

Improving shared decision-making in breast cancer radiotherapy

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Impact section

In this thesis we describe the process of the development, implementation, and testing of a patient decision aid for breast cancer patients who face a preference-sensitive treatment decision for their post-operative radiation treatment (RT). In some patient groups, post-operative RT lowers the local recurrence risk, with no or only little benefit in survival. However, RT can cause side effects. For these patients, deciding on post-operative RT is therefore a preference-sensitive treatment decision. Because there is no best (medical) treatment option for these patients, different patients receive different advice on the best treatment from different clinicians. The aim of the patient decision aid is to support both clinicians and patients to decide together on the best treatment for the individual patient. In this chapter, we describe the impact of this thesis for science and the impact of the work described on a patient decision aid for patients and clinicians.

Scientific impact

Communication of uncertainty in risks in a patient decision aid

The patient decision aid is a computerized, web-based product that describes the advantages and disadvantages of the different treatment options. The advantage of choosing for (more) RT is a decrease in local recurrence risk of the tumor. The patient decision aid gives information on the risk of suffering from a local recurrence, when choosing for the additional radiation treatment and the risk of suffering from a local recurrence when choosing to refrain the additional radiation treatment. That means that the local recurrence risk for patients who choose not to have post-operative RT is displayed next to the possible local recurrence risk for patients who choose to undergo post-operative RT. The same accounts for patients choosing to receive an extra radiation (boost) dose to the place where the tumor was removed by the surgeon. In the development phase of the patient decision aid, we found that clinicians in particular believed that not only the recurrence risk should be communicated in the patient decision aid, but also the uncertainty around these risk estimates. However, not much research has been done on the best way to communicate such uncertainties to patients. We developed a novel method using population diagrams with a stepwise color gradient indicating the uncertainty margin, in combination with numbers and a textual explanation of the numbers and the uncertainty around these numbers (figure 1a and 1b). We presented these population diagrams in an international scientific conference and in a scientific journal. Whether this is an appropriate and comprehensive way of communicating uncertainty to patients in a patient decision aid is still under investigation.

Figure 1a. Population diagram with uncertainty margins for the 10-year local recurrence risk for intermediate-risk breast cancer after mastectomy with and without radiotherapy. The stepwise color gradient indicates the uncertainty margin.

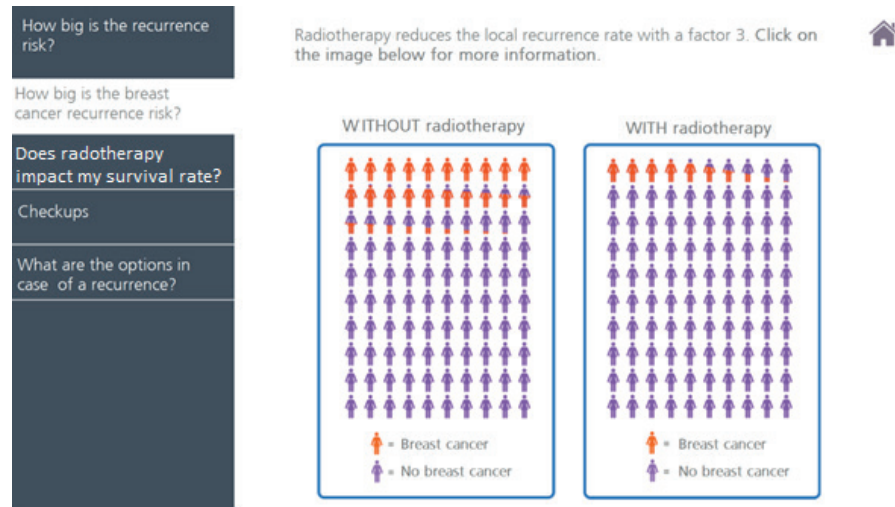
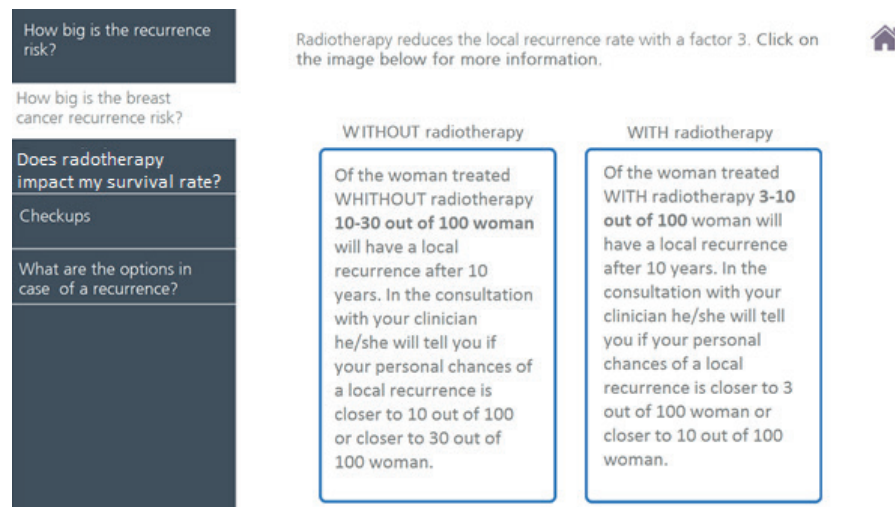


Figure 1b. The population diagram flips when tapped, showing the numbers and the textual explanation of the numbers and the uncertainty around these numbers.



Communication of side effects in a patient decision aid

During the development of the patient decision aid, we also found that patients and clinicians have a different perspective towards the potential side effects. In scientific research and in clinician-patient communication, the side effects are mostly framed by their biological cause. Patients, on the other hand, frame the potential side effects around the possible consequences for their daily life. For example, breast irradiation can cause side effects on the healthy breast tissue. Clinicians frame this effect as scarring of the tissue, but the same side effect is framed as hardening of the breast or deformation of the breast by the patients. In a follow-up to our study, a two-day workshop was organized by members of the research team, in collaboration with other researchers and the National Breast Cancer Association to gather more insight into the patients' perspectives on side effects. This two-day workshop was financed by the Netherlands Organization for Health Research and Development (ZonMw 427003002). The participating ex-patients indicated that they had missed information on the effects of side effects on their daily life, such as not being able to play tennis or not being able to clean the windows. Since until recent, however, most research data are collected from the perspective of the clinician; as a result, not much is known on the incidence and impact of the potential side effect from the patients' perspectives. At this moment, a research proposal is being written for a grant application to tackle this problem.

Implementation of a patient decision aid

In the last decades, many patient decision aids have been developed for various patient categories. There is increasing evidence that patient decision aids have a positive effect on patients and clinicians making a decision together on the best treatment option for the individual patient. Patient decision aids and shared decision-making, however, are not widely implemented in daily clinical practice. The probable reason for this implementation problem is that shared decision-making is a complex process with different barriers and facilitators on different levels of the health care system. Much research is being done on this topic. In our study, we found several facilitators for implementation of the decision aid. First, we found that patients were more likely to use the decision aid if the medical team, with different medical specialists, agreed that the radiation treatment was a preference-sensitive decision. Second, we found that patients who were informed about the decision aid by their treating surgeon, prior their visit to the radiation clinic, were also more likely to use the decision aid. These results are in line with earlier research and therefore confirm the importance of these findings. We presented our results in an international scientific conference and published them in a scientific journal.

Effect of the patient decision aid

In the clinical study, we investigated whether offering the decision aid to patients would result in a decrease in decisional conflict. Decisional conflict is a measurement on "how satisfied" patients are with the decision they have made. The scale measures whether patients feel that they understood what they were deciding on and what the different options were, as well as how sure they felt about their choice. We found that offering the patient decision aid did not result in significant improvements on decisional conflict. We also measured whether the decision aid improved the perceived level of shared decision-making to patients. We did this with two different questionnaires. On both

questionnaires, we found no difference in perceived level of shared decision-making between patients who received the decision aid and those who did not receive the decision aid. Patients who were offered the patient decision aid had more knowledge on the different treatment options and chose less often for a more intensive treatment than patients who were not offered the patient decision aid. These results were published in or submitted to international peer-reviewed journals. They were also presented at an international scientific conference. At this moment, a lot of research is being performed on how patient decision aids in combination with other approaches such as specific training can contribute to improved shared decision-making as well.

Societal impact

Patients

In our study we saw that 77% of the patients who were offered the patient decision aid logged in to the patient decision aid. This is an extremely high percentage compared to papers reported in literature. However, we need to be humble about this number since we have to admit that this number could be an overestimation, because patients who were not interested in using the patient decision aid may also have refused to be included in the trial. Of the patients who logged in to the patient decision aid, 88% declared that they found the patient decision aid to be useful or partly useful for the decision-making process. In addition, we saw that patients who received a link to the patient decision aid had more knowledge on the different treatment options than patients who did not receive a link to the patient decision aid. The patient decision aid remains available online at no cost, and no login is required. The patient decision aid is available through www.beslissamen.nl. Patients can also find a link to the patient decision aid on the website of the national breast cancer association at <https://online-ondersteuning.borstkanker.nl/>. Thus, the patient decision aid is also available for future breast cancer patients with a preference-sensitive decision on their radiation treatment.

Clinicians

This project was initiated by radiation oncologists who felt that there was a need for a patient decision aid for breast cancer patients deciding on radiation treatment. As mentioned before, in patients with a preference-sensitive decision on their radiation treatment, different advice is given by different clinicians. Shared decision-making is a complex process and is therefore not always performed in case of these preference-sensitive cases. Therefore, these clinicians believed a decision aid could be a useful tool for them. In the development phase of the patient decision aid, there was great willingness from clinicians from different radiation oncology centers to contribute to the development of the tool. We also saw that inclusion of patients in our trial went very fast, especially when clinicians could offer the link to the patient decision aid. This indicates that the patient decision aid was offered to many patients in a short time period. At the moment, the patient decision aid is still being used in several radiation clinics. We have received positive feedback from clinicians on the use of the patient decision aid, as well as on their awareness of the importance, and on their skills of performing shared decision-making.