

Concerns and coping during cancer genetic risk assessment

P. Bennett¹*, C. Phelps², J. Hilgart³, K. Hood⁴, K. Brain³ and A. Murray⁵

¹Department of Psychology, School of Health and Human Sciences, University of Swansea, Swansea, UK

²School of Psychology and Counselling, Swansea Metropolitan University, Swansea, UK

³Institute of Medical Genetics, School of Medicine, Cardiff University, Cardiff, UK

⁴South East Wales Trials Unit, School of Medicine, Cardiff University, Wales, UK

⁵Cancer Genetics Service for Wales, Institute of Medical Genetics, Cardiff and Vale NHS Trust, Cardiff, UK

*Correspondence to:

Department of Psychology,
School of Health and Human
Sciences, University of
Swansea, Singleton Park,
Swansea SA2 8PP, UK. E-mail:
p.d.bennett@swansea.ac.uk

Abstract

Objective: To gain an 'in-depth' understanding of patients' concerns and their related coping strategies during the genetic risk assessment process.

Methods: Participants were the 'usual care' arm of a trial of a coping intervention targeted at men and women undergoing assessment of genetic risk for familial cancer. Participants completed questionnaires measuring the degree to which they experienced up to 11 concerns and which of 8 coping strategies they used to respond to each of them at entry into the programme and 1 month subsequently (before they received their risk information).

Findings: A majority of participants were at least 'quite worried' about all the identified concerns, although the levels of concern fell over the waiting period. Participants used several strategies in response to their varying concerns – although a primary coping strategy for each concern was identifiable. The emotion-focused strategies of acceptance and positive appraisal were generally used in response to concerns they could not change, and seeking social support was used primarily to gain information, but not emotional support from their family. Cluster analysis identified three unique clusters of coping responses.

Conclusions: Genetic risk assessment comprises a number of different stressors each of which is coped with using different strategies.

Copyright © 2011 John Wiley & Sons, Ltd.

Keywords: genetic risk assessment; coping; cancer; oncology

Received: 9 June 2010
Revised: 17 January 2011
Accepted: 24 January 2011

Introduction

Around a quarter of the people who undergo genetic risk assessment will experience significant levels of emotional distress at some time [1,2]. In addition, many will experience significant levels of worry [3,4]. How they cope with these emotional and cognitive experiences will influence their emotional state during, and perhaps following, the risk assessment process. Bennett *et al.* [4], for example, found a positive correlation between emotional distress and the use of avoidant and acceptance-resignation coping, and confrontational coping to be associated with high levels of intrusive worries [5]. The latter finding, in particular, emphasises the potential consequences of a mismatch between any coping strategy and its applicability to the context in which it is used. The goodness-of-fit hypothesis [6,7] states that coping is most effective when it matches the demands of the situation. Essentially, where the situation can be changed, problem-focused strategies will prove the most effective: where the

situation is unchangeable, emotion-focused strategies may be the best response. Importantly, the use of unmatched coping strategies may actually increase any distress associated with a particular concern. The ability to respond flexibly and appropriately to the changing demands of varying contexts has been explored by Cheng [8].

The assessment of coping strategies presents a number of challenges, and the measures of coping are inevitably limited in the issues they address and the information they obtain. The compromise adopted by most scales, such as the COPE [9], Coping Inventory for Stressful Situations [10] and Ways of Coping Questionnaire [11], is driven by psychometric theory which requires several items to form scales derived by factor analysis and measuring a limited number of higher order constructs – usually emotion-, problem-focused, or avoidant coping. Such measures typically require the individual to note how frequently they have used up to 40 or more individual coping strategies in response to an identified stressor, with item scores combined into between two- or three-dimensional scales. Thus,

the emphasis of the widely used coping measures is on the type of coping used rather than the nature of the stressor the individual is responding to. This approach strives to achieve psychometric rigour but frequently fails to identify exactly what the individual is coping with. This is typically described (where it is specified) in short phrases, such as 'your condition', 'undergoing cancer genetic risk assessment' and so on. Accordingly, it is not clear what coping strategies have been used in relation to what elements of the 'cancer genetic risk assessment' process. Indeed, while both Murphy [12] and Appleton *et al.* [13] provided rich qualitative information on the experience and coping with being at risk of cancer, and Hilgart *et al.* [14] explored the experience of receiving risk information, there remains little normative data about the concerns of individuals and the coping strategies they use during the genetic risk assessment process.

The present paper uses the Genetic Risk Assessment Coping Evaluation [GRACE: 15] to explore these issues. It identifies the prevalence of a number of concerns experienced by both men and women undergoing the assessment for genetic risk of familial cancer at entry into the risk assessment process and 1 month later, before they have received their risk information. It also reports the coping responses used in response to each of these concerns at both time points and considers the findings in relation to the goodness-of-fit [6,7] and coping flexibility [8] models.

Method

The genetic risk assessment coping evaluation (GRACE)

The GRACE was developed to track coping responses during the early stages of cancer genetic risk assessment: between referral into a clinical genetics service and notification of the level of risk. It asks participants to rate the degree of worry associated with 11 possible sources of stress (the concern items) using a four-point scale (not at all/not applicable to very much so), and which of 8 coping strategies they used to cope with each concern, ticking the relevant box(es) to indicate which were used.

The concerns were:

1. Not understanding the risk assessment process.
2. Having to wait for information about one's risk.
3. Completing the Family History Questionnaire (FHQ; a self-completed history of cancer within the family sent to all patients at entry into the genetics service).
4. Asking family members about their family history of cancer.

5. How the individual would cope if found to have an 'increased' risk of cancer.
6. How the individual's family would react if they were found to have an 'increased' risk of cancer.
7. Whether the individual would be eligible for genetic testing.
8. Possible future decisions about surgery.
9. The impact of being at 'increased' risk of cancer on lifestyle.
10. The implications of being at 'increased' risk for cancer for other family members.

The coping strategies selected were:

1. *Distraction*: Did things to take my mind off it.
2. *Acceptance*: Accepted there was nothing I could do.
3. *Information seeking*: Searched for more information about it.
4. *Positive appraisal*: Focused on the positive aspects.
5. *Emotional expression*: Talked or wrote about what I felt.
6. *Social support*: Sought support from family and/or friends.
7. *Role model*: Thought of positive role models.
8. *Planning*: Made a plan of action and followed it.

The questionnaire allowed participants to identify one 'other' (self-defined) relevant stressor and/or coping strategy. Further details of the development of the GRACE are reported in Phelps *et al.* [15].

Procedure

As part of the CARIAD trial, all new referrals into the Cancer Genetic Service for Wales (CGSW) for the assessment of genetic risk for breast/ovarian or colo-rectal cancer were randomised to receive standard information (usual care) or standard information plus a self-help coping leaflet [16]. Among other questionnaires, participants completed the GRACE on referral and 1 month later – before they were informed of their risk level. As the CARIAD trial involved an intervention designed to encourage the use of specific coping strategies, only data from participants in the usual care condition (who did not receive the coping intervention) are reported here.

Results

The usual care group comprised 301 individuals at baseline and 226 at 1-month follow-up. Of these, 208 completed the GRACE at both time points. Eighteen questionnaires were uncodable due to missing data or inaccurate completion and 14

participants were excluded from the analysis as they were notified of their risk level before completion of the 1-month follow-up questionnaire. Accordingly, the total number of participants for whom data are reported here is 194. Of these, 166 were females and 28 were males. Their mean age was 47.5 years ($SD = 13.49$). Seventy-five percent were married or co-habiting and 74% were educated to at least secondary education level.

Concerns

Table 1 reports the percentage of men and women reporting being at least 'quite worried' (level 3 of a four-point scale) by each of the potential concerns. At time 1 (T1), over two-thirds of the cohort reported concerns about the implications for family members of a positive (increased risk) result, how their family would react and how they would personally cope if found to be at 'increased' risk. Other concerns relating to the process of screening, decisions to be taken following knowing their risk status and the impact of genetic risk on lifestyle were still highly prevalent within the group. McNemar tests were used to test the significance of any changes in the percentage of participants reporting the use of each strategy over time. These revealed a significant reduction across the cohort between T1 and time 2 (T2) on measures of concerns relating to the implications of the risk assessment for family members ($\chi^2 = 12.15$, $p < 0.001$), how family members would cope with the participant being at 'increased risk' for cancer ($\chi^2 = 7.875$, $p < 0.001$), decisions about possible surgery ($\chi^2 = 10.173$, $p < 0.001$), the availability of genetic screening ($\chi^2 = 18.62$, $p < 0.001$) and having to wait for risk information ($\chi^2 = 4.02$, $p < 0.05$). In addition, χ^2 analyses revealed a clear trend indicating a lower percentage of men than women experienced some degree of worry in response to

each of the potential concerns. At T1, these differences were significant for concerns relating to how participants would cope if found to be at risk, whether they could obtain increased health screening and having to wait for risk information (see Table 1). At T2, they were significant for having to wait for risk information and not understanding the risk assessment process.

Five participants reported 'other' concerns at Time 1. These related to further treatment, how family members would feel about the risk assessment, how family members not at risk would cope if other family members were at risk and problems with their immediate family being deceased. At Time 2, one woman reported being worried about any possible impact on fertility.

Coping

Table 2 shows the percentage of participants to report engaging in each of the coping strategies in response to a concern identified at T1, at both T1 and T2.¹ The data show a wide variability in the use of coping strategies. Planning, distraction, using a role model and emotional expression were the least-used strategies, whereas acceptance, positive appraisal and seeking social support were the most frequently used. Friedman tests revealed consistent and statistically significant ($p < 0.001$) differences in the use of each coping strategy across the various concerns, with the exceptions of emotional expression at T1 where the differences across the various concerns were at the 5% level and emotional expression at T2 which did not differ significantly in response to any of the concerns. One additional coping response, using religion, was reported by one participant.

McNemar tests showed that the percentage of participants reporting the use of each strategy at each time was relatively consistent. Of the 88 potential differences across time (11 concerns $\times$ 8

Table 1. Percentage of men ($n = 28$) and women ($n = 166$) to report being at least 'quite worried' by each potential source of stress at baseline and 1-month follow-up

	Time 1			Time 2		
	Female	Male	χ^2	Female	Male	χ^2
Implications for family members if at increased risk	73.2	66.7	0.489	58.5	53.8	0.203
How family would react if at increased risk	72.0	60.0	1.49	57.9	57.7	0.000
How I would cope if at increased risk	67.3	40	6.95*	53.4	50.0	0.098
Possible decisions about surgery	54.6	34.6	3.59	39.5	26.9	1.509
Impact on lifestyle if at increased risk	50.3	40.0	0.921	44.4	34.6	0.883
Being able to get increased screening	48.8	26.9	4.32*	27.8	26.9	0.008
Having to wait to find out risk	47.3	23.1	5.34*	38.8	18.5	4.14*
Asking family members about cancer in family	41.1	23.1	3.15	35.4	26.9	0.715
Being eligible for genetic testing	36.9	26.9	0.968	27.8	26.9	0.00
Completing the FHQ	36	25.9	1.04	30.7	19.2	1.43
Not understanding risk assessment process	24.4	15.4	1.02	19.0	3.7	3.86*

* $p < 0.05$.

Table 2. The number of people to report being at least 'quite worried' by each concern at T1, and the percent of these individuals to use each coping strategy in response to this issue at T1 and T2

	N*	Distract	Distract 2	Accept	Accept 2	Seek info	Seek info 2	Appraise	Appraise 2	Emote	Emote 2	Social	Social 2	Role model	Role model 2	Plan	Plan 2
Not understanding assessment	122	12.3	10.7	33.6	24.6	34.4	17.2***	36.9	26.2	8.2	4.9	31.1	19.7*	14.8	12.3	6.6	1.6
Waiting for risk	140	22.1	21.6	64.3	51.1*	10.7	2.2**	25.7	23.6	9.3	5.0	26.4	12.9**	9.3	4.3	1.4	0.7
Completing FHQ	133	6.0	4.5	20.3	14.3	29.3	25.6	27.8	15.8*	9.0	3.8	40.6	32.3	9.0	3.8	5.3	8.3
Asking family members	130	6.2	6.9	16.9	14.6	30.8	14.6***	25.4	19.2	12.3	6.9	51.5	30.8***	6.2	7.7	8.5	9.2
How cope if at increased risk	169	15.4	11.3	32.5	33.9	24.9	11.3**	39.1	31.5	11.2	6.0	34.3	23.2*	20.7	23.2	12.4	7.7
How family would react	175	7.4	16.0	26.3	21.7	12.3	2.9***	37.7	24.0**	12.6	7.4	26.3	20.6	10.9	9.7	8.6	6.3
Being eligible for genetic testing	128	6.2	7.0	23.4	23.4	28.9	9.4***	38.3	30.5	6.2	7.8	21.1	14.1	7.0	5.5	4.7	3.1
Possible decisions about surgery	143	13.3	11.2	21.1	15.4*	25.0	9.8***	31.2	25.2	14.1	3.5**	24.2	18.9	13.3	10.5	3.9	5.6
Obtaining increased screening	132	4.5	6.1	14.4	10.6	18.9	7.6**	43.9	43.2	9.1	4.5	12.1	12.1	4.5	3.8	5.3	3.8
Impact on lifestyle	128	11.7	18.5	30.5	23.2	14.8	8.2	30.5	28.1	13.3	5.5*	26.6	17.1*	10.9	9.6	12.5	6.8*
Implications for family members	159	7.5	15.7	21.4	28.9	15.1	8.8*	32.7	24.5**	12.6	8.2	29.6	21.4**	10.7	12.6	10.1	9.4

Changes over time: McNemar test: *** $p < 0.001$; ** $p < 0.01$; * $p < 0.05$. Changes across concerns: all are significant at the 0.001 level except Emote (emotional expression) at the 0.05 level. Emote 2 is not significant.

coping strategies), only 21 differences were found to be significant, and these related primarily to information seeking and the use of social support. As can be seen in Table 2, there were significant reductions in information seeking in response to all concerns except the impact of genetic risk on lifestyle and completing the FHQ. The use of social support in response to concerns relating to not understanding the assessment process, waiting for risk, asking family members, how the participant would cope if at risk, the impact of being at risk on lifestyle and the implications of being at risk for family members also fell significantly.

A second analysis involved identifying whether there was a dominant strategy for dealing with each of the differing concerns. This involved a three-stage process: (1) identifying the most used coping strategy in response to each concern (at either T1 or T2), (2) identifying all those participants who used this strategy and (3) identifying the percentage of these participants to use other coping strategies in response to this concern. As a worked example, in Table 3, the most frequently used coping strategy in response to the concern of not understanding the risk assessment process was the use of positive appraisal. Of those that used this coping strategy, 9% also used distraction, 13% used emotional expression and so on. Overall, the data show that participants used one dominant strategy for coping with each concern (which were limited to positive appraisal, acceptance and seeking family/social support) and, while they also used other coping strategies, they used these much less often.

A final analysis involved a cluster analysis to determine whether groups of individuals could be identified who used a similar set of strategies in response to each of the concerns. We undertook a two-stage cluster analysis with distance assessed using log-likelihood and selected the optimum number of clusters using the Schwartz–Bayesian Criteria (BIC). This approach identified four clusters of individuals based on their reported coping styles for the different stressors (Table 4). The largest cluster contained 52% of the sample and therefore defined the 'average' for the whole sample. Clusters 3 and 4 identified two groups of individuals with broadly consistent coping styles across stressors, one focussed on acceptance (cluster 3) and the other focussed on emotional expression and social support (cluster 4). Cluster 1 identified a group of individuals who showed lower than the average usage of either of these for two main stressors.

Discussion

The present study provides a follow-up to the baseline measures of the GRACE reported by Phelps *et al.* [15]. It adds follow-up data, a more

Table 3. The percent of participants to use secondary coping responses in response to identified concerns (and primary coping responses)

Concern/primary coping	Secondary coping responses							
	Distract	Seek info	Appraise	Emote	Social support	Role model	Plan	Accept
Not understand T1/appraise	8.9	35.6		13.3	35.6	22.2	8.9	31.1
Waiting for risk T1/accept	17.8	8.9	24.4	10.0	26.7	10.0	0.0	
Complete FHQ T1/social	3.7	33.3	16.7	16.7		13.0	7.4	14.8
Asking family T1/social	7.5	41.8	26.9	17.9		10.4	11.9	9.0
Cope with risk T1/appraise	16.7	31.8		19.7	47.0	28.8	19.7	31.8
Family reaction T1/appraise	4.5	21.2		15.2	31.8	18.2	10.6	18.2
Testing eligibility T1/appraise	2.0	30.6		4.1	30.6	12.2	4.1	10.2
Surgery? T2/appraise	3.2	19.4		6.5	22.6	6.5	3.2	19.4
Increased screen? T1/appraise	3.4	17.2		8.6	12.1	8.6	10.3	5.2
Lifestyle impact T1/accept	4.7	11.6	23.2	11.6	23.2	2.3	7.0	
Family implications T1/appraise	10.2	25.4		16.9	47.5	13.6	11.9	15.3

Table 4. Identified clusters and their distinguishing features

Cluster	1	2	3	4
Size	48	101	21	23
Distinguishing features*	↓ Acceptance for waiting ↓ Social support for FHQ		↑ Acceptance (9/11 stressors)	↑ Emotive (9/11 stressors) ↑ Social support (9/11 stressors) ↑ Role model for lifestyle and waiting ↑ Information seeking for asking family

*Significantly different from whole sample using chi-square with three df and Bonferroni corrected critical value of 20.5.

detailed analysis of the coping used in response to the various identified stressors and across genders, as well as data relating to the role of primary and secondary coping efforts in response to the various concerns and any consistent coping patterns used across the concerns. As far as we are aware, this detailed analysis of coping, at a normative level, has not been previously been reported in this or other health-related contexts.

The most highly endorsed concerns were those relating to the potential future consequences of being at high risk, both in terms of personal impact and its consequences for family members. Of note is that these concerns were highest at the beginning of the risk assessment process, and then fell as time progressed. There appears to be some habituation to concerns raised by the initiation of the risk assessment process. That said, 1 month into the risk assessment process, over half the participants were still experiencing some degree of concern in relation to these issues. Mid-rank concerns involved specific issues related to the consequences of being at risk: decisions about surgery, the impact on lifestyle if found to be at risk, whether or not the individual would be eligible for genetic testing. Finally, there was a cluster of concerns experienced by around 20–40% of the cohort focusing on the risk assessment process: asking family members about cancer, completing the FHQ, waiting for risk information and not understanding the risk assessment process. Some of these concerns are an

inevitable consequence of the risk assessment process. However, the final concern, not understanding the risk assessment process, was experienced by around 20% of the women and 10% of the men. This is remediable, and should be a key target of information for any service, in the light of this evidence and the evidence summarised by Edwards *et al.* [17] noting that a key information need during genetic counselling related to understanding the testing process—even more so than genograms or technical explanations of genetic inheritance.

Participants reported a range of coping strategies in response to each concern. The degree to which each strategy was used varied considerably across the various concerns, but all coping strategies were used in response to all concerns both at baseline and 1-month follow-up: although the use of planning at T2 in response to the issue of waiting for risk information was very limited. The most highly endorsed coping strategies throughout the risk assessment process were emotion-focused: positive appraisal (used by between 25 and 44% of the participants in response to various concerns at T1, and 16 and 43% at T2), acceptance (14–64 and 10–51%) and seeking support from family or friends (12–51 and 12–31%). Given that the problems most people were dealing with were essentially ‘unresolvable’ during the waiting period, this predominant use of emotion-focused coping appears to fit the demands of the situation faced by

these individuals. That said, the least endorsed coping strategies also included emotion-focused coping strategies. A relatively low number of participants used distraction (5–22% at T1 and 4–22% at T2), and even fewer expressed their emotions through talking or writing (6–14 and 4–8%). Finally, one problem-focused coping strategy was used in response to most concerns, information seeking (11–34 and 3–26% at time 2). Together, these results suggest that the dominant coping strategies were emotion-focused: they were aimed at reducing the emotional impact of the assessment process. By contrast, the problem-focused strategies, such as planning, were used relatively infrequently.

Of note also were the findings that two groups of participants almost uniquely used one coping strategy in response to the genetic risk assessment process: positive appraisal ($n = 37$) and social support ($n = 21$), respectively. The majority of participants had no consistent response to any of the concerns they may have experienced, while a much smaller number of individuals consistently used a more variant range of coping strategies in response to their concerns. It is possible that the participants using a limited range of coping strategies found some benefit from them, and in the absence of any measures of coping effectiveness, this possibility cannot be excluded. However, the coping flexibility seen by Cheng [8] as being the optimal coping response was found among the relatively few participants, who engaged in a number of coping responses. Among these individuals, there appears to have been some matching between concerns and coping. Distraction, for example, was used most frequently in response to concerns related to waiting for risk information, as was acceptance. These concerns elicited relatively low levels of information seeking and planning. By contrast, the predominant response to concerns that would benefit from active engagement such as completing the FHQ or asking family members about the family history of cancer evoked active problem-focused coping: information seeking and seeking support from family and/or friends.

The predominant use of emotion-focused coping by many of the participants is likely to be of maximal benefit during the risk assessment period. There is little most people can do to change the primary cause of any concerns. However, if such individuals are subsequently found to be at high or moderate genetic risk of cancer, the optimal coping strategy may be less clear. They may shift from a situation in which (for most) emotion-focused coping is the optimal approach, to one where they have to actively engage in decision making and appropriate behavioural change for at least some of the time. At this point, they may benefit from using both emotion- and problem-focused coping strategies. Future research needs to examine how,

and with what success, patients negotiate this transition between optimal coping strategies.

The study has a number of limitations. The phrasing of the questions, both in terms of concerns and coping, was occasionally vague, matching the language of the focus groups and allowing some flexibility of meaning so as not to be too inflexible. However, this does result in a lack of exactitude in relation to the exact nature of the concerns or coping engaged in. It is possible that too few coping strategies were presented allowing for no discrimination between, for example, seeking family and social support. The number and choice of coping responses were based on feedback from piloting the questionnaire, and the need to not overburden respondents—and only one additional coping strategy was identified. Nevertheless, it may be beneficial to consider at least discriminating between types of social support given the high use of this coping response. Finally, the data were subject to a lot of analyses, increasing the risk of type 1 errors.

The data have a number of implications for the delivery of genetic risk assessment services. In particular, they highlight the level of concerns and informational needs individuals experience during the assessment period. Some concerns were inevitable given the process of risk assessment, relating to the time taken to find their risk, completion of the FHQ and asking family members about their health and ill-health. Other more existential worries related to how they would cope if found to be at heightened risk for cancer, and the implications of this for other family members. More concrete concerns, such as not understanding the risk assessment process (identified by around two-thirds of the cohort), could be addressed through the provision of relevant information. In addition, some patients may have benefited from information about, for example, the implications of risk on genetic testing, lifestyle and potential decisions about surgery. Although a minority of individuals may want and seek such information, those who use problem-focused coping as their preferred coping style may find such information of value, even before it is definitively relevant to their circumstances.

In terms of coping responses, the data identified two relatively small groups of individuals using distinctive and consistent coping strategies in response to a majority of concerns. One group predominantly used acceptance, whereas the other used a combination of emotional expression and social support. How effective these were in reducing distress is unclear. However, given the acknowledged positive benefits of acceptance within therapies such as Acceptance and Commitment Therapy [18], this may be a beneficial coping strategy to use. Of note also was that the one concern which did not elicit either emotional expression or seeking social support

among the latter group was the completion of the FHQ (which required active problem-focused coping). Accordingly, the use of emotion-focused coping does appear an appropriate response to issues faced by participants. Nevertheless, the limited range of coping responses within these groups may indicate a lack of coping flexibility [8]. In addition, the potential stress placed on support systems (and in particular close family) suggests that they too may benefit from some form of supportive intervention. We [15] and Appleton *et al.* [19] have developed self-help interventions focusing on a range of coping strategies for people during and following genetic risk assessment. It is possible that these could usefully be augmented to provide a wider range of coping strategies and also be made appropriate and available to other family members. In addition, the GRACE could be used as a tool by counsellors to identify concerns and coping strategies that could form a focus of counselling sessions as appropriate.

Note

1. As presenting full statistical data for the large number of analyses conducted in this part of the Results Section would make this text extremely unwieldy, they are not presented. However, full statistical analyses are available from the corresponding author.

References

1. Brain K, Norman P, Gray J, Rogers C, Mansel R, Harper P. A randomized trial of specialist genetic assessment: psychological impact on women at different levels of familial breast cancer risk. *Br J Cancer* 2002;**86**:233–238.
2. Watson M, Foster C, Eeles R *et al.* Psychosocial impact of breast/ovarian (BRCA1/2) cancer-predictive genetic testing in a UK multi-centre clinical cohort. *Br J Cancer* 2004;**91**:1787–1794.
3. Gramling R, Anthony D, Lowery J *et al.* Association between screening family medical history in general medical care and lower burden of cancer worry among women with a close family history of breast cancer. *Genet Med* 2005;**7**:640–645.
4. Bennett P, Wilkinson C, Turner J *et al.* Psychological factors associated with emotional responses to receiving genetic risk information. *J Genet Counsel* 2008;**17**: 234–241.
5. Bennett P, Wilkinson C, Turner J *et al.* Factors associated with intrusive cancer-related worries in women undergoing cancer genetic risk assessment. *Fam Cancer* 2009;**8**:159–165.
6. Lazarus RS, Folkman S. *Stress, Appraisal and Coping*. Springer: New York, 1984.
7. Forsythe C, Compas B. Interaction of cognitive appraisals of stressful events and coping: testing the goodness of fit hypothesis. *Cognitive Ther Res* 1987;**11**: 473–485.
8. Cheng C. Cognitive and motivational processes underlying coping flexibility: a dual-process model. *J Pers Soc Psychol* 2003;**84**:425–438.
9. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989;**56**:267–283.
10. Endler NS, Parker JDA. *Coping Inventory for Stressful Situations (CISS): Manual*. Multi-Health Systems: Toronto, Canada, 1990.
11. Folkman S, Lazarus RS. *Manual for the Ways of Coping Questionnaire*. Consulting Psychologists Press: Palo Alto, CA, 1988.
12. Murphy AE. Dealing with the uncertainty of getting cancer. *Eur J Cancer Care* 1999;**8**:233–237.
13. Appleton S, Fry A, Rees G, Rush R, Cull A. Psychosocial effects of living with an increased risk of breast cancer: an exploratory study using telephone focus groups. *Psycho-Oncology* 2000;**9**:511–521.
14. Hilgart J, Phelps C, Bennett P, Hood K, Brain K, Murray A. 'I have always believed I was at high risk...' The role of expectation in emotional responses to the receipt of an average, moderate or high cancer genetic risk assessment result: a thematic analysis of free-text questionnaire comments. *Fam Cancer* 2010;**9**:469–477.
15. Phelps C, Bennett P, Jones H. The development of a cancer genetic-specific measure of coping: the GRACE. *Psycho-Oncology* 2010;**8**:847–854.
16. Bennett P, Phelps C, Brain K, Hood K, Gray J. A randomized controlled trial of a brief self-help coping intervention designed to reduce distress when awaiting genetic risk information. *J Psychosom Res* 2007;**63**:59–64.
17. Edwards A, Gray J, Clarke A *et al.* Interventions to improve risk communication in clinical genetics: systematic review. *Patient Educ Counsel* 2008;**71**:4–25.
18. Pull CB. Current empirical status of acceptance and commitment therapy. *Curr Opin Psychiatry* 2009;**22**: 55–60.
19. Appleton S, Watson M, Rush R *et al.* A randomised controlled trial of a psychoeducational intervention for women at increased risk of breast cancer. *Br J Cancer* 2004;**90**:41–47.