

Project title

Communicative aspects of decision aids for cancer patients making a decision about treatment: Qualitative and quantitative approaches

Coordinators and supervisors

Project coordinators

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Project Summary

Project description

When someone is diagnosed with cancer, difficult decisions about treatment need to be made. Following the ethical rule of respecting a patient's autonomy (which is also enshrined in law (WGBO, 1995)), doctors need to encourage patients to make their own decisions regarding treatment (or non-treatment). In the light of the development of various (adjuvant) therapies for cancer, cancer patients are nowadays often faced with different treatment options (Kil & Koole, 2013). Since these options – such as the option between breast amputation on the one hand and breast-saving therapy in combination with radiotherapy – may have similar results from a medical point of view, the “right choice” depends heavily on the patient's preferences. In breast cancer treatment, these preferences often also involve cosmetic results. Therefore, most women are, in addition of the oncological treatment also offered some form of reconstructive treatment. Also in the case of prostate cancer, patients often have the option between surgery on the one hand, and radiotherapy/chemotherapy on the other. Additionally, in some cases of prostate cancer, patients are offered the option of “watchful waiting”. Typically, there is no single ‘best’ treatment option, and the benefits and risks of different options cannot be known in advance precisely.

Even though it is the patient who have to make the decision, this does not mean that doctors should abandon patients on their autonomy. Indeed, patient's autonomy does not necessarily mean that patients should be left alone while making decisions. Hence the current idea of **shared decision-making** (SDM) (Salzburg, 2011; Stiggelbout et al., 2012). To enhance the process of SDM, the process in which doctor and patients productively communicate about medical options and patients' preferences, patients and doctors can make use of **decision aids**. These are tools that can help patients to play a role in decision making, together with their doctor, by making the decision points explicit, and linking them to options and possible outcomes (Leigh et al., 2011; Bilimoria et al., 2013; Knops et al., 2013). A systematic review of 115 clinical trials involving decision aids (Stacey et al., 2017) suggests that they can make patients more knowledgeable about treatment options, without making them more anxious,

than patients who receive general information. Importantly, studies suggest that patients are more inclined to opt for the less invasive treatment, without apparent negative effects on health outcomes or well-being, when they use decision aids (Knops et al., 2013).

Although the cumulative positive evidence about the effects of these decision aids is strong, there are two important issues with the scenario just described, which we aim to address with the current project.

- (1) Even though decision aids have much potential, far too little attention has been paid to the **communicative aspects** of such tools. For instance, a core aspect is how to **present information** about risks and uncertainties. It is well established that understanding and appreciating risks is difficult for patients (e.g., what does an increase in life expectancy of 4% really mean?). As such, over the years, various guidelines and best practices for this have been developed (Gigerenzer & Edwards, 2003), such as the use of **plain language** (Holmes-Rovner et al., 2005) or the combination of textual and visual explanations (**multimodality**) (Garcia-Retamero & Galesic, 2010; Spiegelhalter et al., 2011). In addition, and especially in the case of preference-sensitive decisions, another important aspect is the extent to which the decision aids are **personalized** (Salkeld et al., 2016). Until now, however, it is not known whether currently available decision support tools for patients with prostate cancer really make use of the suggested guidelines and insights from (risk) communication research.
- (2) Despite the fact that more than 500 decision aids have been developed to help patients make choices about treatments (Elwyn et al., 2006), they are still **not widely used** and little is known about **implementing** them into routine clinical practice (Feldman-Stewart & Brundage, 2004; Silvia & Sepucha, 2006). In fact, relatively few studies have addressed strategies for introducing decision aids to patients who are making a complex decision about treatment (Entwistle et al., 2004).

Using insights from health and risk communication (DCC) and (digital) ethnographic research (DCU), the goal of the present project is to tackle these two issues by relying on both quantitative (issue 1) and qualitative (issue 2) approaches.

Objectives

The main objectives of the current project are to (1) systematically identify and analyze currently available decision aids (for patients with a specific type of cancer) on a number of communicative aspects (e.g., information presentation, risk communication and personalization), and to (2) explore the barriers and facilitators for implementing decision aids into clinical practices. As a result, two projects have been proposed.

Project 1: A quantitative analysis of communicative aspects of decision aids (DCC)

The first issue outlined above regarding the communicative aspects of decision aids calls for a quantitative approach, during which the DCC student will perform a systematic review. First, a corpus of currently available decision aids for patients who are making a decision about treatment for a specific type of cancer will be constructed. This systematic process involves preliminary searches, piloting of study selection process, and eventually a formal screening of search results against pre-defined eligibility criteria. In the next phase, data from the identified decision aids will be extracted, after which the decision aids will be critically analyzed and assessed on a number of communicative aspects (e.g., information presentation, readability, methods to explain statistical outcomes, and the extent to which the decision aids are personalized).

Project 2: A qualitative analysis of the implementation of decision aids into clinical practice (DCU)

To explore the various reasons why available decision aids are very little used in actual medical practice, the DCU student will conduct a qualitative study, including semi-structured interviews with oncological surgeons/radio therapists/ internists (N=10), specialized nurse-practitioners (N=10), designers of decision aids (N=5) and patients (10). This will be organized via hospitals and patient organizations, and coordinated by the Netherlands Comprehensive Cancer Organization (IKNL). If possible, the research trainee will also attend to general counselling meetings in which the use of decision aids is explained to patients. The intended research site is the Elizabeth Tweesteden Ziekenhuis (ETZ) at Tilburg.

Collaboration and project results

This project requires insights from health communication provided by DCC, and insights from (digital) ethnography provided by DCU. Moreover, the project relies on both **quantitative research** (systematically identifying and analyzing decision aids) and **qualitative research** (conducting interviews with doctors and patients). Even though both types of research will be carried out in parallel (the DCC trainee will be supervised by prof. dr. Krahmer, prof. dr. Pauws, and their PhD-student Ruben Vromans; the DCU trainee by prof. dr. Slatman and dr. De Haan), the results of both approaches will be combined and eventually result in a joint publication (aiming for Journal of Medical Internet Research (JMIR): Cancer, Medical Decision Making or Health Care Analysis). Moreover, the entire team (students, coordinators and supervisors) will meet on a monthly basis. Furthermore, project results will be jointly presented at the Research Traineeships Program symposium in December 2018.

Furthermore, the project is highly relevant for projects that are currently running (e.g., a recently funded DSC/t PhD grant (Krahmer, Pauws, & Vromans), and NWO-VICI grant (Slatman)), and also contributes to Tilburg University's impact theme "[Enhancing Healthcare and Wellbeing](#)". There are also close collaborations with [the Netherlands Comprehensive Cancer Organisation](#) (IKNL, Eindhoven) and [the Elizabeth Tweesteden Ziekenhuis](#) (ETZ, Tilburg).

Project timeline

Trainee	Month	Task	Milestone
DCC	1	Start project	
	2	Preparation / Pilot	Eligibility criteria forms
	3 – 6	Collection decision aids	Corpus decision aids
	7 – 10	Analysis decision aids	Findings analysis
	11 – 12	Write paper	Draft paper
DCU	1	Start project	
	2	Preparation interviews	
	3 – 7	Conduct interviews	Interviews
	8 – 10	Analysis interviews	Findings analyses
	11 – 12	Write paper	Draft paper

Research Trainee Profile

We are looking for two enthusiastic students, preferably at the Research Master or Master levels (though excellent Bachelor students are also considered), who have excellent communication skills and are interested in health care, especially oncology and patient care. For at least one of the trainees, interviewing skills are required (see project 2).

Application information

Applications, including a motivation and resume, should be sent to both Emiel Kraemer (E.J.Kraemer@uvt.nl) and Jenny Slatman (J.Slatman@uvt.nl).

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