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Psychosocial Aspects of Hereditary Cancer (PAHC) questionnaire: development and testing of a screening questionnaire for use in clinical cancer genetics

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Abstract

***Background*: Up to three-quarters of individuals who undergo cancer genetic counseling and testing report psychosocial problems specifically related to that setting. The objectives of this study were to develop and evaluate the screening properties of a questionnaire designed to assess specific psychosocial problems related to cancer genetic counseling.**

***Methods*: We adopted the European Organisation for Research and Treatment of Cancer Quality of Life Group guidelines to develop the Psychosocial Aspects of Hereditary Cancer (PAHC) questionnaire, a 26-item questionnaire organized into six problem domains: genetics, practical issues, family, living with cancer, emotions, and children. The Distress Thermometer and a question per domain on the perceived need for extra psychosocial services were included as well. We administered the questionnaire and the Hospital Anxiety and Depression Scale to 127 counselees at the time of genetic counseling and 3 weeks after DNA test disclosure. As a gold standard to evaluate the screening properties of the questionnaire, participants underwent a semi-structured interview with an experienced social worker who assessed the presence and severity of problems per domain.**

***Results*: A cutoff score representing responses of 'quite a bit' or 'very much' to one or more items within a given problem domain yielded moderate to high sensitivity across domains. A cutoff of 4 on the Distress Thermometer yielded high sensitivity. The questions regarding the perceived need for extra psychosocial services yielded high specificity and negative predictive values.**

***Conclusion*: The Psychosocial Aspects of Hereditary Cancer questionnaire in combination with the Distress Thermometer can be used as a first-line screener for psychosocial problems within the cancer genetic counseling setting.**

Introduction

Systematic use of patient-reported outcomes (PROs) can facilitate the detection and discussion of both physical and psychosocial health problems in daily clinical oncology practice [1–6]. Enhanced communication can, in turn, result in better understanding and trust between clinicians and their patients, and better patient management [7]. Studies of the effect of routine PRO assessment in clinical practice on patients' functioning and well-being have yielded mixed results [3–6]. It has been suggested that PRO assessments are more likely to impact favorably on psychosocial health when the information provided is concrete and specific to the setting in which it will be used [1,8].

Approximately one-quarter of those who undergo genetic counseling and testing for cancer report clinically relevant levels of distress, anxiety, or depression [9]. These emotional reactions are measured typically with generic questionnaires, such as the Hospital Anxiety and Depression Scale (HADS), the State Trait Anxiety Inventory, the Impact of Event Scale, and the Center for Epidemiological Studies Depression Scale [10–12]. These generic questionnaires do not, however, assess the specific psychosocial problems of individuals undergoing genetic counseling [13,14].

It has been reported that up to approximately three-quarters of individuals experience specific problems during cancer genetic counseling [15]. Ideally, these problems should be addressed during genetic counseling to help individuals understand and adapt to the psychosocial implications of their situation [16]. However, genetic counselors tend to communicate unidirectionally and focus primarily on biomedical issues [17]. Within the cancer genetic counseling setting, where individuals typically have only two contacts with their genetic counselor, the use of a specific psychosocial screening questionnaire may be of particular value in facilitating communication, enhancing care, and ultimately resolving the counselees' problems [18].

There are several questionnaires available for assessing psychosocial issues in the genetic counseling setting, including the Psychological Adaptation to Genetic Information Scale [19], the Multidimensional Impact of Cancer Risk Assessment [20], and the Genetic Risk Assessment

Coping Evaluation [15,21]. The Psychological Adaptation to Genetic Information Scale and Multidimensional Impact of Cancer Risk Assessment were both developed to measure the psychological impact and adaptation to genetic test results (thus after the genetic counseling process is completed) and therefore do not address other potentially relevant issues concerning cancer genetic counseling such as worries about undergoing cancer risk assessment. Although the Genetic Risk Assessment Coping Evaluation measures specific concerns and coping during genetic counseling and is a promising tool for use in daily clinical practice, it does not assess some important areas such as the burden of having (had) cancer or experiencing cancer in the family.

The primary objectives of the current study were to develop and evaluate a questionnaire designed specifically to identify a broad range of psychosocial problems experienced by individuals undergoing genetic counseling and testing in the oncology setting.

Methods

Development of the Psychosocial Aspects of Hereditary Cancer questionnaire

We adopted the four phases of the European Organisation for Research and Treatment of Cancer Quality of Life Group guidelines for questionnaire development [22]. First, we conducted an extensive literature search (February 2009) in PubMed with the MeSH terms 'genetic counseling', 'neoplasms', 'psychology', and combinations thereof. This search resulted in a total of 167 relevant articles. Simultaneously, we undertook semi-structured interviews with eight health-care providers experienced in cancer genetics (4–20 years of experience). This included clinical geneticists, genetic counselors, psychologists, and social workers. Combined, the information derived from the literature search and the expert interviews resulted in a provisional list of 52 issues specific to the cancer genetic setting. A questionnaire with this provisional list of issues was then sent to another group of experts ($N = 18$, range of experience 1–17 years), all of whom were members of the Dutch Society for Psychosocial Oncology's Working Group on Familial Cancer. On the basis of their feedback, 22 issues were deleted as being either insufficiently relevant or redundant. Subsequently, four former counselees who had completed the genetic counseling process were interviewed about the relevance of the 30 issues included in the revised provisional list and were asked if there were any additional issues that they believed should be added. On the basis of these latter interviews, four issues were deleted; none were added.

In the second phase, we operationalized these issues into questionnaire items. We organized the questions into six problem domains: genetics, practical issues, family, living with cancer, emotions, and children. The number of questions generated per topic area ranged from 2 (for practical issues) to 6 (for family-related problems). Each item had a 4-point Likert-type response scale ranging from 1, 'not at all', to 4, 'very much'. Additionally, for each problem domain, a question was included about interest in talking with a psychosocial health-care professional (response choices *yes* or a *no*). The Distress Thermometer (DT), a visual analog scale ranging from 0 to 10 ('no distress' to 'extreme distress'), was also added to the questionnaire as a measure of general psychological distress [23].

In the third phase, the provisional questionnaire was sent to 56 former counselees to further evaluate the relevance of the questions, their phrasing, and whether any additional issues needed to be included. Completed questionnaires were received from 25 individuals, of whom 17 were subsequently interviewed by telephone to obtain more qualitative information about their questionnaire responses. This resulted in a few minor changes in the phrasing of the questions; no changes were made in the questionnaire content. An online version of the provisional questionnaire, the HADS [24], and the sociodemographic questions was pilot tested among 15 counselees of the family cancer clinic of the Netherlands Cancer Institute in Amsterdam. The questionnaire was translated from Dutch to English using forward–backward translation procedures.

The fourth and final phase of the questionnaire development process consisted of testing the resulting questionnaire, the Psychosocial Aspects of Hereditary Cancer (PAHC) questionnaire in a larger group of counselees (Appendix 1). The methods and results of this fourth phase are reported subsequently.

Participants

Between January and December 2010, all individuals, index patients as well as relatives, who were scheduled for genetic counseling with a clinical geneticist or genetic counselor at the family cancer clinic of The Netherlands Cancer Institute were eligible to participate in the study. Participants had to be older than 18 years and have sufficient command of the Dutch language to be able to complete the questionnaires. For logistic reasons, counselees were initially invited only if it was possible to also schedule an interview with a psychosocial worker prior to the counseling session.

Study procedures

Eligible individuals were asked to return the consent form by mail. A reminder letter was sent 1 week before the genetic counseling session. Participants completed sociodemographic questions, the provisional PAHC questionnaire, the HADS, and the DT. Additionally,

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participants underwent a semi-structured interview with one of three experienced social workers about their psychosocial problems. All participants completed questionnaires and interviews at two points in time: (1) at the time of the initial genetic counseling session and (2) approximately 3 weeks after the counseling session during which DNA test results were disclosed. Participants who did not undergo DNA testing were not invited for the second assessment.

We originally planned to have all participants complete the first questionnaire and undergo the semi-structured interview *prior* to seeing their genetic counselor. Toward this end, participants were asked to come to the clinic 40 min prior to their counseling session. However, because of practical reasons, one-third of participants completed the questionnaires immediately after their counseling session and underwent the semi-structured interview by telephone within 3 days.

At the second assessment after DNA testing, the provisional PAHC questionnaire was modified slightly. For example, because at this time the DNA test result had already been disclosed, items related to concerns about whether to go for testing were deleted. The modified PAHC questionnaire, the HADS, and the DT were mailed to the participants 3 weeks after the counseling session during which the DNA test results were disclosed. A telephone interview with the psychosocial worker was scheduled within a week after the questionnaires had been returned. Reminders were sent via mail after 2 weeks. The institutional review board approved the study.

Gold standard: ratings by the psychosocial workers

Because no comparable, validated questionnaire was available, interviews conducted by experienced social workers were used as 'gold standard'. This is in line with development procedures of other screening tools [25]. The interviews were carried out by three clinical social workers experienced in counseling individuals with psychosocial problems related to cancer genetics. They were instructed to pose questions about all six domains covered by the PAHC questionnaire, but without being aware of the specific content (i.e., items) of the questionnaire. For each domain, they rated the presence and severity of possible problems on a 3-point scale: (1) no problem; (2) a minor problem that could probably be dealt with by the genetic counselor; or (3) a major problem requiring referral to specialized psychosocial services. All interviews were audiotaped for purposes of assessing inter-rater reliability. In total, the three social workers independently rated five audiotaped interviews of each of the other social workers.

Statistical analysis

To evaluate the screening properties of the PAHC questionnaire, we first dichotomized the scores of both the questionnaire and the interview to establish two cutoffs or thresholds per psychosocial domain; one more liberal and one more stringent. For the questionnaire, which employs a 4-point response scale, the more liberal cutoff was based on the following criteria: the respondent had a score of 2 or more (i.e., indicating 'a little', 'quite a bit', or 'very much') on at least one item within a given problem domain. The alternative, more stringent cutoff was based on a score of 3 or more on at least one item within a given domain (i.e., 'quite a bit' or 'very much').

Similarly, the social workers' ratings based on the clinical interview (1 = no problem, 2 = minor problem, and 3 = major problem) were dichotomized in two ways, one more liberal and the other more conservative, namely, (1) the counselee had any degree of problem within a given domain (i.e., either minor or major problems) or not (2) the counselee had a major problem within a given domain that required referral to specialized psychosocial services (versus having no or only a minor problem).

The combinations of these thresholds yielded four different sets of 2×2 tables. A first 2×2 table was based on both liberal thresholds. The second 2×2 table was based on the more stringent threshold for the questionnaire (i.e., a score of 3 or greater) and the more liberal rating of the social worker (minor or major problem versus no problem). The third 2×2 table was based on both stringent thresholds. And finally, the fourth 2×2 table was based on the more liberal threshold on the PAHC questionnaire with the more stringent rating of the social worker. This latter 2×2 table was considered less relevant, and thus results based on that categorization are not presented.

We calculated the sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) of the PAHC questionnaire on the basis of these sets of 2×2 tables. Sensitivity is the proportion of true cases (as classified by the social worker) that was detected as such by the screening questionnaire. Conversely, specificity is the proportion of true negative cases (again as classified by the social worker) that was detected as such by the questionnaire. The PPV is the proportion of true positive cases detected by the questionnaire and so classified by the social workers versus the total number of cases identified by the questionnaire. Finally, the NPV is the proportion of true negative cases detected by the questionnaire and so classified by the social workers versus the total number of cases, which were identified as negative on the basis of the questionnaire alone. In all of these analyses, the social workers' ratings were used as the gold standard against which the questionnaire scores were evaluated. Prior to evaluating the screening properties of the questionnaire, we first examined the inter-rater reliability of the social workers' ratings (percentage of agreement).

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We also evaluated the screening properties of the items that asked the participant if he or she felt that he or she needed professional help for any given problem domain. Here, again, the ratings based on the interviews held by the social workers (i.e., should the participant be referred) were considered the gold standard. Finally, we calculated the area under the curve of the receiver operating characteristics curve and evaluated the screening properties of the DT, using the HADS as the criterion measure (a cutoff of 15 for the total score of the HADS).

In selecting the preferred cutoff scores for the questionnaire domains and for the DT, we were primarily concerned with achieving a relatively high sensitivity (i.e., capturing those individuals with a problem) and preferably a high PPV (i.e., a high percentage of those who screen positive actually having a problem) [26]. This optimizes the likelihood of correctly identifying counselees experiencing problems that merit further attention. Sensitivity, specificity, PPV, and NPV were rated as follows: poor (<0.2), fair ($0.2 \leq 0.4$), moderate ($0.4 \leq 0.6$), good ($0.6 \leq 0.8$), and very good ($0.8 \leq 1$) [27]. Finally, the percentage of participants who screened positive on the questionnaire was taken into account in establishing the optimal threshold.

Results

Participants

In total, 263 eligible counselees were invited to participate in the study, of whom 139 (53%) agreed to do so. Reasons for non-participation included logistical/scheduling problems ($n = 23$), perceived emotional burden ($n = 20$), lack of interest ($n = 13$), and not wanting to be audiotaped ($n = 3$). Thirty-nine counselees provided other reasons, and 26 did not provide a reason.

Complete data (both questionnaire and interview) were available for 127 of the 139 participants (91%) at the first assessment. Of the 139 participants, some did not undergo DNA testing ($n = 35$), did not return the second questionnaire ($n = 13$), or did not have complete interview data at the second assessment ($n = 17$). Complete data of 74 participants were available at the second assessment. To evaluate the screening properties of the DT at the second assessment, we also included the 17 participants who completed these questionnaires (without having undergone an interview), resulting in 91 cases. Table 1 presents the sociodemographic characteristics of the participants.

Inter-rater agreement

Inter-rater agreement between the social workers was moderate, ranging from 53% to 62% across the problem domains. Given this, all statistical analyses were first conducted for each psychosocial worker separately. The results were very similar across the individual social workers, and thus we based the final analyses on the combined ratings of the social workers.

Table 1. Sociodemographic characteristics of the study sample ($n = 127$)

Age (years) [range]	Mean 47 [18–78]
	N (%)
Gender	
Male	23 (18)
Female	104 (82)
Marital status	
Married/steady relationship	100 (78)
Single	15 (12)
Divorced	7 (6)
Widow/widower	5 (4)
Education level[a]	
Low	29 (23)
Middle	39 (31)
High	58 (46)
(Former) Cancer diagnosis	
Yes	64 (50)
No	63 (50)

[a] $n = 126$, one participant has unknown educational level.

Questionnaire screening properties

Table 2 shows the results of three 2×2 tables comparing the counselees' questionnaire scores with the ratings of the social workers. First, we compared the most liberal criteria for both sources (i.e., any degree of problem). The sensitivity of the questionnaire domains ranged from 0.79 for 'practical issues' to 1.0 for 'living with cancer'. The PPV ranged from 0.41 for 'practical issues' to 0.73 for 'genetics'. Specificity ranged from 0 for 'living with cancer' to 0.43 for 'practical issues', with a NPV ranging from 0 for 'living with cancer' to 1 for 'children-related issues'. Using this liberal cutoff score for the questionnaire, the percentage of patients who screened positive varied between 65% for practical issues to 100% for living with cancer.

Second, we compared the same results when using a cutoff of 3 or higher (i.e. 'quite a bit' or 'very much') on at least one item within a given questionnaire problem domain and a minor or major problem as rated by the social worker. In this case, sensitivity ranged from 0.35 for 'practical issues' to 0.91 for 'living with cancer', and the PPV ranged from 0.57 for 'problems with family' to 0.87 for 'genetics'. Specificity ranged from 0.30 for 'living with cancer' to 0.88 for 'practical issues', with a NPV ranging from 0.38 for 'children-related issues' to 0.73 for 'practical issues'. Using this cutoff, between 20% (for genetic-related issues) and 83% (for living with cancer) of the counselees screened positive on the PAHC questionnaire.

Third, we compared the results on the basis of a cutoff of 3 or higher on at least one item within a given questionnaire domain and a rating of a major problem by the social worker. With these cutoffs, the sensitivity of the

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Table 2. Screening properties of the questionnaire with different cutoffs

	%	Sensitivity	Specificity	Positive predictive value	Negative predictive value
2 or greater (counselee rating) versus minor or major problem (social worker rating)					
Genetics	94	0.97	0.14	0.73	0.63
Practical issues	65	0.79	0.43	0.41	0.80
Problems with family	89	0.95	0.18	0.55	0.79
Living with cancer	100	1	0	0.64	0
Emotions	89	0.95	0.23	0.70	0.71
Children	98	1	0.04	0.58	1
3 or greater (counselee rating) versus minor or major problem (social worker rating)					
Genetics	47	0.58	0.78	0.87	0.43
Practical issues	20	0.35	0.88	0.60	0.73
Problems with family	48	0.54	0.58	0.57	0.55
Living with cancer	83	0.91	0.30	0.70	0.67
Emotions	29	0.35	0.82	0.78	0.40
Children	58	0.57	0.41	0.59	0.38
3 or greater (counselee rating) versus major problem (social worker rating)					
Genetics	47	0.84	0.59	0.27	0.96
Practical issues	20	0.67	0.81	0.08	0.99
Problems with family	48	0.83	0.54	0.08	0.98
Living with cancer	83	1	0.19	0.13	1
Emotions	29	0.63	0.76	0.27	0.93
Children	58	1	0.45	0.13	1

%, percentage of individuals who were screened positive with this cutoff on the PAHC questionnaire.

questionnaire ranged from 0.63 for 'emotions' to 1.0 for 'living with cancer', and the PPV from 0.08 for 'practical issues' and 'problems with family' to 0.27 for genetics and emotions. The specificity ranged from 0.93 for 'emotions' to 1.0 for 'living with cancer' and 'children', with a NPV ranging from 0.93 for 'emotions' to 1.0 for 'children-related issues' and 'living with cancer'. Using this cutoff, between 20% (for genetic-related issues) and 83% (for living with cancer) of counselees screened positive on the PAHC questionnaire.

The analysis of the data from the second assessment, 3 weeks after the DNA test disclosure, yielded a very similar pattern of results to that based on the first assessment (data not shown).

On the basis of these results, we choose a cutoff of 3 (i.e. 'quite a bit' or 'very much') on any item within a domain of the questionnaire as indicative of a problem meriting further attention (i.e., screen positive). Using this cutoff, we were able to avoid a situation in which almost all counselees would screen positive on at least one domain but still have sufficient sensitivity and PPV. Also, with a cutoff of 3, the specificity and NPVs were within acceptable ranges.

Perceived need for professional psychosocial services

The screening properties of the questionnaire item regarding the perceived need for psychosocial care per domain are shown in Table 3. The sensitivity of this item ranged from 0.21 for 'living with cancer' to 0.71 for 'children', with a PPV ranging from 0.06 for 'practical issues' to 0.39 for 'emotions'. Specificity ranged from 0.73 for 'children-related issues' to 0.88 for 'living with cancer', with a NPV ranging from 0.88 for 'genetics' to 0.99 for 'practical issues'. On the basis of this single item, between 13% (for 'living with cancer') and 30% (for 'children') of participants was found to be interested in receiving additional psychosocial services at the first assessment. The perceived need for psychosocial care was consistently much lower at the second assessment (data not presented).

Table 3. Screening properties of the perceived need for psychosocial care at the first assessment

	%	Sensitivity	Specificity	Positive predictive value	Negative predictive value
Genetics	25	0.42	0.78	0.25	0.88
Practical issues	27	0.67	0.74	0.06	0.99
Problems with family	20	0.67	0.83	0.16	0.98
Living with cancer	13	0.21	0.88	0.18	0.90
Emotions	22	0.69	0.85	0.39	0.95
Children	30	0.71	0.73	0.18	0.97

%, percentage of participants that requested extra services.

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The Distress Thermometer

Receiver operating characteristics curve analysis of the DT against the HADS (cutoff = 15) at the first assessment yielded an area under the curve of 0.81. A cutoff for the DT score of 4 resulted in the most optimal balance between sensitivity and specificity. The sensitivity of the DT was 0.83, the PPV was 0.33, the specificity was 0.63, and the NPV was 0.94 (Table 4). Results of this analysis for the second assessment were comparable (data not shown).

Discussion

In this paper, we have reported the results of a study that investigated the screening properties of the PAHC questionnaire, together with the DT in detecting counselees' specific psychosocial problems. We were unable to identify a single cutoff value for the PAHC questionnaire that yielded optimal screening properties across all of the problem domains, and that did not result in all participants screening positive on at least one domain. This suggests that, from a pure measurement perspective, it might make most sense to select a different cutoff value for each of the domains of the questionnaire. However, from a practical perspective, we believe that such a strategy would be cumbersome and confusing to genetic counselors in the daily clinical practice setting. As a compromise, we have chosen a cutoff of 3 (i.e., 'quite a bit' or 'very much') for all domains of the PAHC questionnaire and a cutoff of 4 for the DT.

In establishing the threshold score for the PAHC questionnaire, we gave more weight to sensitivity and PPV as screening properties, as opposed to specificity and NPV. We did so in order to correctly identify counselees experiencing problems that merit further attention, which is of particular importance in the clinical practice setting. With the chosen cutoff of 3, the PPVs were quite reasonable, but not all domains yielded high sensitivity for detecting individuals with *any degree* of problem (minor or major). However, the questionnaire's sensitivity was good to very good in identifying counselees with a major problem (Table 2).

The question regarding the perceived need for psychosocial care was found to have very good screening properties for identifying counselees who *do not* wish to talk with a specialized psychosocial worker and do not require such specialized services (i.e., high specificity and NPV). This question is less useful in identifying those who express a desire for extra counseling and actually require it (i.e., low to moderate sensitivity and PPV). This emphasizes the importance of having the genetic counselor probe further when a counselee expresses interest in speaking with a specialized psychosocial worker. This also suggests that the counselor should pay extra attention to those who do not express interest in being referred to specialized psychosocial services, but do report serious problems on the PAHC questionnaire as it has frequently been observed that highly distressed patients often do not make use of specialized psychosocial services [28,29].

Our goal was to develop a questionnaire for use in clinical practice. Therefore we emphasize again that the thresholds that we recommend here are based, in part, on practical considerations arising from the need to easily interpret the results of the questionnaire in the context of a busy clinical practice. This questionnaire, with its simple thresholds, can guide genetic counselors toward problems areas that merit discussion during genetic counseling.

To our knowledge, this is the first report on the validity of the DT when used in the cancer genetics setting. We found that a threshold score of 4 yielded the best tradeoff between sensitivity (high) and specificity (moderate). Within the oncology setting in the Netherlands, the recommended threshold for the DT is 5 [30]. As has been the case in previous studies, we found that a threshold of 4 yields high NPVs but low PPVs. This emphasizes the need to use the DT only as a first-line screener for generalized distress, requiring further probing by the counselor before referrals are made to specialized psychosocial services [31].

Several limitations of the study should be noted. First, only 53% of those invited to participate in the study did

Table 4. Screening properties of the Distress Thermometer at the first assessment

Score on DT	%	Sensitivity	Specificity	Positive predictive value	Negative predictive value
1	86	1	0.17	0.21	1
2	74	0.96	0.31	0.23	0.97
3	60	0.87	0.46	0.26	0.94
4	46	0.83	0.63	0.33	0.94
5	39	0.78	0.69	0.36	0.94
6	33	0.74	0.75	0.40	0.93
7	26	0.56	0.81	0.39	0.89
8	14	0.39	0.91	0.50	0.87
9	2	0.04	0.98	0.33	0.82
10	0	0	1	0	1

%, percentage of participants who screened positive when using this cutoff.

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so. However, there were no significant difference between participants and non-participants on available sociodemographic and clinical variables. Also, response rates are less important for this type of study in that the focus is on comparing self-reported problems with social workers' ratings *within* subjects. Second, the inter-rater reliability of the social workers' ratings of the participants' problems was only moderate. However, no other gold standard was available, and similar procedures have been used in other questionnaire validation studies. We would also note that the screening properties of the PAHC questionnaire based on the combined ratings of the social workers were very similar to those based on each social worker's ratings separately.

The study also has several noteworthy strengths. First, we used a standardized and structured procedure for developing the questionnaire, which involved both health-care professional and patient input. Second, we evaluated a range of possible thresholds for defining an individual as having clinical relevant problems, and we were able to identify a single threshold value for all of the questionnaire domains, one that exhibits quite reasonable screening properties. The availability of a single cutoff across the questionnaire domains will facilitate its use in daily clinical practice.

In conclusion, the PAHC questionnaire, together with the DT, can be used as a first-line screener for detecting psychosocial problems of individuals undergoing cancer genetic counseling and testing. Future work is needed to determine the best ways of implementing the questionnaire in daily clinical practice, and to investigate how its use affects counselor–counselee communication, timely detection of psychosocial problems, and the management of those problems. Toward this end, we are currently conducting a randomized, controlled trial in which use of the PAHC questionnaire is being compared with usual care.

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Appendix A. The Psychosocial Aspects of Hereditary Cancer Questionnaire (PAHC)

Psychosocial Aspects of Hereditary Cancer Questionnaire

	Not at all	A little	Quite a bit	Very much	
Hereditary predisposition					
1. Are you worried about the chance of being a carrier of a genetic mutation?	1	2	3	4	
2. Are you worried about having to choose whether or not to go for genetic counseling and testing?	1	2	3	4	
3. Are you worried about the choice of possible preventive options (screening or surgery)?	1	2	3	4	
4. Are you worried about coping with the (future) DNA test results?	1	2	3	4	
5. Are you worried about (fulfilling) your plans for having children?	1	2	3	4	N/A
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
Practical issues					
6. Are you worried about the impact of genetic testing on your daily life (at home, at work, at school, or with hobbies)?	1	2	3	4	
7. Are you worried about the impact of genetic testing on obtaining insurance or mortgage?	1	2	3	4	
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
Family and social environment					
8. Do you feel misunderstood by your partner/family/social circle with respect to genetic testing?	1	2	3	4	
9. Are you bothered by lack of support about genetic testing from your partner, family, or your social circle?	1	2	3	4	
10. Are you worried about your immediate family's functioning because of genetic testing?	1	2	3	4	
11. Are you worried about the contact with family members about genetic testing?	1	2	3	4	
12. Are you worried about coping with cancer within the family?	1	2	3	4	N/A
13. Are you burdened by feelings of responsibility towards family members related to genetic testing?	1	2	3	4	
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
Emotions with respect to genetic counseling and testing					
14. Do you feel anxious?	1	2	3	4	
15. Do you feel tense?	1	2	3	4	
16. Do you feel depressed?	1	2	3	4	
17. Do you feel insecure about the future?	1	2	3	4	
18. Do you have questions about life and death?	1	2	3	4	
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
Living with cancer					
19. How emotionally burdensome is it for you that family members have cancer?	1	2	3	4	N/A
20. How emotionally burdensome is losing a family member because of cancer?	1	2	3	4	N/A
21. How emotionally burdensome is your diagnosis or treatment for cancer?	1	2	3	4	N/A
22. Are you worried about the chance of getting cancer (again)?	1	2	3	4	
23. Are you worried about the chance that family members will get cancer?	1	2	3	4	
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
If you have children (if you do not have children please proceed to question 27)					
24. Do you feel guilty about the chance of passing on to your children your possible genetic alterations?	1	2	3	4	
25. Are you worried about telling your children the results?	1	2	3	4	
26. Are you worried about the chance of your children developing cancer?	1	2	3	4	
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		
27. Are there any other issues related to genetic testing that bother you or that you are worried about? If yes, which issues?					
Would you like to speak with a psychosocial worker in addition to the clinical geneticist/genetic counselor about these issues?			Yes/No		

NA, not applicable.