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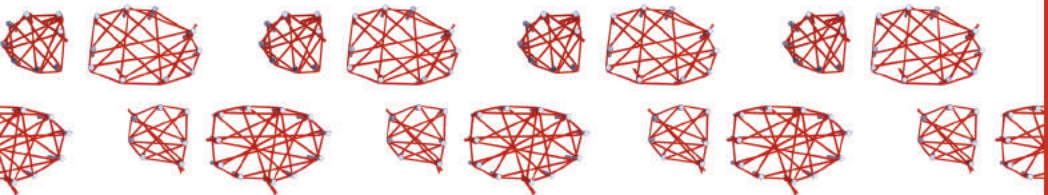
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Chapter 9

General discussion



With the rapid advances in the field of medicine, more and more treatment strategies can become available for the same condition – making decision making more complex. Involving patients in a shared decision making (SDM) process is increasingly the preferred approach to making healthcare decisions when more than one reasonable option is available.¹⁻³ These decisions are called ‘preference-sensitive’.^{4;5} Examples include decisions about (neo-)adjuvant cancer treatments. Foregoing these treatments is often a clinically viable option,⁶⁻⁸ making the involvement of patients in selecting the best treatment strategy crucial.

There are several arguments for following the principles of SDM. SDM is associated with improved patient satisfaction, lowered anxiety and decisional conflict and may improve quality of life and reduce physical complaints.⁹⁻¹¹ Also, SDM may reduce unwarranted practice variation, and by that, possibly reduces health care costs and waste as well.¹²⁻¹⁴ Evidence on costs and cost-effectiveness is equivocal,¹⁵⁻¹⁷ and advocates of SDM argue that costs should not overshadow the underlying principles of SDM. The main imperative for SDM “must rest on the principles of good clinical practice, respecting patients’ right to know. Patients’ informed preferences should be the basis for professional actions”.¹⁸ In the Netherlands, the importance of patient involvement in treatment decision making is acknowledged by the minister of Health, Welfare and Sport, Edith Schippers.¹⁹ Indeed, the legislation (Medical Treatment Agreements Act, WGBO) states that healthcare providers are obligated to inform patients on possible treatment strategies, in writing if desired by the patient.²⁰

Still, some question the feasibility of SDM in daily clinical practice, and claim that SDM fails to acknowledge the imbalance in knowledge and power between the clinician and the patient.^{21;22} Time constraints, patients’ incapability, or clinical situation are often cited as barriers for SDM.^{23;24} Indeed, in daily clinical practice, it still seems challenging to follow the principles of SDM.^{25;26}

To accomplish SDM, three key steps need to be followed:

Step 1: Creating choice awareness,

Step 2: Discussing treatment options in detail, and

Step 3: Discussing patients' values and preferences and deciding what is best.^{2:27;28}

Taking these three steps as the starting point, our aim was to assess to what extent the key steps of SDM are followed in daily clinical practice in preference-sensitive decisions on (neo-)adjuvant cancer treatment. In this chapter, we give an overview of the main findings, and discuss them in relation to the existing literature on SDM. Subsequently, recommendations for future research and clinical practice are provided.

Step 1. Creating choice awareness

'Making a treatment decision' as a reason for the encounter

The first step in SDM is for both the clinician and the patient to acknowledge that there is a decision to be made. This step has received relatively little attention in the literature to date,²⁶ even though it is pivotal for SDM.² Prior research found that many patients facing a decision with marked trade-offs between benefits and harms were not aware that a treatment decision had to be made.²⁹ Oncologists can create choice awareness by explicitly stating that making a treatment decision is the reason for the encounter. Our research showed that oncologists rarely express this need to make a treatment decision, and instead, use the consultation to explain the one treatment strategy they have to offer (Chapter 2). By that, oncologists miss a crucial opportunity to create choice awareness and to engage patients in the SDM process. Our findings align with results from a systematic review by Couët and colleagues.²⁶ They described studies that used the OPTION instrument, which is used to observe the extent to which clinicians involve patients in decision making.^{26;30} OPTION is often used to measure SDM, even though the scale only assesses

clinicians' behaviour. Couët found that awareness of treatment choice was created in only one in three studies. This is still higher than the 3% that we found in our study, which might be due to the differing clinical contexts. The only studies that identified the creation of some degree of choice awareness were outside the field of oncology.

Creating choice awareness as part of setting an agenda

Stating a reason for the encounter can be seen as a part of setting an agenda for the consultation. Evidence suggests that collaboratively setting an agenda increases patient centeredness in various ways – increased patient and clinician satisfaction, greater patient empowerment, and more two-way information exchange to support individualized treatment decisions.³¹⁻³³ Collaboratively agenda setting, creating choice awareness, and indicating that the patient's views count may help patients realize that multiple treatment strategies are available and a decision needs to be made. To date, research on agenda setting has mainly been conducted within primary care. In future research, the effects of collaboratively setting an agenda and creating choice awareness in the pre-treatment consultations in specialty care on patients' satisfaction, empowerment, and involvement, and on the extent of two-way information exchange should be further explored.

Appropriately creating choice awareness might be a simple, inexpensive, yet effective step in empowering patients to participate in treatment decision making. In our study described in Chapter 2, we were unable to assess whether an oncologist explicitly mentioning that a treatment decision needs to be made is associated with enhanced patient involvement in decision making, given the small number of consultations where this occurred. Therefore, in a recent pilot study, we offered lay people – as proxies for newly-diagnosed cancer patients – reasons for the encounter as stated in daily clinical practice. Results suggest that the stated reason for the encounter can have a significant effect on people's perception of choice.

Choosing between two treatments versus declining treatment

The option of foregoing (neo-)adjuvant treatment was not explicitly addressed as a viable one in any analysed consultation with rectal or breast cancer patients. Earlier research on preference-sensitive treatment decisions has found similar results.^{25;34;35} Alternative options or the option of foregoing treatment may be presented only when a patient is not eligible for a certain treatment.³⁶ This approach is not concordant with the SDM model or informed consent norms. To patients, choosing between two possible treatment strategies – for example surgery alone or radiotherapy followed by surgery in rectal cancer – might feel less burdensome than declining the one treatment the oncologist has on offer.³⁷ Therefore, if foregoing (neo-)adjuvant treatment is a viable option, it should explicitly be presented as such.

Best timing for creating choice awareness

Above, we have focused on the pre-treatment consultation as the time point to create choice awareness. However, the best timing to create choice awareness might be prior to this consultation. During multidisciplinary team meetings, almost all patients are discussed and possible treatment strategies are identified for each individual. In the case of preoperative radiotherapy for rectal cancer, the surgeon discusses the treatment recommendation from the multidisciplinary team with the patient.²⁵ To facilitate SDM, clinicians should be aware that the recommendation from the multidisciplinary team is not a final decision, especially in preference-sensitive decisions – as this would leave little to no room for patients' values and preferences to be considered. Indeed, research shows that clinicians mainly focus on medical information exchange and rarely discuss patients' characteristics or preferences in multidisciplinary team meetings.^{38;39} If the recommendation from the team is presented as a final decision early on in the healthcare experience, patients may perceive this as the 'right' treatment and it could be difficult to later create awareness of choice. Returning to the case of preoperative radiotherapy in rectal cancer, the surgeon could, for example, explicitly indicate that the patient will be referred to a radiation oncologist to talk about the preoperative radiotherapy, and the pros and cons of this neo-adjuvant treatment. Such statement will help patients

realize that there is more than one reasonable option available, and that a decision still needs to be made. We must ensure that throughout the whole healthcare system, the principles of SDM are followed in making preference-sensitive decisions in collaboration with the patient. Thus, the first step of SDM reaches beyond one consultation; the multidisciplinary team discussion and the referring clinician(s) should be part of the process of creating choice awareness as well.

Taking this one step further, the best timing to create choice awareness might even be prior to the specialty consultation, namely before becoming a patient and entering the healthcare system. Even before individuals experience the emotions that accompany a serious diagnosis as cancer, they can be made aware that healthcare treatment decisions need to be made and that their views count. In the Netherlands, cancer societies (for example 'KWF Kankerbestrijding'), patient advocacy groups (for example 'Darmkanker Nederland'), and the Foundation for Idealistic Advertising (SIRE, Stichting Ideële Reclame) may be the best organizations to be involved in such a national advertising program.

Creating choice awareness in clinicians

One reason why oncologists rarely create choice awareness could be that they themselves perceive little choice. As we have shown in Chapter 8, there is considerable variation between clinicians in their preferred treatment, and they generally seem to prefer the treatment of their specialty. This has been shown in earlier research as well.^{40;41} It is important that clinicians are aware of their preferences and make these preferences transparent to their colleagues and patients. National treatment guidelines aid in identifying preference-sensitive decisions and creating choice awareness in clinicians. In general, treatment guidelines provide little or no recommendation on the patient's role in deciding about treatment. The Dutch treatment guideline on colorectal cancer is the exception, as it explicitly states that the decision on preoperative radiotherapy is difficult and should involve the patient.⁶ Also, in the latest revision of these guidelines, several treatment recommendations have been rewritten to provide more room to choose between multiple treatment strategies. For all adjuvant

cancer treatments that may be preference-sensitive decisions, treatment recommendations should consider a similar approach. Preference-sensitive decisions could be identified and described as such in the guidelines, and the relevance of patient's views in deciding about treatment should explicitly be incorporated.⁴²⁻⁴⁴

Clinical recommendations

Step 1. Creating choice awareness.

- Be aware that the recommendation from the multidisciplinary team is not a final decision.
- When referring patients: State that the patient will be referred to another clinician to discuss the pros and cons of the possible treatment strategy/strategies.
- At the start of the consultation: State that there are multiple treatment strategies available, that a decision needs to be made, and that the patient's views matter.
- If foregoing adjuvant treatment is a viable option, present it as such.

Step 2. Discussing treatment options in detail

Communicating benefits and harms of treatment options

Most cancer patients in developed countries prefer to have as much information as possible, regardless of whether it is positive or negative.^{45,46} Regarding treatment harms, over nine out of ten cancer patients indicate to have a strong need for this information.⁴⁷ At the same time, the more information is given, the less patients usually remember.⁴⁸ Depending on the total amount of information given, it is expected that about 40-80% of information is forgotten immediately after the consultation.⁴⁹ Research suggests that this percentage decreases when information is tailored to the patient's frame of reference.^{50;51} These

caveats do not imply that information should not be provided, but rather highlight the importance of consensus on which information should be given.

In Chapter 3 we showed considerable variation both in the number and type of benefits and harms that were discussed during pre-treatment consultations between radiation oncologists and rectal cancer patients. This variation was seen between and within radiation oncologists. We found no consistent association between the oncologists' information provision and patient characteristics. These findings imply that some patients receive limited information, while other patients are informed extensively on their treatment option(s). We expect that these findings are not specific to this clinical case and that such variation might be present in information provision in other preference-sensitive decisions as well.²⁵ The variation in information provision indicates a lack of clarity on which benefits and harms should be discussed with patients, and this hampers the process of SDM.

In our study described in Chapter 4, we reached consensus among treated rectal cancer patients and radiation oncologists on which benefits and harms of preoperative radiotherapy should be discussed in the pre-treatment consultation. We composed a core list of topics that should always be addressed. Interestingly, all topics on the core list are long-term benefits and harms of rectal cancer treatment. We assessed congruence between the results of our consensus-study and daily clinical practice and found that on average, patients receive information on fewer than half of the topics from the core list. Even more striking, local control (the benefit of preoperative radiotherapy) was the only topic from the core list that was addressed in almost one in ten patients. None of the harms was discussed. Previously, Pass and colleagues found that cancer patients actually notice that benefits of treatment are discussed more often than harms.⁵²

The need for implementing our core list in daily clinical practice has been clearly demonstrated. Incorporating the core list in the Dutch guidelines for the treatment of rectal cancer will be the first step.⁶ Using our core list as a checklist during the consultation can help clinicians to structure their conversation on the benefits and harms of treatment. Also, the core list could be offered to patients

prior to the consultation to encourage them to discuss certain topics with their radiation oncologist.

In our Delphi-study, we found considerable overlap between topics that patients and oncologists consider necessary to be addressed during pre-treatment consultations. We also showed that patients are capable of prioritizing those benefits/harms that they think are most important. Patients' perspectives are valuable when creating such core lists, and the method we used seems feasible for creating core lists for other treatments and other cancer types.^{53;54} A first step to ensure that patients are informed consistently and sufficiently throughout their treatment process is to develop a core list for the pre-surgery consultation between the surgeon and the rectal cancer patient.

Time pressure as a barrier

For oncologists, time pressure may be an important barrier to using our core list in daily clinical practice.²³ In general, many fear that following the principles of SDM will lengthen the duration of consultation and present clinicians with greater time constraints than they already have. ^{23;28;55} In Chapter 3 we found that consultations last longer when more benefits and harms were addressed. However, in the current practice, a median of seven benefits and harms are discussed with patients eligible for short-course preoperative radiotherapy followed by a low anterior resection. For this patient group, our core list consists of only seven benefits/harms for female, and eight for male patients, which is similar to the current standard practice.

Although we found an increase of consultation length for the discussion on benefits and harms, we have no information on the association between consultation length and overall degree of SDM. Discussing benefits and harms of treatment is required by law and does not necessarily constitute SDM. However, there is no systematic increase in consultation duration when SDM is implemented.⁵⁶ In the Netherlands, several health insurers have indicated that hospitals can claim costs for the extra time that clinicians may need to inform patients, even if these efforts do not lead to active treatment.⁵⁷ Unfortunately,

no more than one in four hospitals offered this opportunity for extra time to their clinicians in the past year.⁵⁸ Policy makers and health insurers should expand their collaboration and commitment to stimulating person-centred care that is unconstrained by time or reimbursement incentives for active treatment.

Communicating probabilities

Communicating probabilities relevant to the treatment decision is complex but essential, as probabilities often are the foundation of clinicians' treatment recommendations and help determine the importance of potential benefits and harms. Research has shown that the format (i.e., words, numbers) in which probabilistic information is presented can have significant effects on patients' interpretation of probability and on their readiness to undergo treatment.⁵⁹⁻⁶¹ In a literature review on risk communication, Zipkin and colleagues recommended avoiding the use of only verbal labels (non-numerical probability statements) to improve patients' understanding, since there is a high degree of variability in their interpretation.⁶²⁻⁶⁶ We confirmed these findings in our study described in Chapter 6, where we found considerable variation in how individuals interpret the verbal labels frequently-used in oncology. This variability could be especially problematic when clinicians communicate probabilities relevant to decision making.

In Chapter 5, we found that radiation oncologists almost always mention probabilities of the beneficial effect of preoperative radiotherapy on local control. In contrast, probabilities of harms of treatment often go unmentioned. We found no consistent association between the oncologists' provision of probabilities and patient characteristics, except that oncologists mentioned significantly fewer probabilities to less educated patients. If radiation oncologists communicated probabilities of local recurrence, they tended to present a relative risk, stating that preoperative radiotherapy will reduce the probability of local recurrence by half. In line with recommendations from Zipkin and colleagues, the radiation oncologists also presented the absolute risk or the absolute risk reduction in most cases.⁶² This approach helps to avoid steering patients towards one treatment strategy. In preoperative radiotherapy in rectal cancer, numerical probabilities are available and known to most Dutch

oncologists.^{6;67-69} We found that radiation oncologists only used verbal labels to convey a probability in one-third of the cases, despite the potential pitfall of variability in interpretation.

We did not find an association between formats the oncologists used to convey probabilities and the correctness of patient's estimates. In general, we found that patients tended to *overestimate* the probability of getting a local recurrence if adjuvant treatment with radiotherapy is foregone, and to *underestimate* the probability of harms occurring after radiotherapy treatment. This has been found in previous research as well.⁷⁰ As it could have been difficult for patients to remember the exact probabilities mentioned, we also assessed whether patients estimated the correct *effect* of radiotherapy treatment on major treatment outcomes. Most patient estimated the effect of radiotherapy on local control correctly. In contrast, the effect on harms was most often estimated incorrectly. Over one-third of patients believed that adding radiotherapy to surgical treatment decreases the probability of faecal incontinence, while in fact, preoperative radiotherapy increases the risk from about 40 to 60% in patients without a stoma.⁷¹ This suggests that many patients are overly optimistic and believe that there is no harm in undergoing preoperative radiotherapy. An explanation for this belief might be sought in post hoc justification. In most cases, the treatment decision had already been made when we assessed patients' understanding. As a result patients may have had the desire to justify the decision of undergoing preoperative radiotherapy as being the correct one, and one which will do them no harm.⁷² Individuals might have an optimistic bias, where they *perceive* that they are at less risk than their peers, enabling them to meet their psychological needs, such as hope and reassurance.^{70;73}

Evidence-based medicine and shared decision making

In recent years, the relationship between SDM and evidence-based medicine has been increasingly recognized and explored.⁷⁴ Evidence-based medicine has contributed to the understanding that many treatment strategies have marginal benefits, next to possible harms.¹⁸ In an SDM process, evidence can be brought into the consultation, and can be discussed with the patient, along with

discussions on the patient's preferences.⁷⁵ These patient's preferences are, in addition to the medical evidence, a core ingredient of evidence-based medicine. If patients are not provided with the evidence, or if they do not understand the provided evidence, they are unable to form evidence-informed preferences, leading to preferences that might not be 'true'.^{74;75} The steps of SDM are inextricably linked to evidence-based medicine.⁷⁴ Oncologists should be careful to mention both benefit and harms of treatment with corresponding probabilities whenever possible and stay alert to patients' potential misunderstanding.⁷⁶

In the example of preoperative radiotherapy in rectal cancer, evidence on benefit and harms of treatment – together with the numerical probabilities – is available and known to most Dutch oncologists. For many other treatments, this might not (yet) be the case. It could be that the occurrence of benefit or harms of treatment have not been established in randomized trials, that they have been established but not reported in literature, or that available evidence is conflicting. Randomized trials might have a focus on harms of treatment, but the specified outcomes might not necessarily be the same that patients believe are important. We must therefore ensure that all clinical trials assess and report possible harms of treatment that are of interest to the patient.

It is also conceivable that clinicians, especially when they treat patients with different kinds of diseases, are unable to constantly be up to date with the latest evidence. In our studies on rectal (Chapter 3) and endometrial (Chapter 8) cancer, clinicians indicated that they treat about two or three patients per month, on average, with these conditions. In both studies, there were clinicians that reported treating fewer patients per month. Thus, all clinicians' knowledge of the evidence and recommendations from the guidelines may not be completely up to date, which is undesirable for relatively common diseases like rectal cancer. Regarding the provision of information, one way of enabling clinicians to communicate the latest evidence to their patients is to provide them with easy-to-use tools.⁵³ Examples of such easy-to-use within-consultation tools are Option Grids, developed by Elwyn and colleagues.⁷⁷ These grids are summary tables of answers to questions that patients frequently ask, accompanied by a document containing the latest evidence.⁷⁸ Also, prediction models, such as Adjuvant online for early-stage breast cancer, might help clinicians in using the latest available evidence, and in determining and communicating personalized probabilities.⁷⁹ More general, we must ensure that

all patients are *treated* by a clinician who is up to date and experienced in treating patient with their disease.⁵³ Centralizing care may be one way to accomplish this.⁵³ Centralizing care could be done on an institutional level, or on a clinician level (specialization), meaning that clinicians are required to treat a minimum number of patients per year. To come to this minimum number, clinicians could cover multiple (regional) institutes. Specialized nurse practitioners could also play a role in supporting oncologists in informing patients; however, we must ensure that providing information on benefits and harms of treatment takes place before the treatment decision is made. The latter might sound evident, but a recent study showed that harms of treatment are often presented after deciding on adjuvant treatment.⁸⁰

Clinical recommendations

Step 2. Discussing treatment options in detail.

- Discuss both benefits and harms of treatment with the patient.
- Create and use a core list of benefits and harms to assist the discussion on adjuvant treatment.
- Avoid the use of verbal labels (non-numerical statements) when possible.⁶²
- When presenting a relative risk (“half the risk”), present absolute risks as well (“from 11 to 6%”).⁶²
- Stay alert to the patient’s potential misunderstanding and regularly check the patient’s understanding.

Step 3. Discussing patients’ values and preferences and deciding what is best

As Street and de Haes stated, “clinicians are experts in medical options and their clinical implication, but patients are experts in terms of the impact of these decisions on their everyday living”.⁸¹ In the previous paragraphs, we have seen how oncologists provide patients with relevant information on the treatment(s). This is minimal and necessary – but not sufficient – condition for SDM. It is

crucial that patients convey their values regarding benefits and harms of treatment and their treatment preferences to their treating oncologist.

Discussing and considering patients' values and treatment preferences

Involving patients in the decision making process is justified by the extent to which patients' values and preferences regarding treatments and treatment outcomes differ.⁸² As research has shown great variation in patients' values and preferences,^{83:84} and how difficult it is to predict these⁸⁴⁻⁸⁶ it is important for clinicians to explore the patient's values and treatment preferences so that these can be considered in choosing a treatment strategy that best fits the patient.⁸⁷ The SDM model states that patients' values and treatment preferences should be elicited,^{2:27:88} but the evidence available suggests that this does not happen in daily clinical practice.⁸⁹⁻⁹¹

In Chapter 7 we showed that rectal cancer patients' values concerning benefits and harms of preoperative radiotherapy are discussed for only one out of ten benefits/harms addressed. Overall, more than half of patients did not voice any values during their consultation with the radiation oncologist. If values regarding benefits or harms of treatment were discussed, they most often concerned long-term major outcomes of radiotherapy, such as local recurrence, faecal incontinence and different aspects of sexual dysfunction. This is consistent with our findings in Chapter 4, where we showed that patients and oncologists consider these long-term major outcomes necessary to discuss in the pre-treatment consultation. Patients' treatment preferences were voiced in only about one in five consultations.

Evidence shows that it is difficult for clinicians to predict patients' values or treatment preferences, and we must therefore be alert to the 'silent misdiagnosis' of these values and preferences.⁹² After providing patients with all relevant information, oncologists can explicitly invite patients to share their views.³⁰ In our study described in Chapter 7, we showed that this happens in about one in five consultations. In these consultations, the radiation oncologist explicitly indicated that the patient's views were to be considered in deciding about preoperative radiotherapy. In several consultations, the patient did not voice any values or treatment preferences in response to the oncologist's

invitation, and the oncologist did not probe any further. Patients' non-response might be due to the unexpected invitation from oncologists to voice their values and treatment preferences. As discussed above (Chapter 2), oncologists rarely indicate upfront that a treatment decision needs to be made. Therefore, many patients might not realize that foregoing (neo-)adjuvant treatment is a viable option and that they may use the provided information to think about their values and treatment preferences and discuss these with their oncologist.⁹³ Appropriately creating choice awareness might be a first step for patients to realize that their values and treatment preferences are of importance in the treatment decision, and that they should therefore voice these views and participate in treatment decision making.

Despite the above, most patients with rectal cancer felt they had shared the treatment decision with their radiation oncologist to some extent (Chapter 7). We found that patients perceived a more active role in treatment decision making when their values or treatment preferences had been discussed during the consultation, or when the oncologist indicated to consider these values or preferences in the decision making process. This is an important finding, which is consistent with the SDM model. We thus showed that discussing and explicitly considering patients' values or preferences will not only help choosing what is best for each individual patient, it will also make patients feel more involved in deciding about treatment. Perceived active involvement has been shown to lead to better patient outcomes.^{9,94}

Preference for active treatment

On average, rectal cancer patients require only a small beneficial effect of preoperative radiotherapy to consider it worthwhile,⁸³ which we also found true for patients with endometrial cancer regarding postoperative vaginal brachytherapy. However, large variation existed between patients in individual treatment preferences (Chapter 8).⁸³ Previous research has shown that cancer patients have a strong preference for seeking active treatment.³⁷ Cancer patients also describe considerable pressure from family members, clinicians or support groups to seek active treatment.³⁷ In our study described in Chapter 8,

more than half of the irradiated and non-irradiated patients with endometrial cancer indicated choosing postoperative vaginal brachytherapy, even if it would have no additional benefit. This seems irrational, but has been found in earlier studies as well.^{72;83} The strong preference for active treatment is possibly caused by anticipated regret and the wish to have done everything one could. We must be aware that the 'best' treatment option, for some patients, may not only depend on the medical outcomes that patients can expect to experience, but also on whether these outcomes are achieved actively or passively.⁹⁵ As stated above, the principles of SDM are especially relevant when there is more than one medically *reasonable* option available and the treatment decision is preference-sensitive. SDM does not imply that *all* possible treatment strategies, including medically *unreasonable* options, are offered to patients.

Involvement in the decision making process versus involvement in the final decision

One of the most often used arguments against implementing SDM is that patients do not want to participate in decision making.^{23;96} In Chapter 8 we showed that most patients with endometrial cancer preferred to share the decision with their clinician. This has also been found in previous research, in cancer care and other settings.⁹⁷⁻⁹⁹ Some argue that clarifying the patient's desired role should be a separate step or sub-step in the SDM model.^{96;100} If so, research implies that this step should occur after providing the patient with information. Many patients who are initially hesitant to be actively involved in decision making, prefer a more active role once they have received information on possible treatment options.¹⁰¹ It is important to realize that SDM is comprised of an entire process of steps to be taken, instead of just a final decision only.⁹⁶ Even if the patient does not wish to make the final decision, the clinician should create choice awareness, discuss the treatment options in detail and elicit the patient's values and preferences in order to incorporate the patient's view in a treatment recommendation. By that, a treatment recommendation does not hamper the process of SDM, as long as this recommendation is based on both available evidence and patient views.

Values clarification methods

Our study described in Chapter 7 showed that patients' values and treatment preferences are not systematically elicited during the pre-treatment consultations. We have seen that the patient might need more encouragement from the oncologist, or, as some patients in our study indicated, more time to think about their preferences. One way of helping patients to gain insight on their values and preferences is to offer them methods to help them become clear on their values.¹⁰² This values clarification method can be completed prior to the consultation, or perhaps even better: following the consultation but prior to the treatment decision. We are working on the implementation of such a tool regarding preoperative radiotherapy in rectal cancer.¹⁰³⁻¹⁰⁵ The effect of this tool on the communication about patients' values and preferences during the consultation, and on patients' participation in the decision making process, as well as the patients' satisfaction with the tool will be evaluated.

Decision support tools

In the course of this chapter, several tools to support the conversation between clinicians and patients and the process of treatment decision making, such as Option Grids, prediction models and values clarification methods, have been mentioned. These tools are so-called 'decision support tools'. Decision support tools are developed to encourage an SDM process, but it is important to be very clear that using decision tools is not equivalent to SDM.¹⁰⁶ Nationally as well as internationally, significant investments have been made in the development and implementation of these interventions.^{107;108} The value of decision support tools focusing on the second and third step of SDM has been clearly demonstrated,¹⁰⁷ but despite great efforts, they have not yet become part of routine clinical practice.^{109;110} Several barriers for implementation are mentioned in the literature, such as lack of clinical support, competing priorities and scheduling problems.¹⁰⁹ One could doubt whether the development and maintenance of such disease-specific tools is, at this point in time, the first priority. As stated earlier, concentrating on the first step of SDM and creating choice awareness in all patients – or in all citizens – might be a universal, simple, inexpensive, yet effective way in empowering patients to participate in medical decision making.

Once there is a change of mind set and people are aware that there are choices to be made in healthcare and that their personal views matter, the effect of disease-specific decision support tools might be enlarged. Choice awareness can be seen as a prerequisite for SDM.

Clinical recommendations

Step 3. Discussing patients' values and preferences and deciding what is best.

- Indicate that the patient's views are important to consider in treatment decision making.
- Explicitly invite patients to share their values regarding benefits and harms of treatment and their treatment preferences.
- SDM is not about the decision, it is about the conversation.¹¹¹ Even if the patient refers the final decision to you, make a treatment recommendation based on the patient's values and preferences.

Conclusion

In this thesis, we aimed to gain insight in the process of shared decision making in the setting of adjuvant cancer treatments. We observed clinician-patient consultations in daily clinical practice, and developed a core list of information that should be provided in the pre-treatment consultation. We showed that the key steps of shared decision making are followed to a limited extent. Choice awareness is rarely created in pre-treatment consultations on (neo-)adjuvant cancer treatment, and the option of foregoing these treatments is omitted consistently (Step 1). There is large variation in information provision on possible treatment strategies. Patients tend to overestimate the beneficial effect of treatment, and to underestimate the probability of harms (Step 2). Finally, patients' values and treatment preferences are elicited in only a minority of consultations. If patients voice their values or treatment preferences, or if the oncologist indicates to consider these, patients perceive a significant more

active role in the decision making process (Step 3). Our results show that opportunities are missed to engage patients in a process of shared decision making, but small changes in doctor-patient communication can facilitate patients' involvement in deciding about treatment.

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