A first step in shared decision making. Developing a decision aid for the choice of anal cancer radiotherapy

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A FIRST STEP IN SHARED DECISION MAKING DEVELOPING A DECISION AID FOR THE CHOICE OF ANAL CANCER RADIOTHERAPY

INTRODUCTION

In recent decision making (SDM), clinicians and patients participate in an option-based conversation, such that joint preferences and mutually desired outcomes can be incorporated into treatment decisions.

There is compelling evidence that patients who are active participants in managing their health care have better outcomes than patients who are not.

The use of decision aids supports SDM, and this contribution describes the practical processes and learning outcomes of developing a decision aid in a clinical setting.

AIM

In curative cancer radiotherapy there is a possible trade-off between the risks and benefits of a higher or lower radiation dose.

A pilot trial of elective target dose de-escalation for anal cancer patients, incorporating patient preference, was introduced and a decision aid has been developed to support the decision making for the patient according to radiation dose, side effects, and quality of life.

The decision aid was designed by a recognized option grid developed by the group of Glyn Elwyn.

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METHODS AND MATERIALS

We conducted a literature review about SDM with additional focus on patient and radiotherapy nurse perspectives. Literature was held withradiation oncologists and radiation therapists.

Communicating of risk and benefit was a topic of great relevance and hence it was important to define the best tool needed for the SDM consultation.

A decision aid was developed in cooperation with clinical collaborators. Two patients undergoing radiotherapy were asked to feedback. The decision aid was revised and three other patients were asked for feedback during their routine follow-up consultations.

RESULTS

We specifically considered variations on SDM in anal and cancer radiotherapy setting using our first pilot trial, in which consensus was to design a simple option-based decision aid.

All patients asked had critical and complex parts of view on the decision aid. Patients reported feeling that they understood their choices and would have been able to make their choices even more if they were asked.

Importantly, if 3 of 5 patients interviewed and they would like to have been more informed. They would have liked the patients and nurses to provide more information on late effects and the treatment. The decision aid could be made an interesting choice.

The final decision aid consisted of a visual representation, side-by-side comparison of common questions and has no polynomial patients.

CONCLUSIONS

Significant clinical learning outcomes were SDM theory, complexity of designing decision aids and awareness of the process of training patients about their radiotherapy treatment.

We observed a quality of published data on late effects relating to patient specific outcomes. This demonstrates the need to sustain research activities into early patient treatment.

Patients were effective partners in the development of the decision aids patient feedback was essential for refining the decision aid and educating clinical staff.

A pilot SDM protocol has received ethics approval, and four patients were already enrolled.

A considerable proportion of SDM in the decision-making process has been conducted within the "RTresearch team".

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PLEASE NOTE: For any choice, it is not our task for you to worry if your tumour is completely disappeared or that you will experience fewer side-effects.

You will be choosing between increasing the chance that the tumour completely disappear or that you will be experiencing fewer side-effects.

HIGHER RADIATION DOSE

I want to increase my chance of the tumor completely disappear at the same time, I am increasing my risk of side-effects, which might affect my quality of life.

LOWER RADIATION DOSE

I want to decrease my risk of side-effects, and possibly increase my quality of life.

GROUP OF INTEREST

The higher radiation dose

The lower radiation dose

MRS. SOERENSEN CHOOSES THE LOWER RADIATION DOSE

She has been diagnosed with anal cancer. She has been treated with radiotherapy. She has been treated with a stoma. She has been treated with chemotherapy, if you choose the lower radiation dose. However, we recommend that you do not opt out of chemotherapy if you choose the lower radiation dose.

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