Shared decision making in oncology: A model based on patients’, health care 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.

KEYWORDS
cancer, interviews, model, oncology, perspectives, SDM, shared decision making, stakeholders, treatment decision making, views

1 | BACKGROUND

The majority of cancer patients favour active patient participation in decision making1-3 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 (ie, 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
therefore decided that further clarification of the concept of SDM is imperative.

Our focus was on the conceptualisation of SDM in oncology, for various reasons. There is a strong impetus but also a lack of implementation of SDM in oncology.\textsuperscript{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.\textsuperscript{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,\textsuperscript{13} often within a limited time.\textsuperscript{14} All this may result in significant feelings of vulnerability and fear in patients.

A communication model of SDM recognising the communication process as the vehicle for decision making in cancer treatment has been described.\textsuperscript{15} We identified only one model in oncology describing the actual SDM process. This model describes oncologist behaviour only,\textsuperscript{12} whereas most SDM models from outside oncology also describe patient behaviour more or less explicitly.\textsuperscript{6} Also, qualitative studies in oncology indicate that both patients and oncologists consider patient behaviours as part of SDM.\textsuperscript{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 (ie, 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 whom 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 (Table S2).\textsuperscript{21} The Medical Ethical Committee of the Leiden University Medical Center (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 Reiner de Graaf, Delft) in the Netherlands were approached and interviewed. These oncologists were each asked to recruit two cancer patients (any diagnosis) who were greater than or equal to 18 years old, had a life expectancy of over 6 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 greater than or equal to 18 years old and had ended antitumour treatment (excluding hormonal therapy) 6 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 20 euros. Eligibility criteria were as follows: aged greater than 30 years, never diagnosed with cancer, never attended oncology consultations, no cancer diagnosis in significant others in the past 6 months, no chronic disease, and no health care 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 (Box S1) was informed by a systematic literature search conducted in October 2014 on what SDM in oncology constitutes according to cancer patients and oncologists.\textsuperscript{16-19,22} First, 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,\textsuperscript{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 health care 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 (Box S1). 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,\textsuperscript{16,19,22} and from oftencited SDM models\textsuperscript{12,14,23,24} (Box S1). Finally, we asked patients about their disease characteristics.

Our interview guide was pilot tested for feasibility with two research assistants and one clinician.\textsuperscript{25} Next, one of three trained interviewers (H.B.R., N.v.D.B., and M.B.T.) conducted the interviews, which lasted 30 to 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 (M.J.F., M.B.T., and N.v.D.B.) 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 (H.B.R.) 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 (N.v.D.B. and H.B. R.) independently checked whether each formed cluster indeed represented a coherent collection of codes, based on the underlying data fragments, ie, 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 (H.B.R. and A.H.P.).

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, and 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 and 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.

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 care professionals focussed 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.
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.

Express importance of patient’s 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.

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 fitted 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.

### Table 1

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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).

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 and 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 are 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 conceptualisation 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 oncologist and patient 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, eg, 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 health care 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 care34 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. Second, 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. Third, we did not perform a member check because of 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 Fourth, 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 predefined 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 fulfill 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.

5 | 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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CONFLICT OF INTEREST

None.

REFERENCES


SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.