

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

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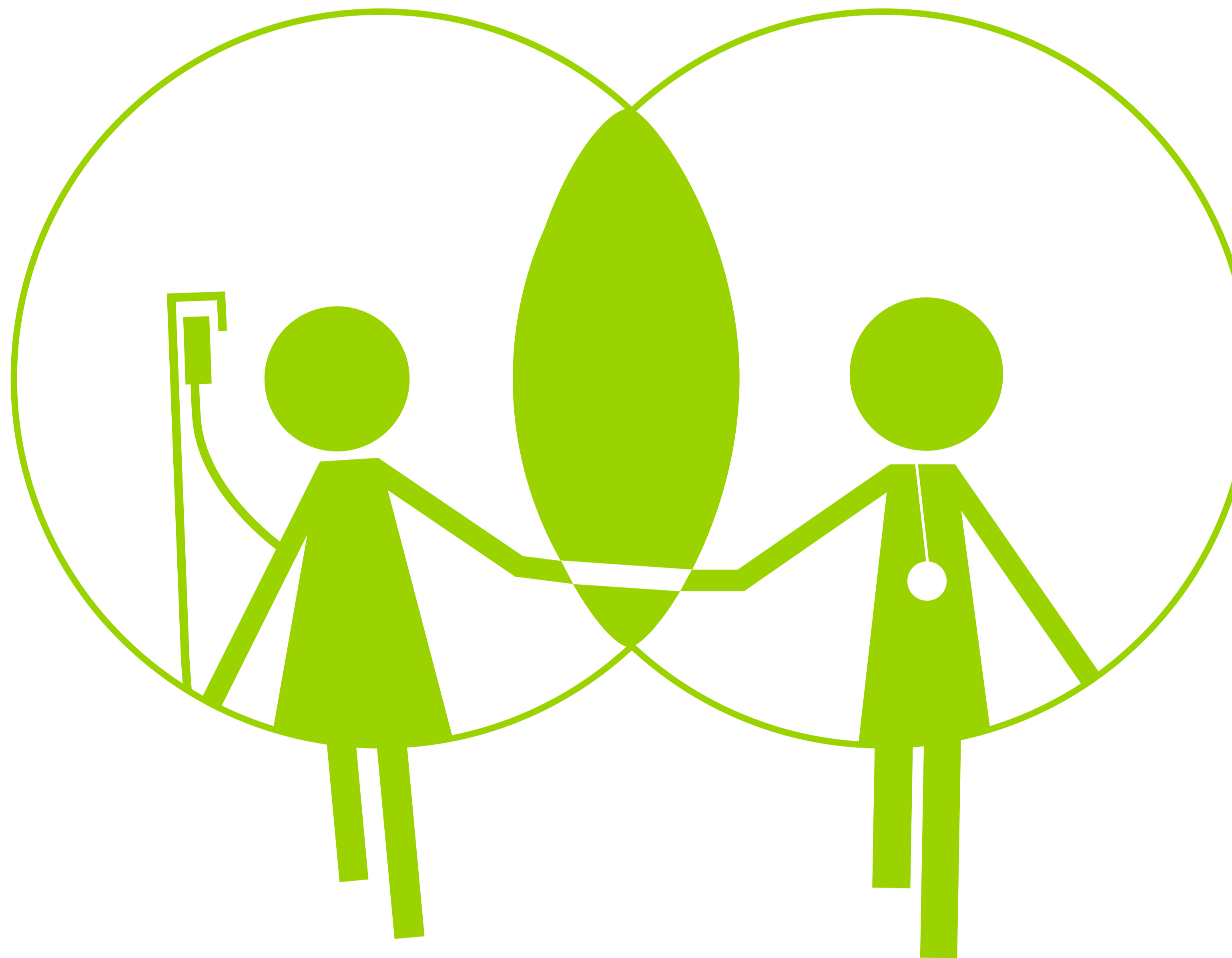
A FIRST STEP IN SHARED DECISION MAKING DEVELOPING A DECISION AID FOR THE CHOICE OF ANAL CANCER RADIOTHERAPY

INTRODUCTION

In shared decision-making (SDM), clinicians and patients participate in an options-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 passive recipients of care.

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.



CONCLUSION

Significant clinical learning outcomes were SDM theory, complexity of designing decision aids and awareness of the process of involving patients as partners in their radiotherapy treatment.

We observed a paucity of published data on late effects relating to patient-specific outcomes. This emphasises the need to orient research outcomes into a more patient-centred direction.

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

Our SDM protocol has received ethics approval, and four patients is already enrolled.

AIM

In curative anal 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 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 inspired by the recognized option grid developed by the group of Glyn Elwyn.

METHODS AND MATERIALS

We reviewed relevant literature about SDM with additional focus on patient and radiotherapy-nurse perspectives. Interview were held with national and local experts on SDM in non-radiotherapy domains.

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 for feedback. The decision aid was revised and three other patients were asked for feedback during their routine follow-up consultations.

RESULTS

No specifically relevant literature on SDM in an anal cancer radiotherapy setting was found. For our first pilot trial, the consensus was to design a simple qualitative decision aid.

All 5 patients asked had critical and useful points of view on the decision aid. Patients reported feeling that they understood the options presented and would have been able to make the choice they were asked for.

Importantly, all 5 patients interviewed said they would like to make the choice themselves. Three patients said they would prefer more information on late side effects before their radiotherapy treatment, to be able to make an informed choice.

The final decision aid consisted of a visual illustration, side-by-side comparison of common questions and two hypothetical patient stories.

ACKNOWLEDGEMENT: The pilot trial of elective target dose for radiotherapy for patients with anal cancer and the work with the decision aid has been conducted within the "RTresearch team".

The "RTresearch team" is a multidisciplinary team set up by Department of Medical Physics, The Radiotherapy Department and Department of Oncology, Vejle Hospital. The team consists of Medical Physicists, Radiotherapy Nurses and Oncologists working under the objective that research and development within radiotherapy continuously are conducted at an international level.

DECISION AID

RADIOTHERAPY DEPARTMENT, VEJLE HOSPITAL

You've now had a conversation with your doctor about the radiotherapy treatment. We can offer different options for your treatment.

We can vouch 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 to be aware of your preferences when you make your choice of treatment. These next pages are intended to help you make your choice.

FACTS ACUTE 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. Some long-term side effects are enduring and could be difficult to treat.

HIGHER RADIATION DOSE:
I want to increase my chance of the tumor completely disappearing. At the same time, I am increasing my risk of side effects, which might affect my quality of life.

PLEASE NOTE:
For any choice, it is not guaranteed that your tumor will completely disappear or that you will experience fewer side effects.

You will be choosing between increasing the chance that the tumor disappears OR decreasing the chance that you experience side effects.

LOWER RADIATION DOSE:
I want to decrease my risk of side effects, and possibly increase my chance for a good quality of life. The chance that the tumor completely disappears will decrease slightly.

DECISION AID

FREQUENTLY ASKED QUESTIONS	HIGHER RADIATION DOSE	LOWER RADIATION DOSE
How many times should I have radiotherapy?	You will be treated in 28 episodes, 5 days a week.	You will be treated in 25 episodes, 5 days 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 opt out of 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 specifically diarrhea, excoriation and pain around your anus.	
What are the long term side effects?	Chronic ulceration and bleeding from the rectum. Inability to hold stool. Diarrhea or constipation. Mucus or blood in the stool. Fatigue fractures in the bones of the pelvis. Pain in the pelvis. Frequent need to urinate. For women: narrowing of the vagina or dryness. For men: erectile dysfunction.	Chronic ulceration and bleeding from the rectum. Inability to hold stool. Diarrhea or constipation. Mucus or blood in the stool. Fatigue fractures in the bones of the pelvis. Pain in the pelvis. Frequent need to urinate. For women: narrowing of the vagina or dryness. For men: erectile dysfunction.
What is my risk of long term side effects?	The risk of long term side effects is generally higher. In particular, the risk of chronic ulceration and bleeding in the gut is slightly higher. The sphincter muscle of the rectum can be affected more, and thus the risk of urgently needing to defecate is higher.	The risk of long term side effects is generally smaller. In particular, the risk of chronic ulceration and bleeding in the gut are slightly lower. The sphincter muscle can be spared more, and the risk of urgently needing to defecate is lower.
What are my risks of metastases?	You have the same risk with either option. Acute side effects are specifically diarrhea, excoriation and pain around your anus.	
What are my risk of going through surgery and get a stoma?	The risk is the same but has different causes. At the higher dose, your risk of surgery and a stoma will be higher due to long term side effects	The risk is the same but has different causes. At the lower dose, your risk of surgery and a stoma will be higher due to the tumor not completely disappearing.

DECISION AID

RADIOTHERAPY DEPARTMENT, VEJLE HOSPITAL

MR. HANSEN CHOOSES THE HIGHER RADIATION DOSE

Mr. Hansen is 67 years old and has been diagnosed with anal cancer. He is recommended for radiotherapy treatment, and has been discussing risks and benefits with the doctors and the nurses in the department. He has also been reading about the illness and possible side effects.

A couple of years ago, Mr. Hansen retired and he is enjoying life with his wife. Mr. Hansen has a big family with lots of grandchildren, and the time he spends with his family means a lot to him. He enjoys staying at home and he feels safe with his family.

For many years, Mr. Hansen and his wife have not been active sexually, therefore he is not concerned of the risk of erectile dysfunction after the radiotherapy treatment.

Overall, he wanted to increase the chance of getting cured from the cancer by radiation therapy, and therefore he chose the higher radiation dose.

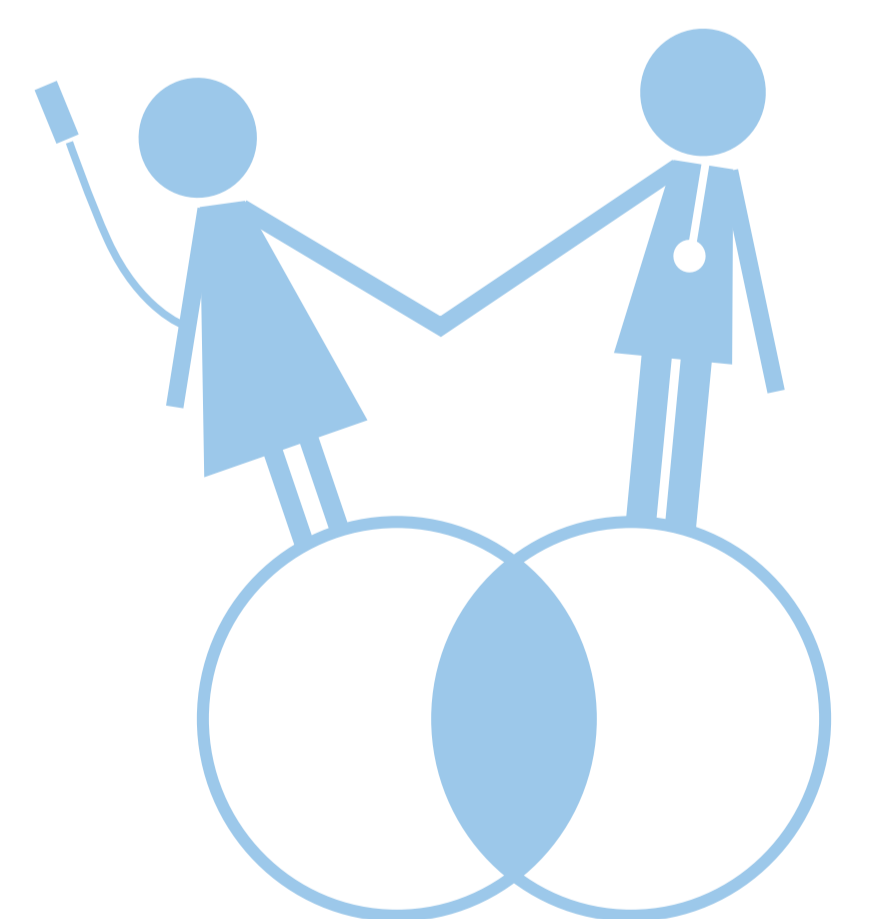
MRS. SOERENSEN CHOOSES THE LOWER RADIATION DOSE

Mrs. Soerensen is 73 years old and has been diagnosed with anal cancer.

She is recommended for radiotherapy treatment, and has been discussing risks and benefits with the doctors and the nurses in the department. She has also been reading about the illness and possible side effects.

Mrs. Soerensen lost her husband 10 years ago. She has many friends and enjoys socializing a lot. It means very much to Mrs. Soerensen, that she looks nice and that she can go out whenever she wants. She does gymnastics and swims with her friends.

Mrs. Soerensen would be really sad if she had to use diapers due to bleeding or faecal incontinence since she feels it will limit her social activities. This is why Mrs. Soerensen chose the lower radiation dose.



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