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## The Perceived Personal Control (PPC) Questionnaire as an Outcome of Genetic Counseling: Reliability and Validity of the Instrument

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The perceived personal control (PPC) questionnaire was developed by Berkenstadt and colleagues as an outcome measure for the evaluation of the process of genetic counseling. The present study aimed to further assess the psychometric properties of a Dutch version of the instrument. Data were used from two samples. A reproductive genetic counseling sample (n=140), which included pregnant and non-pregnant women, and a cancer genetic counseling sample (n=181), also consisting of women only. Counsees completed questionnaires before and following their first consultation. Besides the PPC these questionnaires addressed counsees' degree of concern, risk perception and satisfaction with the consultation. The following psychometric properties were assessed: acceptability, internal consistency, dimensionality, and validity. The instrument was well accepted as indicated by few missing items. The internal consistency was good for the total PPC (Cronbach's alpha: 0.79–0.81), reasonable for the original subscales of 'decisional' and 'behavioral control' (>0.60), but unacceptable for the subscale of 'cognitive control' (<0.60). The original three-factor solution was not confirmed; a one-factor solution proved most stable. Significant differences between pre- and post-counseling PPC scores support the PPC's construct validity. Concurrent validity was confirmed by positive associations with counsees' satisfaction although non-significant (concern) and unexpected (risk perception) results were also found. When used as a one-dimensional scale, the PPC has its value as an outcome measure in research addressing genetic counseling. However, the instrument's validity needs to be further assessed.

### INTRODUCTION

Whereas most medical specialties can use illness and health indicators to evaluate the effectiveness of their interventions, such outcome measures are not valid for clinical genetics. Geneticists do not treat patients, but offer counseling, a process through which people affected by or at risk of a hereditary disorder are told about its possible consequences, the probability of developing or

transmitting the condition of concern, and the ways in which this may be prevented or ameliorated [Pilnick and Dingwall, 2001]. How then to judge whether genetic counseling is effective? What are desired outcomes of counseling?

In their review of the counseling literature, Pilnick and Dingwall [2001] found that some researchers define effectiveness as the impact on reproductive decision-making, leading to a potential reduction in affected births. However, there are ample arguments against genetic disease prevention as a goal for genetic counseling [Biesecker, 2001], such as ethical reasons, the unattainability of prevention due to new mutations and unknown causes of most birth defects, and a more assertive approach of the disabled community. More recently, researchers generally consider other outcome measures, such as counselees' recall or knowledge, their risk perception, anxiety reduction and/or satisfaction. Clearly, outcomes have to be related to the goals and the process of genetic counseling. Broadly, these goals can be organized in three themes; to inform and educate counselees, to facilitate informed decision making and to support counselees and help them cope [Wang et al., 2004]. For the latter goal of offering support and enhancing coping, relevant outcomes include: psychological distress, satisfaction with the consultation, uncertainty reduction, quality of life and perceived personal control (PPC) [Bernhardt et al., 2000; Biesecker and Peters, 2001; Wang et al., 2004].

PPC was first introduced as an outcome variable of genetic counseling by Shiloh et al. [1997] and Berkenstadt et al. [1999]. Several underlying processes may lead to increased feelings of control as a result of counseling. By informing and educating counselees—about genetic transmission, the associated risks for the counselee and his next of kin and about the condition of concern—uncertainty will be reduced. Nevertheless, those counselees with high-risk perceptions and concerns will probably feel less control over their situation as compared to those who judge their risk to be low or have few concerns [Audrain et al., 1997]. By offering decisional support, counselees may be helped to weigh alternative options, making them more satisfied and confident about their decisions [Green et al., 2004], thus increasing their sense of mastery. The provision of coping and emotional support during counseling may increase counselees' sense of being able to deal with the threatening situation, in terms of actual problem solving as well as in terms of dealing with the emotions. Overall, counselees who gain a greater sense of control as a result of counseling will most likely be more satisfied about the genetic services provided to them [Shiloh et al., 1997].

Berkenstadt et al. developed a questionnaire for the measurement of the concept of PPC. Based on the work of among others, Averill [1973], Taylor [1983], and Thompson et al. [1993], three separate control dimensions were distinguished and incorporated in the questionnaire: (1) behavioral control, that is, the availability of an instrumental response, (2) cognitive control, that is, the processing of information so as to make a potentially threatening situation less stressful, and (3) decisional control, the opportunity to choose among various courses of action. Initial testing of the instrument among subjects with a variety of genetic problems led the authors to conclude that the PPC was reliable and valid, as indicated by a three-factor structure and associations with counselees' knowledge, satisfaction, and general evaluations of the genetic counseling [Shiloh et al., 1997; Berkenstadt et al., 1999]. However, the authors also noted the need for additional validation studies. We could find only one study in which the PPC was used since its development [Davey et al., 2005].

In view of the recommendation to consider counselees' experience of control as a valuable outcome for evaluating genetic counseling and considering the limited data with the PPC so far, the present study set out to further establish the psychometric properties of this instrument. More specifically, we aimed to assess the reliability and validity of the Dutch version of the PPC. Data from two different study samples were used under the assumption that if the PPC showed satisfactory psychometric properties in two different settings, this would lend extra robustness to the findings.

## **MATERIALS AND METHODS**

### **The PPC Questionnaire**

The PPC asks counselees to indicate their subjective perception of how much control they believe to have over their genetic problem using nine items with a three-point response scale (0=do not agree, 1=somewhat agree, 2=completely agree). The questionnaire represents the three dimensions of control: cognitive (e.g., "I feel I understand the problem that brought me to genetic counseling"),

behavioral (e.g., ‘I know what I can do to alleviate the problem’), and decisional (e.g., ‘I feel I can make decisions that would influence future outcomes’). A total score is calculated (ranging from 0 to 2) by adding the item scores and dividing this by the total number of items, with higher scores indicating more control.

The English version of the PPC was translated in Dutch by two native Dutch-speaking persons with a profound knowledge of English because of their place of residence (USA and UK). Both versions were compared by two researchers (ES and CA), and a revised Dutch version was sent to two native English translators in order to be retranslated in English. These last translations were compared to the original English version and accounting for some small differences between these versions, a final Dutch adaptation was made.

Data were used, derived from two separate investigations: study 1, addressing the quality of reproductive genetic counseling in pregnant as compared to non-pregnant women and study 2, addressing communication in cancer genetic counseling. Both studies were approved by the respective hospital ethical review committees.

## Study 1: Reproductive Genetic Counseling

### *Participants and procedure*

The reproductive genetic counseling sample comprised consecutive pregnant and non-pregnant women between the ages 16 and 43, with a presumed familial condition who had their first appointment for genetic counseling at the department of Clinical Genetics of the Academic Medical Center in Amsterdam. Women who were unable to speak or read Dutch or who were referred because of an adverse outcome at prenatal diagnosis were not enrolled in the study.<sup>1</sup> Consenting participants completed a pre-counseling questionnaire in the waiting room before the consultation. Following the consultation, counsees received a short questionnaire, which they were asked to complete at home. After two weeks, non-responding counsees were telephoned and encouraged to respond. The study also included audio recording of consultations [Aalfs et al., 2005].

Of the women approached for the larger study, 200 agreed to participate (87%). We subsequently excluded 16 non-pregnant women for whom the main condition of concern was hereditary cancer from the study, because we wanted the sample to differ from the cancer genetic counseling sample. Data of 140 women (76%) could be used for the current analyses. The women’s mean age was 30 years (SD=5.1; range: 16–42), 12% had a lower educational level, 52% had high school level and 36% had completed higher vocational training or university. The most frequently reported disorders involved mental retardation (20%) and congenital abnormalities (e.g., cleft lip/palate) (20%), closely followed by chromosomal abnormalities, mainly Down syndrome (18%). Twenty-four of these women (17%) were affected themselves, meaning that they had the condition and/or were carrier of the gene mutation, and 82 (59%) were pregnant.

Of the 140 women who completed the first questionnaire, 115 (82%) also completed the post-counseling questionnaire. Non-responders on the second questionnaire were significantly younger (M-responders =30.7 (SD=4.6), M-non-responders= 27.8 (SD=6.4);  $t=2.21$ ;  $df=29.8$ ;  $P=0.04$ ) and had significantly higher pre-visit PPC scores ( $t=2.33$ ,  $df=133$ ,  $P=0.02$ ) as compared to responders. No differences were found as regards to level of education, pregnancy (yes/no), affected (self or partner vs. other relatives), perceived risk, or degree of concern.

### *Instruments*

Counsees completed the PPC before and following their initial consultation. Risk perception was assessed before counseling by means of a question asking the counslee to indicate the chance of their unborn child developing the condition of concern on a scale from 0 to 100%, further referred to as ‘absolute risk.’ In addition, counsees were asked to indicate how this percentage was experienced (‘Do you experience this risk as . . .’) on a scale ranging from 0=very low to 10=very high. This risk is further referred to as ‘experienced risk.’

<sup>1</sup> This was because the larger study aimed to assess women’s agenda before and communication during their first consultation, i.e., unaffected by prior information of a health care professional.

The degree of concern of women was assessed before counseling with the question: How much do you worry about the health of your child? (0=not at all to 10=very much).

The patient satisfaction questionnaire (PSQ) [Blanchard et al., 1986; Ong et al., 2000] was used to measure women's satisfaction following the consultation. It consists of five items measuring counsees' satisfaction with (a) the way their needs were addressed, (b) their active involvement in the interaction, (c) information received, (d) emotional support received, and (e) the interaction in general. Answers were given on visual analogue scales (VAS) ranging from 0=not at all satisfied to 100=extremely satisfied. An overall satisfaction score was obtained by averaging the responses to the five questions. Internal consistency (Cronbach's  $\alpha$ ) of the PSQ in this study was 0.90.

## Study 2: Cancer Genetic Counseling

### *Participants and procedure.*

Participants for this study were recruited from the consecutive new referrals for cancer genetic counseling at the department of Medical Genetics of the University Medical Centre Utrecht. Inclusion criteria were aged 18 years or older and being the first in the family to seek genetic counseling. Counsees who agreed to participate were sent a questionnaire a few days before their consultation and were asked to complete it before their visit at the clinic. As part of a larger investigation [Pieterse et al., 2005a,b,c], women were also asked to consent with their consultation to be videotaped. The post-visit questionnaire was handed out by the counselor who asked the counsees to complete it as soon as possible. For the purpose of the present paper, only women are included in the sample (91% of the original sample).

Of all eligible counsees, 204 (33%) agreed to participate and data were available for 200 of them (98%), the majority ( $n=181$ ; 91%) being female. The women's mean age was 44 years ( $SD=9.5$ ; range: 18–72). Twenty (11%) counsees had a lower educational level, 48% had high school level and 41% had completed higher vocational or university education. One hundred twenty-seven (70%) were counseled for suspected hereditary breast cancer, 25 (14%) for colon cancer, 11 (6%) for breast and colon cancer, 9 (5%) for ovarian cancer, and 9 (5%) for other types of cancer. Half of the participants (56%) were unaffected but with a family history of cancer, and 79 (44%) were affected with cancer themselves.

The post-visit questionnaire was completed by 163 (90%) of the 181 counsees. Non-responders on the second questionnaire were significantly less often affected themselves ( $\chi^2=11.89$ ,  $df=1$ ,  $P<0.01$ ). No other significant differences were found.

### *Instruments*

As in study 1, counsees completed the PPC before and after their first consultation.

Risk perception was assessed before counseling by means of a question asking the counselee to indicate the chance of developing cancer on a scale from 0 to 100% (absolute risk). In addition, counsees were asked to indicate their experienced risk ("Do you experience this risk as . . .") on a five-point scale (very low, low, not low/not high, high, and very high). The degree of concern before counseling was indicated by the scores on the Dutch version of the impact of events scale, with the event defined as 'seeking genetic counseling for hereditary cancer' [Horowitz et al., 1979; Brom and Kleber, 1985]. Participants rated the frequency of intrusive (seven items) and avoidant (eight items) cognitions using a four-point scale (0=not at all, 1=rarely, 3=sometimes, 5=often). An overall IES-worry scale was obtained by averaging the response on the 15 items. Internal consistency (Cronbach's  $\alpha$ ) of the IES-scale in this study was 0.85.

Satisfaction with the consultation was assessed by means of an eight-item scale, asking for counsees' satisfaction with several aspects of the counseling such as professional expertise, information, the degree of client-centeredness and the interaction in general. Items were scored on a 10-point scale (1=extremely bad, 10=excellent). An overall satisfaction score was obtained by averaging the response on the eight items. Internal consistency (Cronbach's  $\alpha$ ) in this study was 0.92.

## *Analyses*

All subjects with complete data were included in the separate analyses: no imputation techniques for missing data were used. To check for a possible confounding role, associations were assessed between counselees' PPC scores and age, level of education, pregnancy and whether the counselee (or partner in the reproductive sample) herself was affected with the condition of interest.

The acceptability of the PPC was indicated by assessing the non-response for individual items. The instruments' reliability was determined by calculating the scales' (total and original subscales) internal consistency, using Cronbach's alpha. Principal component analyses (PCA) using a non-orthogonal rotation method (Oblimin with Kaiser rotation;  $\delta=0$ ) were performed on both the pre- and post-visit data to investigate the dimensionality of the PPC. We chose for a non-orthogonal approach to do justice to the fact that we expect subscales to be related because each of them intends to measure an aspect of an individual's general perception of control. Given the assumed structure of the instrument, PCA's with three factors were performed first. Next, a PCA was performed to determine the number of factors, using eigenvalues greater than one and factor-loadings of 0.30 or above as a criteria. Finally, a one-factor PCA was performed.

Construct validity is generally determined by testing hypotheses concerning the construct to be measured. Construct validity was assessed by comparing counselees' pre- and post-visit PPC scores using paired t-tests, assuming that their scores would significantly increase as a result of counseling. Additionally, the instrument's concurrent validity was determined by calculating associations (Pearson's correlations or Spearman rho) between counselees' pre-visit PPC-scores, risk perception ('absolute risk' and 'experienced risk') and degree of concern. Likewise associations were calculated between counselees' post-visit PPC and satisfaction scores. Associations were also calculated for post-visit satisfaction and changes in perceived control, by using the residual post-visit PPC-scores, that is, controlling for pre-visit PPC-scores. Because of a priori expectations, tests for significance were one-sided.

## **RESULTS**

### **Study 1: Reproductive Genetic Counseling**

#### *Acceptability*

The PPC was well accepted with percentages of missing items varying between 0.7 (n=1) and 2.1 (n=3) before and 0 and 2.6 (n=3) after the visit (see Table I). Five (4%) counselees omitted one or more items pre-visit and 4 (3%) at post-visit.

#### [ TABLE I ]

#### *Reliability*

The pre-visit internal consistency for the total scale was 0.79. The original subscales had internal consistencies of 0.51 (cognitive control), 0.69 (decisional control), and 0.60 (behavioral control). Post-visit, the total scale had an alpha of 0.81 and the subscales of 0.54, 0.79, and 0.70, respectively. These reliability scores can be considered satisfactory for the overall scale ( $>0.79$ ), reasonable for the subscales 'decisional' and 'behavioral control' ( $>0.60$ ), but unacceptable for the subscale of 'cognitive control' ( $<0.60$ ).

#### *Dimensionality*

The three-factor solution on the pre- and post-visit data explained 61% and 66% of the variance, respectively. However, it did not yield three factors which could be interpreted as intended, that is, indicative for cognitive, decisional and behavioral control. Moreover, the pre-visit data led to another item-distribution than the post-visit data. In the subsequent PCA's we identified two factors with

eigenvalues greater than 1, explaining 51 and 56% of the variance, respectively, but which again were inconsistent for the pre-visit as compared to the post-visit data.<sup>2</sup>

Given the low internal consistencies of the original subscales and the inconsistent factor structure, we choose in favor of a one-factor solution. This yielded one factor explaining 39% and 43% of the variance of pre-visit and post-visit scores, respectively (see Table II). Corrected item total correlations for the overall scale are presented in Table II.

## [ TABLE II ]

### *Validity*

Pre- and post-visit PPC scores were unrelated to counselees' age and level of education and PPC scores did not differ between pregnant and non-pregnant, or between affected and non-affected counselees. Given these results, these variables were not controlled for in subsequent analyses. Average PPC-scores are presented in Table II.

We assumed that counseling should lead to increased perceptions of control in counselees. This expectation was confirmed, as indicated by a significant increase in mean PPC-scores (paired  $t=5.49$ ,  $df=109$ ,  $P<0.001$ ).

The PPC was not significantly associated with women's pre-visit perceptions of risk ('absolute' nor 'experienced'), nor with their degree of concern. Also, no significant association was found between post-visit PPC and satisfaction scores, nor with changes in PPC scores.

In trying to understand this unexpected lack of associations, analyses were performed for the pregnant and non-pregnant and affected and unaffected women separately. In non-pregnant women ( $n=43$ ) and affected women ( $n=23$ ), higher post-visit satisfaction was found to be significantly associated with higher PPC-scores ( $r=0.26$ ,  $P<0.05$  and  $r=0.48$ ,  $P<0.05$ ), respectively). No other significant associations were found in these subgroup analyses.

## **Study 2: Cancer Genetic Counseling**

### *Acceptability*

The PPC was also well accepted in this sample, with percentages of missing items varying between 2.8 ( $n=5$ ) and 6.1 ( $n=11$ ) before and 0 and 3.7 ( $n=6$ ) after the visit (see Table I).

Eleven (6%) counselees omitted one or more items pre-visit and 14 (9%) counselees at post-visit, which is slightly higher than in the reproductive genetic counseling sample.

### *Reliability*

The pre-visit internal consistency was 0.80 for the total scale and 0.57 (cognitive control), 0.68 (decisional control), and 0.73 (behavioral control) for the original subscales. Following the visit, alpha's were 0.81 for the total scale and 0.42, 0.78, and 0.77 for the respective subscales. As in the reproductive genetic counseling sample, the reliability is satisfactory for the overall scale, reasonable for the subscales 'decisional' and 'behavioral control,' but unacceptable for the subscale of 'cognitive control.'

### *Dimensionality*

The three-factor solution in this sample explained 63% of the variance in pre-visit scores and 65% of the variance in post-visit scores, but factors could again not be clearly interpreted. Subsequent PCA's yielded a two-factor solution for the pre-visit data, which differed from the two-factor solution in the reproductive counseling sample. A three-factor solution was obtained for the post-visit data. As a result, we again choose in favor of a one-factor solution. This yielded one factor explaining 39% and 41% of the variance for the pre- and post-visit data, respectively (see Table II). Corrected item total correlations for the overall scale are presented in Table II.

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<sup>2</sup> Data may be obtained from the authors.

### *Validity*

As in the reproductive counseling sample, pre- and post-visit PPC-scores were unrelated to counselees' age and level of education and no differences in PPC-scores were found between affected and non-affected counselees. These variables were therefore not controlled for in subsequent analyses. Average PPC-scores are presented in Table II.

A significant increase in mean PPC-scores (paired  $t=-6.87$ ,  $df=148$ ,  $P<0.001$ ) was found which is in line with our assumption that counseling should lead to increased perceptions of control in counselees.

Pre-visit PPC-scores were positively associated with counselees' risk perceptions ('absolute':  $r=0.17$ ;  $P<0.05$  and 'experienced': spearman  $\rho=0.17$ ;  $P<0.05$ ). This implicates greater perceptions of control with increased risk perception, which is contrary to expectations.

Post-visit, the higher their PPC-scores or the greater the change in PPC-scores, the significantly more satisfied the counselees were ( $r=0.26$ ,  $P<0.005$ ;  $r=0.31$ ,  $P<0.001$ ).

As in the reproductive genetic counseling sample, no significant association was found between counselees' pre-visit degree of concern and their PPC-scores.

The same analyses were performed for the subgroups of affected and unaffected counselees. In the counselees affected with cancer no significant association was found between pre-visit PPC-scores and risk perception but the higher their post-visit PPC-scores, the higher their satisfaction ( $r=0.36$ ;  $P<0.005$ ). In the unaffected counselees, PPC-scores were associated with perceived risk ('absolute':  $r=0.30$ ;  $P<0.005$  and 'experienced': spearman  $\rho=0.32$ ;  $P<0.005$ ) but not with satisfaction.

## **DISCUSSION**

In this study we assessed the psychometric properties of a Dutch version of an existing instrument, the PPC questionnaire, developed to assess counselees' feelings of being in control as related to the possibility of carrying a hereditary condition. The results show that the total score of the PPC has its value as an outcome in research addressing the process of genetic counseling. The questionnaire is acceptable to counselees as indicated by few missing items. More important, the total PPC score is reliable; construct validity is indicated by significant differences between pre- and post-visit scores, and some positive associations were found with counselees' degree of satisfaction. The fact that this study includes data from two distinct samples lends strength to these findings, as does the fact that these results are in line with findings from Davey et al. [2005].

It is of note that not all results supported the PPC's psychometric properties. The original instrument was developed to reflect three distinct dimensions of control: behavioral, decisional, and cognitive control. It was claimed that these three dimensions were reflected in the data, thus supporting the use of three separate scales. The developers of the instrument, however, provided very little information on how the dimensionality of the PPC was assessed and details on the outcomes other than the eigenvalues were not presented. Also, no reliability information was provided on the separate scales [Shiloh et al., 1997; Berkenstadt et al., 1999]. Our data suggest that the instrument's presumed dimensionality is not robust: in both samples the three-factor structure could not be confirmed.

Given our findings, we recommend to use the PPC as a one-dimensional instrument. Such use of the PPC leads to consistency between samples and moments of assessment. However, this is at the expense of variance explained: the one-factor solution explained on average 40% of the variance.

Regarding the PPC's concurrent validity, the general lack of significant associations in the reproductive genetic counseling sample was unexpected and, as for our part, remains unexplained. On closer examination, we found non-pregnant women with a higher sense of control to be more satisfied about the consultation. Genetic counseling for familial genetic conditions in women who are already pregnant differs from counseling in non-pregnant women. A pregnancy creates time constraints, as a result of which important decisions have to be made in a short period of time, preventive measures are limited and the only 'therapeutic' option in most cases will be termination of the pregnancy. The referral is often not initiated by the woman herself, and may induce worry and distress [Aalfs et al., 2004]. As a result, pregnant women's own sense of control may be relatively less important for their satisfaction. Rather, they may allow health professionals more control as a means to cope with the urgency and threat of the situation.

Higher PPC scores were further only significantly associated with satisfaction in the subgroups of affected counselees, that is, only in those who themselves (or their partners in the reproductive genetic

counseling sample) had been diagnosed with cancer or another condition. Clearly, these counselees have greater knowledge of and experience with the condition of concern, which must have influenced the content of the visit. For them, a greater sense of control in terms of knowing what to decide and how to act apparently leads to greater satisfaction with the consultation as compared to non-affected counselees.

Intriguing is the finding that, in the cancer genetic counseling sample, the higher the pre-visit perceived risk in non-affected counselees, the more they felt to be in control. Unfortunately, we cannot provide an explanation for this counterintuitive result.

The differences between our findings and those of the developers of the PPC may reflect cross-cultural differences, not accounted for in the translation process from the original Hebrew, to the English and Dutch versions of the questionnaire. From the literature on cross-cultural adaptations of health-related quality-of-life measures, it is known that the transposition of a measure from its original cultural context by simple translation may be hampered because of language and cultural differences. Moreover, the perception of a concept, that is, of control, and the way it is expressed may vary from culture to culture [Guillemin et al., 1993]. Another difference between our investigations and those of the developers is that we assessed the perception of control following the first visit whereas in their investigation the PPC was administered after the end of counseling (mean duration of 1–3 months in 60% of the cases; range 1–14 months) [Berkenstadt et al., 1999].

The study is subject to limitations. In the cancer genetic counseling sample, the response rate was low (33%) and it is thus questionable how representative this sample is for the larger population of women seeking cancer genetic counseling, although a comparison between decliners and participants showed no significant differences in gender, referral pathway, type of cancer or family history of cancer and a small difference in age. Participants were on the average 2.1 years older than decliners [Pieterse et al., 2005c]. Low participation may partly be explained by the extra effort that was required from potential participants, as they were asked to send back a reply slip. Helmes et al. [2000] showed that interest in participation in a study on genetic counseling decreased as study requirements increased. In a similar vein, low participation may have been due to the fact that participants were asked to consent with their counseling visit to be videotaped [Howe, 1997]. In contrast, counselees in the reproductive counseling sample were asked to have their visit recorded on audiotape, which is generally experienced as less intrusive than video-taping.

A subgroup of counselees (n=50) in the cancer genetic counseling sample visited a counselor who had received individual feedback on his or her communication skills [Pieterse et al., in press 2006]. Although the feedback did not address counseling skills as related to enhancing counselees' sense of control, we nevertheless investigated whether PPC scores were higher in counselees who visited a trained as compared to those who visited an untrained counselor. No differences in PPC scores were found.

Construct validity could be assessed only for those counselees who completed both the pre-visit and post-visit questionnaire; 82% in the reproductive genetic counseling sample and 90% in the cancer genetic counseling sample. Results of the nonresponse analyses tentatively suggest that when the genetic problem was of less personal relevance, that is, the counselee was younger, felt more in control or was unaffected, study participation declined. Our data need to be interpreted in light of this potential bias.

The two investigations described in the current study used different instruments to assess counselees' degree of concern and satisfaction. This might explain the differences in associations with the PPC. It would, however, have made the results with the PPC stronger if hypothesized associations were found, regardless of the variation in instruments. Finally, the gender of our samples was 100% female, which may have affected our findings. Yet, Berkenstadt et al. [1999] found no gender differences when investigating PPC properties.

In the literature concerning the process of genetic counseling there is a recurrent plea for outcome measures, which reflect the goals of counseling. In order to validly draw conclusions about the effectiveness of counseling characteristics, the outcome measures used need to be undisputed. At this moment, the PPC seems satisfactory for use as a measure of counselees' perceptions of control over the genetic problem facing them. However, additional investigations are definitely needed to further assess the instrument's validity. In particular, the construct validity deserves closer scrutiny.

Therefore, a known-groups approach, making comparisons between groups known to differ in their level of perceived control, can be used. Convergent validity, that is, the degree to which the instrument is related to already existing instruments intended to measure the same construct under investigation, might be established by assessing the association with other instruments capturing feelings of control, such as the mastery scale [Pearlin and Schooler, 1978].

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## TABLES

TABLE I. Percentages of Missing Items of the PPC

Items	Reproductive counseling		Cancer counseling	
	Pre-visit n = 140 (%)	Post-visit n = 115 (%)	Pre-visit n = 181 (%)	Post-visit n = 163 (%)
1. I think I understand what problem brought me to genetic counseling	0.7	0.0	2.8	0.0
2. I feel I know the meaning of the problem for my family's future and me	1.4	0.9	3.3	0.6
3. I think I know what caused the problem	1.4	0.9	3.9	2.5
4. I feel I have the tools to make decisions that will influence my future	2.1	0.9	6.1	1.8
5. I feel I can make a logical evaluation of the various options available to me in order to choose one of them	0.7	0.9	5.5	3.7
6. I feel I can make decisions that will change my family's future	1.4	0.9	5.0	3.7
7. I feel there are certain things I can do to prevent the problem from recurring	1.4	2.6	6.1	3.7
8. I feel I know what to do to ease the situation	2.1	2.6	6.1	3.1
9. I think I know what should be my next steps	2.1	2.6	6.1	3.1

TABLE II. Corrected Item-Total Correlations and Mean-Scores ( $\pm$ Standard Deviation) for a One-Factor Solution for the Pre- and Post-Visit PPC Data

PPC-items	Reproductive counseling		Cancer counseling	
	Pre-visit	Post-visit	Pre-visit	Post-visit
1. I think I understand what problem brought me to genetic counseling	0.39	0.43	0.27	0.19
2. I feel I know the meaning of the problem for my family's future and me	0.55	0.47	0.49	0.45
3. I think I know what caused the problem	0.28	0.38	0.42	0.38
4. I feel I have the tools to make decisions that will influence my future	0.53	0.65	0.68	0.61
5. I feel I can make a logical evaluation of the various options available to me in order to choose one of them	0.57	0.56	0.54	0.55
6. I feel I can make decisions that will change my family's future	0.57	0.66	0.45	0.58
7. I feel there are certain things I can do to prevent the problem from recurring	0.37	0.59	0.50	0.60
8. I feel I know what to do to ease the situation	0.49	0.52	0.48	0.60
9. I think I know what should be my next steps	0.58	0.58	0.60	0.63
Eigenvalue	3.5	3.9	3.5	3.7
Percentage of variance explained	39%	43%	39%	41%
Mean total score	1.08 $\pm$ 0.44	1.28 $\pm$ 0.47	1.10 $\pm$ 0.43	1.36 $\pm$ 0.44

## REFERENCES

1. Aalfs CM, Mollema ED, Oort FJ, de Haes JCJM, Leschot NJ, Smets EMA. 2004. Genetic counseling for familial conditions during pregnancy; an analysis of patient characteristics. *Clin Genet* 66:112–121.
2. Aalfs CM, Oort FJ, de Haes JCJM, Leschot NJ, Smets EMA. 2006. Counselor-counselee interaction in reproductive genetic counseling: Does a pregnancy in the counselee make a difference? *Patient Educ Couns* 60:80–90.
3. Audrain J, Schwartz MD, Lerman C. 1997. Psychological distress among women seeking genetic counselling for breast-ovarian cancer risk: The contribution of personality and appraisal. *Ann Behav Med* 19:370–377.
4. Averill JR. 1973. Personal control over aversive stimuli and its relationship to stress. *Psych Bull* 80:286–303.
5. Berkenstadt M, Shiloh S, Barkai G, Bat-Miriam-Katzelson M, Goldman B. 1999. Perceived Personal Control (PPC): A new concept in measuring outcome of genetic counseling. *Am J Med Genet* 82:53–59.
6. Bernhardt BA, Biesecker BB, Mastromarino CL. 2000. Goals, benefits and outcomes of genetic counseling: Client and genetic counselor assessment. *Am J Med Genet* 94:189–197.
7. Biesecker BB. 2001. Goals of genetic counseling. *Clin Genet* 60:323–330.
8. Biesecker BB, Peters KF. 2001. Process studies in genetic counseling. *Am J Med Genet* 106:191–198.
9. Blanchard CG, Ruckdeschel JC, Fletcher BA, Blanchard EB. 1986. The impact of oncologists' behaviors on patient satisfaction with morning rounds. *Cancer* 58:387–393.
10. Brom D, Kleber RJ. 1985. De Schok Verwerkings Lijst (The Dutch Impact of Event Scale). *Ned Tijdschr Psych* 40:164–168.
11. Davey A, Rostant K, Harrop K, Goldblatt J, O'Leary P. 2005. Evaluating genetic counseling: Client expectations, psychological adjustment and satisfaction with service. *J Genet Couns* 14:197–206.
12. Green MJ, Peterson SK, Wagner Baker M, Friedman LC, Rubinstein WS, Mauger DT. 2004. Effect of a computer based decision aid on knowledge, perceptions and intentions about genetic testing for breast cancer susceptibility. *J Am Med Ass* 46:442–452.
13. Guillemin F, Bombardier C, Beaton D. 1993. Cross-cultural adaptation of health related quality of life measures: Literature review and proposed guidelines. *J Clin Epidemiol* 46:1417–1432.

14. Helmes AW, Bowen DJ, Bowden DJ, Bengel J. 2000. Predictors of participation in genetic research in a primary care physician network. *Cancer Epidem Biom Prev* 9:1377–1379.
15. Horowitz M, Wilner N, Alvarez W. 1979. Impact of Event Scale; a measure of subjective stress. *Psychosom Med* 41:209–218.
16. Howe A. 1997. Refusal of videorecording: What factors may influence patient consent? *Fam Pract* 14:233–237.
17. Ong LML, Visser MRM, Lammes FB, de Haes JCJM. 2000. Doctor-patient communication and cancer patients' quality of life and satisfaction. *Patient Educ Couns* 41:145–156.
18. Pearlin LI, Schooler C. 1978. The structure of coping. *J Health Soc Behav* 19:2–21.
19. Pieterse AH, Ausems MGEM, van Dulmen AM, Beemer FA, Bensing JM. 2005a. Initial cancer genetic counselling consultation: Change in counselees' cognitions and anxiety, and associations with addressing their needs and preferences. *Am J Med Genet Part A* 137A:27–35.
20. Pieterse AH, van Dulmen AM, Ausems MGEM, Beemer FA, Bensing JM. 2005b. Communication in cancer genetic counselling: Does it reflect counselees' pre-visit needs and preferences? *Br J Cancer* 92:1671–1678.
21. Pieterse AH, van Dulmen AM, Ausems MGEM, Schoemaker A, Beemer FA, Bensing JM. 2005c. QUOTE-gene(ca): Development of a counselee-centered instrument to measure needs and preferences in genetic counseling for hereditary cancer. *Psycho-oncology* 14:361–375.
22. Pieterse AH, van Dulmen AM, Beemer FA, Ausems MGEM, Bensing JM. 2006. Tailoring communication in cancer genetic counseling through video-supported feedback: A controlled pretest-posttest design. *Patient Educ Couns* (in press).
23. Pilnick A, Dingwall R. 2001. Research directions in genetic counselling: A review of the literature. *Patient Educ Couns* 44: 95–105.
24. Shiloh S, Berkenstadt M, Meiran N, Bat-Miriam-Katzelson M, Goldman B. 1997. Mediating effects of perceived personal control in coping with a health threat: The case of genetic counseling. *J Appl Soc Psychol* 27:1146–1174.
25. Taylor SE. 1983. Adjustment to threatening events. *Am Psychol* 38:1161–1171.
26. Thompson SC, Sobolev-Shubin A, Galbraith ME, Schwakovsky L, Cruzen D. 1993. Maintaining perceptions of control: Finding perceived control in low control circumstances. *J Pers Soc Psychol* 64:293–304.
27. Wang C, Gonzalez R, Merajver DS. 2004. Assessment of genetic testing and related counseling services: Current research and future directions. *Soc Sci Med* 58:1427–1442.