



Patient values and treatment preferences

Considering patient values and treatment preferences enhances patient involvement in rectal cancer treatment decision making



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ABSTRACT

Background: The shared decision making (SDM) model states that patients' values and preferences should be clarified to choose a strategy that best fits the patient. This study aimed to assess whether values and preferences of rectal cancer patients are voiced and considered in deciding about preoperative radiotherapy (PRT), and whether this makes patients feel more involved in treatment decision making. **Methods:** Pre-treatment consultations of radiation oncologists and patients eligible for PRT were audiotaped ($N = 90$). Tapes were transcribed and coded to identify patients' values and treatment preferences. Patients filled in a post-consultation questionnaire on their perceived involvement in decision making ($N = 60$).

Results: Patients' values were voiced for 62/611 of benefits/harms addressed (10%), in 38/90 consultations (42%; maximum 4 values per consultation), and most often related to major long-term treatment outcomes. Patients' treatment preferences were discussed in 20/90 consultations (22%). In 16/90 consultations (18%), the oncologists explicitly indicated to consider patients' values or preferences. Patients perceived a significantly more active role in decision making if their values or preferences had been voiced or considered.

Conclusions: Patients' values and treatment preferences are voiced or considered in a minority of consultations. If they are, this increases patients' perceived involvement in the decision making process.

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Shared decision making (SDM) in the clinical encounter has become increasingly important in modern health care, both from an ethical and a clinical point of view [1,2]. Applying the principles of SDM is especially relevant when treatment decisions are preference-sensitive, i.e. in the absence of a 'best choice' from a clinical perspective or when individual patients' valuation of benefits and harms may strongly vary [3–5]. One such preference-sensitive decision is the decision about short-course preoperative radiotherapy (PRT) in the treatment of patients with localized rectal cancer [6]. The beneficial effect of PRT on local control, compared to surgery only, has been clearly demonstrated, but PRT does not convey an additional overall survival benefit [7]. Moreover, PRT is associated with a higher risk of adverse effects, the most important of which are faecal incontinence and sexual dysfunction [8,9]. Research has shown great variation in how

individual patients value possible benefits and harms of PRT and these valuations are not consistently related to patient characteristics [10,11]. Moreover, it turns out to be difficult for clinicians to accurately judge patients' values for health outcomes or patients' treatment preferences [10,12,13]. Patients should therefore explicitly voice their values and treatment preferences during the consultation with their radiation oncologist, so that these can be considered in choosing a treatment strategy that best fits the patient. Most SDM models state that clinicians should elicit patients' values and preferences [2,14,15] in treatment decision making, but little research has been conducted on whether this actually happens in daily clinical practice [16,17].

This study aimed to assess (1) the extent to which patients' values regarding benefits and harms of PRT and patients' treatment preferences are voiced during decision consultations about PRT for rectal cancer, (2) if these values and preferences are explicitly considered in deciding about treatment, and (3) whether patients feel more involved in treatment decision making when their values or preferences are discussed or considered during decision making.

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Methods

Study population

This study was conducted in six of the 21 radiotherapy centres in The Netherlands in the context of a large multicentre study on communication and treatment decision making during decision consultations on PRT for rectal cancer [18]. All patients eligible for short-course PRT followed by a low-anterior resection (sphincter-saving operation) were eligible for inclusion.

All radiation oncologists working in one of these centres and treating patients with rectal cancer were asked to participate.

Procedure

First consultations, usually the only consultation prior to the start of the treatment, of participating radiation oncologists with consecutive eligible rectal cancer patients were audiotaped. 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 1 week after the consultation, to assess their perceived involvement in treatment decision making. Patients who filled in the post-consultation questionnaire more than 14 days after the consultation were excluded from the analyses ($N = 5$). 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 Center approved the study.

Measures

Audiotapes of the consultations were transcribed verbatim and coded using an adapted version of the ACEPP (Assessing Communication about Evidence and Patient Preferences) coding scheme [19]. By using this coding scheme, all utterances on patient values concerning health-related benefits and harms of treatment and on patients' treatment preferences were identified. We considered all patient statements on the importance of a specific benefit/harm or on the implication of a benefit/harm for the patient's everyday life as patient values (e.g., "that's my biggest fear, that something will change in that area" (sexual dysfunction); "I'm not someone who finds sex very important, not at my age" (erectile dysfunction); "if I become incontinent, than I won't be able to go to concerts anymore" (long-term faecal incontinence); "I don't want to live in constant fear of it coming back" (local recurrence)). All statements containing an *opinion* of the patient regarding possible treatment strategies were considered as a treatment preference (e.g., "I want the radiotherapy anyway"; "I think we must seize all opportunities to prevent it coming back"; "I actually don't favor undergoing the radiation, I find the risks too great and the benefit too limited"). If a patient consented with the treatment that the oncologist proposed without any further comment or opinion (oncologist: "so, let's do this?", patient: "yes"), this was not considered as a treatment preference. Utterances of patients' companions were coded as the patient's, unless the patient contradicted the statements.

First, we coded per benefit or harm addressed whether patients voiced a value (yes/no) and who initiated the matter (oncologist/patient). Second, we coded whether patients made any explicit comments about their treatment preferences (yes/no). Finally, we coded whether oncologists explicitly indicated to consider patients' values and/or treatment preferences in deciding about treatment (e.g., "you have to think about this, it's a difficult choice, everybody weighs these outcomes differently", yes/no), regardless

of whether the patient actually voiced a value or treatment preference.

Two raters independently coded the same 10 (11% of total number) audiotapes. Inter-rater agreement was substantial (Cohen's $K = 0.88$) [20]. The remaining tapes were coded by either one of the two raters (intra-rater agreement based on eight (9%) tapes per rater coded twice with a time difference of 19 months, Cohen's $K = 0.67$ and 0.87).

In the post-consultation questionnaire, we assessed patients' perceived decisional role using a modified version of the Control Preferences Scale (CPS), in which participants were asked to select one of five statements on decisional role [21,22]. The roles ranged from (A) I made the decision about PRT alone, through (B) I made the decision about PRT after considering my radiation oncologist's opinion, (C) my radiation oncologist and I made the decision about PRT together, (D) my radiation oncologist made the decision about PRT after considering my opinion, to (E) my radiation oncologist made the decision about PRT alone.

Statistical analyses

Descriptive statistics were used to report patients' and oncologists' characteristics, and the number of values and preferences discussed. The number of values discussed was compared by patients' age, gender, being accompanied by a companion during the consultation and patients' educational level with Spearman correlations, Mann-Whitney U -tests, and Kruskal-Wallis tests. The discussion of treatment preferences (yes/no) was compared by patients' age, gender, being accompanied during the consultation and patients' educational level with Chi-square tests and Kruskal-Wallis tests, as applicable. CPS-scores were compared by the discussion of values or preferences (yes/no) and the explicit consideration of values or treatment preferences (yes/no) with Mann-Whitney U -tests. Significance testing was done two-sided at $\alpha = 0.05$.

Results

We approached 128 eligible patients, all diagnosed between November 2010 and April 2014. Twelve patients (9%) could not be reached and twenty-one (17%) refused to participate. Ninety-five patients (74%) agreed to have their consultation audiotaped. Five of them were excluded from the analyses because of incomplete audiotaping. Of the remaining 90 patients, 60 (67%) completed the post-consultation questionnaire, a median of 4 days after the consultation (range, 0–13). No significant differences were found for patients' age, gender, or educational level between those who did versus did not complete the post-consultation questionnaire.

All 21 radiation oncologists approached agreed to participate and audiotaped a median of four consultations (range, 1–11).

In Table 1 participant demographic and work-related (radiation oncologists) characteristics are listed.

Oncologists and patients discussed patients' values in 29/90 consultations (32%), patients' treatment preferences in 11/90 consultations (12%), or both in 9/90 consultations (10%). In the other 41/90 consultations (46%), neither patient's values, nor their treatment preferences were addressed.

Per consultation, a median of seven benefits and harms of PRT were addressed (range, 2–12), summing up to in total 611 discussions on benefits and harms in the 90 consultations. Patients' values concerning these benefits and harms were voiced in 62/611 cases (10%), in 38/90 consultations (42%, maximum of 4 values per consultation). Values most often related to sexual dysfunction ($N = 30/62$, 48%, e.g., erectile dysfunction or ejaculation disorder (men), vaginal dryness (women) or sexual problems in general),

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