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Patient explicit consideration of tradeoffs in decision making about rectal cancer treatment: benefits for decision process and quality of life

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ABSTRACT

Introduction: Patient preferences are often not discussed in treatment decisions in oncology. We introduced an online values clarification method (VCM) to help newly diagnosed rectal cancer patients participate in shared decision making about short-course preoperative radiotherapy.

Material and Methods: We offered a link to the VCM to a subset of consecutive patients before the pretreatment consultation with the radiation oncologist. Consultations were audiotaped and coded for expressions of patient preferences. Patients were asked to complete pre- and post-consultation questionnaires. Questionnaires assessed values clarity, decision regret and presence and impact of fecal incontinence and sexual problems.

Results: Of 135 patients who had their consultation audiotaped and completed questionnaires, 35 received and accessed the VCM-link. Patients in the VCM-group slightly more often expressed preferences during consultations. Questionnaire data showed that patients in the VCM-group did not differ in how clear their values were, but experienced lower regret and less impact of treatment harms at 6 months follow-up; differences were non-significant but in the same direction at 12 months.

Discussion: This is the first study to assess the effect of an adaptive conjoint analysis-based VCM on actual patient-clinician communication, and long-term decision regret and impact of treatment harms. Being explicitly invited to think about treatment benefits and harms seems to help patients to live with treatment consequences.

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Introduction

Shared decision making (SDM) is increasingly advocated when more than one treatment strategy is available [1]. This is often the case in oncology, but low levels of SDM are reported [2,3]. Moreover, patient preferences for treatments and outcomes of treatment are not often discussed [4–6]. When decisions have significant long-term consequences it can be difficult and take time for patients to judge what is most important to them [7], but this information is essential for SDM. Treatment preferences can greatly differ among patients, and between patients and physicians, potentially leading patients to accept treatments that they would rather have not if left unspoken. Values clarification methods (VCMs) support patients in weighing treatment harms and benefits [8,9] and may therefore prove useful tools to support patients in articulating what is important to them when discussing treatment decisions with their physician. Most (80%) VCMs are part of patient decision aids [10]. VCMs have led to patients feeling better equipped to make decisions and to higher patient wellbeing following decisions, but results are mixed [8,11]. Importantly, VCMs that show the implications of patients' stated preferences may be associated with positive outcomes, but algorithms to estimate how well an option would suit the individual patient present problems of usability and measurement [11,12]. We developed a stand-alone VCM based on adaptive conjoint analysis that asks patients to make explicit tradeoffs between treatment benefits and harms. The adaptive feature ensures that the tradeoffs presented to patients are individually tailored. Conjoint analysis has been extensively used in preference research at population levels, but not as a method to clarify individual-level preferences [13].

The decision whether or not to undergo short-course preoperative radiotherapy (five fractions of five Gy in 1 week) in early stage rectal cancer typically is a decision that depends on patient preferences. Radiotherapy increases the local control rate, however at the cost of increased rates of fecal

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Supplemental data for this article can be accessed here.

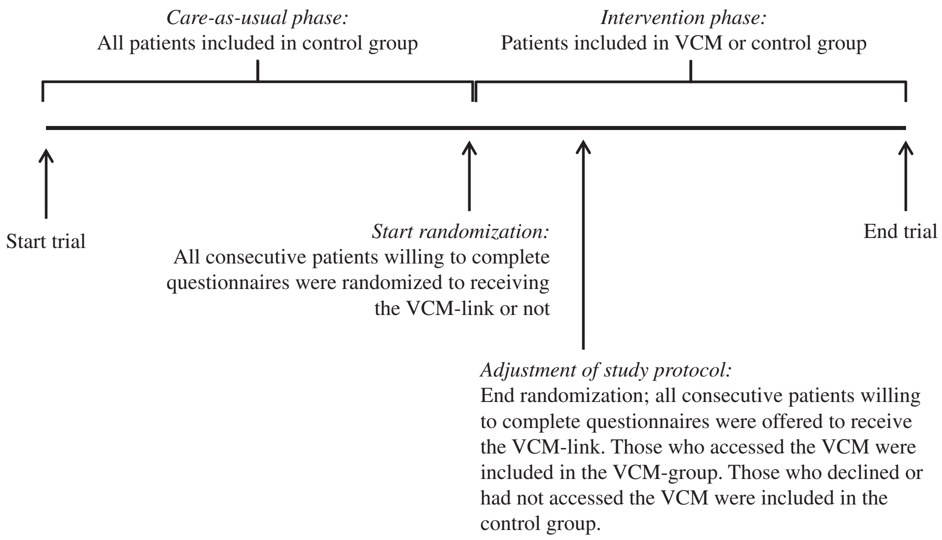

Figure 1. Design of the study. VCM: values clarification method.

incontinence and sexual dysfunction [14–16]. Survival benefit was only reported in stage III patients [14,17]. In previous research, we found preferences for radiotherapy to vary widely among treated rectal cancer patients, as well as between patients and radiation, medical and surgical oncologists [18]. An earlier study suggested that patients understood the VCM well, that the majority would discuss the VCM-results with their radiation oncologist, and that two-thirds of patients expected it to be helpful in their decision [19]. We hypothesized that the VCM would aid newly diagnosed patients to become more confident on their preferences and to voice them during consultations. Consequently, patients' preferences would be more often integrated in treatment decisions and patients would experience less regret over the decision and would cope better with treatment harms.

This study examined in newly diagnosed rectal cancer patients if accessing the VCM was associated with (1) more frequent expression of preferences during consultations with radiation oncologists, (2) improved patient evaluation of decision making processes, and (3) less negative impact of treatment harms. Further, we assessed patients' evaluations of the VCM.

Material and methods

Design

This multicentre, prospective cohort study was conducted in six Dutch radiotherapy centers. The study was designed to start with a period in which consecutive patients were included to assess care-as-usual [2,20], followed by a period in which consecutive patients were randomized to either receive a link to the online VCM before the consultation with the radiation oncologist (VCM-group), or not (control group). Randomization took place at patient level and was stratified by patient gender and radiation oncologist. Our design allowed us to compare outcomes in control patients before and after the start of the randomization, to check for potential contamination caused by radiation oncologists seeing both control and intervention patients.

Unfortunately, the study turned out to be unfeasible. The Dutch clinical guidelines were updated during the study, resulting in less indications for preoperative radiotherapy and therefore in fewer eligible patients. Nine months after randomization started the protocol was adjusted, and the VCM was offered to all subsequent patients (Figure 1). Those patients who then declined to receive or did not access the VCM-link were included in the control group.

Participants

We asked radiation oncologists treating rectal cancer patients to invite all patients eligible for short-course radiotherapy (5 × 5 Gy) followed by low-anterior resection (i.e., T2N0-1M0 or T3N0-1M0, located at 5–15 cm from the anal verge) to join the study.

Procedures

Patients received information about the study in the letter from the radiation oncologist inviting them to the consultation. All radiation oncologists and patients provided written informed consent, thereby agreeing to have the consultation audiotaped and to complete questionnaires. In case patients declined, we asked their consent to audiotape their consultation and recorded their gender. Patients in the intervention phase randomized to the VCM-group and all patients after the protocol was adjusted also gave consent to receive a link to the online VCM, and to be interviewed post-consultation. The research team contacted the patients to answer possible questions shortly after the patients had received the study information, and to send the VCM-link. The Leiden University Medical Center institute review board approved the original and adjusted study protocols (NL31747.058.10) .

The patients in the VCM-group received the VCM-link by e-mail, to access the VCM preconsultation at home or at the clinic, whichever they preferred. Consultations were audiotaped. Patients were further asked to complete questionnaires in the week before (T0) and after (T1) the consultation, and at six (T2) and 12 (T3) months' follow-up. The patients in the VCM-group underwent an audiotaped telephone interview at T1 to ask about their evaluation of the VCM.

Radiation oncologists were asked to complete a pre-study questionnaire (T0) and a brief questionnaire after each consultation (T1).

Values clarification method

The online VCM was introduced as a questionnaire asking patients how important they considered treatment benefits and harms, and was designed similar to our previous study [21]. The VCM started with lay explanations of the three outcomes (local recurrence, fecal incontinence, and male or female sexual dysfunction), and stated that survival was the same across situations. It then asked patients to rate how important they considered differences between best and worst probabilities of outcomes, that varied within a clinically realistic range [15–18] (Table 1) and were shown using frequencies and icon arrays [22] (Supplement, Section 1).

Next, the VCM asked patients to indicate their preference for five pairs of two outcomes, followed by five pairs of three outcomes, where outcome probabilities differed in each pair (Supplement, Section 2). The adaptive software chose each new pair such that the outcomes would be nearly equal in value to that patient, based on the patient's earlier answers. The VCM did *not* label treatment options.

Table 1. Treatment outcomes and probabilities included in the VCM (Frequencies out of 100 patients).

Outcome	Explanation	Probabilities of outcome(from best to worst)		
Probability of recurrence of the tumor at the site (all patients)	This is the likelihood that the tumor recurs in the same area in the pelvis. If the tumor recurs, it causes problems, among which pain. A tumor recurrence is often difficult to treat. The likelihood of cure becomes smaller for that reason.	2	6	10
Probability of fecal incontinence (all patients)	This is the likelihood of losing stools unintentionally. How often people loose stools unintentionally, and how much, differs between people	35	50	65
Probability of sexual dysfunction (men)	This is the likelihood that men experience sexual problems, such as problems with getting an erection (=erectile dysfunction) and/or problems with ejaculation.	50	60	70
Probability of sexual dissatisfaction (women)	This is the likelihood that women are dissatisfied with their sexual life. This can have many reasons.	5	15	25

VCM: values clarification method.

The final page of the VCM showed the patient's relative importance for the three outcomes in percentages, calculated by ordinary least squares regression analysis (Supplement, Section 3) [21]. It did not show which treatment should suit the patient best. Patients could print their results to bring to the consultation. We informed the radiation oncologists that some patients would be asked to complete a computerized questionnaire that indirectly assesses preferences for treatment outcomes. We underlined that they should deliver care as usual and should not take the initiative to discuss the VCM.

Measures

All variables were assessed using questionnaires, except for expressions of preferences (audiotapes) and evaluation of the VCM (interview).

Background characteristics

At T0, we assessed patients' socio-demographic characteristics (age, gender, marital status, highest completed education) and radiation oncologists' gender, age, years of practice in radiation oncology, and number of new rectal cancer patients treated monthly.

Expression of preferences

We transcribed audiotapes of the consultations verbatim and two trained raters coded the conversations using an adapted ACEPP (Assessing Communication about Evidence and Patient Preferences) coding scheme [23]. With this scheme, we coded whether patients uttered a treatment preference, and the number of preferences they uttered for different treatment benefits and/or harms [3]. We considered remarks from companions as representing patients' opinion if patients did not contradict these. Inter-rater agreement, based on 10 transcripts, was substantial (Cohen's $K = 0.80$) [24] and intra-rater agreement, based on eight transcripts coded twice with a 19 months' time interval, was good (Cohen's $K = 0.75$ for both raters).

Decision making

At T1, we asked the patients to rate: perceived room to think about treatment benefits and harms and to give their opinion about radiotherapy during the consultation, on a seven-point scale (range, 1 'not at all' to 7 'a lot'). We assessed decisional conflict using the Decisional Conflict Scale [25,26], and report on how clear the patients felt about their values using the three-item Values-subscale ($\alpha = 0.71$; range scores, 0–100). Higher scores indicate *less* clear values. At T2 and T3, we assessed decision regret using the five-item Decisional Regret Scale [27] ($\alpha = 0.78$–0.88; range scores, 0–100). Higher scores indicate more regret.

We asked the radiation oncologists at T1 if a treatment decision had been made (not yet, radiotherapy, no radiotherapy), whether the decision had already been made preconsultation or if it still was fully open, and if already made, by whom (referring physician, multidisciplinary tumor board, patient, and/or radiation oncologist).

Presence and perceived impact of treatment harms

At T0, T2 and T3, we administered the EORTC QLQ-CR29 [28] to assess fecal incontinence and sexual problems. We report the six-item incontinence subscale (α = 0.63–0.78; range scores, 0–100) and the two single, gender-specific items assessing sexual interest (range scores, 1–4). Higher scores indicate more fecal incontinence and less sexual interest, respectively. At T1 and T2, we assessed the impact of fecal incontinence using the 30-item Incontinence Impact Questionnaire [29,30], adapted to assess fecal instead of urinary incontinence (α = 0.93–0.94; range scores, 0–400). In addition, we assessed the impact of male and female sexual problems using the Female Sexual Distress Scale [31,32] (the scale could be used unchanged in men; α = 0.85–0.95; range scores, 12–60). Higher scores indicate higher impact of incontinence and sexual problems.

Evaluation of the VCM

Patients in the VCM-group were asked for feedback on the VCM using an open question, and whether (yes/no): the VCM had provided them insight in treatment benefits and harms, they had printed the results, they had discussed these with the radiation oncologist, and if the VCM had helped them in making the decision. Responses to the open question were transcribed verbatim and two raters from outside the project team categorized them in consensus.

Statistical analyses

We used descriptive analyses to report participants' characteristics, treatment choice and evaluation of the VCM. We compared the VCM versus control groups regarding age, gender, education and baseline levels of incontinence and sexual problems, using *t*-tests and Chi-square tests. Differences between groups regarding patient preferences for treatment and treatment outcomes (RQ1) were tested using median tests. Differences regarding patient evaluation of the decision process (RQ2) and impact of treatment harms (RQ3) were assessed using linear regression analyses correcting for significant baseline differences. For all participants who completed at least one questionnaire, missing questionnaire items were imputed using multiple imputation ($m = 100$ imputed datasets, predicting missing values by age, gender, education, VCM (yes/no) and all total questionnaire scores) [33]. Estimated standard deviations shown are averaged standard deviations over imputed data sets. All analyses were conducted in SPSS version 23 (IBM Corporation, Armonk, US). Significance was tested two-sided at $\alpha = 0.05$.

Results

Participants

We approached 228 eligible patients between November 2010 and December 2014 (Figure 2). Forty-seven (21%) declined participation, 138 (61%) agreed to participate and 43 (19%) agreed to only having their consultation audiotaped. Thirty-five patients received the VCM-link and all went through the task at home, except for one at the hospital; $N = 34$ completed the VCM a median of 2 days preconsultation (range, 0–12 days before) and one completed it 1 day post-consultation. The participants went through the VCM in 17 ± 10 min on average. The 35 patients in the VCM-group were interviewed; one participant could not remember completing it.

Recordings of 8/181 (4%) consultations were missing due to logistic reasons. Companions were present in 152/173 (88%) consultations. At T0, T1, T2 and T3, 12%, 16%, 62%, and 53% of questionnaire items were missing, respectively.

There were no significant differences in age, education, marital status and quality of life between the VCM ($N = 34$) and control ($N = 101$) groups at baseline (Table 2). There were relatively more men in the control group. Gender was not significantly different between patients agreeing to also complete questionnaires ($N = 135$) and those agreeing to audiotaping only ($N = 43$). The 24 radiation oncologists were 39 ± 7.1 years old, 71% were female, and they had 8 ± 6 years of experience as radiation oncologist.

Treatment decision

The radiation oncologists indicated that a tentative treatment decision had been made preconsultation for 129/131 patients (98%, 7 missing values); either by the tumor board and/or by the referring physician (92%), or the patient together with referring physician (8%); final and tentative decisions were identical in 120/129 (93%) patients and different in 5/129 (4%); the final decision was postponed in 4/129 (3%) patients. Overall, it was decided that 122/131 (93%) patients would undergo preoperative radiotherapy and 4/131 (3%) would not, and the decision was postponed in 5/131 (4%) patients.

Expression of treatment-related preferences

The patients in the VCM-group ($N = 34$) uttered a median of one outcome preference (range, 0–3) per consultation, compared to a median of none (range, 0–3) in the control group ($N = 139$); the groups did not significantly differ in number of utterances when considering only treatment outcomes included in the VCM (local recurrence, incontinence, sexual problems) or any treatment outcome. There were slightly more consultations in the VCM versus control group in which patients expressed a treatment preference, however not significantly (29% vs. 24%, $p = .66$).

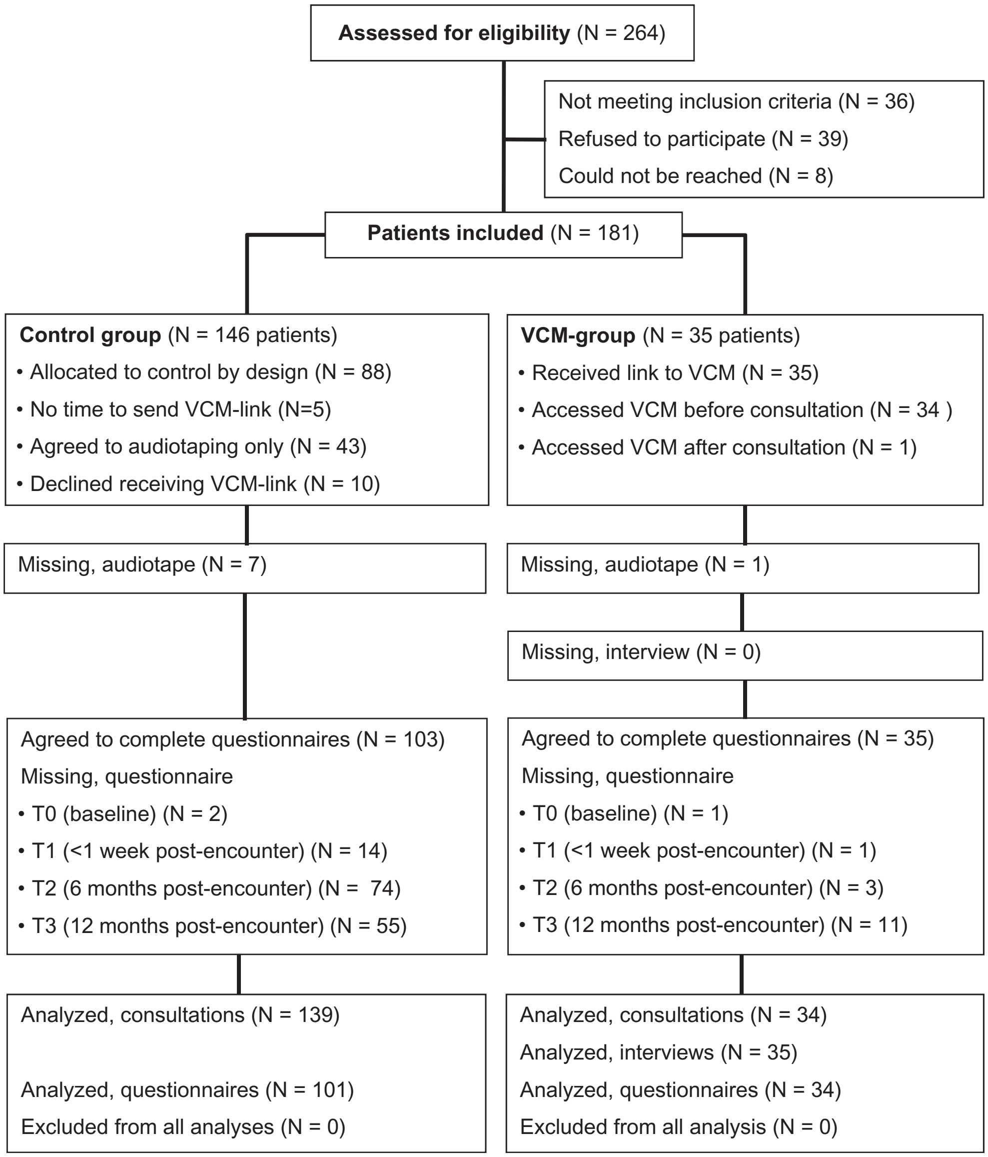

Figure 2. Study diagram. VCM: values clarification method.

Table 2. Baseline characteristics of the patients who completed $\geq$1 questionnaire ($N = 135$).

	VCM-group, $N = 34^a$	Control group, $N = 101^a$	Total, $N = 135$
Male gender (%)	53	74*	69
Mean age in years ± SD	64.0 ± 7.7	64.5 ± 9.7	64.4 ± 9.2
Married (%)	82	79	80
Educational level (%)			
Low	30	33	33
Intermediate	33	40	38
High	36	27	30
Fecal incontinence score	23.7 ± 17.7	25.9 ± 19.0	25.3 ± 18.7
Reduced sexual score	3.2 ± 0.79	3.1 ± 0.74	3.1 ± 0.75
Sexual dysfunction score	1.5 ± 0.77	1.8 ± 0.95	1.7 ± 0.92

VCM: values clarification method.

[a] One patient in the VCM-group and two patients in the control group did not complete the questionnaire at T0.

$^*p < 0.05$.

Perception of the decision making process

The patients in both groups did not differ at T1 in the extent to which they reported to have had time to think about their options and to provide their opinion during the consultation, or to be clear about their values (Table 3). The patients in the VCM-group felt significantly less regret over the decision at T2 ($p = .005$, Table 3).

Table 3. Mean scores and standard deviations on post-consultation questionnaires by group.

	VCM-group ($N = 34$)		Control group ($N = 101$)	
	M	SD	M	SD
Time to think about benefits/harms of preoperative radiotherapy	5.2	1.35	5.2	1.53
Time to provide opinion about benefits/harms of preoperative radiotherapy	5.2	1.52	5.2	1.46
Values unclarity	31.1	25.3	33.0	24.8
Decision regret, T2	18.0	18.2	33.0**	20.6
Decision regret, T3	28.6	26.5	36.3	26.4
Incontinence, T2	33.6	21.5	43.9	20.6
Incontinence, T3	37.0	15.3	32.7	17.3
Impact of incontinence, T2	90.1	71.3	170.3**	71.0
Impact of incontinence, T3	107.9	71.5	126.9	76.2
Reduced sexual interest, T2	3.3	0.83	3.3	0.89
Reduced sexual interest, T3	3.0	0.76	3.0	0.87
Sexual dysfunction, T2	2.1	1.23	2.8	1.32
Sexual dysfunction, T3	2.3	1.19	2.6	1.24
Impact of sexual problems, T2	24.0	9.76	29.1*	7.63
Impact of sexual problems, T3	26.6	11.5	31.3	12.1

VCM: values clarification method; T1: week post-consultation; T2: 6 months follow-up; T3: 12 months follow-up.
*$p<.05$,
**$p<.01$.

Presence and impact of treatment harms at follow-up

The patients in both groups did not differ in reported fecal incontinence or sexual problems at T2 and T3 (Table 3). The impact of incontinence and of sexual problems was significantly lower in the VCM-group at T2 ($p < .001$ for incontinence, $p = .029$ for sexual problems; Table 3).

VCM Evaluation

The patients' overall opinions on the VCM could be categorized as: providing insight (18%, 5/28), being doable (25%, 7/28), superfluous (7%, 2/28), difficult to understand (21%, 6/28) or distressing (29%, 8/28). When asked specifically, 32% (8/25) of patients indicated that the VCM provided them better insight in treatment benefits and harms, 56% (19/34) had printed the results, 38% (13/34) said they mentioned the results to their radiation oncologist, and 15% (5/34) stated that the VCM had influenced the decision, one of whom considered the task upsetting/distressing.

Discussion

This is one of few studies assessing associations between offering an adaptive conjoint analysis-based VCM and actual treatment decision making and outcomes in newly diagnosed cancer patients. To our knowledge, it is the first to assess its effect on patient–clinician communication, decision regret, and longer-term impact of treatment harms. The results suggest limited but notable effects.

The patients who had completed the VCM expressed somewhat more often their views on treatment and treatment outcomes than the patients who had not, although such utterances were still uncommon. This points to very limited discussion between patients and clinicians on how patients consider benefit-harm tradeoffs. Such discussion would help patients to clarify their personal balance of benefits and harms. This limited discussion may further explain that values clarity in patients who had versus had not accessed the VCM were similar, a result that was also found in a study in patients with knee osteoarthritis [34]. Another explanation may be that treatment options were not identified in the VCM. In the only other study offering an adaptive conjoint analysis-based VCM prior to treatment decision making, for treatment of knee pain, patients showed higher decisional self-efficacy and felt better prepared than patients who received an information leaflet. VCM-output in that study showed which treatment should fit the patient best. Offering explicit VCM-based recommendations makes it easier for patients to use the VCM-results than only showing how they weigh attributes [12]. However, the reliability of the calculation is insufficient to accurately predict individual preferences [21] and may therefore steer patients towards options that fit less well. How results of conjoint-based VCMs should be incorporated in patient-clinician discussions requires further research [12,14].

An important finding is that patients who completed the VCM felt less regret over the treatment decision at follow-up, especially 6 months later. Further, this group experienced less impact of fecal incontinence and sexual dysfunction 6 months after treatment. The difference between the groups was no longer significant at one-year follow-up but was still in the same direction. As hypothesized, explicitly considering tradeoffs may have helped patients to better understand the pros and cons involved, and supported them to live with the consequences later on. We may assume that the differences found for regret and impact of fecal incontinence are clinically relevant, given the size of the group differences. For impact of sexual dysfunction a change of five points (on a 12–60 scale) may not be relevant to many patients, but may nevertheless be meaningful to an individual patient.

One-in-three patients who had accessed the VCM reported that it had helped them to gain insight in treatment benefits and harms. It had helped one-in-six to decide. This proportion is markedly lower than the 60% in treated patients who had completed the VCM for a hypothetical decision in our earlier study, and also lower than has been reported in other studies [35,36]. The finding that radiation oncologists reported that almost all decisions had been made before the consultation, either by the referring physician or the tumor board without input from the patient, may at least partly explain this result. Despite patients' perceived room to consider treatment options and to give an opinion during consultations, patients clearly lacked room to contribute. Moreover, some patients mentioned spontaneously to have experienced the VCM as a research tool, and not an actual decision support. Half of the patients who completed the VCM considered it difficult or distressing. This is not surprising as making benefit/harm tradeoffs is inherently hard, and paying attention to potential, significant treatment harms is upsetting.

Three limitations are noteworthy. First, the VCM-group was small, mainly because patients could not be reached in time to be offered the VCM preconsultation. Many patients were sent in by surgeons from other medical centers than those of the participating radiation oncologists, which hampered the practical execution of the study. Some patients declined receiving the VCM-link and a few of them explicitly referred to inexperience with computers. This was noted as a barrier in other studies as well, even among patients who had said to feel comfortable using computers [14,37]. Possibly, a preference to decline the VCM is associated with lower preferences to participate in decision making, and as such act as a confounder. It seems unlikely though that this would be associated with regret or impact of treatment harms. We introduced the VCM as an additional questionnaire rather than a support tool, as the latter seemed inappropriate to patients who would be randomized to the control group. We did not change the way we introduced the VCM after we adapted the protocol. Had the VCM been introduced as a tool to help patients clarify what is important to them in making the treatment decision, this could have increased the number of participants agreeing to receive the VCM-link. Second, we had a relatively high proportion of missing data at follow-up. Applying complete-case analyses would have further reduced the amount of usable data, and could have introduced bias. For this reason we used multiple imputation techniques that are designed to reduce bias by predicting what the missing data could have been; the uncertainty of those predictions is taken into account from the variation among multiple imputations [33]. Third, we did not ask radiation oncologists to incorporate the VCM-results in the consultation. We viewed the VCM primarily as a tool for supporting patients' thinking and weighing, and aimed to secure assessing the effect of going through the VCM and not of asking clinicians to elicit patients' preferences. However, patient interventions usually have more impact when also endorsed by clinicians or even complemented with an intervention for clinicians [38]. We expect that clarifying the potential helpfulness of the VCM for determining preferences in the process of reaching treatment decisions will enhance its perceived relevance, and that our findings show an underestimation of its potential effect.

This is the first study to assess the effect of an adaptive conjoint analysis-based VCM on actual patient–clinician communication, and long-term decision regret and impact of treatment harms. Decisions to undergo short-course preoperative radiotherapy in rectal cancer had in almost all cases been made prior to the consultation, without patient input. The VCM hardly could affect final decisions in this setting. Even so, our results suggest a favorable effect of being explicitly invited to think about benefits and harms of treatment on the extent to which patients endorse treatment decisions and can live with treatment consequences. Further research is needed to assess how the VCM could become part of the decision making process.

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Disclosure statement

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