Evidence-based surgery: Dissemination, communication, decision aids
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Interpreting patient decisional conflict scores: behavior and emotions in decisions about treatment

Anouk M. Knops, Astrid Goossens, Dirk T. Ubbink, Dink A. Legemate, Lukas J.A. Stalpers, Patrick M.M. Bossuyt

ABSTRACT

Background: Patient decision aids facilitate treatment decisions. They are often evaluated in terms of their effect on decisional conflict, as measured by the Decisional Conflict Scale (DCS). It is unclear to what extent lower DCS scores are accompanied by observable patient behavior or emotions.

Objective: To help interpret DCS scores.

Design: In a Dutch university hospital, statements on behaviors or emotions during decision making were collected from asymptomatic aneurysm patients and healthy employees. Subsequently, they rated the intensity of decisional conflict each statement expresses on a 1-to-10 scale. Selected statements were prospectively tested in aneurysm patients and cancer patients facing treatment dilemmas.

Measurements: Associations between patients’ DCS scores and reported behavior and emotions were analyzed using logistic regression analysis.

Results: Participants provided 363 statements on behaviors and emotions during decision making, of which 28 were mentioned more than four times. Nine forms of behavior and emotions were selected as they were graded with the least variable median ratings of intensity of decisional conflict. Among 100 patients facing a treatment dilemma, each point increase in DCS lowered their odds for “immediately making the decision” (OR 0.96, 95% CI 0.93 to 0.98), whereas the odds of “fretting regularly” (OR 1.05, 95% CI 1.02 to 1.08) and “feeling nervous when thinking of the decision” (OR 1.04, 95% CI 1.01 to 1.06) were higher.

Conclusions: A decrease in decisional conflict scores leads to less decision postponing behavior, fretting and nervousness. Research should focus on which DCS scores are needed to make deliberate decisions and which scores hinder patients in decision making.
INTRODUCTION

Whenever multiple treatment options are available, without one option being superior, patient preferences need to be incorporated in treatment decision making. This may be challenging to patients, especially in high-stake decisions involving risk, loss or regret.\textsuperscript{1,2} For example, women considering adjuvant radiotherapy after surgery for endometrial cancer have to weigh the reduced risk of tumor recurrence against the risk of radiation-induced harm.\textsuperscript{3} Men offered PSA screening have no guarantee that taking the test decreases their overall mortality risk, while participating in screening may expose them to the potential harm of diagnostic follow-up and iatrogenic consequences of prostate cancer treatment.\textsuperscript{4,5}

Patient decision aids have been developed to explore patient preferences and values and to facilitate decision making.\textsuperscript{6} These tools contain information on treatment options and outcomes, related to the patient’s health status. Such decision aids are often considered to be effective if a controlled study has shown that their use lowers scores on the Decisional Conflict Scale (DCS).\textsuperscript{6-8} This DCS expresses the degree of uncertainty within an individual about which course of action to undertake.\textsuperscript{1,9}

To those using the DCS it is not always intuitive how to interpret the magnitude of the scores. It is unclear what observable behavior or emotions are expressed by patients at different levels of decisional conflict. Some symptoms like hesitation, verbalized concern, self-focusing and restlessness, were defined when the concept of decisional conflict was initially introduced.\textsuperscript{1} It was suggested that people with high decisional conflict scores were more likely to delay the decision, to change their mind or to express decisional regret.\textsuperscript{10} One study found that increasing decisional conflict scores independently predicted men blaming their doctor for bad outcomes if they had undergone PSA testing for prostate cancer.\textsuperscript{11} Nevertheless, the empirical documentation of these behavioral expressions of decisional conflict in the healthcare setting is limited.

If signs and symptoms of patients in decisional conflict could be identified, this would help to further validate the DCS and interpret the magnitude of DCS scores. Moreover, one could determine the extent to which DCS scores need to be decreased in order to realize an improvement that is, besides statistically significant, also relevant to the patient.

To be able to interpret numeric DCS scores, we collected statements on behavior and emotions people experience during decision making. We invited patients and healthy hospital employees to rate the intensity of decisional conflict that each statement expresses, and prospectively tested them in other patients faced with decisions about treatment. In our analysis, we compared these patients’ DCS scores with the extent to which they reported behavior and emotions associated with decisional conflict.
METHODS

This study was conducted in a Dutch university hospital and comprised three phases, based on Thurstone’s classic method of equal-appearing intervals. This method is used to measure the attitude towards a given construct. First, a large number of statements is collected that relate to the construct being measured. Second, judges rate these statements in categories of favourableness towards the construct. The statements with the least variable median ratings are used to construct a questionnaire. Third, participants administer the questionnaire by agreeing or disagreeing with each item. The ethical board waived formal ethical approval as the study neither intervened in the patients’ medical treatment nor affected their psychological integrity.

Phase I: Collecting statements about behavior and emotions in decision making

The first phase was conducted in two groups of participants. Patients with an asymptomatic abdominal aortic aneurysm were informed by their doctor and were asked verbal consent to participate in the study immediately after their visit to the outpatient clinic. The second group consisted of healthy employees of the hospital’s Clinical Epidemiology and Quality Assurance departments. They were approached by the investigators via email. These two groups were selected to secure a wide range of reported behaviors and emotions when experiencing decisional conflict.

Participants provided written statements about behavior they had displayed, or emotions they had experienced while having to make important decisions (e.g. “I ask my family for advice”, or “I become nervous whenever I think of the decision”). They could think of both medical and other important decisions they had been facing, which had been either easy or difficult to decide about. Two investigators independently assessed all statements. They removed statements from the resulting list if they were incomplete or when both investigators found them unrelated to decision making behavior. Disagreements in classification were reconciled by discussion with a third investigator. In the same way, similar statements were grouped. A frequency table was drawn for the list of statements. Statements were regarded as being representative and included in the second phase if they had been mentioned more than four times.

Phase II: Rating the intensity of decisional conflict each statement expresses

In the second phase of the study, other aneurysm patients visiting the outpatient clinic at that particular time were approached, together with the same hospital employees that had been invited to participate in phase I. They judged the intensity of decisional conflict as expressed by each of the included statements on behaviors and emotions. Participants were instructed to think of somebody who has to make a difficult decision about undergoing
major surgery. They were asked to grade each statement on a 1 to 10 scale, using round numbers, with 1 representing no uncertainty and 10 meaning severe uncertainty about which course of action to undertake. Median values and interquartile ranges (IQR) of the ratings were then calculated for each statement. The statements with the least variable median ratings were selected as they represent the most specific intensity of decisional conflict.

Phase III: Prospective testing of the statements with patients in decision about treatment

In the third phase, a convenience sample of aneurysm patients and cancer patients who had just discussed treatment options with their doctor at the outpatient clinic, were invited. Newly diagnosed aneurysm patients had discussed whether or not to undergo elective surgery. Prostate cancer patients and endometrial cancer patients had discussed the pros and cons of (adjuvant) radiotherapy.

The remaining list of statements, representing specific degrees of decisional conflict, was presented to them in a questionnaire to fill out at home once-only. This also contained the DCS in Dutch, the items concerning anxiety from the Hospital Anxiety and Depression Scale, and some demographic questions. For each statement developed in the first two phases of the study, participants were invited to reflect whether they actually displayed the behavior or experienced the emotion as specified. They could respond to the statement by either “yes, this is applicable to me” or “no, this is not applicable to me”.

Statistical analysis

The presence of the reported behaviors and emotions was related to decisional conflict scores as measured by the DCS, by means of logistic regression analysis. There the DCS score was used as the independent variable and the presence or absence of the behaviors or emotions as the dependent variables. Effects are reported as odds ratios per point increase on the DCS, with 95% confidence intervals. Given the multiple logistic regression analyses, we focused on p-values less than 0.01 in identifying significant associations between reported behaviors and emotions and DCS scores.

Confidence intervals around the odds ratios were estimated to be about 0.05 wide. This effectively means that significant odds ratios of 1.04 or higher (per DCS score unit) could be found at the 1% significance level. Data were processed and analyzed using SPSS 16.0 (SPSS, Chicago, IL, USA).
RESULTS

Phase I: Collecting statements about behavior and emotions in difficult decisions

Following their visit at the outpatient clinic, 31 consecutive asymptomatic aortic aneurysm patients provided 123 statements about behavior they had displayed or emotions they had experienced while making difficult decisions. Of the 117 hospital employees invited, 29 (25%) replied. They produced another 240 statements. After face evaluation and grouping of similar statements, 28 statements were taken to the second phase (Figure 1).

Figure 1. Flowchart of gathering statements on behaviors and emotions in decisions about treatment.
Phase II: Rating the intensity of decisional conflict each statement expresses

In the second phase, 48 asymptomatic aneurysm patients and 42 out of 117 hospital employees (36%) graded the intensity of decisional conflict of each statement, taking the point of view of someone who has to decide about major surgery and actually encounters the stated behavior or emotion. Nineteen statements had an IQR of three or more on the 10-point scale and were therefore discarded. The median rating values of the remaining nine statements ranged from two to eight (Table 1).

Table 1. Ratings of decisional conflict as judged for behavior one may display and emotions one may experience during treatment decision making.

<table>
<thead>
<tr>
<th>“Considering the decision I have to make:…”</th>
<th>Median rating (IQR*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I make the decision immediately</td>
<td>2 (1-2)</td>
</tr>
<tr>
<td>I only think of it when somebody else reminds me</td>
<td>3 (2-4)</td>
</tr>
<tr>
<td>I only think of it during quiet moments, for example at home or during a walk</td>
<td>4 (3-5)</td>
</tr>
<tr>
<td>I ask for advice from friends and family, as I do not know what decision is best for me</td>
<td>6 (5-7)</td>
</tr>
<tr>
<td>I search for fellow-sufferers to ask for their personal experiences with the decision</td>
<td>6 (5-7)</td>
</tr>
<tr>
<td>I fret regularly regarding what decision is best for me</td>
<td>7 (6-8)</td>
</tr>
<tr>
<td>I keep postponing it</td>
<td>7 (6-8)</td>
</tr>
<tr>
<td>I become nervous whenever I think of it</td>
<td>7 (6-8)</td>
</tr>
<tr>
<td>I feel restless all the time because of the decision</td>
<td>8 (6-8)</td>
</tr>
</tbody>
</table>

*IQR: interquartile range

Phase III: Prospective testing of the statements with patients in decision about treatment

In the third and final phase, 100 aneurysm and cancer patients completed the questionnaire. Particularly male patients of about 70 years of age and with varying levels of education participated (Table 2). After the visit to their doctor in which treatment options were explained and pros and cons were discussed, about half of the patients stated to be sure regarding their preferred treatment option (Table 2). They had a median DCS score of 27 (IQR 15 to 39) on a 100-point scale. About half of all patients stated to have made their decision immediately, to think of the decision when someone else reminded them, or to think of the decision during quiet moments, like at home or during a walk (Table 3). Patients agreed less often as to the statements that had been rated with a higher intensity of decisional conflict in the second phase of the study.

Three questionnaires could not be used in the univariate logistic regression analysis due to missing DCS scores. Based on the remaining 97 questionnaires, three out of nine statements showed a significant association between DCS score and the likelihood of
Table 2. Characteristics of patients in treatment decision making prospectively testing the statements.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal aortic aneurysm patients</td>
<td>66 (66)</td>
</tr>
<tr>
<td>Cancer patients</td>
<td>34 (34)</td>
</tr>
<tr>
<td>Males</td>
<td>78 (78)</td>
</tr>
<tr>
<td>Age</td>
<td>70 (SD* 9)</td>
</tr>
<tr>
<td>Level of education</td>
<td></td>
</tr>
<tr>
<td>Secondary education</td>
<td>41 (41)</td>
</tr>
<tr>
<td>High school</td>
<td>30 (30)</td>
</tr>
<tr>
<td>College</td>
<td>29 (29)</td>
</tr>
<tr>
<td>Treatment preference</td>
<td></td>
</tr>
<tr>
<td>Sure</td>
<td>53 (53)</td>
</tr>
<tr>
<td>Unsure</td>
<td>47 (47)</td>
</tr>
<tr>
<td>Decisional Conflict (0 to 100 scale)</td>
<td>27 (IQR 15-39)</td>
</tr>
<tr>
<td>Anxiety (0 to 21 scale)</td>
<td>4 (IQR 2.8)</td>
</tr>
</tbody>
</table>

* SD: standard deviation

Table 3. Association between decisional conflict scores as measured by the DCS and patients’ reported behaviors and emotions.

<table>
<thead>
<tr>
<th>“Considering the decision I have to make:”</th>
<th>No patients agreeing to the statement</th>
<th>Odds Ratio (95% CI†)</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DCS* 0-24 N=46</td>
<td>DCS* 25-49 N=39</td>
<td>DCS* 50-74 N=11</td>
</tr>
<tr>
<td>I make the decision immediately</td>
<td>37</td>
<td>19</td>
<td>4</td>
</tr>
<tr>
<td>I only think of the decision when somebody else reminds me</td>
<td>18</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>I only think of it during quiet moments, for example at home or during a walk</td>
<td>25</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>I ask for advice from friends and family, as I do not know what is best for me</td>
<td>10</td>
<td>11</td>
<td>2</td>
</tr>
<tr>
<td>I search for fellow-sufferers to ask for their personal experiences</td>
<td>8</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>I fret regularly regarding what decision is best for me</td>
<td>7</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>I keep postponing the decision</td>
<td>1</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>I become nervous whenever I think of the decision</td>
<td>5</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>I feel restless all the time because of the decision</td>
<td>9</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

* DCS: Decisional Conflict Scale; Odds ratio per unit change; † 95% confidence interval
patients reporting to express the corresponding behavior or emotion (Table 3). For each point increase in DCS, the odds of “immediately making the decision” were 4% lower (OR 0.96, 95% CI 0.93 to 0.98). The odds of “fretting regularly” (OR 1.05, 95% CI 1.02 to 1.08) and “feeling nervous when thinking of the decision” (OR 1.04, 95% CI 1.01 to 1.06) increased with 5% and 4% respectively. Resulting from these ORs, a 10-point increase in DCS score lead to a 34% decreased odds of immediately making the decision, 63% increased odds of fretting regularly, and a 48% increased odds of nervousness.

In Figure 2, the number of patients who agreed with these three statements is plotted against several levels of decisional conflict. An increase in DCS score from 20 to 30 points was associated with a substantial decrease in number of patients who made the decision immediately (from 73% to 57%). The same increase in DCS score was associated with more patients fretting regularly about their treatment decision (from 18% to 26%) and becoming nervous (from 9% to 22%).

![Graphs showing reported behavior and emotions during treatment decision making, related to decisional conflict scores](image)

**Figure 2.** Patients’ reported behavior and emotions during treatment decision making, related to decisional conflict scores
DISCUSSION

In this study we evaluated associations between DCS scores and the likelihood of expressing specific behaviors or emotions, previously identified as associated with important decisions. The odds of fretting regularly and feeling nervous when thinking of the decision were higher in those with higher decisional conflict scores, whereas the odds of immediately making the decision were lower.

Six other forms of behavior and emotion, which were judged to express a moderate intensity of decisional conflict, were not significantly associated to the DCS. Apparently, these behaviors and emotions are expressed independent of the strength of a patient’s rational dilemma about treatment. The three associations found between behavior or emotions and DCS score were rather weak. For example, a considerable number of patients with high DCS scores stated not to display the forms of behavior and emotions despite of their attribution to the category of high conflict. These weak associations may be explained by the fact that the DCS was not developed to measure decision making behavior or emotions, but to measure a patient’s internal conflict in medical decisions. The forms of behavior and emotions we indentified here may, for instance, depend more strongly upon character traits than on the psychological burden of having to make a treatment decision.

Although decisional conflict is all about what people go through when confronted with a difficult decision, the concept of decisional conflict has rarely been related to behavioral outcomes, emotional states, or measures of character traits in the hospital setting. In a clinical trial on active surveillance for early prostate cancer, higher DCS scores were associated with higher neuroticism scores, whereas high extraversion was associated with lower DCS scores. Patients with strong intentions regarding invitations to influenza vaccination, genetic testing, treatment options for localized prostate cancer and early stage breast cancer were found to have lower levels of decisional conflict than those whose intentions were uncertain.

In the end, a decision between several reasonable options has to be made that fits patient preferences and values regarding treatment outcomes. Pathologic degrees of decisional conflict might lead to decisions with disadvantageous benefit versus harm tradeoffs and even unwanted treatment outcomes like death or severely impaired quality of life.

Therefore, a reduction in decisional conflict is usually the primary outcome measure in studies in which patient decision aids are deployed to facilitate treatment decision-making. The underlying theory of the DCS is that high scores could lead to hyper-vigilant coping strategies, in which patients make hastily decisions that give immediate relief from the stress and conflict. Yet, the full range of consequences is overlooked because of emotional excitement and limited attention.
However, some degree of decisional conflict may actually be essential to make high-stake therapy decisions.\textsuperscript{2,21} Although empirical studies are lacking, according to the concept of decisional conflict patients should be sufficiently aroused and motivated to engage in decision making.\textsuperscript{1} We advocate refinement of the expressions of decisional conflict into a continuum: more studies are needed to discriminate between benign features of decisional conflict, leading to deliberate health decisions, and harmful symptoms of decisional conflict, and in which range of DCS scores these symptoms may occur. Moreover, studies should also consider the time frame: there may be a time in which features of decisional conflict are very healthy but persistence for too great a time may be harmful.

Several potential limitations need to be addressed regarding the present study. First, the process for selecting the measures putatively related to decisional conflict was not built on a specific theory or driven by professionals in treatment decision making. We explicitly chose to follow a pragmatic approach, by involving patients and healthy volunteers in identifying the forms of behavior and emotions, in order to attune to daily practice and to illustrate decisional conflict scores in concrete terms of daily life. Second, the external validity of our findings might be limited, since predominantly male patients of about 70 years of age were included. Third, higher levels of decisional conflict were underrepresented in our patient sample, which corresponds to previous findings of patients overestimating their stability while in decision making.\textsuperscript{22} Therefore, we were unable to make more refined analyses for patients with scores at the upper end of the scale and chances to detect significant associations of those behavioral responses which correspond with a higher Decisional Conflict declined. Further research is warranted with a different case mix of patients, in terms of demographic data and levels of decisional conflict.

In conclusion, future users of the DCS may be interested to learn that a decrease in decisional conflict scores leads to less fretting, nervousness, and decision postponing behavior. In contrast, DCS scores are not seamlessly associated with other behavior or emotions, such as the likelihood of asking for advice from friends or family or seeking contact with other patients facing the similar decision. Future research should focus on which levels of decisional conflict are needed to make deliberate decisions, which levels would hinder patients in decision making and doctors should act upon, and to what extent DCS scores need to be decreased in order to realize an improvement that is relevant to the patient.

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