Measuring shared decision making in oncology: an informed approach

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4

SHARED DECISION MAKING IN ONCOLOGY: A MODEL BASED ON PATIENTS', HEALTHCARE PROFESSIONALS', AND RESEARCHERS' VIEWS

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ABSTRACT

Objective

To construct a model of shared decision making (SDM) about cancer treatment by conducting an extensive consultation of stakeholders, informed by the literature.

Methods

We interviewed 76 stakeholders: cancer patients, potential future patients, oncologists, nurses, and SDM researchers. We asked: “If I say ‘Doctors and patients making decisions together about cancer treatment’, what does this make you think about?”. Ideas were further solicited by presenting 19 cards each describing a possible SDM element. Interviews were inductively coded and analysed, and the emerging themes were integrated into a model.

Results

The model that was based on participants’ views, assigns specific roles in SDM to both oncologists and patients. Oncologists determine possible treatments; emphasise the importance of patients’ opinion; explain treatment options; get to know patients; guide patients; and provide treatment recommendations. Patients ask questions; express thoughts and feelings; consider options; offer opinions; and decide or delegate decisions to oncologists. Outside consultations patients search for information, prepare questions, and consider options.

Conclusions

Next to oncologists’ role, cancer patients also have a clear role in SDM about cancer treatment, during and outside consultations. Patients should receive the support they need to fulfil this requirement.

1. BACKGROUND

The majority of cancer patients favour active patient participation in decision making[1-3] as do oncologists.[4, 5] What this participation actually entails for shared decision making (SDM) remains inconsistent between models of SDM. The SDM models published to date differ in whose behaviour is seen as key to SDM (i.e., clinicians' only, or both clinicians' and patients').[6]

Despite this lack of clarity several instruments have been developed to measure SDM, which may take a patient, clinician, and/or observer view. Agreement between scores of patients, clinicians, and observers regarding the same consultation is poor.[7-9] These findings suggest that current SDM measures do not refer to a single construct, or that perceptions of SDM occurrence differ depending on the viewpoint.[7] In a recent review of SDM instruments, we noted that frequently developers do not or only vaguely define SDM.[10] We therefore decided that further clarification of the concept of SDM is imperative.

Our focus was on the conceptualization of SDM in oncology, for various reasons. There is a strong impetus but also lack of implementation of SDM in oncology.[11, 12] A better understanding of what SDM about cancer treatment entails, could support its implementation. Further, cancer is exemplary for a potentially life-threatening disease in a care setting surrounded with uncertainties.[12] Moreover, oncologists and cancer patients often meet for the first time when a treatment decision is required, and then need to choose between options that often have irreversible and enduring side-effects,[13] often within a limited time.[14] All this may result in significant feelings of vulnerability and fear in patients.

A communication model of SDM recognizing the communication process as the vehicle for decision making in cancer treatment has been described.[15] We identified only one model in oncology describing the actual SDM process. This model describes oncologist behaviour only,[12] whereas most SDM models from outside oncology also describe patient behaviour more or less explicitly.[6] Also, qualitative studies in oncology indicate that both patients and oncologists consider patient behaviours part of SDM.[16-20] Therefore, the aim of the present study was to construct a model of SDM about cancer treatment by conducting an extensive consultation of stakeholders, informed by the literature.

2. METHODS

2.1 Study design

In the Netherlands, patients most often make treatment decisions with their oncologist in outpatient clinics, increasingly supported by oncology nurses in a separate consultation. Individual interviews were held with cancer patients, potential future patients, oncologists (i.e., surgeons, medical oncologists, radiotherapists, pulmonologists, gynaecologists, and urologists), nurses, and SDM researchers, to determine what constitutes SDM in oncology. Potential future patients were members of the general population. They may face a cancer diagnosis in the future, but are not influenced by the experience of making actual cancer treatment decisions. This is relevant as the cancer patients that we interviewed often mostly described and justified their personal experiences. We report the study according to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Appendix A).[21]

The Medical Ethical Committee of the Leiden University Medical Centre (LUMC) approved the study (P14.207), which was conducted according to the Dutch Medical Research Involving Human Subjects Act.

2.2 Participant recruitment

Oncologists from one academic medical centre (LUMC) and two non-academic hospitals (Haga Hospital, The Hague, and Reinier de Graaf, Delft) in the Netherlands were approached and interviewed. These oncologists were each asked to recruit two cancer patients (any diagnosis) who were ≥18 years old, had a life expectancy of over six months and were currently scheduled for a (pre-) treatment consultation (referred to as ‘current patients’ below). Additionally, we asked five oncologists from different specialties to each approach five disease-free patients who were ≥18 years old and had ended anti-tumour treatment (excluding hormonal therapy) six to 24 months earlier.

We contacted all current and disease-free patients who agreed to participate to plan an interview at their home or at the hospital, for current patients in combination with an existing appointment, whichever they preferred. Disease-free and current patients did not receive reimbursement except for travel expenses for disease-free patients. Potential future patients were recruited through advertisements in local newspapers, were interviewed at the LUMC, and received a gift card worth twenty euros. Eligibility criteria were: aged >30 years, never diagnosed with cancer, never attended oncology consultations, no cancer diagnosis in significant others in the past six months, no chronic disease, and no healthcare training. We applied purposive sampling to ensure diversity with regard to gender, age, and education. We approached oncology nurses who are involved in decision making and SDM researchers through our network. All professionals were interviewed at their workplace. We obtained written informed consent from current, disease-free and potential future patients.

2.3 Data collection

The interview guide (Appendix B) was informed by a systematic literature search conducted in October 2014 on what SDM in oncology constitutes according to cancer patients and oncologists.[16-19, 22]

We started the interview with questions on the participant’s demographic characteristics, and for professionals, work-related details. Second, we asked this question: “If I say ‘Doctors and patients making decisions together about cancer treatment’, what does this make you think about?”. In Dutch, there is not one generally-accepted term for SDM, and the terms used have slightly different semantic connotations. We also know from the literature that cancer patients consider the concept of participation in decision making unfamiliar,[19] so we chose the most easy variant: ‘making decisions together’ (samen beslissen in Dutch). We asked about doctors, but emphasised that they could think of other relevant healthcare providers, and that we wished to hear their views on SDM, rather than specific descriptions of their consultations. We started out with this open-ended question to allow the participants to respond based on their personal views. We compiled a list of probes and additional questions to elicit more in-depth responses (Appendix B). We kept focus on whether aspects were or were not SDM-specific, but we did not explicitly ask whether aspects were required for SDM or not. Third, to encourage further elaboration we presented the participants with 19 paper-based cards, each describing one SDM element, collected from qualitative studies about SDM in oncology[16-19, 22] and from often-cited SDM models[12, 14, 23, 24] (Appendix B). Finally, we asked patients about their disease characteristics.

Our interview guide was pilot-tested for feasibility with two research assistants and one clinician.[25] Next, one of three trained interviewers (HBR, NvDB, MBT) conducted the interviews, which lasted 30-60 minutes. During some interviews with current cancer patients, a companion was present, who sometimes corroborated what a patient said, or answered questions asked of the patient; these responses were coded if relevant to our research question. Each interview was audiotaped and transcribed verbatim.

We thoroughly evaluated the transcripts of the first few interviews within each participant group to ensure that we were collecting answers to our research question. The interview guide was adapted in an ongoing process throughout the study, as is common in qualitative research.[26]

Data saturation, defined as no new themes emerging in the last three consecutive interviews, was determined based on the interviews with current patients only, for pragmatic reasons.

2.4 Data analysis

Three coders (MJF, MBT, NvDB) coded the transcripts per participant group. The three coders first independently coded all the transcripts of the current patients, and regularly compared their coding. Two of the three coders then independently coded the transcripts from the other participant groups. Code labels were detailed, and developed inductively. The same list of labels was used to code each participant group, and extended whenever necessary. The coders finalised the coding in consensus meetings. During the coding process, the research team met regularly to discuss emerging issues and the findings. The definitive coding was entered in Atlas.ti, version 7.5.12.

One researcher (HBR) clustered the codes of the interviews with the current patients and then those of the interviews with the oncologists based on the code labels. Next, two researchers (NvDB, HBR) independently checked whether each formed cluster indeed represented a coherent collection of codes, based on the underlying data fragments, i.e. axial coding. If necessary, they moved particular codes to different clusters, combined clusters, built new clusters, or renamed clusters, all in consensus. Then the researchers independently examined the codes of the remaining participant groups that had not yet been included in a cluster up to that point. In consensus, they determined to which cluster it belonged or whether a new cluster should be formed. Finally, the researchers identified the clusters that are part of the SDM process itself, and those that represent SDM barriers or facilitators; only the former are reported here. This resulted in an overview of clusters for each participant group separately. Those clusters were organised into themes and integrated into a model for all participant groups.

In the following, we focus on the common denominator among participant groups. When striking contradictions emerged from the analysis, either within a participant group or between groups, these are explicitly described. When only one participant group mentioned a theme, we state this. Quotations were selected to illustrate the themes and were translated into English (HBR, AHP).

3. RESULTS

3.1 Participants

We performed interviews with 76 participants, between July 2015 and September 2016 (Table 1). Twenty-three oncologists were approached, and 16 participated. Thirty current patients provided informed consent, 22 of them actually agreed to be interviewed. Current patients who did not agree to be interviewed often mentioned disease and/or treatment related reasons. At the time of the interview, 17 were or had been treated with curative intent, five with palliative intent. Eight disease-free patients were invited and agreed to be interviewed. Thirty-one of the 38 potential future patients who contacted us were eligible, and 16 were purposively selected and interviewed. We approached eight nurses and interviewed the six who reported to be involved in decision making. Nine SDM researchers were approached and eight of them agreed to be interviewed. Data saturation was reached in current patients.

Table 1. Characteristics of current and disease-free patients, potential future patients, oncologists, oncology nurses, and SDM researchers

	N or Mean (SD)
Current and disease-free patients	30
Sex, female	14
Age, years	62 (11.6)
Primary tumour type	
Colorectal	12
Lung	5
Prostate	4
Endometrial	4
Oesophagus	1
ENT	1
Mamma	1
Ovarian	1
Bone	1
Education level	
Low	4
Intermediate	18
High	8
Potential future patients	16
Sex, female	9
Age, years	58 (11.0)

Education level	
Low	2
Intermediate	6
High	8
Oncologists	16
Sex, female	6
Age, years	48 (10.6)
Years since start oncologist training	12.3 (9.0)
Specialty	
Medical Oncology	4
Surgery	4
Pulmonology	2
Radiotherapy	2
Urology	2
Gynaecology	2
Oncology nurses	6
Sex, female	5
Age, years	46.2 (9.8)
Specialty	
Medical oncology	3
Palliative care	1
Gynaecology	1
Urology	1
SDM researchers	8
Sex, female	5
Age, years	51.9 (5.7)
Function	
Researcher	4
Researcher/clinician	2
Policy maker	2

3.2 Participants’ views about what SDM in oncology entails

Participants often immediately mentioned specific roles for both patients and oncologists when asked what the phrase ‘Doctors and patients making decisions together about cancer treatment’ made them think about. They rarely first described a more general process, without any specific actor.

> *Then you think that you are going to draw up a plan together [silence]. Then you discuss together. The doctor discusses the options and then you sort of start to look into whether it fits or is useful or anything. (potential future patient, male, 65, intermediate education level)*

Participants emphasised oncologists’ expertise, based on medical knowledge and experience. Each participant group mentioned this, although the exact wording differed. This expertise comes with responsibilities, and is reflected in oncologists informing, guiding, and giving patients treatment recommendations. Conversely, the participants identified a lack of expertise in patients, as patients have no medical training.

> *So I think for sure that in deciding together, then the expert and the lay person and the feeling of the lay person work together, and the expertise of the expert. (current patient, male, 67, high education level)*

One patient stated that patients can have medical expertise from searching the internet. An SDM researcher explicitly emphasised that patients are experts on their own lives and on living with the disease. Generally, current and disease-free patients and potential future patients focused more than other participants on what patients should do in an SDM process, while SDM researchers and health professionals focused more explicitly on oncologists' behaviours.

Overall, eight themes were identified and are described below, and these were integrated into a model of SDM (Figure 1). SDM in oncology includes both the consultation and the time outside the consultation. Most oncologist and patient SDM behaviours during consultations are reciprocal. For example, when patients ask for information, oncologists provide information. Similarly, oncologists provide information and patients ask questions about it. It is of minor importance *who* is responsible for making the final decision, the focus is on the distinct roles *during* the SDM process.

3.2.1 Determine possible treatment options

Oncologists determine the possible treatment options for patients before or during consultations, based on medical and patient factors. Oncologists may explicitly mention which treatment options are possible and which are not.

> *If I go to the solicitor [...], then I go and see how the request I have fits within the law. And it is also a little bit like that the other way round I think when you visit the doctor, then you also expect that he has thought up for you if something is or is not compatible with life. (oncologist, female, 35, medical oncologist)*

3.2.2 Express importance of patient's opinion

The SDM researchers stated that during consultations, oncologists should invite patients to become involved in decision making. The other participants additionally mentioned more specific oncologist behaviours underlining the importance of patients' opinion: oncologists state during consultations that a) there is a choice to be made between various options, b) it is the intention to make decisions together, c) the patient's opinion is important, and/or d) the patient decides. Patients only mentioned c and potential future patients only mentioned b, both in response to the paper-based cards.

> *I mean, a patient visits a doctor with a particular health concern or problem and the doctor can, I think actually in all cases, there are some exceptions, but in fact in all cases he can say that he is the expert, but only regarding the medical content, but that the decision also depends on the preference of the patient. So that he makes it clear that there is a choice to be made in which the patient can take part. (SDM researcher, male, 54, researcher)*

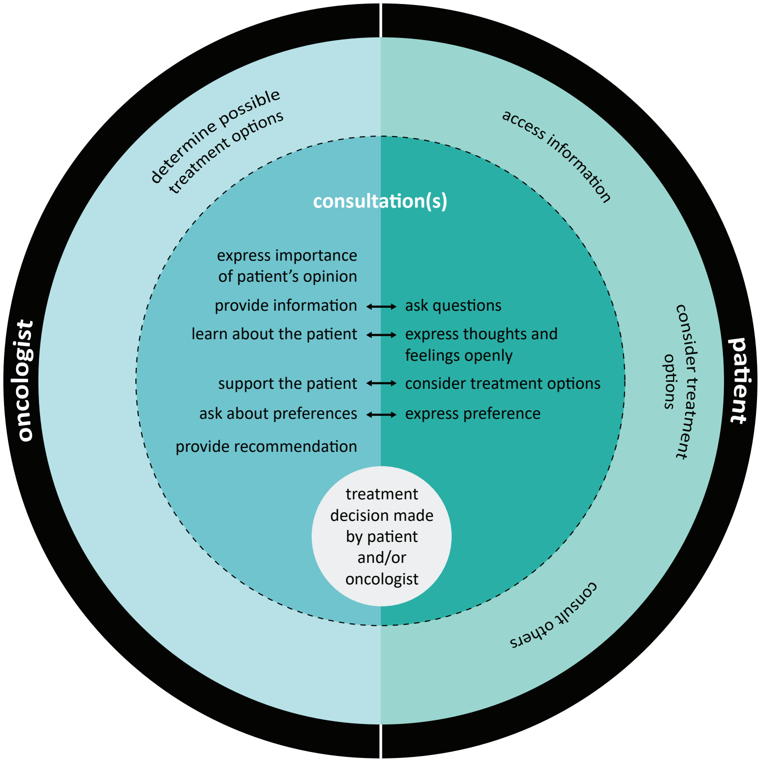

Figure 1. Model of shared decision making (SDM) in oncology, depicting oncologist and patient behaviours as they unfold over time, during as well as outside consultations

3.2.3 Provide information and ask questions

Oncologists provide information about the disease, and present the treatment options; they include the pros and cons and the associated probabilities. Oncologists explain treatment outcomes into some detail at least. Oncologists are open and honest, and their information is accurate, clear, and complete.

> *Properly tell what is going on and not play hide and seek. (current patient, male, 71, high education level)*

Some participants mentioned this to be especially relevant as contradictory information confuses and disturbs patients, as online information may do. Oncologists determine their patients' level of understanding, and clarify any issues if necessary. Patients ask questions when things are not clear.

3.2.4 Learn about the patient and express thoughts and feelings openly

Oncologists make efforts to get to know their patients, for example by asking what is important for them.

> *Everyone has a different perspective on life. […]How you, with whom, how you grew up or not, in how you see things and how you cope with things. So you, we all cope differently with illness and with anxiety. And that's also your job for some part, to try and figure that out, and to find out what the hidden agenda is and so that you can provide everyone with the best care. (oncologist, female, 39, gynaecologist)*

The patients and potential future patients explicitly mentioned that patients should express their thoughts and feelings openly.

> *Also be clear towards, towards the doctor. First. (Interviewer: And be clear about what?) About your feelings and healing process and what you want. (current patient, female, 58, intermediate education level)*

An oncologist pointed out, however, that oncologists cannot force patients to express themselves.

3.2.5 Support the patient and consider treatment options

Patients think about what is important for them, consider and weigh the options and their pros and cons, including the associated probabilities. Patients use the information that they received from their oncologist, or found themselves, to figure out the best option for themselves. Oncologists support this deliberation throughout the decision process, using the knowledge they gained about the patient to do so.

> *The whole idea of SDM is that the patient has the most important voice in it of course.[silence] And as a doctor you should coach that, counsel well […]. You should not let a patient swim. So throw all the information over the wall and say: well, please tell me. (oncologist, male, 44, surgeon)*

3.2.6 Consider treatment options outside the consultation

The participants consider time outside the consultation as part of SDM. Patients use this time before, after, or in-between consultations to consider the treatment options and discuss these with their family, friends, acquaintances, or general practitioner.

> *But I would indeed say wait a day or so or two days, talk about it, and think about it for a moment. And then maybe make another appointment. That seems to me. ((Interviewer: You're saying; talk about it for a moment?) Yes, with the family, talking about it with the partner, children. (Interviewer: At home too..) Let it sink in for a bit, because it can be overwhelming and you cannot do that right away, it just is not possible. I think. (disease-free patient, female, 66, intermediate education level)*

This time can further be used to search for information and/or prepare questions. Some participants explicitly mentioned that patients are never obliged to search for information.

3.2.7 Provide recommendation and express preference

Oncologists provide treatment recommendations and their expertise lends them the authority to do so.

> *It's like with a boiler-serviceman, he can say what's needed to make that boiler run well and that doctor can also advise me there. (Interviewer: And you say which boiler it should be?) Yes, exactly. (current patient, male, 70, high education level)*

Some participants mentioned that treatment recommendations should be substantiated with patient preferences. Patients express their opinion on the treatment options, after oncologists have asked for it or at their own initiative.

3.2.8 Make the treatment decision

Participants across groups expressed different ways in which final decisions can be made. Some said that patients make the decision, since it concerns their own body and life.

> *Well, I think the decision lies with yourself. If you think like, I do absolutely not feel like it. It sounds terrible to me to do all that. Then you should not do it. But that decision lies with you. Nobody can force you. It is your own body. (current patient, male, 71, high education level)*

Others described it more as patients deciding by accepting or rejecting oncologists' treatment recommendation, and by oncologists then respecting patients' choice.

> *But there are patients who do not want to have surgery for breast cancer. As professional this is quite hard to take. In the end you have to respect that, that it is a choice. (oncologist, male, 44, surgeon)*

Others again mentioned that oncologists should decide for patients when patients do not want to decide.

> *You lead the conversation. If not do it, this, if do it, that, what is your life? What do you think is important? What do you think is not important? That is what you offer and a patient can go into it. [...] And some patients say 'Fine, you decide because you know what is best for me'. Fine, but then that also, that doesn't matter. (nurse, male, 49, medical oncology)*

The participants explained that patients ultimately decide, as they always have the right to refuse a treatment proposal. A few participants explicitly mentioned that making the final decision cannot be done together; ultimately the oncologist or the patient formulates the decision.

4. DISCUSSION

To the best of our knowledge, this is the first conceptualization of SDM in oncology informed by such an extensive consultation of stakeholders. We interviewed a large number of stakeholders, providing rich data and representing a broad range of opinions. Our interview method was open and gave participants full opportunity to share their views. All these perspectives were integrated into a comprehensive model of SDM in oncology. Our model suggests that oncologists have a prime role in the SDM process but that patients have an important role as well. This finding is in line with several SDM models developed for other settings.[6]

Importantly, time outside consultations is an essential part of SDM in oncology, and not merely a facilitator. That is, SDM extends to the world of the patient and is not confined to the space where oncologists and patients meet. Others recently advocated that SDM in fact 'needs to centre on the person, rather than the medical encounter'.[27] Outside the consultation, patients can consider their options, consult others, or search for information, all as part of the SDM process. Indeed, ideas of patients' family members about treatment options may influence patients.[28] Furthermore, cancer patients are known to search for information beyond consultations, e.g. on the internet, in books, through other media, or by consulting others with experience with cancer.[16, 29-31] Our and others'[32] findings highlight the importance of including a so-called "Time Out" in cancer treatment decision making, with at least two consultations, to make important decisions. Our findings further have implications for measuring SDM in oncology; it seems essential to include measures of patient behaviours within and outside consultations.

Oncologists get to know their patients, which aligns with the call to clinicians to view the healthcare experience through the patient's eyes.[33] Meanwhile, cancer patients openly share their symptoms, concerns, thoughts, and feelings with their oncologist, corroborating earlier findings among primary care patients and clinicians; patients' honesty was identified as important to SDM, to enable clinicians to support patients.[34, 35] Clinicians, in turn, should explore patients' thoughts, feelings, and fears.[35] Our and others'[20] results suggest that cancer patients need to consider their treatment options, and that oncologists need to support and guide patients in this process.

Providing a treatment recommendation is part of SDM. This finding confirms results from patient interviews in primary care[34] and oncology.[36] This may cause tension; cancer patients may prefer a clear recommendation as part of SDM, but recommendations may influence them in ways they are not aware of.[37] Oncologists should therefore refrain from providing a recommendation too early in the process, before it can involve patients' preferences.
With regard to the final decision, some participants stated that patients make the final call. Other participants reported that within SDM oncologists can make the final decision. These opposed opinions support results on views about SDM from primary care patients.[34] SDM in oncology is an interactive exchange and it seems of minor importance who makes the final call, as long as the process of decision making is about involving patients, eliciting their values, and incorporating these in the final decision.

4.1 Study limitations

Our study should be considered in light of several limitations. First, we do not know how many current and disease-free patients were asked to participate by their oncologist and refused, and for what reasons. Also, eight current patients who initially had agreed to participate later refused participation, and they often mentioned their disease and/or treatment as reason. This may have resulted in a sample of patients with a better prognosis or less burdensome treatments. Also, the included patients were highly educated, resulting in potential biases towards a role in SDM that may be challenging for other patients. Secondly, we analysed the data towards the end of completing data collection, and determined data saturation in current patients only, for pragmatic reasons. Post hoc analysis showed that Figure 1 would include the exact same elements if it were only based on perspectives of current patients. Thirdly, we did not perform a member check due to the large sample and because we would risk the need to omit and/or revise findings because participants had reservations regarding our findings, even if it was a correct representation.[38] Fourthly, participants often elaborated solely on their own experiences, which may have limited their considerations of what SDM looks like. In addition, it is very well possible that participants' role preferences influenced their conceptualisation of SDM. Finally, we did not ask about the order of behaviours as part of the SDM process. In figure 1, we depict an order of behaviours based on what seemed most natural. In reality, it might be that SDM is more of a dynamic process,[35, 39] in which oncologist and patient behaviours are intertwined, rather than following a pre-defined order of demarcated phases.

4.2 Clinical implications

Our findings have implications for efforts to implement SDM in oncology. More explicitly than other studies, ours suggests that patients have an active role: it is important in SDM that patients are open about their thoughts and consider their options, during as well as outside consultations. It may be helpful to inform patients that active patient behaviour, such as asking questions, may facilitate SDM.[11] Note that SDM should not be imposed on patients and that some patient behaviour, such as expressing feelings, may be required for an SDM process to occur, but that patients should receive the support they need to fulfil this task. The need for support can very well depend on the extent to which a patient prefers to have a role in decision making, as well as on other patient- or decision-related characteristics. Our findings are based on interviews in which stakeholders were asked specifically about SDM in oncology, the model is likely to be applicable to other clinical settings as well, but this remains to be tested.

4.3 Conclusion

SDM in oncology is a dynamic process in which both patients and oncologists have their roles during as well as outside the consultation, and these roles complement each other.

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Appendix A.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	HBR, NvDB, MBT (see section 2.3)
2.	Credentials	What were the researcher's credentials? E.g. PhD, MD	MJF, AHP, AMS: PhD; TvdW: PhD, MD; HBR: MSc
3.	Occupation	What was their occupation at the time of the study?	HBR: PhD student; MJF, TvdW, AMS, AHP: senior researcher; NvDB: research assistant; MBT: research assistant and specialized nurse in oncology
4.	Gender	Was the researcher male or female?	HBR, NvDB, MBT, TvdW, AMS, AHP: Female; MJF: Male
5.	Experience and training	What experience or training did the researcher have?	HBR: a two-day qualitative interview course, a two-day Atlas.ti course, experience with previous qualitative study; MJF: training in qualitative data analysis, several qualitative and mixed method studies; NvDB: fifteen years' experience in qualitative interviewing; MBT a two-day qualitative interview course, fifteen years' experience in qualitative interviewing; TvdW: qualitative training as part of career development, 25 years' experience in designing, performing and reporting qualitative research ; AMS: a two-day qualitative interview course, training in qualitative data analysis on the job during PhD research, 20 years' experience in supervision of many qualitative studies; AHP: qualitative training as part of career development award, several qualitative studies
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No, except for MBT, who knew the nurses and some of the experts that she interviewed

7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*	No direct information about non-interviewing authors; participants knew that the interviewers were the investigators for the study
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *e.g. Bias, assumptions, reasons and interests in the research topic*	In some cases, after the interview was completed the interviewer talked further about SDM and/or related issues with the participant during which discussion the interviewers gave their own opinion

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*	Grounded theory (see section 2.4)

Participant selection

10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Purposive sampling of potential future patients and convenience sampling of all other participants (see section 2.2)
11.	Method of approach	How were participants approached? *e.g. face-to-face, telephone, mail, email*	Oncologists by email and sometimes by phone, current patients face-to-face, disease-free patients face-to-face or by mail, potential future patients by advertisements, nurse practitioners and SDM researchers by email (see section 2.2)
12.	Sample size	How many participants were in the study?	76 (see section 3.1)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Unclear for some participant groups and described for others (see section 3.1 and 4.2)

Setting

14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Home, hospital or workplace (see section 2.2)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	During some interviews with current patients a companion was present (see section 2.3)
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Reported in Table 1

Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	We present the interview guide (see section 2.2 and appendix B) and it was pilot tested (see section 2.3)
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording (see section 2.3)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Interviewers made notes during interviews as reminders for themselves; notes were not used in the analyses
21.	Duration	What was the duration of the interviews or focus group?	30-60 minutes (see section 2.3)
22.	Data saturation	Was data saturation discussed?	Yes (see section 2.3, 3.1, and 4.1)
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?	Three (see section 2.4)
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Codes were derived from the data (see section 2.4)
27.	Software	What software, if applicable, was used to manage the data?	Atlas.ti, version 7.5.12 (see section 2.4)
28.	Participant checking	Did participants provide feedback on the findings?	No (see section 4.1)
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g. participant number*	Yes (see section 3.2)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes (see results section, table 1, and figure 1)
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes (see section 3.2 and figure 1)
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes (see section 3.2.2, 3.2.3, 3.2.4, 3.2.6, 3.2.7 and 3.2.8)

Appendix B.

Interview guide, including statements regarding SDM in oncology

1. SDM in oncology

If I say 'Doctors and patients making decisions together about cancer treatment', what does this make you think about?

Probes:

If 'making decisions together' would happen the way you think it should look like, what would we see exactly?
How should 'making decisions together about cancer treatment' look like, according to you?
What fits with 'making decisions together about cancer treatment' according to you?

To what extent do you think 'making decisions together about cancer treatment' is possible?

To what extent may doctors contribute to making decisions together about cancer treatment? And in which way?

To what extent may patients contribute to making decisions together about cancer treatment? And in which way?

To what extent can we speak of 'making decisions together' if a doctor gives a recommendation?

2. Statements about SDM in oncology

The 19 cards with statements were laid on the table for the participant to look at.

Please take a look at the cards and choose the statements that belong most to 'making decisions together about cancer treatment', according to you.

Patient receives information[16,18,19,22]
Patient gives her/his view on the different treatment options[18]
Patient asks questions[18,19]
Patient tells about feelings and symptoms[18]
Patient compares treatment options[16,19]
Patient takes responsibility[17]
Patient gathers information[16]
Patient is involved in making the final decision[16,18,19]
Doctor provides the odds of benefits and harms[24]
Doctor presents treatment options[19]
Doctor helps patient to think about what is important to him/her[23]
Doctor indicates that the patient's opinion is important[23]
Doctor gives a recommendation[17]
Doctor invites patient to be involved in making the decision[12]
Doctor states at the beginning of the consultation that it is the intent to make a treatment decision[23]
Doctor asks questions[19]
Doctor takes responsibility[17]
Doctor is involved in making the final decision[14]
Tasks are divided between doctor and patient[17]