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 internal 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 making their health care have better outcomes than patients who are passive recipients of care. There is an increasing demand to engage patients in decision making.

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

AIM

In contrast with cancer radiotherapy there is a possible trade-off between the risks and benefits of a higher or lower radiation dose. A joint aim of the target dose deciliation for anal cancer patients, incorporating patient preferences, was introduced and a decision aid had to be 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 the recognized option guide developed by the Danish Cancer Society.

METHODS AND MATERIALS

We reviewed relevant literature about SDM with additional focus on patient- and radiotherapy nurse perspectives. Literature was held with radiologists on SDM and radiotherapy nurses.

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

A decision aid was developed in cooperation with clinical colleagues. Two patients undergoing radiotherapy were asked to feedback. The decision aid was revised and three other patients were asked for feedback during their radiotherapy.

No specifically relevant literature on SDM in an anal cancer radiotherapy setting were found and three other patients were asked for feedback during their radiotherapy.

RESULTS

We particularly emphasized literature on SDM in oncology and radiotherapy settings. Literature was held with radiologists on SDM and radiotherapy nurses.

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

A decision aid was developed in cooperation with clinical colleagues. Two patients undergoing radiotherapy were asked to feedback. The decision aid was revised and three other patients were asked for feedback during their radiotherapy.

The final decision aid consisted of a visual representation of some long-term side-effect information of common questions and has no patient-pertinent palatal changes.

CONCLUSION

Significant clinical learning outcomes were seen in SDM, complexity of designing decision aids and understanding the process of involving patients in their radiotherapy treatment.

We observed a neutral feedback of data on late effects relating to patient-specific outcomes. This emphasizes the need to assess research outcomes into the overall patient context.

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

Our SDM protocol has received ethics approval, and four patients are already included.

DECISION AID

RADIOTHERAPY DEPARTMENT, VEJLE HOSPITAL

You’ve now had a consultation with your doctor about the radiotherapy treatment. We can offer two different options for your treatment.

We can search for the safety of either treatment option below, as they are both allowed by the national Danish guidelines.

There will be different advantages and disadvantages for you to consider. Therefore, it’s important for you to assess your performance when you make your choice of treatment. Three next pages are intended to help you make your choice.

FACTS

ACCESS SIDE EFFECTS: Acute side effects occur during the treatment phase and typically go away a few weeks after treatment is finished.

LONG-TERM SIDE EFFECTS: Occurs from 3 months after your treatment. Long-term side effects are enduring and could be difficult to treat.

LOWER RADIATION DOSE

I want to decrease my risk of side effects, and possibly increase my chances of a good quality of life. This is why the tumor completely disappear or that you will experience 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.

HIGHER RADIATION DOSE

FREQUENTLY ASKED QUESTIONS

HEIGHER RADIATION DOSE

LOWER RADIATION DOSE

How many treatments should I have radiotherapy?

You will be treated in 28 treatments. 3 treatments a week.

You will be treated in 25 treatments. 5 times a week.

Will my chemotherapy be affected by my choice?

Your chemotherapy will not be affected by your choice.

However, we recommend that you do not quit chemotherapy if you choose the lower radiation dose.

What is my risk of acute side effects?

You have the same risk with either option. Acute side effects are significantly decrease, evacuation and pain around your anus.

What is my risk of acute side effects?

Chronic straining and bloating from the rectum, inability to make a bowel movement or evacuation. Nervous or constipated.

What is my risk of long-term side effects?

Chronic straining and bloating from the rectum, inability to make a bowel movement or evacuation. Nervous or constipated.

What is my risk of long-term side effects?

Cancer of the rectum can be affected recurrences, and this risk of appearing becomes lower as the time goes by.

What is my risk of rectal cancer side effects?

The risk of rectal cancer side effects is generally higher. In particular, the risk of increasing the chance that the tumor does not completely disappear.

What is my risk of rectal cancer side effects?

The risk of rectal cancer side effects is lower. In particular, the risk of appearing becomes lower as the time goes by.

What are my risks of incontinence?

What are my risks of incontinence?

The risk of defecation is lower.

The risk of incontinence is generally higher.

What are my risks of incontinence?

The sphincter muscle can be affected and you might lose stool. Fatigue fractures in the bones of the pelvis. Pain in the area, discomfort need food and urge. For women: narrowing of the vagina or dryness. For men: erectile dysfunction.

What are my risks of incontinence?

The sphincter muscle can be affected and you might lose stool. Fatigue fractures in the bones of the pelvis. Pain in the area, discomfort need food and urge. For women: narrowing of the vagina or dryness. For men: erectile dysfunction.

ECRS 2016: 19-20 September

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REFERENCES:
The trial data used to support the recommendation for patients with anal cancer and the work with the decision aid has been conducted within the "ECCRS trial team.

This project was supported by Aarhus University, Faculty of Health Sciences. The content of this work is the responsibility of the authors, and it does not necessarily reflect the views of the sponsors.

The final decision aid and written radiotherapy consultation are conducted on an experimental basis.

No specific studies for the decision aid have been completed.

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