
Original Research

Knowledge and Expectations of Women Undergoing Cancer Genetic Risk Assessment: A Qualitative Analysis of Free-Text Questionnaire Comments

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Individuals undergoing cancer genetic risk assessment have been found to have a poor understanding of the process, which may affect how well they cope with learning their risk. This paper reports free-text data from questionnaires completed by women undergoing a randomised controlled trial of a psychological intervention. Of the 268 women undergoing genetic assessment for familial breast/ovarian cancer risk who were invited to take part in the trial, 157 women returned research questionnaires. Of these, 97 women provided free-text comments upon referral to a cancer genetics clinic, 62 provided comments whilst waiting for risk information (average, moderate or high), and 36 women provided comments following notification of risk. This paper reports a thematic analysis of the free-text data. Themes reflected individuals' poor knowledge and uncertainty about genetic risk assessment. How well individuals responded to learning their risk depended upon whether expectations had been met. Regardless of risk, individuals undergoing cancer genetic risk assessment are likely to benefit from increased information about its process and timescales, and access to increased psychological support. Free-text comments can provide valuable data about individuals' expectations and knowledge of genetics services.

KEY WORDS: breast/ovarian cancer; knowledge; qualitative; risk assessment; uncertainty.

INTRODUCTION

Previous research has indicated that individuals have a poor understanding of genetics (Henderson

and Maguire, 1998, Watson *et al.*, 1998) and the genetic risk assessment and testing process (Hallowell *et al.*, 1997). In the UK, services which provide genetic risk information and advice to individuals concerned about their family history of cancer are not just aimed at those at high risk requesting predictive genetic testing. Whilst there are wide regional variations across the UK in the way in which cancer genetics clinics operate (Wonderling *et al.*, 2001), many follow a similar referral and assessment structure to that adopted by the Cancer Genetics Service for Wales (CGSW), in line with recommendations from the Calman-Hine Report (1995), the Harper Report (1998) and findings from the TRACE study (Brain *et al.*, 2000).

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A referral for genetic risk assessment usually comes from an individual's General Practitioner or hospital specialist. Upon referral to CGSW, an individual receives a letter and a family history questionnaire (FHQ) which examines their family history along with other medical details. The process of collecting and verifying this information with cancer registries and pathology means that the duration between referral and receiving personal risk information is usually at least four weeks and is often longer. Other cancer genetics centres in the UK have been found to have waiting times between referral and receipt of risk information ranging from four to 53 weeks, although not all use family history questionnaires as the first part of the triage process (Wonderling *et al.*, 2001). Evidence suggests that this waiting period has the potential to raise anxiety (Phelps *et al.*, 2005; Cull *et al.*, 1999).

In the case of CGSW referrals for breast/ovarian cancer risk, the majority of individuals are identified as at either average risk (<15% lifetime risk) or moderate risk (15–24% lifetime risk). All average risk individuals are notified of their risk through a letter. They do not receive any specialist support and are referred back to their General Practitioner, although the letter includes the telephone number of a genetic counselor. Individuals at moderate risk of breast cancer are notified of their genetic risk and screening options through a letter alone. However, women at moderate risk of both breast and ovarian cancer are invited to a genetic counseling clinic to discuss options for managing ovarian cancer risk, including ovarian screening and risk reducing oophorectomy. If they fall into the appropriate age category (40 to 49 years for breast cancer, 35 years or over for ovarian cancer) moderate risk women are offered annual breast and/or ovarian screening as part of research studies.

Individuals categorised as high risk have a greater than 25% lifetime risk of developing breast-ovarian cancer. High risk individuals are invited to a genetic counseling clinic to discuss the implications of their increased risk status. In addition to increased screening for women aged over 35 years, options may include risk reduction surgery such as prophylactic oophorectomy and mastectomy. Predictive genetic testing can only be offered to high risk individuals when a mutation is detected in a living affected relative and this information shared within the family, a process which may take years.

Such testing is offered within the framework of in-depth genetic counseling, originally developed within the context of Huntington's disease (Harper, 1997).

The receipt of personal risk information can evoke a complex mix of both positive and negative responses including relief, anxiety, guilt and anger (Lynch *et al.*, 1997; Dorval *et al.*, 2000; Bonadona *et al.*, 2002). However, little is currently known about how individuals' expectations and knowledge of the assessment process influence how they cope with the assessment and learning their risk. This paper reports on free-text data obtained from questionnaires distributed as part of an exploratory randomised controlled trial. This trial evaluated the effectiveness of a brief self-help coping intervention involving distraction techniques in reducing distress amongst women undergoing assessment of familial breast/ovarian cancer risk. Evidence of the potential effectiveness of the intervention is reported elsewhere (Bennett *et al.*, [in press](#)), but it is of note here that it had no impact on emotional or coping responses to the assessment process. This paper specifically focuses upon the free-text comments women were asked to provide about their thoughts and feelings as they progressed through the genetic risk assessment process.

The free-text section of the questionnaire asked participants to describe their main thoughts as they progressed through the assessment, allowing them to reflect and report on their experiences and what was important to them. Free-text comments on research questionnaires are an often neglected data-source (Pill *et al.*, 2003) and yet provide rich data that increases our understanding of how and why individuals react to health assessments. Within cancer genetics, despite the multitude of questionnaire studies conducted on the impact of genetic risk assessment/testing (for reviews see Braithwaite *et al.*, 2004; Broadstock *et al.*, 2000; Meiser and Halliday, 2002) none have reported an analysis of free-text comments. Rather, qualitative data have been collected via interviews or focus groups (Appleton *et al.*, 2000; Pasacrete, 1999; Skirton, 2001). The aim of gathering free-text data was to increase understanding of how individuals experience the assessment process and to our knowledge is the first attempt to track women's responses as they progress through the early stages of cancer genetic risk assessment in their own written words.

METHODS

Participants and Recruitment

Eligible participants were women referred into the Cardiff area of CGSW between February and December 2003 for assessment of familial breast/ovarian cancer risk. Information about the study was distributed alongside standard information sent to new referrals. Participants were randomised to receive either the usual information received upon referral (letter, introductory leaflet and family history questionnaire), or the usual information in addition to the intervention (a distraction-based coping leaflet). Participants were asked to complete a postal questionnaire on three occasions: upon referral (Time 1), whilst waiting for genetic risk information i.e. average, moderate or high (Time 2), and after notification of risk (Time 3). For both study groups, the information pack indicated to which group the individual had been randomised and included the baseline assessment questionnaire. Women who agreed to participate in the study were asked to return their completed consent form and questionnaire. Women with and without a personal diagnosis of cancer were eligible for inclusion.

Research Questionnaires

The primary outcome of the trial was the Impact of Event Scale (IES, Horowitz *et al.*, 1979) which comprises two sub-scales that can be combined to provide a global distress score, or two separate sub-scales measuring the frequency of intrusive thoughts concerning undergoing cancer genetic risk assessment, and the frequency of avoidance behaviors. At each time-point, in addition to the IES, basic demographic and clinical data (e.g. source of referral) was collected along with measures of coping, emotions and appraisals. Each questionnaire also provided one large space for free-text comments, accompanied by the following statement anchored to the relevant time point:

*We are interested in any thoughts you may have had about undergoing cancer genetic risk assessment since your referral/in the last two weeks/since being informed of your risk. **These thoughts may be positive or negative.** If you have found yourself thinking about certain issues relating to cancer genetic risk assessment since your referral/in the last two weeks/since being informed of your risk, please write down the issues you have been thinking about in the spaces below.*

Analysis

The free-text comments from the questionnaires were imported into NUD*IST, a computerised software package which aids the analysis of qualitative data by facilitating coding, indexing and retrieval of data. A thematic analysis was conducted (Marks and Yardley, 2004) and axial coding was used to link subordinate themes to the main themes and also to other subordinate themes. Where possible, comparisons were made by sub-group such as time of questionnaire, risk group (average, moderate, high) and study group (intervention or control). Reliability was maintained through comparison of coding of the same data by multiple members of the research team (Silverman, 1993), thereby resolving ambiguities in coding by discussion amongst the researchers.

RESULTS

Sample Characteristics

Of the 268 women invited to participate in the trial, 157 returned the Time 1 questionnaire, 99 returned the Time 2 questionnaire and 56 returned the Time 3 questionnaire. There were no significant differences in response rates of study groups (intervention versus control) at any time-point. Of those returning their questionnaires, 97 made free-text comments at Time 1, 62 made free-text comments at Time 2 and 36 provided free-text at Time 3, following notification of risk (see Table I). Just

Table I. Participants Who Provided Free-Text Comments at Each Time-Point

Time 1 (upon referral)		Time 2 (waiting to learn risk)		Time 3 (post risk-notification)	
N returning questionnaires	157	N returning questionnaires	99	N returning questionnaires	56
N providing free-text comments (% of Time 1)	97 (61.8%)	N providing free-text comments (% of Time 2)	62 (62.6%)	N providing free-text comments (% of Time 3)	36 (64.3%)

Table II. Baseline Characteristics of Women Who Did and Did Not Provide Free-Text Comments at Time 1

Variable	Women providing free-text comments at Time 1 (Total <i>n</i> = 97)	Women not providing free-text comments at Time 1 (Total <i>n</i> = 60)	χ^2	<i>P</i>
	<i>n</i> * (%)	<i>N</i> * (%)		
Study group				
Intervention	50 (51.5)	33 (55.9)	.14	.71
Control	47 (48.5)	26 (44.1)		
Age* (categorical)				
Under 40 years	40 (42.1)	21 (35.6)	.50 (fisher's exact)	
Over 40 years	55 (57.9)	38 (64.4)		
Marital status				
Married or cohabiting	69 (72.6)	43 (72.8)	1.55	0.82
Highest qualifications*				
O-level or equiv.	39 (41.1)	23 (39.0)	4.73	.32
Degree	25 (26.3)	11 (18.6)		
Children*				
At least 1 child	74 (76.3)	45 (76.3)	.99	.91
Referral method				
GP	58 (59.8)	40 (69.0)	1.39	.50
Hospital doctor	29 (29.9)	14 (24.1)		
Referral				
Suggested by GP	36 (37.1)	20 (34.5)	2.52	.47
Suggested by self	20 (20.6)	17 (29.3)		

Note. (*) Not all *n*'s will add up to total number due to missing numbers and not all categories being displayed. A full table can be obtained from the authors.

under half (*n* = 47) of those providing comments at baseline also provided comments at Time 2, with an additional 15 participants also providing comments at Time 2. Fourteen respondents provided free-text comments at all three time points, with only three respondents providing comments at Time 3 only.

Of the 36 respondents providing free-text at Time 3 (post-risk notification), four individuals were at average risk, 22 were at moderate risk and 10 were at high risk. None of the participants in the trial had received genetic testing at the time of the study. Ten of these participants (27.8%) had received their risk result within one month of referral, 23 (63.9%) received their risk results between two and four months after referral, and three participants (8.3%) had to wait longer than four months to receive their risk results. Two of the latter were at moderate risk, and one at high risk. These participants may have had complicated family histories which took longer than normal to validate, or may have had difficulty collecting and returning the necessary information.

The characteristics of those women who provided free-text comments on the baseline (Time 1) questionnaire were compared with those who only answered the closed questions (see Table II). No significant differences emerged on any of these baseline variables.

The only variable to differ significantly between those providing comments at baseline and those not doing so was that of distress, as measured by the Impact of Event Scale (Horowitz *et al.*, 1979). As shown in Table III, a significantly higher proportion of women with high levels of distress at baseline were more likely to provide additional free-text comments than women with lower levels of distress. However, there were no further differences in levels of distress between those providing free-text comments and those not doing so at either follow-up time point.

Thematic Analysis

The thematic analysis revealed much uncertainty amongst participants which stemmed from a poor understanding of the risk assessment process. There was a strong desire amongst many respondents to increase their knowledge and understanding of their genetic risk, and its implications for themselves and their family. However, many participants held inaccurate expectations of the assessment process. Reactions to risk assessment results appeared to be influenced by the degree to which individuals' expectations of the assessment process had been met, and their confidence in the information given. The

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Table III. Levels of Distress in Women Who Did and Did Not Provide Free-Text Comments at Each Time Point

Variable	Women providing free-text comments	Women not providing free-text comments)	χ^2	P
	n* (%)	N* (%)		
Level of distress at baseline	Total n = 97	Total n = 60		
High	47 (49.0)	16 (28.6)	6.35	0.04
Moderate	16 (16.7)	11 (9.9)		
Low	33 (34.4)	29 (51.8)		
Level of distress at Time 2	Total n = 62	Total n = 25		
High	16 (27.6)	9 (28.1)	1.89	0.39
Moderate	14 (24.1)	4 (12.5)		
Low	28 (48.3)	19 (59.4)		
Level of distress at Time 3	Total n = 36	Total n = 20		
High	11 (30.6)	6 (30.0)	0.74	0.61
Moderate	6 (16.7)	5 (25.0)		
Low	19 (52.8)	9 (45.0)		

Note. (*) not all n's will add up to total number due to missing numbers and not all categories being displayed.

intervention did not appear to influence participants' experiences or expectations of the assessment process.

Motivation for Undergoing Cancer Genetic Risk Assessment

Putting One's Mind at Rest. Some participants were hoping that undergoing cancer genetic risk assessment would provide reassurance that they were not at increased risk of cancer and allay what they perceived as somewhat irrational fears about developing cancer. "I am glad there is someone out there to talk to if need be and hope the assessment will put my fears and worries to rest" [1009, Time 1]. This hope was also associated with some anxiety about the potential outcome. "A positive answer from this assessment would put my mind at ease, although I realise it may not be the positive answer I receive" [1298, Time 2].

Knowing the Score. In contrast to those who were hoping for reassurance, other respondents believed that the uncertainty of not knowing was much worse than receiving potentially unfavourable risk information, and thus were actively seeking information about their risk. "I am the type of person who needs to know what she is facing, if anything at all. To my mind the not knowing is far more stressful and worrying to me" [1051, Time 1]

For many participants, the willingness to receive potentially unfavourable risk information was linked to a belief that, if found to be at risk, engaging in appropriate health behaviors and surveillance would in-

crease their chances of detecting cancer at an early stage and thus increase their chances of survival.

Although I am little scared of the result, I think that it is better for me to know the risk both to myself and my daughter so that we can be careful and if necessary, "catch it" at an early stage. That way I have the best possible chance [1049, Time 1]

Whilst waiting for genetic risk information however, there was again a suggestion of some anxiety beginning to unfold during this period, caused by having to wait "... I do find I think about it every day and NEED TO KNOW now that I've made the decision to move forward" [1094, Time 2].

Seeking screening/Genetic testing. Some individuals were clearly hoping to access increased screening or surveillance by entering the assessment process. For these individuals, the referral appeared to represent a means to an end, with little apparent desire for genetic counseling. "I just want to get regular mammograms and scans and this is the only way to possibly get there for free" [1064, Time 1].

Similarly, a number of respondents also stated that they wanted genetic testing, "I would like to know if I am at a higher risk and if there is a blood test or similar that could be taken on a 3 or 6 month basis for peace of mind, to enable early treatment if needed" [1322, Time 1], although many comments reflected a poor knowledge of the assessment and predictive genetic testing process and the length of time it takes, as the following excerpt illustrates.

why does it take so long to assess? ... When am I likely to hear anything? If risk is great, how soon for surgery? Should I be visiting my GP? Will he

know more than me at the moment? I am not getting any younger and need to get this sorted ASAP [1080, Time 2].

Anxieties About Genetic Risk Assessment

Fear of Learning One's Risk. Despite considering referral for genetic risk assessment as a positive step in relation to learning more about risk and screening, a number of participants also simultaneously acknowledged harbouring anxieties about the potential implications of going through cancer genetic risk assessment. *"I'm very nervous of the outcome of this assessment too, but I myself for peace of mind must be assessed to know."* [1011, Time 1]

Upon referral and whilst waiting for genetic risk information, a number of participants commented that they were unsure of how they would cope with potentially unfavourable risk information.

to worry and perhaps think you have an increased risk is very different from seeing it written in black and white that you are definitely at an increased risk. I am not sure how I will react when my assessment is made [1231, Time 1].

Some of these women were not convinced that undergoing the assessment was the right thing for them. *"If I was found to be at risk would that make me more miserable waiting for the inevitable to happen? . . . only want to talk to someone to look at options, may not continue with it."* [1362, Time 1]

Relaying risk. Concern for family members was a commonly reported driving force behind seeking genetic risk information. *"I am more worried about the risk to my daughter than myself"* [1224, Time 1]. Despite feeling responsible for gaining information about familial cancer risk, there was much concern amongst participants regarding the psychological impact of such information upon family members, and how it should be relayed *"If I am at risk what do I tell my children?"* [1216, Time 1].

Additionally, one participant stated that she was not sure if her four sisters would like to find out if they were at high risk, as their other sister had recently died of cancer and *"none of them will talk about it"* [1391b, Time 1].

Collecting Family History Information. Four participants indicated that they had found having to contact family members in order to collect the necessary information to complete the family history questionnaire to be difficult and somewhat anxiety pro-

voking by highlighting the extent of cancer in their families as these excerpts demonstrate:

My family history has turned out to be quite complicated which has worried me. I've also found it really difficult to get the information together [1386, Time 2]

I hadn't really thought too much about the risk of inherited cancer (or tried not to think about it) until I completed the risk assessment and realised how many members of my family had died of cancer [1195, Time 2]

Impact of Receiving Risk Assessment Results

Whilst the numbers providing free-text comments following notification of risk are small, they offer some insight into individuals' reactions to receiving risk information.

"Average Risk" Of the four participants informed that they were not at increased risk of developing cancer, two appeared reassured and relieved by their average risk result. One woman stated that *"It was good to know that I don't have an increased risk of cancer. Very pleased to receive my risk assessment as it was much better than I expected"* [1087, Time 3]. Similarly, another woman indicated that learning she was not at increased risk had reduced her cancer specific worry caused by her family history: *"the information has helped me remove a worry that I might get breast cancer in the future because my older sister suffered breast cancer"* [1409, Time 3].

In contrast, another participant questioned the accuracy of her assessment and conveyed a lack of confidence in how the risk was calculated:

I hope they are right. I'd better tell my sister. There was not enough detail of how the risk assessment was carried out and the process and calculations involved. I felt they just took information off me and then a couple of months later said "oh, you're ok" without explaining the how or why they have come up with that answer [1279, Time 3].

For the remaining respondent, it appeared that going through the assessment process without informing other family members had created tension between her and her sisters, despite learning that she was not at increased risk, as revealed in the following excerpt:

my sisters found out about the assessment and they didn't like [it] because they said that they had the right to know. My sisters said how could I keep it to

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myself, if it [had] came back positive, would I [have been] able to keep it to myself and not tell them?. My sisters have asked me not to do anything like this again without asking them, as they didn't want to know the results at all [1391b].

“Moderate Risk” Some participants were not surprised at being at increased risk of cancer, and appreciated the opportunity for increased screening and advice on appropriate health behaviors. *“My moderate risk is what I expected, I don't feel worried about my risk assessment. I have known for over twenty years I have an increased risk and am grateful for the extra screening available to me”* [1208, Time 3].

However, other comments from women who had not yet reached the age at which increased screening was available expressed disappointment and some anxiety over being given an increased risk notification but no immediate increased screening. These individuals may fail to be satisfied with this risk information as they remain faced with uncertainty about their future:

Since having received the results of the genetic [assessment], I have had mixed thoughts. Mainly glad that I can be screened from age of forty, but afraid of the fact that my fortieth birthday is five years away and what can happen in that time [1298, Time 3].

Similarly, one participant given a moderate risk result indicated some concern regarding whether the risk assessment had been accurately calculated: *“I do worry that since I have only one sister and my mother had no sisters there are not enough female relatives to give a broad enough assessment”* [1068, Time 3].

Whilst some participants found the risk letter informative, others were disappointed to receive notification of their risk though a letter alone.

I was very disappointed that the information I received was nothing I didn't already know. I spent a considerable amount of time gathering information on my family and did become anxious to receive a standard letter which I found very disappointing... [1386, Time 3].

“High risk” The few comments provided by the ten participants given a high risk result who provided additional text were all positive. Some of these women appeared to be reassured by the support provided during their face-to-face consultation with the genetic counselor and satisfied with the level of information provided. *“I found the information given*

to me during my risk assessment to be adequate to answer all my concerns” [1124, Time 3]

In particular, some respondents clearly obtained reassurance and support from their genetic counselor: *“Don't feel so alone or burdened with problem by support which I feel is there now if I need it/or have to talk to someone”* [1094, Time 3]. There did not appear to be a great deal of surprise amongst those told that they were at high risk: *“although I have been advised that I am in a high risk category the information given to me at my assessment was what I expected to hear—no surprises”* [1088, Time 3]

DISCUSSION

The data reported in this paper represents one of the few attempts to track patients' experiences of undergoing the early stages of cancer genetic risk assessment in their own written words. Our results indicate that many women have concerns about being at risk and seek information so that they can reduce their anxiety and minimise risk to family members. However, there is a poor understanding of the process and timescales involved, which can create anxiety. How well individuals adapt to their risk appears to depend upon whether their expectations of the assessment process have been met. Our findings were consistent with previous evidence that many individuals are motivated to undergo cancer genetic risk assessment in order to learn more about the risk to themselves and other family members (e.g. Brain *et al.*, 2000; Collins *et al.*, 2000). There is a pervasive belief that such assessment is a route to accessing screening and genetic testing, leading to early detection and prevention (Skirton, 2001; Fraser *et al.*, 2003; Holloway *et al.*, 2004). The main concerns of individuals in this study related to a fear of how they would cope with being at risk and the implications of this knowledge. Accordingly, interventions designed to improve an individual's perceived ability to cope with cancer genetic risk assessment and its implications may help to reduce distress (Berkenstadt *et al.*, 1999; Codori *et al.*, 1999; Vernon *et al.*, 1999).

Both prior to and after the receipt of genetic risk information, many individuals have a poor understanding of the assessment process. The provision of more information involving greater explanation of the assessment process, its timescales, and how risk is calculated may help to reduce anxieties and result in more accurate expectations of the assessment and better adaptation to risk. Some individuals

may be particularly vulnerable to anxiety whilst waiting for genetic risk information (Phelps *et al.*, 2005). Wonderling *et al.* (2001) identified that individuals referred into cancer genetics services in the UK may wait a considerable length of time before receiving personal risk information. It is therefore understandable that anxieties may persist until risk information is provided, given that individuals either appear to seek reassurance or access to increased screening and/or genetic testing (Collins *et al.*, 2000; Fraser *et al.*, 2003).

This study also provides further evidence that completing a family history questionnaire can evoke distress. Genetics services which use family history questionnaires as part of their initial triage process may be therefore be creating a barrier preventing the more anxious people from entering the assessment process in the first place (Leggatt *et al.*, 2000; Geer *et al.*, 2001). The increasing demand for genetic information within the resource constraints of the UK NHS means that it is unlikely that genetic counselors will be able to see every referral in clinic, or be able to work through every questionnaire with each patient. Accordingly, genetics services should endeavour to make such questionnaires as simple and easy to follow as possible. Detailed guidance should also be available in written format, including “frequently asked questions,” which could also be made available on a patient web-site. In the near future, alternative ways of providing cancer genetics services involving devolving the management of average and moderate risk women to special cancer units and primary care (McIntosh *et al.*, 2004; McAllister *et al.*, 2002) may make it easier for all individuals to receive some degree of face-to-face contact with a relevant health professional, and may reduce the need to complete complex family history questionnaires prior to receiving any information.

Many participants reported positive reactions to notification of risk, suggesting that the receipt of any information about familial risk of cancer is welcomed. As previously found, individuals at increased risk often welcome the opportunity to access increased surveillance or genetic testing (Brain *et al.*, 2002; Scott *et al.*, 2005). However, learning that one is at increased risk but not eligible for genetic testing or other risk management options because of age-related guidelines can also increase anxiety (Huiart *et al.*, 2002; Fry *et al.*, 2003). The dilemma between feeling responsible about passing on genetic risk information to family members, and wanting to avoid causing distress or disrespecting others’ desires is

clearly an important factor in the transmission of genetic risk information within the family (Green *et al.*, 1997; Hallowell, 1999; Foster *et al.*, 2004).

Many individuals told that they are at the same risk as the average population continue to want increased surveillance and predictive genetic testing (Michie *et al.*, 1996; Brain *et al.*, 2002; Holloway *et al.*, 2004) and may remain as concerned as higher risk individuals about developing cancer (Ritvo *et al.*, 1999; Kent *et al.*, 2000; Bish *et al.*, 2002). In the present study, the lack of reassurance reported by two respondents may have been a consequence of receiving their risk information in a letter, rather than through a face-to-face consultation. This supports previous findings in the UK where those notified of their average risk through a letter desired not only more information about how their risk was calculated but also wanted a follow-up consultation (Holloway *et al.*, 2004; Phelps *et al.*, 2004). In the UK, the NICE guidelines (McIntosh *et al.*, 2004) have encouraged the greater involvement of primary care in the management of such average risk individuals, including the provision of psychological support where needed, as some individuals may feel that they have been denied access to their genetics service and benefit from additional support and advice (Bottorff *et al.*, 2000; Scott *et al.*, 2005).

Whilst there is existing evidence to suggest that those at high risk may have unmet information and support needs (Thewes *et al.*, 2003; Iredale *et al.*, 2003), our results highlight a need to identify whether those at average and moderate risk may also benefit from more information and/or psychological support. Given that individuals at different levels of risk subsequently receive different levels of care, there is a need to identify how well individuals cope with the receipt of their risk information and from which interventions they are most likely to benefit.

METHODOLOGICAL LIMITATIONS

The findings reported in this paper do not necessarily reflect the experiences of all women who undergo cancer genetic risk assessment. Many of the results discussed may reflect women who experience anxieties upon referral and who are likely to have specific concerns. However, the fact that there was no difference in the levels of distress between those providing free-text comments at follow-up and those not doing so suggest that the data captured may also be generalisable to those with lower levels of distress.

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There is a need to acknowledge that the relatively small amount of data presented makes it difficult to identify how representative these themes are of the wider population. The large proportion of drop out in those providing free-text comments over time also makes it more difficult to generalise the results. Larger longitudinal studies are needed to capture more data on important outcome variables such as emotions, coping and distress. In depth qualitative interviews would also increase our understanding of longer-term reactions to risk assessment results.

It is possible that the coping intervention administered to some participants as part of the randomised trial, whilst not administered until after completion of the baseline questionnaire, also influenced responses during the follow-up questionnaires. However, the fact that the trial results revealed no overall difference between those receiving intervention or normal treatment on emotions and coping variables suggests any such interference to be minimal.

Despite these limitations, this paper reveals how making more systematic use of free-text comments on questionnaires can increase our understanding of patients' expectations of, and reactions to, undergoing cancer genetic risk assessment. This is of course true of other qualitative methodologies such as in-depth interviews, which would also involve a more rigorous sampling method and allow researchers to further explore interesting issues raised during the course of the dialogue (Green and Thorogood, 2004). We do not propose that the use of free-text data is an equally strong methodology as interviews. However, such comments, which are regularly collected on research questionnaires but seldom analysed in any depth, are a much under-used but potentially highly valuable resource.

CONCLUSIONS

The provision of better information about the process and timescales of cancer genetic risk assessment and access to psychological support may result in more realistic expectations of the assessment process and lead to better adaptation not only to the assessment process itself but also to level of risk. This paper has highlighted how free-text comments on questionnaires, whilst traditionally underutilised, can provide valuable data on individuals' expectations, knowledge and understanding of health services.

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