CHAPTER 8

General discussion and future directions
General discussion

The purpose of this thesis was to investigate the current situation regarding SDM in patients with stage I NSCLC, exploring several issues relevant for SDM in practice. The thesis addressed three central research questions, which will be discussed in this chapter.

Research question 1: “What is the patient’s perspective on patient participation in treatment decision making, and what aspects do stage I NSCLC patients find important?”

Our findings showed that most patients, including those with cancer, preferred a shared role in medical decision making. A great majority of stage I NSCLC patients reported not being offered both treatment options (surgery and SABR). Partly as result of this perceived lack of choice, this patient group may have found a guiding role of clinicians relatively important in the decision process, more than their own active participation.

Research question 2: “What is the clinician’s perspective on patient participation in treatment decision making and what influences clinicians’ treatment recommendations for stage I NSCLC patients?”

Our results suggest that for many of the clinicians involved in the treatment of NSCLC, surgery and SABR were not viewed as equal treatment options. In addition, the patient’s preference was not routinely and systematically taken into account in treatment recommendations, at least in hypothetical situations with patient cases. Instead, clinicians’ treatment recommendations were driven by patient-related characteristics typically associated with patients’ age and vulnerability, as well as by clinician characteristics and beliefs.

Research question 3: “What information about the new treatment option SABR is currently available on the Internet for stage I NSCLC patients and how can this information be improved?”

Our study found that there was minimal online information available on SABR as a treatment option, and that the information did not necessarily correspond to patients’ own information needs. It appeared that both the content (different information than what experts initially thought important) and information presentation (texts and formats that did not support patient understanding) needed to be improved. An iterative process involving both experts and patients was successful in making such improvements.
Discussion of the findings

The failure to incorporate SDM in early stage lung cancer care

An important problem identified in this thesis was the failure to employ SDM to a significant extent in the care for stage I NSCLC patients. One of our main findings was that early stage lung cancer patients reported that the two treatment options (i.e., surgery and SABR) had not been discussed with them, in both the qualitative and quantitative part of the mixed methods study. This result was further supported by the fact that in our binary choice experiment among clinicians, the patient’s preference did not very much influence clinicians’ treatment recommendations. Together, these findings suggest that thoracic oncologists did not routinely involve early stage lung cancer patients in treatment decision making. The failure to involve patients in the treatment decision making process is of concern in light of recent data showing comparable outcomes after both these treatments, but also in light of growing consensus amongst health policy research that patients should be proactively involved in decision making, and that they should receive accurate information about their treatment options [1,2].

These findings may indicate a lack of awareness of clinicians of the fact that many cancer patients should, can and want to be involved in treatment decision making. This could arguably arise because stage I NSCLC patients themselves currently still display a rather passive attitude, and tend to ask for guidance from clinicians. However, previous research suggested that a passive attitude can change into a more active role when patients are presented with outcome and risk information about different treatment options [3]. If stage I NSCLC patients were to be presented with information on both treatment options, they might attach more importance to their own active role in decision making.

Another explanation for not involving patients in SDM might be that many clinicians do not see equipoise of surgery and SABR. This was confirmed in the binary choice experiment among clinicians, in which 45% did not consider SABR to be equal to surgery and the patient’s preference was only moderately important for treatment recommendations. The absence of randomized clinical trials (RCTs), which are considered the gold standard of unbiased evidence in evidence-based medicine, is important in this context. Evidence from a RCT would probably convince clinicians more of the existing equipoise between the treatments. The current situation for stage I NSCLC care resembles other clinical settings where new treatment options were developed as alternatives to conventional options. For example, in breast cancer care, radical mastectomy was traditionally considered the standard of care, until RCTs in the 1970s demonstrated that less extensive surgery was equally effective for women with breast cancer, and did not compromise
Numerous studies have been conducted to explore the increasing role of patients in treatment decisions [4-7] and multiple decision aids have been developed and implemented [8-11]. Currently, equipoise of these treatment options and the preference-sensitive nature of the decision are no longer controversial.

It is also possible that clinicians who do see equipoise, and who also are supportive of the idea of SDM, may nevertheless incline towards surgery which has been better well-established in clinical guidelines, and are thus less likely to seek involvement from their patients. Previous studies have shown that in cases where one treatment option has been well-established (and a second treatment is relatively new), clinicians are less favorable toward SDM and are more influenced by the benefits of therapy as presented in published guidelines [12,13].

Furthermore, literature suggests that although many clinicians tend to report support for SDM, treatment decisions are typically made more often by the clinician alone than in collaboration with the patient [14-17]. Apart from a potential tendency to follow well-established treatment options in guidelines, it might thus also be that clinicians still – consciously or unconsciously – behave in a paternalistic way, as has been documented [18-21]. As already noted, paternalistic behavior of clinicians involved in stage I NSCLC care might have been provoked by a more passive attitude of patients. A recent review of patient reported barriers to SDM found that even if patients are able to participate in treatment decisions, they may still feel unwilling to engage with their clinicians due to modifiable factors such as the belief that their clinician knows best [22]. However, a paternalistic attitude of clinicians might also occur because clinicians are uncertain about how to practice SDM, or because they want to protect their patients from choice stress or from dealing with uncertainty [20].

**The patient’s perspective and SDM concepts**

An interesting question based on our findings is how the patient’s perspective on the decision process, which focused on guidance from clinicians and clinicians being empathetic, relates to formal conceptualizations and definitions of SDM. The concepts emphasized in the literature mainly relate to creating awareness of equipoise by outlining all options and mentioning that there is no best option to the patient, presenting the harms and benefits of every option to the patient and their probabilities, eliciting patients’ ideas, concerns and expectations, supporting the patient in the deliberation process, and sharing the responsibility for the decision [19]. These aspects might not fully capture facets
found important in SDM by patients themselves in this thesis, such as guidance from clinicians in stage I NSCLC care. A definition of SDM that does take the patient’s perspective more fully into account might thus be needed.

Furthermore, when measuring SDM in practice, one should ideally incorporate aspects that are important to the receivers of care. By incorporating the patient’s perspective, one could obtain a better understanding of the patient-centeredness of care. On the other hand, a potential caveat might be that patients find some aspects of less importance because they do not completely know beforehand what SDM might entail or could yield for them. Such issues can be adequately solved by letting different stakeholders systematically participate in the development of patient-experience measures of SDM, analog to approaches such as the Consumer Assessment of Health Providers and Systems (CAHPS) methodology in the U.S. [23] and the Consumer Quality Index (CQ-index), in the Netherlands. For the CQ-Index, for example, three main stakeholders (i.e. patients, healthcare professionals and health insurance providers) participate in tripartite consensus meetings about the content of patient-experience questionnaires [24,25]. Qualitative research into the priorities of patients in the healthcare process, as is performed among stage I NSCLC patients, is typically the first step to gaining insight into aspects that need to be incorporated in the patient survey. Stakeholder meetings are used to further extend or refine the patient survey.

**Integrating SDM in the lung cancer care process**

An essential question raised in this thesis is how SDM should be implemented in the typical care process of stage I NSCLC. We found that an interplay between clinician-related characteristics influenced treatment recommendations, and in particular, taking into account the patient’s treatment preferences. Compared with surgeons, pulmonologists and radiation oncologists appeared to be less influenced by the preference of the patient, at least in hypothetical vignette cases. It should be noted that pulmonologists are often the first clinician patients speak to after a diagnosis is made, and they may be best placed to explain both treatment options to patients, to elicit patient’s preferences, and to support the patient in treatment decisions [26]. Our findings suggest that pulmonologists should be explicitly trained in SDM approaches. Both radiation oncologists and surgeons should also attempt to elicit and understand the perspective of patients who are treated by them. However, their role in the treatment decision making process might be slightly different than that of pulmonologists. It is necessary for these multidisciplinary teams to reflect on their different roles in the decision making process, in order to achieve an efficient care process in which stage I NSCLC patients get well-informed. For example, the ‘Interprofes-
sional Shared Decision Making (IP-SDM) Model could be used to develop such a multidisciplinary implementation strategy [27].

Information provision to older lung cancer patients

Our results indicated that the routine patient information provided by clinicians was often suboptimal, and that patients preferred other information than what was presented in a consultation. This difference between patients' needs and what patients receive has been reported in previous studies on other treatment-related information [28-30]. It means that experts cannot always adequately evaluate patients' information needs, and that in order to develop good quality information, patients themselves need to be consulted. Providing good quality and understandable information might be of particular importance when patients are older, as is the case in stage I NSCLC patients. Older patients have particular problems with processing and using health-related information, tend to process information more slowly [31] and have a worse recall of information [32]. In addition, older patients have relatively lower levels of health literacy and patient activation, compared to younger patients [33], which may complicate the use of information in decision making. This raises the question of how good quality information to stage I NSCLC patients can be guaranteed in the healthcare process, and how it can be adequately adjusted to patients' needs and information processing.

This question also pertains to web-based information more in general, for example websites of healthcare providers who offer treatments. As shown in chapter 7, most patients indicated that they had accessed the Internet for additional information after their visit with their clinician. Notably, patients with low health literacy levels and low educational levels especially reported the behavior to search for more information. Previous studies into patients' web behavior showed that patients often find information of poor quality on the Internet, for example on discussion boards about a certain topic with incorrect and low quality information [34,35]. This may particularly be the case for people with lower health literacy. But even information on websites from hospitals themselves may not always be complete or unbiased [36].

In our study, patients with inadequate health literacy levels struggled to comprehend unfamiliar medical vocabulary or concepts such as tumor, lymph node and cure. Such misunderstandings have been often reported in other studies [37]. Given the increasing options and complexity of cancer care, which require more involvement of patients in treatment decision making, and the fact that there is a greater prevalence of low health literacy in older cancer patients (whose numbers will increase until 2040) [38], the
magnitude of this problem is probably growing and guidelines for information presentation will thus be of great importance. International Patient Decision Aids Standards (IPDAS) describe several formats to presentation of pros and cons of treatment options and in particular risk communication formats. In addition, IPDAS gives several suggestions for research and practice to address health literacy in, for example, developing PDA’s by assessing health literacy levels in study samples and selecting a strategy to ensure that the language of the PDA is written at a level that is understood by the majority of the targeted patient group [39].

**Methodological considerations**

Strengths and limitations were discussed for each individual chapter. The most important strength of this thesis is that we captured the perspectives of both the patients and clinicians on patient participation in treatment decision making for stage I NSCLC. The essential overall methodical aspects of this thesis are stressed in this section.

First, there are general limitations of self-reported data about the decision process among patients and clinicians, such as a potential recall bias. For example, 71% of patients in the mixed methods study indicated that both treatment modalities had not been discussed with them. We do not know for certain, however, if both treatment options were indeed not explained to patients. Some patients may not have remembered that both options were discussed due to poor recall of their conversation with their clinician [40], as patients were only included 2-6 months after being informed of their diagnosis and treatment plan. Furthermore, if patients received information about their diagnosis during the same appointment in which options were discussed, their recall may have been affected due to stress or emotional factors. The ability to actively listen and make treatment decisions has been shown to be affected by people’s emotional state [41].

Second, for the studies among clinicians, we used hypothetical patient cases. We acknowledge that these studies were undertaken in a virtual online setting, and that patient preferences may be elaborated on more strongly in a face-to-face discussion. Additionally, in chapter 7 we studied which factors influenced whether the clinician’s treatment recommendation was in line with patient’s preferred treatment in stage I NSCLC. This preferred treatment only mentioned ‘surgery’ or ‘SABR’ and did not explain the reasons for this decision. In a real-life consultation, patients have the opportunity to express and explain their preferences more thoroughly to their clinician. However, studies have in general shown that a vignette study boasts high ecological validity and the ability to successfully predict individual behavior [42,43].
Implications for healthcare practice, health policy and research

Healthcare practice and health policy

It seems important to engage clinicians more for SDM, so that they can activate patients. The findings of our mixed methods study showed that patients did not consider an active role for themselves as being very important. However, if clinicians do not have a ‘choice talk’ [44] with patients in which it is explained that patients are in a position to choose between treatment options, the same patients will be less stimulated to take part in the decision process. Therefore, it seems important that clinicians speak with patients about choice options and actually explain that a choice is to be made. Additionally, it is important to guide patients in the decision making process, as our patients mentioned that this guidance is important to them. Seen in this light, developing and using a lung cancer PDA may currently be a step too far. If clinicians fail to see equipoise and do not have a choice talk with patients, a PDA will not be used in practice. Implementation strategies in this clinical setting should therefore rather focus on how clinicians may discuss the choice with patients, in particular in a phase in which direct comparative studies of the two treatment options are lacking. An important question is how clinicians can help patients in understanding the evidence that is available and how they can guide them in making a decision. It may be useful for clinical guidelines to include a section that explicitly states that it is necessary to discuss both treatment options with their advantages and disadvantages with patients and to elicit patients’ preferences. More in general, it is important to train medical students and clinicians more thoroughly in SDM, and to create awareness about their role in SDM. Previous research has shown that SDM training sessions do increase SDM implementation into clinical practice [45,46].

Apart from the clinicians’ role, it seems also important to encourage patients themselves to adopt a more active role in decision making. Research has shown that encouraging patients to ask questions (e.g., ‘ask three questions’ in the UK MAGIC program) leads clinicians to provide higher quality information about therapeutic options and their benefits and harms, without increasing consultation length [47,48]. Implementing such a strategy in lung cancer care, analog to the MAGIC program, would involve sending leaflets to lung cancer patients who have to make a decision prior to their consultation with their pulmonologist and presenting posters in the medical office of pulmonologists. These posters and leaflets display three questions that can be asked during a consultation: 1) What are my options?; 2) What are the benefits and risks of those options?; and 3) How likely are the benefits and risks of each option to occur?
**Research**

An important area to address in future research is to further explore the role of user testing of information in the field of SDM. Our study showed that not all information provided by the experts was relevant or understandable for patients (e.g., medical terminology and understanding of the scientific evidence). When patients do not understand the information provided on a website, it is unlikely that the information will be used. Our results would therefore argue for the development of information in iterative efforts with multidisciplinary teams, in which both experts and the targeted patient group itself are involved. In addition, thorough think-aloud interviews with targeted patients would seem necessary to improve the presented information, for example on the medical terminology, on a website. This involvement of patients concerns more than simply asking patients about their preferences for information and their general evaluation of a new website, as it is known that information that patients think that they prefer does not necessarily lead to better understanding and decision support [49].

Another important research topic for SDM is to more fully investigate the decision making process by clinicians. It is essential to explore why clinicians do not fully involve cancer patients in treatment decision making. Previous descriptive research has identified perceived barriers and particular attitudes among clinicians that might be obstacles for SDM [50]. However, such studies do not shed light on how clinicians think or make trade-offs when confronted with particular patient cases. As shown in the binary choice experiment described in this thesis, an interplay between clinician-related characteristics influenced treatment recommendations and in particular led to taking into account the patient’s treatment preference. The results of this experiment provided us with valuable suggestions as to how the care process of stage I NSCLCL patients might be improved in order to stimulate SDM, for example that convincing clinicians of equipoise and specifically training pulmonologists seem warranted. Choice experiments among clinicians are somewhat uncommon in the scientific literature on SDM, at least in comparison to choice experiments among patients [51-53]. However, in SDM, decisions are thought to be shared by patients and clinicians, so the decision process of clinicians might be as relevant as that of patients.
Conclusion
The work performed in this thesis showed that patients currently do not participate actively in treatment decision making, clinicians do not actively consider patients’ preferences when making decisions and the information available to patients is suboptimal to support patient participation in SDM. A key problem appears to be the lack of perceived equipoise among clinicians regarding choice of local treatment. It seems that opportunities to practice SDM in stage I NSCLC are being missed. Small changes in clinician-patient communication, such as having a choice talk during clinical encounters and, in a next stage, the use of a PDA may facilitate patients’ involvement in deciding about surgery and SABR.
Reference list


