

Summary

Many patients with stage I non-small cell lung cancer (NSCLC) are in a position to choose between two curative treatment options, namely a surgical resection and stereotactic ablative radiotherapy (SABR). An anatomical surgical resection is the standard treatment option in medically operable patients. SABR is a relatively new treatment option that is increasingly used for medically operable patients who refuse surgery, or for patients who are unfit to undergo this procedure. Currently, also increasing numbers of fit patients with stage I NSCLC are being referred for SABR. This means that patients are, at least theoretically, in a position to choose between these two treatment options. Shared decision making (SDM) seems appropriate in this specific case as there is evidence that SDM contributes to high quality and patient-centred care. The central aim 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, namely: 1) the perspectives of patients (i.e. what are their views regarding participation in treatment decision making and what aspects in decision making do they find important); 2) the perspectives of clinicians (i.e. what are their views regarding patient participation in treatment decision making and what influences their current treatment recommendations for stage I NSCLC patients); and 3) the information available for patients (i.e. 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).

The first part of this thesis considered the current state regarding patient participation in treatment decision making and specifically focussed on patients' own perspective. A literature review (**Chapter 2**) provided an overview of findings about the congruence between patients' preferences regarding participation and their perceived participation in decision making in practice. This review focused on both cancer and non-cancer patients in general. It was demonstrated that the mean of congruence between patients' preference for and perceived participation in decision making was 60%. In case of no congruence, most patients preferred a shared role in treatment decision making, meaning that patients preferred a collaborate process with their clinician. The review suggests that a similar approach to all patients is not likely to meet patients' wishes, since preferences for participation vary among patients. Health care professionals should be sensitive to patients' individual preferences and communicate about patients' participation wishes on a regular basis during their illness trajectory.

In a mixed methods study among patients with stage I NSCLC (**Chapter 3**), it was demonstrated that patients considered guidance by their clinician and clinicians being empathic of great importance in the decision making process. Having an active role themselves was considered of less importance. Another important finding was that in the quantitative study, a majority of patients (71%) reported not being offered both treatment options surgery and SABR, suggesting that SDM was not taking place in many consultations. This might have influenced the importance attached by patients to guidance by clinicians.

In the second part of the thesis, we focused on the clinicians' perspective and how clinicians currently make treatment recommendations. We conducted a binary choice experiment with hypothetical cases provided to pulmonologists, thoracic surgeons and radiation oncologists (**Chapter 4**). These cases (N=126) varied on five patient-related characteristics related to the patient's clinical state and vulnerability, as well to the patient's treatment preference for either (surgery or SABR). Our findings showed that all five patient-related characteristics but also the clinician specialty and clinicians' belief about the equality of surgery and SABR significantly influenced their treatment recommendations. Notably, the patients' preference did not heavily influence clinicians' treatment recommendations. Pulmonologists also appeared to weigh the other patient-related characteristics somewhat differently than the other clinicians, e.g., the general well-being of patients more heavily influenced their treatment recommendations while the patient's age was of less influence for them. High consensus was only reached in a minority of cases. Overall, 55% of participants considered surgery equal to SABR.

Secondary data analysis (**Chapter 5**) provided some further insight into the factors and circumstances that contributed to incorporating or rather disregarding the patient's treatment preference in clinical treatment recommendations. Several interaction effects related to clinical specialty, clinicians' belief about the equipoise of surgery and SABR and clinicians' experienced uncertainty were found, suggesting that such factors interplay in how the patients' preference is dealt with by clinicians. For example, among clinicians who considered the two treatment options to be equivalent, treatment recommendations were more in line with the patient's preference when the patient preferred SABR, when compared to a preference for surgery. On the other hand, among clinicians who did not consider the two treatment options to be equivalent, treatment recommendations were more in line with the patient's preference when the patient preferred surgery, as compared to a preference for SABR. To conclude, the occurrence of SDM in NSCLC care will, at least partly, depend on how clinicians think about the two treatment options and the evidence thereof.

The third part of the thesis addressed the currently available online information about the relatively new treatment option SABR and how current information might be improved. We conducted a web search and analysis of websites in the Netherlands, Germany and United Kingdom (**Chapter 6**). An important finding was that there was only limited information on SABR available and that this information was overall of poor quality. Furthermore, usability and readability were low, especially for patients with low health literacy levels.

We developed a patient website with information about SABR for our patients, and tested it using a qualitative user testing approach (**Chapter 7**). It appeared that the first version, mainly developed from a medical expert perspective, was not considered ideal by patients and that patients preferred receiving different information. Main problems identified related to comprehending medical terminology, understanding the scientific evidence regarding SABR, and appreciating the side-effects associated with SABR. The website was re-designed to solve these problems and included more detailed information about the treatment process, results and side-effects, including additional photographs and video's. It was again tested among patients and was considered more comprehensible and usable.

Implications

Health care practice and health policy

This thesis showed that clinicians and lung cancer patients themselves do not see a clear role according to patient participation in lung cancer treatment decision making. When SDM should become an important facet in clinical practice, patients should become more aware of the fact that there are several treatment options for stage I NSCLC and that they themselves can play an active role in decision making. This can be done by informing patients about both treatment options, asking for their preferences and by encouraging them to ask questions during consultations. Pulmonologists are often the first clinician patients speak to when they hear the diagnoses of lung cancer. In particular pulmonologists, or maybe even specialized oncology nurses, should therefore have at least a 'choice talk' with their patients, and preferably also inform patients about the clinical evidence of both treatment options and actively guide them through the treatment decision making process. In this, it is important to train medical students, clinicians and oncology nurses more thoroughly in SDM and to create awareness about their role in SDM. In addition, 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.

Research

Future research should focus on exploring the decision making process of clinicians more in depth. Previous research has identified perceived barriers and particular attitudes among clinicians that might be obstacles for SDM. However, it is also important to investigate how clinicians think or make trade-offs when confronted with particular difficult patient cases. Furthermore, it is essential to involve patients more systematically when developing patient information, for example when developing a patient decision aid. By involving patients more thoroughly in the iterative development process, information could be improved and better targeted to patient wishes.