

Article

Shared Decision Making in Clinical PracticeDOI: 10.47368/ejhc.2022.102
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CC BY 4.0**Experiences and Needs of Patients with Limited Health Literacy****Janneke Noordman** , **Mariska Oosterveld-Vlug** 

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Maastricht University, the Netherlands**Abstract**

Shared Decision Making (SDM), currently considered a preferred model for making decisions in healthcare, requires that patients have the knowledge and skills to actively participate in the consultation and decision-making process. Patients with limited health literacy (LHL) often fail to do so. To gain insight into the experiences, needs and support for LHL-patients concerning SDM in clinical practice, five focus groups were held with 26 patients with LHL. A focus group discussion guide was developed based on 4-steps SDM models. Data was coded using thematic content analyses. LHL patients participating in this study had little experience with SDM in practice, but do prefer it. Important barriers for this are healthcare provider-related (involving patients too little in decision-making, using medical jargon), patient-related (feeling insecure to play a role in decision-making, inability to understand their diagnosis or information about treatment options), patient-provider interaction-related (relationship of trust) or system-related (too little consultation time). For SDM to take place more often, a shared responsibility between patients and healthcare providers is required. We recommend expanding the SDM models, by adding a step zero (patients understand their diagnosis) and a fifth step (reviewing the decision), to improve the process for LHL patients.

Keywords

Communication, shared decision making, patients, limited health literacy, focus group study.

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Shared decision making (SDM) is advocated as the preferred model for making decisions within healthcare (Stiggelbout et al., 2015; Elwyn et al., 2017). SDM is the process in which the healthcare provider and patient discuss together which medical policy is best for the patient, taking into account all options, advantages and disadvantages, patient preferences and circumstances (Elwyn et al., 2017). Four steps can be distinguished in the process of SDM: (1) The professional informs the patient that a decision is to be made and that the patient's opinion is important (justify 'team-talk'); (2) the professional explains all options and their pros and cons (inform 'option talk'); (3) the professional and the patient discuss the patient's preferences and the professional supports the patient in deliberation (elicit 'patient preferences'); (4) the professional and patient discuss the patient's wish to make the decision, they make or defer the decision, and discuss follow-up (integrate 'decision talk'; Stiggelbout et al., 2015; Elwyn et al., 2017). Several studies show that SDM increases patients' knowledge and risk perception, as well as the quality of the communication and decision making (Faber et al., 2016; Stacey et al., 2017; Coulter, 2018). Patients feel more empowered, show less decisional regret and are more motivated. Consequently, SDM improves quality of care, results in fewer unnecessary treatments, higher patient satisfaction and eventually a better quality of life (Joosten et al., 2008; Elf et al., 2015; Shay et al., 2015). However, the impact of SDM on medication adherence and other medical outcomes is less clear (Joosten et al., 2008; Shay et al., 2015). Moreover, a recent study shows that although the application of SDM in primary care has increased over the years, it is still not optimally applied by general practitioners (GPs; Meijers et al., 2019). The results in secondary care are quite similar and indicate that healthcare providers experience difficulty in applying SDM, especially when communicating with vulnerable patients (e.g., elderly, limited health literate, severely ill patients; Roodbeen et al., 2020; Murugesu et al., 2018; Légaré et al., 2008).

SDM requires that patients have the knowledge and skills to actively participate in the consultation, that they can understand the information and are able to make decisions. Patients with limited health literacy (LHL) often fail to meet these conditions. They have difficulty understanding health information, applying this information to their situation and asking questions about their disease (Nielsen-Bohlman et al., 2004; Sørensen et al., 2012; Rademakers & Heijmans, 2018). In Europe, almost 48% of the general population is considered to have LHL (Sørensen et al., 2015), and 29% of the Dutch population (Heijmans et al., 2019). Among males, elderly, low educated people and people with low economic status, the proportion of LHL is disproportionately high (Van der Heijden et al., 2013; Sørensen et al., 2015). Several studies show that LHL patients have less knowledge about health(care) and ask fewer questions during consultations (Katz et al., 2007; McCaffery et al., 2013).

Supporting tools (e.g., patient decision aids) are often not useful for LHL patients, as they consist of complex written and numerical information about the pros and cons of a certain treatment (Li et al., 2013; Barton et al., 2014). In addition, quite a few decision aids are only accessible online, while several LHL patients experience difficulty in using a computer (Barton et al., 2014). Offering clear health information that is understandable for LHL patients is important, but not sufficient. Information needs to be supplemented with other communication strategies (e.g., using short sentences, familiar words, teach-back techniques) and supporting tools (e.g., question prompt lists), as found in a recent scoping review concerning LHL patients in palliative care (Noordman et al., 2019). To identify the best way(s) to involve LHL patients in the process of SDM, more in-depth insight is needed into barriers and facilitators that LHL patients perceive themselves. Therefore, this study aims to gain insight into the experiences

and needs of LHL patients concerning SDM in clinical practice, and the kind of support they need to (better) participate in the process of SDM.

Methods

Design

A focus group study was conducted to gain in-depth insight concerning SDM from the perspective of LHL patients. During a focus group, a small group of participants discuss a specified topic to give the researcher an understanding of the participants' perspective. Focus groups are defined by the interaction between the invited participants, as well as between the moderator and the participants (Wong, 2008). Especially for LHL patients (or patients with a lower literacy level) a qualitative study is more appropriate than a quantitative study (e.g., filling in questionnaires). During a focus group, the moderators can present simple, low-threshold information and questions and discuss these with LHL patients.

The COREQ (Consolidated criteria for reporting qualitative research; Tong et al., 2007), a 32-item checklist for interviews and focus groups, was used as reporting guideline for our focus group study and included in this manuscript (see Appendix A).

Participants

Participants were included in this study if they were ≥ 18 years, spoke Dutch, and had lower/limited health literacy. Potential participants were recruited through several organisations by email and/or telephone: Stichting ABC (language ambassadors), Stichting Lezen en Schrijven (language ambassadors), Stichting Prago (language education for adults) and a community centre. In addition, members of a panel of the 'Institute for Responsible Medicine Use' (*Instituut Verantwoord Medicijngebruik*) were approached by email and/or by telephone. People could participate if they fulfilled the following two criteria: (1) Visited a general practice or specialised care organisation (hospital) in the last 12 months and, (2) if they answered 'yes' to one or more of the following questions:

1. *Do you find it difficult to understand information about your health and healthcare?*
2. *Do you find it difficult to apply this information to your daily life?*
3. *Do you (sometimes) need help with filling in forms?*

These questions to define LHL were based on the screening questions by Chew et al. (2004). Previous research showed that these brief screening questions are valid to identify individuals with inadequate or marginal health literacy, and that a single of these questions was useful in detecting patients with inadequate health literacy (Chew et al., 2008). Participants were excluded when they did not visit a healthcare provider in the last 12 months, and/or answered 'No', 'No' and 'Never' to the questions of the second criterium, respectively. Potential participants were asked to participate in a focus group discussion about their experiences, needs and support with (shared) decision making in clinical practice. We aimed for a maximum of eight participants per focus group. Groups were formed based on the availability of participants and until data saturation was reached (i.e. recurring themes in all focus groups). Eighteen potential participants were not able to attend a focus group discussion due to illness and therefore did not participate. No participants dropped-out during the study.

Twenty-six people participated in the study, of which 15 were female and 11 male. The age of the participants ranged from 26 to 81 years (mean age 64 years). Almost all participants visited both their primary care provider (i.e. general practitioner or practice nurse (mental health)) and a secondary care provider (medical specialist or nurse) in the hospital or a clinic (mental healthcare) during the last 12 months. Seventeen participants had a chronic disease for which they were treated (e.g., rheumatic disease, asthma, type 2 diabetes, ADHD, lupus, kidney disease, heart- and vascular disease, breast cancer).

Procedure

Five focus groups were held between September and November 2019, with a duration of approximately 60 minutes (range 45-90 min). Four focus groups took place at Nivel (Netherlands Institute for Health Services Research) with four, three, seven, and six participants, respectively. One focus group took place at a community centre, with six participants. A moderator (first author; *PhD, female, experienced researcher in communication in healthcare and SDM*), facilitator (second author, *PhD, female, experienced researcher in nursing and elderly care*) and note-taker (*one of two interns, both BSc and female*) were present during the focus groups. Participants had no prior knowledge of the researchers or interns who conducted the focus groups, other than what was provided as part of the research itself. A discussion guide was created to provide a framework for the moderator to ask and probe questions (Wong, 2008). Members from the advisory board from several organisations (Pharos; the Dutch Patient federation and the Dutch Ministry of Health, Welfare and Sport) provided feedback on the initial discussion guide. In addition, the guide was adapted to the target group by presenting and asking simple, low-threshold information and questions. The discussion guide was structured around three main topics: (1) Experiences with (shared) decision making in clinical practice; (2) needs regarding SDM; (3) (available) supportive tools for SDM in clinical practice. For the first topic, participants were asked to think about a situation with their healthcare provider where a choice had to be made between different treatments, including option for no treatment. Participants then told about their experiences during this situation guided by questions from the moderator about, for example, the setting of the experience, kind of decision(s) made, information provided and patient's preferences. Both 'big' decisions about a treatment (e.g., choosing between chemotherapy or a surgery) as well as 'small' decisions (e.g., choosing between injecting in the right or left arm) could be shared. During the second part, the moderator presented four steps of SDM (Stiggelbout et al., 2015; Elwyn et al., 2017), asked about the participants' experiences in more depth, and related to the four steps of SDM. Facilitators and barriers for SDM and the needs of the participants were discussed. As part of the third and last topic, we presented a case about low back hernia. Participants were asked to imagine that they had a lower back hernia and were faced with two choices: undergo surgery or wait-and-see including physical therapy and/or pain relief. After a discussion about what the participants would need to make such a decision, available supportive tools for SDM and communication aids were presented and handed out to the participants (question prompt sheet, decision aid, photo comic, talking card, three good questions for SDM, audio-record the conversation, write down your questions, teach-back techniques). The participants were asked about each decision aid or supportive tool and which (or none at all) they preferred in making a decision.

All participants signed a written informed consent form before the start of the focus group and they were asked about their background characteristics (sex, age, complaints/illness) by the facilitator or moderator. The focus groups were audio-recorded, summarised in reports and relevant quotes were transcribed verbatim.

Analyses

The reports were coded using thematic content analysis (Green & Thorogood, 2018). First, all reports were read carefully and possible themes were selected by two researchers (JN & MO). The themes were based on the discussion guide (deductive) and additional subjects that emerged during the focus groups (inductive). Initial codes were applied and discussed with a third researcher (JR). Discrepancies between researchers were resolved through discussion, and modifications in initial categories were made when necessary. All themes and patterns that emerged during the analysis are illustrated by multiple quotes which were translated (forwards and backwards) into English and edited, increasing readability without the loss of meaning or context. Data saturation was reached on the basis of recurring themes in all focus groups. The discussion guide and coding scheme are included in Appendices B and C.

Results

Patients' experiences and needs

Overall, the LHL patients in our study could not recall a situation in which they had experienced 'shared decision making' (SDM) with a healthcare provider. LHL patients participating in this study indicated that they had not experienced a treatment choice during their conversations with their healthcare providers, nor had they played a role in the decision making process. This practice is in conflict with the view of most participants in our study as they perceive the process of SDM as ideal for making a decision about a treatment or opting for no treatment. Barriers and facilitators of LHL patients related to the four steps of SDM will be discussed below.

(1) Team Talk. The first step of SDM is announcing that a decision should be made about a treatment (or opt for no treatment) and that the opinion of the patient is important, so that patient and provider can act as a team. LHL patients in this study already miss this first step of SDM. According to the participating LHL patients in our study, in most cases the healthcare provider suggested a treatment and the patient agreed. Often, one option was presented by the provider. However, when multiple options were presented the healthcare provider 'steered' the patients in a certain direction. This was not experienced as problematic by the patients in our study.

“No actually not, it was not mentioned that there is a choice. It was unilaterally decided that it (treatment) is not necessary.” (woman, focus group 1).

Contributing to this, according to the participants of this study, healthcare providers (doctors, nurses and other healthcare providers) were seen as experts who know what's best and which treatment is necessary. Therefore, LHL patients left the decision entirely up to their healthcare provider. In addition, participants experienced difficulties in estimating the medical necessity of a certain treatment.

“Then I agree with that specialist, I assume that the man knows what he is doing.
 (..) I don't make that many choices. He does what he does and it has made me better.”
 (man, focus group 2)

Patients in our study also mentioned that they felt insecure in weighing different options and were afraid to make the wrong choice. Next to being afraid of making the wrong choice, participating patients were also afraid that the healthcare provider labelled them as ‘difficult’, or were afraid to irritate the healthcare provider. These patients did not want to contradict the healthcare provider and left the decision up to them.

“You don't want to be cocky with your doctor. Then they hate you. They don't hide how they feel about you. I've even been told: ‘you have to listen to me’. They don't like it when you contradict them. While they say on the one hand, we want patients to talk with us, on the other hand they don't want that at all and they actually want you to shut up.” (woman, focus group 5)

To be able to participate in SDM, patients in our study mentioned that they would like healthcare providers to explicitly state that a decision is to be made. In addition, the LHL patients in our study indicated that clarity about one's diagnosis or condition (a step 0) is a necessary prerequisite to participate in SDM.

(2) Option Talk. The second step of SDM is providing clear information about the pros and cons of every relevant treatment option. Patients in our study mentioned that often too little information was provided by the healthcare provider about the whole treatment plan, why a certain treatment was not possible, when it was necessary to revisit the healthcare provider and about the reason for a wait-and-see policy. As a result, these patients felt they had no say or felt overwhelmed by the treatment decision.

“Then you go somewhere thinking you are going to have a medical examination. I had not received information, I had no one with me. And then I had a surgery that was so horribly painful that I became unwell. I had not been told about that. I did not ask for those things (haemorrhoids) to be removed at all. I even said on the spot, it doesn't bother me. Yes, but I have had my instructions, says the surgeon.”
 (woman, focus group 5)

To be able to participate in SDM, patients in our study said that they need to know the pros and cons of every option before they make a decision about a treatment or opt for no treatment. Specifically, patients wished to receive information about the chance of success and risks of a certain treatment, what the treatment entails, the impact of the treatment and whether a treatment suits the patient's specific situation and his or her other conditions.

“Based on a drawing, that exactly is explained what will happen with an operation. So that I can make the choice and (know) the risks of the operation. If there is a lot of risk (to undergo the operation), then a second opinion is good, I think.” (woman, focus group 5)

It is important for patients that healthcare providers sufficiently explain the different treatment options in understandable language. However, participating patients in our study frequently mentioned that the provided information by the healthcare provider was too difficult to understand or contained medical jargon. As providers used difficult language, many patients in our study became passive. These patients did not mention to their provider that they did not

understand the information. Some patients in our study did ask healthcare providers to repeat the message, but still had many questions afterwards.

“Then I am outside (the consulting room) and I think: what was that man talking about?” (man, focus group 1)

“The only remark I have, in the hospital, is those big words. Layman’s terms are still not used and I find that annoying. Then they talk about techniques, you must have studied to become a doctor (..) before you can talk about it. But then it (the words) go ‘in here’ and ‘out there’ (points to ears) and then I think ‘Ok fine, hurry up’.” (man, focus group 5)

(3) Patient Preferences. The third step of SDM—taking patient’s preferences into account—seemed to happen more often in practice, but still offers room for improvement. According to the participants, healthcare providers asked patients about their preferences, about what is important in their lives. Patients in this study felt that providers took their preferences into account. Healthcare providers asked the participating patients about how their disease and treatment influenced their leisure time or hobbies. The example below also shows that the patient’s preference influenced the decision between two treatment options.

“I got breast cancer. They took that away. I could choose between going to the hospital every day for radiation and chemo, or right away a treatment with those straws. (..) Just do that (the straws), then I’ll be ready in one go. Otherwise I had to go to the hospital every day, 3 months constantly to the hospital. Well do it like this, in one day.” (woman, focus group 3)

However, other patients in our study mentioned situations in which their preference or situation was not taken into account.

“Then I have to make a choice and I have a lot of questions about what that means for me, for my daily life. Medicines were not successful (...), went to the practice nurse again and asked for an explanation again. Now I know how to use that (medicines). But I still don’t know how to fit that into my daily life.” (man, focus group 1)

Taking patients’ preferences into account, or what is important in patients’ life, is seen as one of the most important steps of SDM by the participating patients in our study. As is illustrated in the example below.

“Yes (important), I could choose that (day or night dialysis). Because first I had dialysis during the day, but it is four hours of dialysis, you have to go there, you have to be disconnected and you have to go home again, so then you almost lost a day. (..) So I asked if it could be done at night. That was possible, because there are only six patients who can, because they are fully booked. And then you have more time during the day and you can do things.” (man, focus group 4)

(4) Decision Talk. Patients in our study said that the process of SDM requires a shared responsibility between patients and healthcare providers. Team talk (step 1) and decision talk (step 2) are seen as tasks of healthcare providers, while discussing patient's preferences (step 3) and decision talk (step 4) are seen as the responsibility of patients.

“Do I want to take that risk, do I want to live longer? Those considerations are up to you. So I totally agree, that if you give the right information and (have) the time and space, then you start making decisions that fit your own life purpose and energy. You can't put everything on a doctor.” (woman, focus group 5)

Some patients in our study wished to be in control during the entire process of SDM, and to make the decision themselves. Alternatively, they indicated that experiences in the past taught them to become more ‘empowered’ in decision making with their healthcare providers because they did not agree with the proposed treatment plan or had doubts about the diagnose or policy.

However, a perceived barrier to SDM is that it is not always clear for patients in our study which healthcare provider (in case of multiple providers) is responsible.

“You just bump into a wall, there is no communication possible. Because the GP says ‘I know nothing’ (about the medication) and the psychologist says ‘we are full until January’ and the psychiatrist says ‘I'm not doing it’ and the practice nurse is not allowed to do it (prescribe medication). And the person who prescribed it (the medication) says ‘you are finished, go back to the GP’.” (woman, focus group 4)

Although the process of SDM consists of four steps according to literature, participants in our study mentioned that a fifth step also belongs to SDM: Reviewing the final decision, especially in case of a wait-and-see policy or changed circumstances. For example, participants indicated the need to discuss the decision and possibilities every year to avoid decisional regret or insecurity of patients.

“That we have an annual check-up moment and that they make decisions based on that. (...) That they explain very well why they have a wait-and-see policy. Yes, you can of course deduce that it is not necessary because otherwise she would have said it (...), but I think they should explain that more clearly.” (woman, focus group 4)

Barriers and facilitators in each SDM stage

Time. Patients in our study experienced too little time during the conversation with their healthcare provider. Time was seen as a barrier for communication in general, and SDM in particular. Patients in our study need the time to think about a decision, for example by discussing the options again with the healthcare provider during a follow-up consultation.

“I think that if a choice is given, provided there is time for it, that it may also be that it may be overwhelming for the patient. That you can also think about it. Sometimes that is not possible of course, but it often comes across as a bit overwhelming like: ‘here you have it, you have to take it’.” (woman, focus group 2)

Patients in our study agreed that the healthcare provider should also take the time for the process of SDM. Some patients in our study already experienced this. A consultation of 10 minutes with their GP is experienced as too little time and asking for double the time (20 minutes) was considered a good possibility.

Confidence. Confidence in the healthcare provider is seen as a facilitator for SDM by patients in our study. Patients' experiences were associated with their relationship (of trust) with their familiar GP, specialist or other healthcare provider.

“I like that she (the GP) does the research and explains it to you. She knows you so well, it seems to me. (..) That she says: ‘You know what, you have to make this choice and you have to take this a step back’. It's great that she is so open and thinks along with me.” (woman, focus group 3)

Support to Participate in SDM. Participants preferred face-to-face information and advice from their healthcare provider during the process of SDM. They also mentioned the need for supportive written or visual information, on paper or digital, but always next to the face-to-face conversation. Patients in our study also indicated the wish to have a multi-disciplinary conversation, in which several healthcare providers discuss the options for treatment together with the patient. When weighting the pros and cons of a decision patients in our study regularly involved significant others (family, acquaintances), other familiar healthcare providers and fellow patients, prior to, during and after the conversation with their healthcare provider.

Participants were not familiar with the existing supportive tools for SDM and communication aids that were presented and handed out during the focus groups. In general, participants appreciated these when presented. According to the patients, the existing supportive tools or aids should be available for all patients. Healthcare providers could hand them out to patients, place them in the waiting room and/or send them to patients over the mail.

Participants in our study preferred the visual aids or tools (for example a ‘photo comic’). Participants were less positive about the available (paper or digital) decision-aids. Participants found them too difficult (i.e. large amount of text and small letters) or confronting (i.e. very detailed information).

Teach-back techniques, or asking the patient to repeat what has been discussed, were considered supportive during the consultation with the healthcare provider. Question prompt sheets (a pre-structured list of questions for patients to choose from) or writing down one's own questions prior to the consultation were seen as a good preparation for the conversation with the healthcare provider. Patients in our study already prepared questions prior to the consultation. Although they liked the idea of recording their conversation with the provider, with their telephone or an audio-recorder, they would be ashamed to record a conversation in practice.

Discussion

This study aimed to explore the experiences and needs of LHL patients concerning SDM in clinical practice, and the kind of support they need to (better) participate in the process of SDM.

Our study showed that SDM is considered uncommon in practice, although LHL patients in our study did prefer it. LHL patients in our study experienced no *Team talk*; they had not experienced a treatment choice during their conversations with their healthcare providers, nor could they play a role in the decision making process. In most cases the healthcare provider suggested a treatment and the patient agreed. This is in line with previous studies (Smith et al., 2009; Spronk et al., 2018), which found that LHL patients consider their participation in decision making as ‘agreeing or not agreeing with the proposed treatment’. While patients with

sufficient health literacy see healthcare providers as fallible people and do not blindly trust what providers recommend. Therefore, they also more actively search for information and treatment options (Smith et al., 2009). However, both LHL patients in our study as well as patients with sufficient health literacy skills in previous studies (e.g., Smith et al., 2009) indicate that the process of SDM requires a shared responsibility between patients and healthcare providers.

Prior to this, we found in our study that it should be clear to LHL patients what their problem or diagnosis is they are going to make a decision about (a step 0). This is in line with the views of healthcare providers, who may struggle with LHL patients as they leave the decision up to them and cannot properly explain their healthcare problem (Murugesu et al., 2018). We also found that LHL patients in our study reported that they were afraid or insecure to oppose their healthcare provider or to make the wrong choice. This is an undesirable situation, as previous research showed that LHL patients are more likely than patients with sufficient health literacy skills to be insecure or regret the decision afterwards (McCaffery et al., 2013). However, another study found that “relatively affluent and well-educated patients” fear being labelled as “difficult patients” which prevents them from participating more fully in their own care (Frosch et al., 2012).

Therefore, healthcare providers could offer more *Team talk*, by stating explicitly that a decision is to be made and involving the patient in it. In addition, providers should make sure patients understand their diagnosis or problem before stating that a decision is to be made. On the other hand, LHL patients should be aware that they can take a more proactive role in the decision-making process or asking others to support them in this process. A previous study showed that teaching SDM content to participants with LHL increased their health literacy skills for SDM and changed the nature of the questions they would ask healthcare providers in a way that would enable shared health decisions (Muscat et al., 2019).

That patients are inclined to agree to treatment is partly due to the fact that they perceive the information and advice of healthcare providers in the decision-making process as too concise and difficult. Previous research also showed that LHL patients generally need information that is simple, recognisable, practical and that explains step by step how to take a particular action (Murugesu et al., 2018). In accordance with other literature (Katz et al., 2007), we found that when it comes to medical jargon, patients do not mention that they do not understand the information or ask for new information. Providers ought to adapt their *Option talk* by sufficiently explain the different treatment options in an understandable language while avoiding medical jargon. Providers could also use ‘teach-back techniques’ during the consultation to check whether the patient understands the explanation. Although this is true for all patients, LHL patients especially would benefit from it (Muscat et al., 2019; 2021). Taking *patients’ preferences* and situation into account is seen by LHL patients in this study as one of the most important steps in SDM. Although there is room for improvement, providers took into account participating patients’ preferences or what is important in their lives. Previous observational studies showed that asking patients about their preferences in the process of SDM is the least discussed topic by providers (Meijers et al., 2019; Couët et al., 2015). It is important for healthcare providers to foster confidence and provide a safe setting so that patients can express their own thoughts and preferences, as well as to explain clearly if it is not possible to implement the patient's preference.

Patients experienced several barriers and facilitators in each SDM stage. Too little time, for patients to think about a decision and for providers to discuss all options, was seen as barrier,

while confidence in the healthcare provider was mentioned as facilitator. Trust in the physician was also found to be associated with SDM in patients with rheumatoid arthritis (Barton et al., 2014). Also among people with sufficient health literacy there is a need for a safe environment and open communication to facilitate shared decision making (Frosch et al., 2012).

Several previous studies also found ‘time’ as a barrier for SDM, both by patients and healthcare providers (Roodbeen et al., 2020; Murugesu et al., 2018; Legaré, 2008). A recent study addressed ‘time for SDM’ from the different perspectives of patients, healthcare providers and health insurers in the Netherlands (Van Dulmen et al., 2020). This study found that patients prefer more time with their healthcare provider during the consultation, while healthcare providers and health insurers want to make better use of the time prior to the consultation (e.g., by means of decision-aids; Van Dulmen et al., 2020). However, more time may not be needed necessarily, as other research suggests that the average time required for SDM is only 3 minutes or less (Stacey et al., 2014). Patients in our study also wished for a multi-disciplinary conversation, in which several healthcare providers discuss the options for treatment together with the patient. This multi-disciplinary conversation might facilitate the SDM process without asking too much time of the healthcare providers. Future research could look into this.

To support LHL patients in SDM, we found that all participants preferred face-to-face information and advice from their healthcare provider during the process of SDM. They also mentioned the need for supportive written or visual information, on paper or digital, but always next to the face-to-face conversation. Most of the participants in the focus groups were not familiar with the existing tools or aids that we presented them. This is in line with previous studies, showing that decision-aids are still rarely used as they are often too complex or not easily accessible to LHL patients (Li et al., 2013; Barton et al., 2014). Decision-aids and other tools should be adapted together with LHL patients, so that they better match the wishes and skills of this target group (McCaffery et al., 2013; Barton et al., 2016). A study into vulnerable populations, including those with limited health literacy, also found that SDM requires inclusiveness in decision support materials and plain language communication (Grabinski et al., 2018). LHL patients in our study preferred the visual aids or tools over the aids with text only. This is in line with a recent RCT, in which it was concluded that a picture based aid had more impact on the key outcomes (e.g., more SDM, higher knowledge, lower decision regret) of women with lower SES and health literacy compared to an aid with text only (Durand et al., 2021).

As LHL patients prefer face-to-face conversations with their healthcare provider, providers could be trained in communication skills to implement SDM in their daily practice, for example by using video-feedback (Noordman et al., 2014). We found that LHL patients like to learn from and rely on the experiences of other people to make a choice. Videos and narratives (stories) are a good way to share these experiences (Rolink et al., 2019).

Finally, we recommend to expand the 4-steps SDM models (Stiggelbout et al., 2015; Elwyn et al., 2017), by adding a step zero (making sure patients understand their diagnosis or problem) and a fifth step (reviewing the decision), to improve the SDM process for LHL patients. Also, offering visual tools or (decision) aids - adapted together with LHL patients to better match their wishes and skills – in addition to face-to-face conversations with healthcare providers could support SDM. A recent study also proposes an expanded model of SDM which incorporates health literacy concepts, including addressing patients’ skills and capacities and modifications to written and verbal information (Muscat et al., 2021).

This study has several limitations. First, the small patient sample is not representative for the population of LHL patients. However, our aim was to gain in-depth insights and therefore this qualitative study is appropriate, because data saturation was reached due to recurring themes in all focus groups. Second, although the screening criteria for LHL that we used in this study are valid (Chew et al., 2008), they are subjective as it reflects the individual's perception and experiences, which may also indicate patient's self-efficacy beliefs and/or dissatisfaction with available information. Future research could include a more robust measurement of LHL. The mean age of the participating patients was also rather high (64 years), so younger patients are underrepresented. Third, we do not know exactly how many times the participants visited (different) healthcare providers during the last 12 months. This could have influenced their experiences with and need for SDM.

Finally, this study focused on the patient perspective. Previous studies have focused on providers' perspective (e.g., Murugesu et al., 2018). In addition, observational research could provide insight in real-life practice between LHL-patients and their providers. To facilitate SDM, future research could also include the perspectives of healthcare insurers and policy makers of healthcare organisations. As shown by Scholl and colleagues, it is necessary to consider the role of organisational and system-level characteristics to support the implementation of SDM (Scholl et al., 2018).

Conclusion

LHL-patients in our study had little experience with SDM in practice, but do prefer it. Important barriers for this are healthcare provider-related (e.g., involving patients too little in decision-making, the use of medical jargon), patient-related (e.g., feeling insecure to play a role in decision-making, inability to understand their diagnosis or information about treatment options) related to the interaction between patient and caregiver (having a relationship of trust) or system-related (e.g., too little consultation time). For SDM to take place more often, a shared responsibility between patients and healthcare providers is required. We recommend expanding the 4-step SDM models, by adding a step zero (making sure patients understand their diagnosis or problem) and a fifth step (reviewing the decision), to improve the SDM process for LHL patients. Offering visual tools or (decision) aids - adapted together with LHL patients to better match their wishes and skills, in addition to face-to-face conversations with healthcare providers, could also support SDM.

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Ethical Approval

The study was carried out according to Dutch privacy legislation. According to Dutch legislation, approval by a medical ethics committee was not required for this study. All participants were informed (in writing and orally) about the study and signed an informed consent form before the start of the study. Data of participants was anonymized. Participants could withdraw their consent at any time; no one did.

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Conflict of Interest

No conflict of interest

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Appendix A

Table 1. The COREQ Checklist (Consolidated Criteria for Reporting Qualitative Research; Tong et al., 2007)

No	Item	Guide Question/Description	Description in this Paper
Domain 1: Research team and reflexivity			
Personal Characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	p. 34
2	Credentials	What were the researcher's credentials? E.g., PhD, MD	p. 34
3	Occupation	What was their occupation at the time of the study?	p. 34
4	Gender	Was the researcher male or female?	p. 34
5	Experience and training	What experience or training did the researcher have?	p. 34
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	p. 34
7	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g., personal goals, reasons for doing the research	p. 34
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g., Bias, assumptions, reasons and interests in the research topic	p. 34
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g., grounded theory, discourse analysis, ethnography, phenomenology, content analysis	pp. 32, 33, 35
Participant selection			
10	Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	pp. 33-34
11	Method of approach	How were participants approached? e.g., face-to-face, telephone, mail, email	p. 33
12	Sample size	How many participants were in the study?	p. 34
13	Non-participation	How many people refused to participate or dropped out? Reasons?	p. 33

Setting			
14	Setting of data collection	Where was the data collected? e.g., home, clinic, workplace	p. 34
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	p. 34
16	Description of sample	What are the important characteristics of the sample? e.g., demographic data, date	p. 34
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p. 35 and Appendix B
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	p. 33
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	p. 35
20	Field notes	Were field notes made during and/or after the interview or focus group?	p. 34
21	Duration	What was the duration of the interviews or focus group?	p. 34
22	Data saturation	Was data saturation discussed?	p. 35
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	p. 35
25	Description of the coding tree	Did authors provide a description of the coding tree?	p. 35 and Appendix C
26	Derivation of themes	Were themes identified in advance or derived from the data?	p. 35
27	Software	What software, if applicable, was used to manage the data?	Not applicable
28	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g., participant number	pp. 35-39
30	Data and findings consistent	Was there consistency between the data presented and the findings?	pp. 35-39
31	Clarity of major themes	Were major themes clearly presented in the findings?	pp. 35-39
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	pp. 35-39

Appendix B

The discussion guide

(1) Welcome [10 min]. Words of welcome. Explanation of (goal of) the focus group. Reminder to fill in an informed consent form and audio-recording of focus group. Opportunity to ask questions. All participants introduce themselves.

(2) Experiences with (Shared) Decision Making in Clinical Practice [40 min]. Ask participants to think about a situation with their healthcare provider (doctor, nurse or other provider) in which a choice had to be made between different treatments, including the option for no treatment. Both ‘big’ decisions about a treatment (e.g., choosing between chemotherapy or a surgery) as well as ‘small’ decisions (e.g., choosing between injecting in the right or left arm) could be shared. If participants thought of multiple situations, they could think of their last experience or an experience they want to share. Each participant briefly describes the situation they have chosen.

Questions to be asked (if applicable):

- *What choice(s) does it concern?*
- *How was this experience for you?*
- *What was the setting of the choice to be made?*
- *Did you know that a choice could or had to be made?*
- *Did you think it was important to be able to participate in the decision-making process? Why (not)?*
- *Where you able to?*
- *Did you receive (sufficient) information about what to choose? If so, what information?*
- *How did you get the information (verbal, folder, website etc) and from who?*
- *Was the information about the choices clear? Why (not)?*
- *Did you receive information about the benefits of the choices?*
- *Did you receive information about the disadvantages of the choices?*
- *What did you find important (or most important) when making a choice? Was this asked by the provider? If so, did the provider act on this?*
- *Did you receive help in making the choice? (for example from your doctor or a relative)*

(3) Needs Regarding SDM [20 min]. Moderator presents the four steps of SDM. Ask participants to reflect in more depth on the situations they mentioned earlier, related to the four steps of SDM.

Questions to be asked (if applicable):

- *Which step do you recognize? Which steps not? why?*
- *In practice: which step does not happen/hardly happens? Why not?*
- *Which step is the most difficult (for you/the provider)? Why?*
- *What do you think the provider could do best? What would you like the provider to do? What do you need?*
- *How do you see your own role? What would be the best thing for you to do?*

- *How can the provider best help you with your choice?*
- *Do you prefer one conversation or multiple conversations with your provider about this? What about a break to be able to think about your choice?*

(4) (Available) Supportive Tools for SDM in Clinical Practice [20-30 min]. Moderator presents a case about low back hernia. Participants are asked to imagine that they have a lower back hernia and are faced with two choices: undergo surgery or wait-and-see policy including physical therapy and/or pain relief.

Questions to be asked (if applicable):

- *What do you need to make such a choice?*
- *What information do you want to receive (e.g., about treatments/outcomes)? At what time (for example, after diagnosis or another moment)?*
- *What kind of support (or none) do you need from your provider?*
- *How could you prepare yourself for a conversation with your provider in which a choice has to be made?*
- *What kind of support do you need yourself?*
- *What kind of support do you need from your partner or anyone else?*

If patients immediately decide on one of the two choices (surgery or wait-and-see), ask why and how they decided this.

After a discussion about what the participants would need to make such a decision, the following available supportive tools for SDM and communication aids are presented and (if available) handed out to the participants: Question prompt sheet, decision aid, photo comic, talking card, three good questions for SDM, audio-record the conversation, write down your questions, teach-back techniques.

Questions to be asked (if applicable):

- *Have you seen these decision aids or supportive tools before? If yes, where/by whom?*
- *What do you think of these decision aids or supportive tools?*
- *Would you like to have a decision aid or supportive tool in making a choice? Or none at all? This does not have to be the ones we handed out.*
- *Do you prefer something (or someone) else in supporting you when making a choice about your health? If yes, what/who?*
- *Which of the decision aids or supportive tools would you like most? Why?*
- *Which of the decision aids or supportive tools would you never use? Why not?*
- *What would you change for this particular decision aid or supportive tool? Why?*
- *How would you like to receive or get informed about possible supporting tools or decision aids? And by whom?*

(5) Closure [5 min]. Thank everyone for their participation. Answer remaining questions or comments. Explain what will happen with the data gathered. Hand out travel declaration forms and gift vouchers.

Appendix C

Table 2. Coding Scheme

Themes	Sub-Themes	Elements
Experiences with SDM	Relevance of SDM for patient's situation	<ul style="list-style-type: none"> - Experience(s) - Experience with decision making, but not SDM - Acute/critical situations
Needs regarding SDM	Participation	<ul style="list-style-type: none"> - Active participation - (more) passive participation
	Other needs	<ul style="list-style-type: none"> - No medical jargon
Step 1: Team Talk	Decision (not) mentioned	<ul style="list-style-type: none"> - Provider as expert - Knowing there is a choice - Step 0: clarity about diagnosis
	Patient's feelings	<ul style="list-style-type: none"> - Insecure - Afraid to irritate provider - Afraid to be labeled as difficult
Step 2: Option talk	Information about pros and cons	<ul style="list-style-type: none"> - Too little information - Too difficult information - Explain different treatment options in an understandable language
	Patient's feelings	<ul style="list-style-type: none"> - Overwhelmed/ become passive - Little say
Step 3: Patient preferences	Taking preferences & patients' situation into account	<ul style="list-style-type: none"> - Provider asks patient about preferences - Taking patients' situation into account - Provider did not ask about preferences/not taking situation into account
Step 4: Decision talk	Shared responsibility	<ul style="list-style-type: none"> - Step 1 & 2 provider; step 3&4 patient - Patients in control - Not clear which provider is responsible - Step 5: review decision
Process of SDM (all steps)	Barriers or facilitators	<ul style="list-style-type: none"> - Time - Confidence
Support	Preferences	<ul style="list-style-type: none"> - Face-to-face contact - Supportive visual/written information - Multidisciplinary conversation - Involve (significant) others
	Use of supportive tools/ decision aids	<ul style="list-style-type: none"> - Familiarity with tools/aid - Opinion on tools/aids - Availability of tools/aids