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The decision evaluation scales

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Abstract

There are several instruments to assess how patients evaluate their medical treatment choice. These are used to evaluate decision aids. Our objective is to investigate which psychological factors play a role when patients evaluate their medical treatment choices. A pool of 36 items was constructed, covering concepts such as uncertainty about and satisfaction with the decision, informed choice, effective decision making, responsibility for the decision, perceived riskiness of the choice, and social support regarding the decision. This pool was presented to patients at high risk for breast and ovarian cancer, awaiting a genetic test result, and facing the choice between prophylactic surgery or screening. Additional measures were assessed for validation purposes. Factor and Rasch analyses were used for factor and item selection. Construct validity of emerging scales was assessed by relating them with the additional measures. Three factors summarised the psychological factors concerning decision evaluation: Satisfaction–Uncertainty, Informed Choice, and Decision Control. Reliabilities (Cronbach's α) of the three scales were 0.79, 0.85, and 0.75, respectively. Construct validity hypotheses were confirmed. The first two scales were similar to previously developed scales. Of these three scales, the Decision Control scale correlated most strongly with the well-being measures, was associated with partner's agreement and physician's preferences as perceived by patients, and with a negative emotional reaction to the information material. In conclusion, the Decision Control scale is a new scale to evaluate decision aids, and it appears to be rooted in health psychological theories. © 2004 Elsevier Ireland Ltd. All rights reserved.

Keywords: Shared decision making; Decisional conflict; Decision satisfaction; Decision control; Regret; Responsibility; Rasch analyses; BRCA1/2

1. Introduction

An increasing number of studies evaluate the effects of involving patients in the medical decision making

process [1]. Patients may be involved, for instance through the provision of information, through values clarification, or by helping patients to formulate their questions. A wide array of outcomes has been used in such evaluations including treatment choice and strength of treatment preference, quality of life outcomes, psychological outcomes such as anxiety, depression, and decisional conflict, satisfaction with care, cognitive outcomes relating to information needs, knowledge and risk perception, and

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outcomes such as use of care, and work absenteeism [2,3].

This study focusses on how patients evaluate the treatment decision itself. In general, these decision related outcomes are meant to assess how patients evaluate the effects of interventions designed to increase patient involvement in decision making, and not to distinguish between patients.

In the study of treatment decisions in the context of decision support interventions, two approaches have been followed: (1) assess the patient's evaluation of the decision making process [4]; and (2) assess the patient's evaluation of the decision. The first approach deals primarily with the quality of the information processing. Improving information processing is an important goal of decision support. For example, Hollen [5] developed a taxonomy of decision styles and decision quality inventories building on the framework developed by Janis and Mann [6]. Related approaches can be found in the coping literature, for instance coping with information [7], and Decision Styles Questionnaire [8]. It has been shown that these concepts can mediate the effectiveness of patient information material.

Our interest, however, is the second approach, i.e. the evaluation of the decision by patients. Such decision related evaluations have been found to be associated with treatment choices [9] or treatment choice intentions [10].

Several scales have been developed: the Decisional Conflict Scale [9], comprising the subscales Uncertainty, and Factors Contributing to Uncertainty; the Effective Decision Making scales; [9] the Satisfaction with Decision scale [11], the Decision Attitude Scale [4], the Satisfaction with decision making process questionnaire [12], the Satisfaction with Decision Made Questionnaire [12], the Decision Self Efficacy Scale [13] the Decision Emotional Control scale [13], and the Decision Regret scale [14]. In general, these scales have shown good internal reliability (Cronbach's α), and test-retest reliability. Evidence supporting construct validity has also been reported.

While a wide array of scales exist, it is unclear to what extent these scales assess different components of decision evaluation. For instance, Decision Uncertainty and Satisfaction with the Decision have generally been found to be strongly correlated [9,11]; but whether both scales tap into the same construct is not known. Furthermore, some scales (e.g. the Decisional Conflict Scale) do not yield similar factor structures when translated into other languages [15].

Our goal is to uncover the factors underlying the evaluation by patients of treatment decisions. It was not our intention to translate existing scales completely or literally. Additional concepts were considered. These concepts emerged after reviewing the above literature [1–15], and the decision making, social psychological, health psychological, and coping literatures. The following concepts were identified: (1) affective evaluation including uncertainty and

satisfaction with the decision; (2) informed choice; (3) effective decision making; (4) responsibility, blame, control; (5) perceived riskiness; (6) social support and social approval. The last three concepts are not covered by existing scales. Responsibility was added because it may affect treatment compliance. Responsibility may modify feelings of regret, which in turn affects decision making [16]. Avoiding blame for future accidents is also believed to affect decision making [17]. Sense of control is believed to affect health outcomes [18]. Perceived riskiness was included because risk is a major dimension in decision making [19]. Social support was included because of its importance in models for health behavior and stress.

2. Methods

2.1. Item construction

The decision items were developed in Dutch by one of us (PFMS). Some of the items were from existing scales, new items were developed for the additional concepts. We considered items from the studies discussed above and a questionnaire kindly provided by Broadstock and Michie [20]. Items were shortened or adapted to get brief unambiguous items. All items were presented to three investigators, of whom two investigated medical decision making from the patients perspective, the third was an expert in questionnaire construction. Items were discarded when they were deemed insufficiently clear or indicative of the concept they were meant to operationalise. Refinement of this process took place in two extra rounds. As a result, 36 items came up. A five-point response scale ranging from 'strongly disagree' (1) to 'do not agree/do not disagree' (3) to 'strongly agree' (5) was used. A complete list of concepts and items is available, also in Dutch, from the first author.

2.2. Study population

The study was implemented in the Family Cancer Clinics of the University Hospitals of Nijmegen, Groningen, and Maastricht in the Netherlands. Both women with and without breast/ovarian cancer who had chosen to undergo DNA-testing were eligible.

2.3. Procedure

Original study aims and detailed methods have been published elsewhere [21,22]. Questionnaires were sent at baseline, T1, that is after blood sampling to test for a BRCA1/2 mutation, at T2, 4 weeks after blood sampling, at T3, 2 weeks after a positive test result and at T4, 3 months after a positive test result. Half of the women received a video and brochure [21], dealing with the decision between

prophylactic surgery or screening for breast/ovarian cancer, 2 weeks after the blood sample, together with a follow-up questionnaire to evaluate this information. The outcome measures have been described in full detail [21,22]. A brief summary is given below.

2.4. Measures

2.4.1. Well-being

Data were collected at all time points on anxiety (STAI) [23], depression (CES-D) [24], and intrusive and avoidance thoughts about cancer in the family (the Impact of Event Scale) [25], and general health during the last week.

2.4.2. Treatment choice

At T2, women were asked what treatment was chosen related to breast cancer risk. The choice was between “prophylactic mastectomy”, “breast cancer screening”, and “undecided”. Women were instructed to imagine that they carried the mutation, while answering the items.

2.4.3. Strength of treatment preference

Strength of treatment preference was asked for the treatment options prophylactic mastectomy and screening on a four-point scale (1 = weak preference; 4 = very strong preference). When treatment choice was “undecided”, a value of zero (no preference) was assigned.

2.4.4. Decision items

The items were asked before (T2) the genetic test result. In the instruction preceding the items, it was made clear that the items pertained to the choice between prophylactic mastectomy and intensive screening for breast cancer. Women were instructed to imagine they carried the mutation, while they answered the items. Prophylactic mastectomy or breast screening was printed in capitals directly above the items on each of the two pages holding the 36 items. Decision items were also asked at T4.

2.4.5. Perceived strength of preference of the specialists

At T4, women were asked whether they felt that the specialists held a treatment preference (yes/no) regarding treatment for breast cancer, and, if so, its strength (1 = weak preference; 2 = strong preference). If no preference was felt to be present, a value of zero was assigned.

2.4.6. Partner agreement

Whether or not partner agreed with their choice was asked at T1, using a seven-point response scale ranging from strongly disagree to strongly agree.

2.4.7. Subjective knowledge

Women were asked to rate their knowledge about prophylactic mastectomy, breast cancer screening, breast self-examination, prophylactic oophorectomy, and ovarian cancer screening.

2.4.8. Amount of information

The amount of received information for the decision related to breast cancer risk was also measured.

2.4.9. Satisfaction with quality of information

Women were offered a series of 13 items on the quality of information regarding cancer risks, efficacy of treatment options, and physical, emotional, and social consequences.

2.4.10. Negative emotional reaction to information material

Women evaluated the brochure and video with three items asking about unpleasant, shocking, and frightening experiences with this material.

2.4.11. Need for support/advice

At T4, women were asked whether they had wanted more support and advice from their specialists regarding their treatment choice on a seven-point scale (1 = strongly disagree; 7 = strongly agree).

2.5. Analyses

The psychometric analyses on the decision items were done on the data obtained at T2. When women had no breasts because of previous curative or prophylactic surgery, answers to decision related questions were coded as not applicable. We did missing data analyses on the decision items. Factor analyses were done to uncover factors underlying decision evaluation. As factors were expected to be associated, an oblique factor solution was sought in order to arrive at a simple structure solution, discarding items that loaded highly on more than one scale. For the Rasch and Reliability analyses, items were recoded to obtain positive correlations among items. Rasch analyses were done on the items belonging to a single factor [26]. As Rasch models are only readily available for dichotomous items, all items were dichotomised by assigning the first three response categories to 0, and the two upper categories to 1. Based on the final item selection, scores of the items were averaged for each of the three scales. Reliability coefficients (Cronbach's α) were calculated. Tests of construct validity were performed by testing hypothesised associations of the Decision Evaluation scales with other measures described above. These hypotheses were generated after the scales were identified but before the relation of the scales with the remaining measures was inspected. We tested hypotheses cross-sectionally regarding the data collected at T2 and also in mutation carriers at T4.

For missing items from multi-item scales, we imputed the mean of the remaining items when at least half of the items were completed.

The number of subjects providing data for the various analyses varied due to missing data and due to non-applicability of some questions.

3. Results

3.1. Number of participants

At study entrance (T1), 453 women were eligible and 390 (86%) gave informed consent [18]. By T2, 368 were still in the study [21]. Ninety-one women had a BRCA1/2 mutation and were therefore eligible for the second part of the study. Three women withdrew after the positive genetic test result due to high emotional distress. The follow-up at T4 and T5 was complete in 88 and 87 women, respectively [2,12].

3.2. Psychometric analyses

Of the 368 women at T2, 22 women were discarded as both their breasts were already removed, either to treat breast cancer that had developed previously to our data collection ($N = 21$), or for preventive reasons ($N = 1$). Three other women with completely missing data were also discarded. Thus data of 343 women remained for psychometric analyses. Table 1 presents their socio-demographic data.

One item ‘I wish I could stick to my decision’ was deleted because of too many missing responses. Of the remaining 35 items, on average, 1.5% of the item responses were missing. Out of the 343 women, 299 (87%) completely filled out the

remaining 35 items, and these were subjected to factor analysis. An interpretable oblique solution was found containing three factors, explaining 34, 7 and 6% of the variance in the data from 35 items.

Items in these factors were subjected to Rasch analyses. After further item selection, three Rasch scales emerged containing five items each. Rasch statistics are available from the first author. These 15 items were translated into English independently by the first author and a professional translator. Discrepancies between the translations were resolved by consensus. In view of the item content and the factor loadings, these scales were labelled as Satisfaction–Uncertainty, Informed Choice, and Decision Control. Higher scores on the Satisfaction–Uncertainty scale indicate higher Satisfaction, and thus lower uncertainty. The reliabilities (Cronbach’s α) of the three scales were 0.79, 0.85, and 0.75, respectively.

The factor analyses on the final item selection is presented in Table 2. The three scales explained 39, 12, and 8% of the total variance of the final 15 items. For each scale, scale values were calculated when responses on three or more items were present. Each scale value was available for at least 96% of the 343 women. The correlations between the scales were moderate (Satisfaction–Uncertainty, Informed Choice) = 0.52, r (Satisfaction–Uncertainty, Decision Control) = 0.56, r (Informed Choice, Decision Control) = 0.41.

Our prior concepts appear to have been only partly confirmed, as the concepts social support and approval, effective decision making, and perceived riskiness were not retained in the final Decision Evaluation scales. When we allowed for five factors to be extracted (results not shown), social support and perceived riskiness items did yield two additional factors. However, these factors added relatively little to the explained variance of the variables in the Factor analysis, and were therefore not retained. In three factor solutions, the items constructed to cover the concepts of social support, responsibility, and effective decision making blended with the factor Satisfaction–Uncertainty. The social support items did not survive further item selection procedures. The perceived riskiness items were correlated with the Decision Control scale, but also did not survive further item selection procedures. Thus, we conclude that there was some evidence for the prior concepts, but these concepts explained little additional variance, and blended with the Satisfaction–Uncertainty or Decision Control factors.

3.3. Validity

The scales should be associated with Strength of Preference regarding the treatment choices for breast cancer. Higher Strength of Preference was expected to be associated with higher Satisfaction–Uncertainty, Informed Choice, and Decision Control scores. The results in Table 3, row 1, support these hypotheses. Sample sizes varied from 302 and 328.

Table 1
Demographic and medical characteristics (%) of the participants

	N	(%)
Sociodemographic		
Age (years)		
40 or younger	148	43
41–49	104	30
50 or older	91	27
Marital status		
Single	23	7
Married or living together	291	85
Widowed/divorced	28	8
Employment status		
Employed	222	65
Other	119	35
Education		
Lower than high school	75	22
High school	179	52
College or higher	82	24
Personal medical history		
No cancer	172	50
Breast cancer only	153	45
Ovarian cancer only	15	4
Breast and/or ovarian cancer	3	1
Familial medical history		
Breast cancer only	155	50
Ovarian cancer Only	11	4
Breast and ovarian cancer	141	46
Known familial mutation		47
First degree relatives with bc or oc		62
First degree relatives died of bc or oc		32

Table 2
Factor loadings (Pattern Matrix) of 15 items in 3 Rasch scales, obtained after oblique rotation

	Satisfaction–Uncertainty	Informed Choice	Decision Control
I expect to stick with my decision	–0.83		
I am satisfied with my decision	–0.82		
I am still doubtful about my choice	0.76		
This is my own decision	–0.66		
I find it hard to make this choice	0.60		
I am satisfied with the information I received		0.83	
I know the pros and cons of the treatments		0.78	
I want more information about this decision		–0.76	
I want a clearer advice		–0.70	
I made a well informed choice	–0.41	0.62	
This decision is made without me			–0.84
I feel pressure from others in making this decision			–0.74
I wish someone else would decide for me			–0.58
My decision frightens me	0.29	–0.26	–0.45
I regret my decision	0.41		–0.43

*Correlations smaller than 0.25 are suppressed.

We hypothesised that Satisfaction–Uncertainty, Informed Choice, and Decision Control were associated with improved well-being. The results in Table 3 confirm these hypotheses. Decision Control showed the largest associations with well-being.

We hypothesised that the scales should be associated with three the information related measures. We expected that better scores on the three information related measures should be associated with higher Satisfaction–Uncertainty, Informed Choice, and Decision Control scores. The associations should also be stronger for the Informed Choice scale. The results in Table 3, rows 6–8, support these hypotheses.

Previously, we found [27] that a negative emotional reaction to a similar video and brochure was associated with a more troublesome resolution of decision process. We expected that lower scores on Decision Evaluation scales would be related to a negative emotional reaction towards the brochure and video. This turned out to be the case,

Table 3, row 9. Decision Control showed the largest association with a negative emotional reaction to the information material. Sample sizes vary from 161 to 163 because these data are from the intervention group.

Women were asked whether the partner agreed with their treatment choice. We expected that partner agreement would have a positive effect on the decision evaluation. These hypotheses were also confirmed (Table 3, row 10). For row 10, *N* varies from 264 to 268, because not all women had a partner.

Table 4 presents mean scores on the scales split out by treatment choice. Decision Evaluation scores were worse in undecided women, (Satisfaction–Uncertainty, $F(2,325) = 30.89$, $P < .0001$; Informed Choice, $F(2,323) = 4.35$, $P = 0.014$; Decision Control, $F(2,325) = 8.33$, $P = 0.003$).

After disclosure of the genetic test result, we asked whether more support or a clearer advice from the physician was needed. We expected lower Satisfaction–Uncertainty, Informed Choice, and Decision Control scores if women

Table 3
Correlations of Satisfaction–Uncertainty, Informed Choice, and Decision control, with Strength of Preference, information related and well-being measures, at T2, 4 weeks after blood sampling

	Satisfaction–Uncertainty	Informed Choice	Decision Control
Strength of Preference	0.64	0.36	0.39
Anxiety	–0.34	–0.25	–0.40
Depression	–0.22	–0.15	–0.30
Intrusion-avoidance	–0.21	–0.12*	–0.28
General health	0.20	0.20	0.19
Subjective knowledge	0.19	0.52	0.23
Amount of information	0.27	0.61	0.23
Satisfaction with quality of information	0.23	0.58	0.22
Negative emotional reaction	–0.19*	–0.24	–0.42
Partner agreement	0.27	0.27	0.20

All remaining *P*-values < 0.001.

* $P < 0.02$.

Table 4

Mean scores (standard deviations) for Decision evaluation scales 4 weeks after blood sampling, for all women, and split out by treatment choice

	Satisfaction–Uncertainty	Informed Choice	Decision Control
Entire population	3.63 (0.70)	3.14 (0.78)	2.97 (0.64)
Prophylactic mastectomy	3.74 (0.60)	3.14 (0.77)	3.02 (0.62)
Screening for BC	3.71 (0.69)	3.21 (0.81)	3.01 (0.64)
Undecided	2.73 (0.40)	2.76 (0.54)	2.51 (0.62)

Responses range from 1 = ‘strongly disagree’ to 5 = ‘strongly agree’. BC: Breast cancer. Across the three Decision evaluation scales, sample sizes vary from 326 to 328 for the entire population, 121 to 124 for Prophylactic mastectomy, 174 to 178 for screening for BC, and 20 to 30 for undecided.

Table 5

Correlations of Decision evaluation scales with need for support and advice, and perceived Strength of preference of physicians, 3 months after a positive test result

	Need for support/advice	Perceived strength of preference of physicians
Satisfaction–Uncertainty	–0.36**	–0.06
Informed Choice	–0.56**	–0.06
Decision Control	–0.59**	–0.30**

N-sizes vary from 69 to 77.

** $P < 0.004$.

indicated the need for more support/advice. The results are presented in Table 5, column 2. The results support our hypotheses.

We also asked whether women perceived the specialists as holding strong treatment preferences. If so, this should be associated with feelings of pressure, one of the items in the Decision Control scale. The results in Table 5, column 3, support this hypothesis, and for the first time provide support for divergent validity of the Decision Control scale as compared to the other two Decision Evaluation scales.

4. Discussion and conclusion

We set out to uncover the dimensions involved in the evaluation of medical decisions from the patient perspective. We uncovered a new concept measured by the Decision Control scale. We confirmed previously uncovered dimensions such as Satisfaction–Uncertainty and Informed Choice.

We discuss first the Decision Control Scale. Control is a central concept in the health psychology literature [18], and thus, in retrospect, the emergence of this concept in the evaluation of medical decisions is not surprising. The separate items of the Decision Control scale suggest that feelings of regret, anxiety, and feeling of being put under pressure occur in women that are low in Decisional Control. Undecided women reported lower levels of Decision Control. In line with findings that control may be a resource that aids in resisting stress [28], Decision Control was the strongest predictor of well-being. Women who were low in control proclaimed a strong need for additional support and treatment advice, however (and paradoxically), such women also showed a strong negative reaction towards the information material.

In general, control is viewed as [28] “a measure of *relatively* stable, cross-situational individual differences ...” in other words, as a relatively stable personality trait or disposition. Regret is one of the items in our Decision Control scale. A dispositional interpretation sheds a different light on previous studies on regret in medical decision making. Brehaut et al. [14] found that women with stronger regret switched treatments more often. We find that, even before treatment was received, undecided women have lower levels of Decision Control, and thus higher levels of regret. Likewise, in a retrospective study, Borgen et al. [29] studied feelings of regret in 370 women who underwent prophylactic bilateral mastectomy. Feelings of regret were 4.26 times more likely when women reported that the discussion about prophylactic mastectomy was initiated by the physician. We found a remarkably similar association: feelings of regret were 5.03 times more likely when women reported pressure from others (another item in the Decision Control scale). But again, this association existed before the genetic test result was known, that is long before these women convened with the specialists, and thus long before surgery was performed. This analysis suggests that regret studies should consider prospective longitudinal study designs to control for dispositional explanations.

Associations between some of the items in our Decision Control scale have been reported previously, thus providing independent support for the validity of this scale. Brehaut et al. [14] developed a regret scale and noted that higher regret occurred in those who preferred their physicians to make decisions. We confirm this association as regret is in our Decision Control scale as well as two items that deal with whether or not the decision is transferred to someone else. Another item in our scale, ‘I wish someone else would decide for me’ was similar to an item used by Sainfort and Booske [4]. He found that this item was not associated with decision satisfaction, and concluded that “the notion of

‘decision responsibility’ ... or perhaps ‘self-efficacy’ ... is an important and independent element of decision satisfaction”. His conclusion is corroborated by our finding that the Decision Control scale, that contained this item, was an additional factor of decision evaluation.

In contrast to previous findings, we found that items from existing uncertainty, satisfaction, and effective decision making scales are located on a single scale. We believe that this finding is not really at odds with previous findings. For instance, three reports [4,9,11] examined uncertainty and satisfaction. O’Connor reported strong correlations between the effective decision making and uncertainty scales, up to 0.66. In Sainfort and Booske [4], one of the items loading on the ‘satisfaction with choice’ scale, namely ‘it was difficult to make a choice’, is similar to the item ‘this decision is hard for me to make’, but the latter item figures in O’Connor’s uncertainty scale. Also, Holmes noted a correlation of 0.54 between satisfaction and uncertainty.

4.1. Limitations

One may question the applicability of our items to decisions that are not final. For instance, satisfaction with a decision (not the process of decision making) and regret are commonly thought to be associated with experiencing good or bad outcomes from a decision, and not with the decision itself. The reader may therefore feel that assessing satisfaction or regret about a decision not yet made is premature. However, regret also occurs when one realizes that good outcomes of a foregone option are no longer possible, that is before outcomes are experienced [16,30]. Specifically, Brehaut et al. [14] defines decision regret “as remorse and distress over a decision”, and not over the outcome. A similar distinction between decision evaluation and outcome evaluation is made in consumer research [4], namely between post-decision and post-purchase satisfaction. In our case, for instance, consider a women who has chosen prophylactic mastectomy and waits for surgery. She may be coping with the future loss of her breasts. She may regret the loss of her breasts, which she could have kept had she chosen the foregone option of breast screening. Furthermore, the data suggested that few women experienced problems answering our satisfaction and regret questions. The satisfaction and regret items were skipped by only 5 and 10 out of 343 women, respectively.

4.2. Practice implications

We found that Satisfaction–Uncertainty and Informed Choice were important dimensions of decision evaluation. The Decision Evaluation scales in turn were moderately correlated with well-being. These associations with well-being were even stronger after a positive test result (up to 0.53). Counselors and clinicians should therefore consider to refer women with low scores on the Decision Evaluation scales to a psychologist. An easy way to check for low

Decision Evaluation scores is to ask whether a decision has been made because undecided women (about 8%) scored worse on the Decision Evaluation scales.

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