. Frosch, S. Rollnick, Dual equipoise shared decision making: definitions for decision and behaviour support interventions, *Implement Sci.* 4 (2009) 75.
- [4] A.M. O'Connor, F. Légaré, D. Stacey, Risk communication in practice: the contribution of decision aids, *BMJ* 327 (2003) 736–740.
- [5] A.M. Stiggelbout, A.H. Pieterse, J.C. de Haes, Shared decision making: Concepts, evidence, and practice, *Patient Educ. Couns* 98 (2015) 1172–1179.
- [6] N. Couët, S. Desroches, H. Robitaille, H. Vaillancourt, A. Leblanc, S. Turcotte, G. Elwyn, F. Légaré, Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument, *Health Expect.* 18 (2015) 542–561.
- [7] M. Kunneman, E.G. Engelhardt, F.L. Ten Hove, C.A. Marijnen, J.E. Portielje, E.M. Smets, H.J. de Haes, A.M. Stiggelbout, A.H. Pieterse, Deciding about (neo-) adjuvant rectal and breast cancer treatment: Missed opportunities for shared decision making, *Acta Oncol.* 55 (2016) 134–139.
- [8] M.L. Clayman, P. Gulbrandsen, M.A. Morris, A patient in the clinic; a person in the world. Why shared decision making needs to center on the person rather than the medical encounter, *Patient Educ. Couns* 100 (2017) 600–604.
- [9] H. Bomhof-Roordink, M.J. Fischer, N. van Duijn-Bakker, M.C. Baas-Thijssen, T. van der Weijden, A.M. Stiggelbout, A.H. Pieterse, Shared decision making in oncology: A model based on patients', health care professionals', and researchers' views, *Psychooncology* 28 (2019) 139–146.
- [10] C. Charles, A. Gafni, T. Whelan, Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango), *Soc. Sci. Med.* 44 (1997) 681–692.
- [11] C. Charles, A. Gafni, T. Whelan, Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model, *Soc. Sci. Med.* 49 (1999) 651–661.
- [12] M.E. Peek, M.T. Quinn, R. Gorawara-Bhat, A. Odoms-Young, S.C. Wilson, M.H. Chin, How is shared decision-making defined among African-Americans with diabetes? *Patient Educ. Couns* 72 (2008) 450–458.
- [13] B.A. Lown, W.D. Clark, J.L. Hanson, Mutual influence in shared decision making: a collaborative study of patients and physicians, *Health Expect.* 12 (2009) 160–174.
- [14] 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) 291–299.
- [15] A.H. Pieterse, M.C. Baas-Thijssen, C.A. Marijnen, A.M. Stiggelbout, Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration, *Br. J. Cancer* 99 (2008) 875–882.
- [16] A. Tong, P. Sainsbury, J. Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *Int. J. Qual. Health Care* 19 (2007) 349–357.
- [17] Statistics Netherlands, *Standaard Onderwijsindeling 2016, Editie 2018/19* [Education categorization standard 2016, Edition 2018/19] (accessed 3 February 2020) Available from https://www.cbs.nl/-/media/_pdf/2019/12/pubsoi2016_ed1819.pdf, (2019) .
- [18] A. Straus, J. Corbin, *Grounded Theory in Practice*, Sage, Thousand Oaks, 1998.
- [19] L. Forbat, J. Henderson, Theoretical and practical reflections on sharing transcripts with participants, *Qual. Health Res.* 15 (2005) 1114–1128.
- [20] A.L. Caress, K. Luker, A. Woodcock, K. Beaver, A qualitative exploration of treatment decision-making role preference in adult asthma patients, *Health Expect.* 5 (2002) 223–235.
- [21] L. Fraenkel, S. McGraw, What are the essential elements to enable patient participation in medical decision making? *J. Gen. Intern. Med.* 22 (2007) 614–619.
- [22] M.K. Paasche-Orlow, M.S. Wolf, The causal pathways linking health literacy to health outcomes, *Am. J. of Health Behav.* 31 (2007) S19–S26.
- [23] R.L.J. Street, Active patients as powerful communicators, in: W.P. Robinson, H. Giles (Eds.), *The New Handbook of Language and Social Psychology*, John Wiley & Sons Ltd, Chichester, 2001, pp. 113–132.
- [24] H. Bastiaens, P. Van Royen, D.R. Pavlic, V. Raposo, R. Baker, Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries, *Patient Educ. Couns* 68 (2007) 33–42.
- [25] G. Elwyn, D. Frosch, R. Thomson, N. Joseph-Williams, A. Lloyd, P. Kinnersley, E. Cording, D. Tomson, C. Dodd, S. Rollnick, A. Edwards, M. Barry, Shared decision making: a model for clinical practice, *J. Gen. Intern. Med.* 27 (2012) 1361–1367.