



## Communication study

# Probabilities of benefit and harms of preoperative radiotherapy for rectal cancer: What do radiation oncologists tell and what do patients understand?



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## ARTICLE INFO

## Article history:

Received 20 February 2015

Received in revised form 1 May 2015

Accepted 14 May 2015

## Keywords:

Rectal cancer

Risk communication

Information provision

Preoperative radiotherapy

Shared decision making

## ABSTRACT

**Objective:** Probabilities of benefits and harms of treatment may help patients when making a treatment decision. This study aimed to examine (1) whether and how radiation oncologists convey probabilities to rectal cancer patients, and (2) patients' estimates of probabilities of major outcomes of rectal cancer treatment.

**Methods:** First consultations of oncologists and patients eligible for preoperative radiotherapy (PRT) ( $N=90$ ) were audio taped. Tapes were transcribed verbatim and coded to identify probabilistic information presented. Patients ( $N=56$ ) filled in a post-consultation questionnaire on their estimates of probabilities.

**Results:** Probabilities were mentioned in 99% (local recurrence), 75% (incontinence), 72% and 40% (sexual dysfunction in males and females, respectively) of cases. Most patients (89%) correctly estimated that PRT decreases the probability of local recurrence, and 10% and 38%/54% that it increases the probability of incontinence and sexual dysfunction in males/females, respectively. Patients tended to underestimate the probabilities of harms of treatment.

**Conclusion:** Our results show that oncologists almost always mention probabilities of benefit of PRT. In contrast, probabilities of harms often go unmentioned. The effect of PRT on adverse events is often underestimated.

**Practice implications:** Oncologists should stay alert to patients' possible misunderstanding of probabilistic information and should check patients' perceptions of probabilities.

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## 1. Introduction

Determining the best choice when facing a treatment decision can be difficult for both clinicians and patients. Over the past decades, patients have become more actively involved as partners in the decision making process [1]. In particular for 'preference-sensitive' decisions, i.e., decisions for which there is insufficient evidence or in which individuals might value benefits and harms of treatment markedly differently, shared decision making (SDM) has become increasingly important [2]. One such preference-sensitive decision is the decision on neo-adjuvant short-course preoperative radiotherapy (PRT) in the treatment of localized rectal cancer [3]. The beneficial effect of PRT on local control in patients with

localized rectal cancer has been clearly demonstrated [4]. However, PRT has not been shown to convey an additional survival advantage [4] and is associated with a higher risk of adverse effects, most importantly faecal incontinence and sexual dysfunction [5,6,7]. Difficulties arise in selecting those patients who benefit most from PRT, which makes it even more relevant to enable individual patients to weigh the benefits and harms of treatment for themselves.

In the process of SDM, the clinical consultation is an opportunity for patients to learn about their treatment options, including no adjuvant treatment, the benefits and harms of each option, and to be supported in making decisions [8]. Communicating probabilities that are relevant to the treatment decision is complex but essential, as probabilities often are the foundation of clinicians' treatment recommendation and help determine the importance of potential benefits and harms. Research has shown that the format (i.e., words, numbers) in which probabilistic information is presented can have significant effects on patients' interpretation of probability and their

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readiness to undergo treatments [9,10,11]. If probabilistic information is presented in words rather than in numbers, patients tend to have a less accurate interpretation of probabilities and overestimate the probability of an adverse event occurring [11,12,13,14]. Furthermore, presenting patients with relative risks appears more persuasive in making health care decisions than presenting the corresponding absolute risks [9].

To date, research on effective methods for risk communication has primarily focused on written communication and the textual or visual representation of probabilities, including the application of these methods in decision aids [15,16,17]. To our knowledge, research on oral risk communication during clinical consultations in which treatment decisions are made has received no attention.

This study had a dual objective. The first aim of the study was to examine whether and how radiation oncologists provide probabilistic information, specifically in what proportion of risk statements they convey a probability using words, numbers, or both, and whether these proportions or the overall number of probabilities mentioned is associated with patients' age, gender and educational level. The second aim was to examine patients' estimates of probabilities of major outcomes of rectal cancer treatment (local control, faecal incontinence, sexual dysfunction), namely, if patients' estimates are correct and whether correct estimates is associated with the format used to communicate probabilities and with patients' age, gender and educational level.

## 2. Methods

### 2.1. Study population

The study was conducted at six of the 18 radiation centres in the Netherlands in the context of a large ongoing multicentre study on communication and treatment decision making during first consultations on PRT. All rectal cancer patients eligible for short-course PRT followed by a low anterior resection (sphincter-saving operation, with a possible risk of faecal incontinence), were eligible for inclusion. All radiation oncologists treating patients with rectal cancer were asked to participate.

### 2.2. Procedure

First consultations, in which the decision about PRT is usually made, of radiation oncologists with consecutive primary rectal cancer patients were audio taped. Participating patients signed an informed consent form and completed a questionnaire to assess socio-demographic details prior to the consultation. Patients were also asked to fill in a questionnaire within one week of the consultation, to assess their estimates of probabilities of major outcomes of rectal cancer treatment. Patients who filled in the post-consultation questionnaire more than 14 days after the consultation were excluded from the analyses ( $N = 3$ ). Radiation oncologists were asked to fill in a questionnaire assessing their socio-demographic and work-related details at the start of the study.

The Medical Ethics Committee of Leiden University Medical Centre approved the study.

### 2.3. Measures

Audio tapes of consultations were transcribed verbatim and coded using the ACEPP (Assessing Communication about Evidence and Patient Preferences) coding scheme [18]. By using this scheme, presented evidence relating to treatment outcomes was identified. Utterances conveying a probability of a patient experiencing benefit and/or harms of treatment were coded as a word ('verbal label'), a number, or both, as applicable. If a verbal label was used, we coded whether the label conveyed a direction of the effect of

PRT ('yes', e.g., *smaller* chance; or 'no', e.g., *small* chance). If a number was used, we coded whether a percentage, a natural frequency (e.g., "5 out of 100"), or both were used. Also, we coded whether the number represented an absolute risk (e.g., "5 out of 100" or "35%"), an absolute risk reduction (e.g., "5% less chance" or "60% of patients with treatment, but 20% of patients fewer without treatment"), a relative risk (e.g., "twice as likely" or "will halve your risk"), or a range around risk (e.g., "about 30–40 patients"). If multiple formats were used to express numerical probabilities on one benefit/harm, all formats used were coded and therefore, categories of numbers mentioned do not add up to 100%.

Two independent raters coded the same ten (11%) audiotapes. Inter-rater reliability was high (Cohen's  $K = 0.80$ ). The remaining tapes were each coded by one rater only; intra-rater reliability based on eight (9%) tapes per rater coded twice with a time difference of 19 months was substantial (Cohen's  $K = 0.67$ – $0.92$ ).

The major benefit of PRT described in the literature is local control, and major harms are faecal incontinence and sexual dysfunction. In the post-consultation questionnaire, patients were asked to indicate side-by-side the absolute probability ranges of each of these three outcomes occurring as a result of one of two treatment strategies: surgery only and PRT followed by surgery (multiple-choice questions, see Fig. 1). The question on local control was framed in terms of 'local recurrence', as we expected this framing to be used in communicating probabilities in daily clinical practice. The question on sexual dysfunction was matched to the patient's gender. For each outcome, we considered patients' answers to be correct if they could reproduce the numerical probabilities that their oncologist had mentioned (i.e., risk recall). If no numerical probability was mentioned, we considered patients' answers to be correct if they ticked the probability ranges for the group averages, as reported in key publications and in the Dutch treatment guidelines (i.e., risk interpretation) [19,20,7,3]. From this point forward, recall and interpretation will be referred to as 'estimate'. If patients' responses indicated that with PRT followed by surgery, compared to surgery only, the probability of a local recurrence is lower, or that the probability of faecal incontinence or sexual dysfunction is higher, we considered the response to reflect the correct effect of PRT.

### 2.4. Statistical analyses

Descriptive statistics were used to report patients' and radiation oncologists' characteristics, and information provision on the probability of patients experiencing benefits and/or harms of treatment. The overall number of probabilities mentioned and the number of verbal labels, numbers, or both used per consultation were not normally distributed, so medians are presented and were compared by patients' gender and patients' interpretation with Mann–Whitney U-tests. Spearman correlations were used to measure linear dependence between overall number of probabilities addressed and number of verbal labels, numbers or both used, and patients' age. Logistic regression analysis was conducted to assess the association between the discussion of probabilities (yes/no) and patients' age. Using  $\chi^2$  tests, patients' correct estimate of probabilities (yes/no) and patients' correct estimate of the effect of PRT (yes/no) were compared by oncologists' use of verbal labels only and by patients' gender and education. Significance testing was done two-sided at  $\alpha = 0.05$ .

## 3. Results

### 3.1. Participants

We approached 128 eligible patients, all diagnosed between November 2010 and April 2014. Twelve patients (9%) could not be

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