European Journal of Human Genetics (2015) 23, 147–151

www.nature.com/ejhg

ARTICLE

Accuracy of recall of information about a cancer-predisposing *BRCA1/2* gene mutation among patients and relatives

Chris Jacobs*[,1], Caroline Dancyger[2], Jonathan A Smith[3] and Susan Michie[4]

This observational study aimed to (i) compare the accuracy of information recalled by patients and relatives following genetic counselling about a newly identified *BRCA1/2* mutation, (ii) identify differences in accuracy of information about genetics and hereditary cancer and (iii) investigate whether accuracy among relatives improved when information was provided directly by genetics health professionals. Semistructured interviews following results from consultations with 10 breast/ovarian cancer patients and 22 relatives were audio-recorded and transcribed. Information provided by the genetics health professional was tracked through the families and coded for accuracy. Accuracy was analysed using the Wilcoxon Signed-Ranks test. Sources of information were tested using Spearman's rank-order correlation coefficient. Fifty-three percent of the information recalled by patients was accurate. Accuracy of recall among relatives was significantly lower than that among patients ($P=0.017$). Both groups recalled a lower proportion of information about hereditary cancer than about genetics ($P=0.005$). Relatives who learnt the information from the patient alone recalled significantly less accurate information than those informed directly by genetics health professionals ($P=0.001$). Following genetic counselling about a *BRCA1/2* mutation, accuracy of recall was low among patients and relatives, particularly about hereditary cancer. Multiple sources of information, including direct contact with genetics health professionals, may improve the accuracy of information among relatives.
European Journal of Human Genetics (2015) **23,** 147–151; doi:10.1038/ejhg.2014.84; published online 21 May 2014

INTRODUCTION

One of the goals of genetic counselling in the context of familial cancer risk is to provide relevant information in order to enable informed decision-making about genetic testing and risk management.[1] Until recently, genetic testing has generally been offered to women with breast or ovarian cancer after completing cancer treatment. However, *BRCA1/2* testing is increasingly offered to women with newly diagnosed breast cancer as part of their oncology management.[2] Thus, the information that the patient understands and recalls about a cancer-predisposing gene mutation may have an impact on treatment decisions as well as on the management of future cancer risks for herself and her relatives.[3,4]

Responsibility for sharing information within families once a cancer-predisposing gene mutation has been identified generally falls on the individual with cancer who receives the initial mutation result.[5] Families prefer information to be passed on by the patient;[6] yet, although most families do appear to communicate genetic information,[5] patients do not always share all information with all at-risk relatives.[7,8] There are many barriers to family communication about hereditary cancer,[9] including lack of a close relationship,[6] reluctance to upset relatives,[10] youth or emotional readiness of relatives,[11] family culture,[8] perception of the risks and benefits of the information[12] and personal beliefs about the causes of genetic illness.[13]

Information about a cancer-predisposing gene mutation does not necessarily lead to changes in risk perception,[1] although the way in which information is communicated within families may influence the uptake of genetic counselling and screening.[14] However, at-risk individuals who are unaware of the implications of a mutation or the available screening protocols may be unable to make informed decisions about whether or not to access genetic testing or screening. For example, in the UK, untested women at 50% risk of a known *BRCA1/2* gene mutation are eligible for equivalent screening to women with a mutation.[15] Much is still unknown about the content of information that is shared within families or whether the accuracy of the information communicated and recalled has an impact on decisions to seek genetic testing or risk management options.

Few studies have investigated the accuracy of the information recalled by cancer patients or their relatives following identification of a *BRCA1/2* gene mutation.

A Belgian study of 107 first-degree relatives of 14 patients with a *BRCA1/2* mutation reported low levels of knowledge among patients and relatives about hereditary breast and ovarian cancer, dominant inheritance, the availability of predictive testing, cancer risks, risk-reducing options and the possibility of prenatal diagnosis.[16] Levels of knowledge about hereditary cancer were found to be higher among patients than among relatives. More recently, a Dutch study found that patients' recall of information about *BRCA1/2* genetic test results was similar to the information provided during genetic counselling, but there were few similarities between the information actually

[1]Department of Clinical Genetics, Guy's and St Thomas' NHS Foundation Trust, London, UK; [2]Cancer Psychological Services, Bart's Health NHS Trust, London, UK; [3]Department of Psychological Sciences, Birkbeck, University of London, London, UK; [4]Research Department of Clinical, Educational and Health Psychology, University College London, London, UK
*Correspondence: Ms C Jacobs, Department of Clinical Genetics, 7th Floor, Borough Wing, Guy's and St Thomas' NHS Foundation Trust, Great Maze Pond, London SE1 9RT, UK. Tel: +44 20 7188 1364; Fax: +44 20 7188 1369; E-mail: Chris.Jacobs@gstt.nhs.uk
Received 11 November 2013; revised 11 March 2014; accepted 18 March 2014; published online 21 May 2014

communicated to the patient and the information recalled by their relatives.[17] The authors concluded that the information was re-interpreted at each stage of the information transfer, highlighting problems with the accuracy of information communicated to relatives by patients.

Encouraging and facilitating family communication is a key element of genetic counselling.[5,9] However, an international review found that none of the guidelines about family communication in genetics detailed how or what information should be communicated.[18] A worldwide survey of genetic counselling practice in facilitating family communication found that, although 90% of participants stated that they always identify at-risk relatives and encourage family communication, 41% never write a letter specifically for at-risk relatives.[19]

This observational study aimed to (i) compare the accuracy of information among patients and relatives following genetic counselling with index patients about a *BRCA1/2* mutation, (ii) compare the accuracy of information about general genetics and hereditary cancer and (iii) examine whether accuracy among relatives improved when information was provided directly by genetics health professionals. This was part of a larger study examining the experience and process of family communication using qualitative and quantitative methods. The qualitative analysis has been reported elsewhere.[8,11,20]

MATERIALS AND METHODS

Participants

Eligible participants were women affected by breast or ovarian cancer who had been found to have a pathogenic *BRCA1/2* mutation following diagnostic genetic testing at one of two NHS regional genetics centres in the UK (patients) and their 'at-risk' biological relatives with whom they had shared the result (relatives). The study sample consisted of 10 patients with breast and/or ovarian cancer and 22 of their relatives (at least two 'at-risk' first-, second- or third-degree relatives of each patient).

Recruitment

All patients receiving diagnostic *BRCA1/2* genetic test results underwent pretest genetic counselling and results were given during a subsequent consultation by a genetics health professional (genetic counsellor or clinical geneticist). Patients were recruited after blood was taken for genetic testing but prior to receiving their test results. The patients recruited their relatives after they had shared the results with them. These relatives may or may not have undergone predictive testing at the time of interview. All participants were over the age of 18 and spoke English. Only families in which the patient and at least two relatives were interviewed were included.

Data were collected between 2006 and 2008. Health professionals consented to audio-recording of the consultations and analysis of clinic letters. Participants consented to audio-recording of consultations (for patients only) and research interviews. Ethics approval was obtained.

Procedure

Two researchers, who were employed consecutively on the project, carried out all of the semi-structured interviews. The patients were interviewed on one occasion ~4 weeks after receiving the genetic test results. The interview schedule addressed the understanding of genetic risk and implications for themselves and their families, whether or not they had informed relatives of the result, how and what information they had given to relatives and how this was received. Specific knowledge questions were not asked. One semi-structured interview was subsequently carried out with each relative, again using an interview schedule. Relatives were asked for details of what and how they were told about the mutation by the patient (ie what words were used, how they reacted to the information, how they perceived their own risk, whether they intended to do anything as a result of the information and the sources of their information). Again, specific knowledge questions were not asked.

The transcripts of the clinic consultations and the post-consultation summary letters were systematically searched for information that had been communicated by the health professional. This was grouped into 'general genetics information' (ie inheritance, the gene involved and genetic counselling/testing for relatives) and 'hereditary cancer information' (ie cancer risk for affected and unaffected individuals and risk management options). Interview transcripts were systematically searched for reference to the information that had been communicated by the genetics health professional. The research team agreed on the coding framework and definitions of accuracy. The transcripts of the patients and relatives were coded independently by two researchers for accuracy compared with the information provided by the health professional. Participants' statements that were correct compared with the information provided by the health professional were coded as 'accurate'. Statements that were incorrect, unknown, not mentioned or incomplete were coded as 'inaccurate'. When a participant made more than one reference to information, these were grouped together and coded once. For example, if the participant had made two references to the same information, one 'accurate' and one 'inaccurate', this was coded as 'inaccurate'. Relatives' transcripts were also coded for the reported sources of information as follows: information provided by the patient only (coded as information level '1'); information provided by the patient and that obtained from the genetics consultation or from a letter from the health professional (coded as information level '2'); and information provided by the patient and that obtained from the genetics consultation and from a letter from the health professional (coded as information level '3').

Analysis

Accurate and inaccurate statements were counted using content analysis[21] and analysed using SPSS (IBM, Hampshire, UK). Because there were different numbers of relatives in each family (either two or three), the mean number of inaccuracies for the relatives in each family was calculated. Accuracy of recall of information for patients was operationalized as the number of accurate statements made during the interview divided by the total number of accurate and inaccurate statements, so that if there were five accurate statements and five inaccurate statements the accuracy score was 0.5 (5/10). Accuracy of recall of information for relatives involved calculating the accuracy score for each relative interviewed, and then calculating the mean score for the relatives as a whole. Thus, if there were two relatives in the family and one had an accuracy score of 0.5 and the other had a score of 0.3, the score for the relatives would be 0.4. Accuracy of recall scores was calculated separately for genetics information and hereditary cancer information as well as for the two combined.

A priori hypotheses concerning differences in accuracy between patients and relatives and between genetics and hereditary cancer information were tested using the Wilcoxon Signed-Ranks test. This evaluated differences between matched pairs of numbers with no assumption about the underlying distribution of those numbers. The alpha was set to 0.05, two-tailed. Although the hypotheses were directional, it is rare to see the use of a one-tailed test in this area, and the sample size was small. Given this, a conservative approach was adopted, and convention of a significance level set at $P<0.05$ was followed.

Sources of relatives' information

The *a priori* hypothesis, that accuracy of recall of information by relatives is positively associated with the number of sources of information, was tested using Spearman's rank-order correlation coefficient. The alpha was set to 0.05, two-tailed.

RESULTS

Participants

Of the patients, six had a *BRCA1* mutation and four had a *BRCA2* mutation; five had breast cancer only, two had ovarian cancer only and three had breast as well as ovarian cancer. The mean age of the patients was 55.5 years (range 34–71). The mean age at diagnosis was 40.8 years for breast cancer (range 28–59) and 56.2 years for ovarian cancer (range 45–63). Among the relatives, 18 were unaffected with

cancer, two had breast cancer (age 45 and 51 years), one had ovarian cancer (age 55) and one had oral cancer (age 63); there were six daughters, four sons, six sisters, two brothers, two nieces and two cousins; 12 were untested, three tested positive, four tested negative and three were awaiting results. The mean age of the relatives was 37.1 years (range 20–65). (These data are shown in the Supplementary Table.)

Volume of information communicated to patients

Overall, 209 information statements were communicated to the patients: 29% (61) relating to general genetics and 71% (148) relating to hereditary cancer. The mean number of information statements communicated to patients was 21 (range 16–26).

Accuracy of recall

The percentage agreement for independent coding of accuracy of participants' statements by two members of the research team (CJ and CD) was 94% (627/667). All disagreements were readily resolved. Table 1 shows accuracy and inaccuracy across all families for all information (the relatives' score shown is the mean score for the relatives in each family).

Accuracy of recall of information overall (in relation to genetics and hereditary cancer combined) was low among the patients following genetic counselling (53%). Accuracy among the relatives was significantly lower (30%) than among the patients themselves (Wilcoxon Signed-Ranks test $z = 2.40$, $P = 0.017$, two-tailed). The overall accuracy of patients and relatives is shown in Table 2.

The accuracy of recall for patients and relatives combined was greater for general genetics information (60%) than for hereditary cancer information (36%) ($z = 2.80$, $P = 0.005$). There was a trend suggesting that this difference was greater for patients than for relatives (Wilcoxon Signed-Ranks test, $z = 1.89$, $P = 0.056$). Table 3 shows accuracy and inaccuracy about general genetics and hereditary cancer information for patients and relatives.

Sources of information

There was a positive association between the accuracy of recall by relatives and the number of sources of information (Spearman's rank-order correlation coefficient $R = 0.88$, $P = 0.001$) (Table 4). This was the case for both hereditary cancer ($R = 0.83$, $P = 0.003$) and general genetics information ($R = 0.72$, $P = 0.02$).

DISCUSSION

Only 53% of the information about general genetics and hereditary cancer recalled by patients was accurate. The reasons for the low levels of accuracy among patients were not investigated in this study. However, it is possible that the high volume of information communicated by health professionals (mean of 21 statements of information) may have contributed to the low recall among patients, as suggested by previous authors.[22,23]

The accuracy of recall among relatives was significantly lower than the accuracy among patients. The reduction in accuracy of recall as information was communicated to relatives is consistent with the findings of previous studies.[16,24] Patients and relatives differed in their experiences of cancer and their age at interview (patients' mean age was 55.5 and relatives' mean age was 37.1). These differences may have contributed to the lower level of accuracy among relatives. As previous research has suggested, there are a number of possible reasons why information may not be recalled following genetic counselling about a *BRCA1/2* mutation, including lack of understanding,[24] individual interpretation or perceived lack of relevance[8] and not valuing the information sufficiently to retain it.[11]

A lower level of accuracy was seen for hereditary cancer than for genetics among patients and relatives. This supports the findings of a previous study on accuracy of recall of patients with cancer and their relatives, which found that information about cancer risk was the least accurately recalled.[25] However, in a study of first-degree relatives undergoing predictive testing for *BRCA1/2* mutations, higher levels of

Table 2 Mean number (percentage) of accurate and inaccurate statements recalled about all information by patients and relatives

Patients, n *(%)*		*Relatives*, n *(%)*	
Accurate	*Inaccurate*	*Accurate*	*Inaccurate*
110.00 (53%)	99.00 (47%)	70.00 (30%)	139.00 (70%)

Table 1 Mean number of accurate and inaccurate statements for each family according to type of family member and category of information

	Patients (one patient per family)				*Relatives (mean for relatives in each family)*			
	General genetics information		*Hereditary cancer information*		*General genetics information*		*Hereditary cancer information*	
Family no	*Accurate*	*Inaccurate*	*Accurate*	*Inaccurate*	*Accurate*	*Inaccurate*	*Accurate*	*Inaccurate*
1	4.00	3.00	9.00	9.00	2.00	5.00	2.00	16.00
2	2.00	2.00	5.00	8.00	2.00	2.00	4.00	9.00
3	7.00	1.00	10.00	8.00	4.50	3.50	6.50	11.50
4	4.00	3.00	6.00	7.00	7.00	0.00	6.00	7.00
5	3.00	3.00	5.00	8.00	4.00	2.00	1.50	11.50
6	2.00	2.00	4.00	12.00	2.67	1.33	2.67	13.33
7	5.00	1.00	10.00	7.00	3.00	3.00	6.50	10.50
8	4.00	1.00	11.00	4.00	3.00	2.00	3.67	11.33
9	2.00	3.00	4.00	7.00	2.00	3.00	0.00	11.00
10	6.00	3.00	7.00	7.00	4.00	5.00	3.00	11.00
Mean	3.90	2.20	7.10	7.70	3.42	2.68	3.58	11.22
Median	4.00	2.50	6.50	7.50	3.00	2.50	3.33	11.17
SD	1.73	0.92	2.69	2.00	1.55	1.56	2.21	2.38

Table 3 Mean number (percentage) of accurate and inaccurate statements recalled about general genetics and hereditary cancer information by patients and relatives

	Patients, n *(%)*		*Relatives,* n *(%)*		*Patients and relatives combined,* n *(%)*	
Information type	*Accurate*	*Inaccurate*	*Accurate*	*Inaccurate*	*Accurate*	*Inaccurate*
General genetics info	39.00 (64%)	22.00 (36%)	34.00 (56%)	27.00 (44%)	73 (60%)	49 (40%)
Hereditary cancer info	71.00 (48%)	77.00 (52%)	36.00 (24%)	112.00 (76%)	107 (36%)	189 (64%)
Mean	55.00	49.50	35.00	69.50	90	119
SD	22.63	38.39	1.41	60.10	24.04	98.99

Table 4 Mean accuracy scores for relatives receiving information from different sources

			Mean scores for relatives in all families			
Source of information	*Information level*	*Family no.*	*Accurate,* n *(%)*	*Inaccurate,* n *(%)*	*Mean*	*SD*
Patient + letter + genetics consultation	3	3, 4	24.00 (52%)	22.00 (48%)	23.00	1.41
Patient + letter/genetics consultation	2	2, 5, 6, 7, 8, 10	40.00 (33%)	82.00 (67%)	61.00	29.70
Patient only	1	1, 9	6.00 (15%)	35.00 (85%)	20.5	20.51

accuracy about hereditary cancer than inheritance were reported.[16] For the cancer patients in this study, general genetics information would have been addressed during pre-test genetic counselling, whereas specific hereditary cancer information may not have been discussed in detail prior to learning the genetic test result. The patients may therefore have been less familiar with some or all of the hereditary cancer information than with the general genetics information. This may have contributed to the lower levels of accuracy about hereditary cancer among patients and relatives.

Giving information about the implications of genetic testing in order to enable informed decision making is an integral component of genetic counselling.[26,27] Yet, it is not known whether the accuracy of information recalled about an identified gene mutation has an impact on the decisions that individuals make regarding genetic testing or risk management. A systematic review of the effect of communicating DNA-based risk assessments on risk-reducing behaviour found that there was insufficient evidence to draw conclusions for practice.[28] Ley's model of effective communication in medical practice stresses the importance of accurate recall, satisfaction and adherence for understanding.[29] However, fuzzy trace theory suggests that individuals encode multiple representations of information with varying precision, enabling understanding of the 'gist' rather than the detail of information.[30] It is possible that understanding the gist of the information is sufficient for individuals to make decisions in this context. It is unclear whether there is a link between accurately recalling the information and the uptake of genetic testing and screening or the information individuals require about a *BRCA1/2* mutation in order to make these decisions.

Relatives who received information from several sources, including from genetics health professionals, reported a higher level of accurate information recall than those who received information from the patient alone. This suggests that multiple sources of information may improve the accuracy of information recalled by relatives. However, why this was the case or how accuracy was improved was not investigated in the study. Previous research has suggested that information provided to relatives by genetics health professionals may involve less interpretation and emotion than that provided by index patients.[24] This would also be in line with the family systems theory,[31] in which illness, or in this case the genetic test result, influences and is influenced by the individuals within the family who interpret and manage interactions relating to the illness.

The patients in this study were tested after completing cancer treatment and were counselled by genetics health professionals with greater knowledge and expertise in genetics than in cancer. The integration of genetics into mainstream medicine will inevitably shift the timing, location and focus of the delivery of information about genetic testing. These discussions are increasingly likely to take place prior to, or during, treatment and to be delivered by health professionals with greater knowledge and expertise in cancer than in genetics. Although these findings are not directly transferable to that scenario, they may provide a basis for further research.

This study was limited to a self-selected sample and the participants were not assessed on recall of specific information. Accuracy of the information recalled compared with the information communicated by the health professional was drawn from qualitative data and involved judgements made by the research team, but the use of an agreed definition of accuracy, the coding framework and a high level of agreement between the two researchers coding independently strengthened the study. Given changes in the public awareness of genetics and in the availability of verbal and written provision of information, there may have been changes in the understanding by relatives since the time of data collection in this study from 2006 to 2008. It follows that the findings may be different if the study were to be repeated now with a new sample. In order to assess the generalizability of the findings, they would need to be replicated on a larger scale and evaluated, and performed in other settings, with different populations, and with patients undergoing genetic testing close to diagnosis.

Further study is needed to examine the reasons for the low level of accuracy, the relevance of the information not accurately recalled, the impact of the inaccurate recall and factors that could influence recall, such as educational level, meaning, context, experience and emotion. Further research would be helpful to identify the information that individuals require in order to make risk management decisions and the extent to which accurate recall of information about a *BRCA1/2* mutation is necessary for such decision making.

CONCLUSION

These findings suggest that following the identification of a *BRCA1/2* mutation in the clinical genetics setting, accuracy of recall of information among patients and relatives is low, particularly about cancer risks and risk management options. The findings highlight the importance of communicating clear and accurate information about general genetics and hereditary cancer to patients and relatives once a gene mutation is identified, and suggest that accuracy of recall among relatives may be improved when the information is communicated via multiple sources of information, including direct contact with genetics health professionals. These findings provide evidence supporting the concern that at-risk relatives may understand little about their cancer risks and risk management options, which could be important for clinical practice.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

This study was funded by a National Institute for Health Research (NIHR) Doctoral Research Fellowship award (the larger qualitative study was funded by a Department of Health grant HSR06). We thank Professor Robert West for his assistance with the statistical analysis, Marietta Papaconstantinou for her contribution to the project, the genetics health professionals for help with recruitment, and the patients and relatives who participated.

DISCLAIMER

This article presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

1 Braithwaite D, Emery J, Walter F, Prevost AT, Sutton S: Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *Fam Cancer* 2006; **5**: 61–75.
2 Pal T, Vadaparampil ST: Genetic risk assessments in individuals at high risk for inherited breast cancer in the breast oncology care setting. *Cancer Control* 2012; **19**: 255–266.
3 Timmermans DR, Ockhuysen-Vermey CF, Henneman L: Presenting health risk information in different formats: the effect on participants' cognitive and emotional evaluation and decisions. *Patient Educ Couns* 2008; **73**: 443–447.
4 Croyle RT, Lerman C: Risk communication in genetic testing for cancer susceptibility. *J Natl Cancer Inst Monogr* 1999; **1999**: 59–66.
5 Hayat Roshanai A, Lampic C, Rosenquist R, Nordin K: Disclosing cancer genetic information within families: perspectives of counselees and their at-risk relatives. *Fam Cancer* 2010; **9**: 669–679.
6 Forrest K, Simpson SA, Wilson BJ *et al*: To tell or not to tell: barriers and facilitators in family communication about genetic risk. *Clin Genet* 2003; **64**: 317–326.
7 Gaff CL, Clarke AJ, Atkinson P *et al*: Process and outcome in communication of genetic information within families: a systematic review. *Eur J Hum Genet* 2007; **15**: 999–1011.
8 Dancyger C, Wiseman M, Jacobs C, Smith JA, Wallace M, Michie S: Communicating BRCA1/2 genetic test results within the family: a qualitative analysis. *Psychol Health* 2011; **26**: 1018–1035.
9 Chivers Seymour K, Addington-Hall J, Lucassen AM, Foster CL: What facilitates or impedes family communication following genetic testing for cancer risk? A systematic review and meta-synthesis of primary qualitative research. *J Genet Couns* 2010; **19**: 330–342.
10 Hughes C, Lerman C, Schwartz M *et al*: All in the family: evaluation of the process and content of sisters' communication about BRCA1 and BRCA2 genetic test results. *Am J Med Genet* 2002; **107**: 143–150.
11 Dancyger C, Smith JA, Jacobs C, Wallace M, Michie S: Comparing family members' motivations and attitudes towards genetic testing for hereditary breast and ovarian cancer: a qualitative analysis. *Eur J Hum Genet* 2010; **18**: 1289–1295.
12 Gallo AM, Gallo AM, Angst DB, Knafl KA: Disclosure of genetic information within families. *Am J Nurs* 2009; **109**: 65–69.
13 Michie S, Smith JA, Senior V, Marteau TM: Understanding why negative genetic test results sometimes fail to reassure. *Am J Med Genet A* 2003; **119A**: 340–347.
14 Peterson SK, Watts BG, Koehly LM *et al*: How families communicate about HNPCC genetic testing: findings from a qualitative study. *Am J Med Genet C Semin Med Genet* 2003; **119c**: 78–86.
15 National Institute for Health and Care Excellence. *Familial Breast Cancer: Classification and Care of People at Risk of Familial Breast Cancer and Management of Breast Cancer and Related Risks in People with a Family History of Breast Cancer CG164*. London: NICE 2013.
16 Sermijn E, Goelen G, Teugels E *et al*: The impact of proband mediated information dissemination in families with a BRCA1/2 gene mutation. *J Med Genet* 2004; **41**: e23.
17 Vos J, Jansen AM, Menko F, van Asperen CJ, Stiggelbout AM, Tibben A: Family communication matters: the impact of telling relatives about unclassified variants and uninformative DNA-test results. *Genet Med* 2011; **13**: 333–341.
18 Forrest LE, Delatycki MB, Skene L, Aitken M: Communicating genetic information in families—a review of guidelines and position papers. *Eur J Huma Genet* 2007; **15**: 612–618.
19 Forrest LE, Delatycki MB, Curnow L, Skene L, Aitken M: Genetic health professionals and the communication of genetic information in families: practice during and after a genetic consultation. *Am J Med Genet A* 2010; **152A**: 1458–1466.
20 Smith JA, Dancyger C, Wallace M, Jacobs C, Michie S: The development of a methodology for examining the process of family communication of genetic test results. *J Genet Couns* 2011; **20**: 23–24.
21 Silverman D: *Interpreting Qualitative Data: Methods for Analyzing Talk Text and Interaction*, 3rd edn. California: Sage, 2006.
22 Cowan N: *Working Memory Capacity*. Hove: Psychology Press, 2005.
23 Howard D: *Cognitive Psychology*. New York, NY: Macmillan, 1983.
24 Vos J, Menko F, Jansen AM, van Asperen CJ, Stiggelbout AM, Tibben A: A whisper-game perspective on the family communication of DNA-test results: a retrospective study on the communication process of BRCA1/2-test results between proband and relatives. *Fam Cancer* 2011; **10**: 87–96.
25 Roshanai AH, Rosenquist R, Lampic C, Nordin K: Does enhanced information at cancer genetic counseling improve counselees' knowledge, risk perception, satisfaction and negotiation of information to at-risk relatives?—a randomized study. *Acta Oncol* 2009; **48**: 999–1009.
26 Shiloh S, Avdor O, Goodman RM: Satisfaction with genetic counseling: dimensions and measurement. *Am J Med Genet* 1990; **37**: 522–529.
27 Resta R, Biesecker B, Bennett R *et al*: A new definition of genetic counseling: National Society of Genetic Counselors' Task Force Report. *J Genet Couns* 2006; **15**: 77–83.
28 Marteau TM, French DP, Griffin SJ *et al*: Effects of communicating DNA-based disease risk estimates on risk-reducing behaviours. *Cochrane Database Syst Rev*, 2010 Oct 6; (10): CD007275.
29 Ley P: Memory for medical information. *Br J Soc Clin Psychol* 1979; **18**: 245–255.
30 Reyna VF: A theory of medical decision making and health: fuzzy trace theory. *Med Decis Making* 2008; **28**: 850–865.
31 White JK, Klein DM: *Family Theories: An Introduction (Understanding Families series)*. Thousand Oaks, CA: Sage, 2002.

Supplementary Information accompanies this paper on European Journal of Human Genetics website (http://www.nature.com/ejhg)