'Going-to-have-cancerness': a study of living with increased risk of BRCA1 and BRCA2 mutations for six South Island women

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ABSTRACT

INTRODUCTION: Mutations in the BRCA (breast cancer) 1 and 2 genes are thought to lead to 5–10% of breast cancers.

AIM: A qualitative study to explore six New Zealand women's experiences of living with increased risk for a genetic susceptibility to breast cancer.

METHODS: Six women were interviewed using semi-structured interviews, to explore their experiences of living at high risk for developing breast cancer due to familial and/or individual genetic susceptibilities. Results were analysed using thematic coding. After a three-year interval, interviewees were contacted again to discuss their experiences (although two were lost to follow-up).

FINDINGS: The women held fatalistic views on developing cancer and drew on family experience as much as biomedical research to assess their situation. They became increasingly immersed in biomedical screening and prophylaxis without accompanying improvement to their peace of mind and with unrealistic ideas of it 'preventing' cancer. The biomedical management options and advice they reported receiving was factually inconsistent and a discrepancy emerged between women's expectations of breast cancer health services (including genetic testing) and the delivered support and services.

CONCLUSION: This small sample group cannot be used to draw implications on the views of the wider group of higher risk patients, but for these six women, genetic testing, screening and prophylaxis have not provided peace of mind; rather the reverse has occurred. The findings are provocative as they challenge the biomedical idea of patients' experience of managing their genetic risk information as routinely positive.

KEYWORDS: Qualitative research; genes BRCA1; genes BRCA2; breast neoplasm; risk

Introduction

This paper explores six patients' experiences of living with a familial and/or individual genetic susceptibility for breast cancer which is the most common cancer diagnosed in females in New Zealand.[1] Only 5–10% of these breast cancers are thought to develop from a genetic susceptibility through mutations in the BRCA (breast cancer) 1 and 2 genes.[2,3] The genetic mutation can be inherited either paternally, maternally or arise de novo[4] and demonstrates variable penetrance. As genetic testing cannot determine who of those with BRCA mutations will develop breast cancer, the age of onset or the severity of the malignancy (if diagnosed), the clinical usefulness of BRCA test results is somewhat difficult to assess.[4–8]

Furthermore, while previously a confirmed genetic susceptibility was thought to place the lifetime cumulative risk for developing breast cancer at 87% by the age of 70,[6,9] there is now disagreement about the magnitude of the risk associated with BRCA1 or BRCA2 mutations[10] and recent meta-analyses of BRCA penetrance provide differing estimates depending upon the sub-populations analysed. Some estimates suggest a 48% cancer risk by age 75 years for BRCA1 and 32% up to 75 years for BRCA2.[11,12] The cumulative risks of

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developing breast cancer at 70 years of age have been estimated to be 55% for BRCA1 and 47% for BRCA2.[12] However, the actual risk level is often unknown for breast (and other cancers)[6] relative to the specific mutation present in the family.[3,8]

Studies of primary health care provision to the affected patients suggest wide cultural variations in practice.[13] Anglo-Saxon countries view the value of genetic testing as a means of preventing cancer in which patients carry high responsibilities for making appropriate lifestyle changes. French guidelines, on the other hand, favour the preservation of fertility and bodily integrity. Variations in referral for genetic testing exist within Anglo-Saxon countries as well[14] with suggestions from the USA for more uniform approaches to both communicating and assessing risk. A recent USA survey demonstrated a trend for family physicians to refer inappropriate (i.e. low risk) patients for genetic testing when the patients themselves request the service.[15] Internationally there have been several studies noting the need for better understanding of the principles of genetic risk assessment by primary and tertiary health care providers;[16,17,18] the value of providing education programmes;[19–22] and the need to focus on education in how to approach the topic of risk in concrete terms within clinical practice rather than in abstracted terms of bioethics or biological science.[23,24] A United Kingdom (UK) study from 2002 exploring patients' understandings of GP consultations over presumed high familial risk of breast cancer indicated that GPs had a major task of reassurance. Failure to reassure in these circumstances resulted from the GPs lacking awareness that patients frequently held very different understandings of the mechanisms of disease and heredity in relation to their specific medical risk.[24]

This paper explores how six New Zealand women lived with the knowledge of the increased familial and/or personal risks of cancers associated with BRCA1 and 2 mutations against the broader backdrop of these studies. This project was conducted as research for a Masters Thesis in Health Sciences (Bioethics).

Methods

A semi-structured interview on the general topic of living with a high familial and/or individual risk of breast cancer, lasting one to two hours, was undertaken with six women who had considered genetic counselling for their perceived high risk for a BRCA mutation. The participants represented five distinct families with increased familial risk for the mutations in the South Island. The first round of interviews was conducted during 2003/2004, the second interviews in 2007, although two participants were lost to follow-up (via illness and relocation). The second interviews captured data regarding the continued experience of living with the knowledge of increased risk.

Table 1 contains a summary of the demographic characteristics of the participants. All six identified with New Zealand European ethnicity and four out of six participants had been tested prior to the first round of interviews. Since the first interviews, two of the participants each have had a sister diagnosed with breast cancer.

The initial interviews covered the topics of participants' experiences of a family history of breast cancer, their understanding of the risk of a predisposition to inherited breast cancer, issues around screening recommendations and prophylactic interventions, influences on deciding whether to undergo genetic counselling and/or testing, the use of genetic testing, impacts on relationships once genetic test results are known, disclosure of any genetic information gained, and methods used to adjust to the information. The second interviews reviewed participants' original comments to evaluate the relevance of the initial findings to their current views.

Data collection and analysis was qualitative, based on audiotaped interviews, transcribed verbatim and returned to each participant for checking. Selected interview passages were thematically coded[25] and then collated into common themes of interest by the first author and checked by the second author.

These results cannot be used to predict wider trends in this subpopulation of high risk women because of the small number of participants; however they do reflect the views of members of five different families within the South Island. Morse suggests that six participants are adequate for distilling the 'essence of experience' and

Stake also supports the intensive study of purposively sampled individuals for such a purpose.[28,29]

Ethical approval was obtained from the Otago, Southland and Canterbury (02/12/197) ethics committees. The low number of participants resulted from initial ethical approval being contingent upon recruitment via a third party (the Genetics Service) with its attendant poor response rate and lengthy time delay. Subsequent approval removed this criterion. Ethics approval required that family members were not made aware of other family members' participation, thus prohibiting the use of a 'snowballing' recruitment strategy.

Findings

The eight themes identified (see Table 2) were common to all six interviewees at first interview. At second interview, themes 1, 5, 6, and 8 emerged as increasingly dominant for the remaining four women in the study.

Discussion

At first interview, all the informants spoke to all eight themes with equal emphasis (Table 2) indicating that the narrative of living with BRCA1 and 2 mutation risk was organised around these social experiences. Over the three-year interval, however, these women's lived experiences of managing high familial and/or personal risks of cancer caused them to shift anxiously towards deeper medicalisation (theme 6) of lives that (for five out of six of them) were seemingly healthy. The women spoke of living with an increased cancer risk as a state of 'hypochondria', 'paranoia', 'stress', 'anxiety' and having it always 'at the back of your mind'. Another less obvious effect was the implication from their GPs that

WHAT GAP THIS FILLS

What we already know: The responsibilities of primary care providers to explain and refer individuals and families for genetic testing is interpreted differently in different cultural settings. Furthermore, patients may not share the same understanding of genetics and heredity as providers, with resulting difficulties in establishing a common base of knowledge.

What this study adds: This small South Island study explores six patients' perspectives of the experiences of living longer-term with personal and familial risk for BRCA1 and 2 mutations. It demonstrates the difference in their understandings of their risk to that of conventional biomedical and primary care accounts of such risk, and the implications of this difference.

Table 1. Demographics and family history

Participants	1	2	3*	4	5*	6
Recruitment method	GS	GS	GS	Advert	Medical Specialist	Advert
Age at first interview	52	45	47	28	52	38
Age at testing	50	43	45	Ineligible	50	Untested
Educational attainment	3 years high school	School cert.	Degree	Masters degree	Polytech cert.	Trade cert.
Participant cancer diagnosis	No	No	No	No	Yes	No
Mutation confirmed	Yes	Yes	Yes	Not tested	No useful result	Not tested
No. of relatives tested —mutation confirmed	5/5	5/5	3/6	–	–	–
No. of relatives tested —no mutation detected	–	–	3/6	–	–	–
No. of relatives diagnosed with breast cancer (at 1st interview)	3	3	5	6	7	3
No. of relatives diagnosed with other cancers (at 1st interview)	–	–	3	4	4	2

GS: Genetic Service

*Lost to follow-up (i.e. moved, presumed deceased) at time of 2nd interview

Table 2. Interview themes with illustrative quotes

Theme	Interview themes with illustrative quotes
1†	**Explaining risk via family histories not biomedicine**
	'I'm heading up to 40 and I'm in the trouble area where Mum was when she was my age'
	'It's not too big a concern for me [ovarian cancer] at the moment because as far as I know there's been no-one in our family that's had ovarian cancer, so it does seem to be that breast cancer is the stronger one...'
2	**Self-image and prophylactic surgical options**
	'It doesn't worry me if I've got something out, it doesn't worry me that I've got something missing'
	'Yes, you can have [breast] reconstructive surgery but it's not the same, it's a part of your body that you are killing'
3	**Genetic fatalism**
	'You can't rail against genetics'
	'Intellectually I can say "oh well, I am not as high a risk as I thought", but emotionally I still expect to die in 20 years time'
4	**Information gathering as risk management**
	'...I went on the Internet and I looked up all sorts of things and read up about how it was quite possible that our high dairy intake could have some effect on breast cancer... so I started on all sorts of dietary changes...'
	'...so I was quite keen to catch up with [the doctor] after that [conference] and just find out what he had found out—cos I just thought there might have been a wee light at the end'
5†	**Lay (mis)understandings of screening and prophylactic interventions**
	'There is self examination, there's the mammography and there's the ultrasound. If you do each of them in isolation you've got one third chance, but if you do all three of them... you should be OK'
	'One of the important things that's happened to me is that since I've known I've decided to get [my] ovaries out and that rules out ovarian cancer... that's one less thing we've got to worry about... maybe happening to us'
6†	**The effects of genetic knowledge on health behaviour**
	'They'll probably find everything is associated with cancer...'
	'The major things I keep up with... I don't have red meat... I stay away from passive smoking...I try to be quite careful...'
7	**Caring for other family members' genetic knowledge**
	'I feel a slight obligation that we should do something, because we have information that they don't'
	'...I have an address for this aunt now [and] I would post her the relevant information to pass on to family members... after testing the reaction to the letter'
8†	**Expectations about medicine's responsibility**
	'...how do I know anymore what is the truth?... even the GP... sometimes even they are not sure'
	'You know, you go onto the [breast screening] register when you turn 50, you can get yourself put on it then it's two yearly. I believe that for people who have got the gene at the highest level, because they are in the highest risk group the screening has to be automatic from the moment they're told, right through'

† Significant themes from 2nd interviews. (Further quotes can be found in Appendix 1 of Crump.[38])

once their status was known, the women would automatically make changes to their lives to avoid cancer, ranging from increased surveillance to dietary changes. To 'do nothing' was not viewed as a viable course of action. Managing this pressure then became another burden leading to a sense of futility or, by failing to adhere to behavioural changes, the experience of guilt. For the four remaining participants, these issues had only intensified (themes 1, 5, 6, 8) by the time of their second interviews. For these reasons we suggest the 'benefits' of testing, screening and prophylaxis appear to have caused some iatrogenic harm. Such negative experiences have been found for other national groups in relation to women's personal estimations of death from breast cancer from genetic, environmental and social causes.[26]

In summary, the overall effect of living with their proven or suspected high risk of cancer for these women was a substantial medicalisation of mostly healthy lives. This is demonstrated in the dominance of themes 1, 5, 6, and 8 over time as women combined various screening modalities in a cumulative manner, attempted behaviour changes, looked to already-diagnosed women in the family for their own futures and increasingly sought medical intervention and guidance for their situation. Further to that, such medicalisation rests on an unproven basis, with recent literature[4,7,8] suggesting great complexity and variation in assessment of lifetime risks of developing cancers and a downward trend in their estimation for the many forms of BRCA1 and 2 mutations. Such medicalisation might be acceptable if the result were to be a reduction in anxiety and fatalism; however for these study participants, their experience of life was better defined in their own words as a far more genetically determined destiny of 'going–to-have-cancerness'. Their self-described lives of anxiety, stress and watchfulness made their common label of the 'at-risk-well' quite inappropriately positive for the effect of the information on their lives. The self-reported advice provided by GPs to these women that genetic testing would provide peace of mind has proved to be incorrect regardless of whether each participant's exposure to increased genetic risk was confirmed, merely familial or unproven.

Part of this negative experience was expressed in the women's dismay at the lack of a BRCA register for high-risk women, as they considered themselves 'abandoned' by the medical professionals. During the time in which they had become alerted to their high risk status, as noted, the lifetime risk of developing cancer from BRCA1 and 2 mutations had been recalculated downwards; however the women were unaware of this trend, despite their information-seeking behaviours (theme 4). Women also expressed their awareness of an underlying imperative from their primary health care providers that, when making the decision about testing, the 'right' decision was to be tested. This belied women's subsequent experiences of resulting difficulties in living—such as insurance problems, difficulty with accessing information, conflicting information, little or no support being provided by the medical establishment, continued uncertainty, feeling responsible for testing and screening, no absolutely preventive options being available, and the impossibility of unlearning the knowledge gained from genetic testing.

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The accepted risk management of high-risk women is through the use of screening and prophylactic measures (e.g. bilateral mastectomy, oophorectomy, and chemoprevention) recommended on the basis of 'presumed efficacy'[30] and 'expert opinion' rather than empirical evidence.[8,10] In line with this, all of the women reported being encouraged to take up long-term screening by their local physicians. However, over time they spoke of the screening as coming to represent a talisman for cancer-free existence. They tended to 'add together' screening procedures for 'increased protection' (theme 5) indicating that participants were confused in their understandings of the advice offered about screening's value. It could also indicate that they were offered inappropriate advice—an aspect of primary health care that has been criticised both nationally and internationally.[27,39] All reported negatively the conflicting nature of the information that they received from this variety of sources and distrust and disillusionment emerged over the level of knowledge expressed by their local GPs. For example, most women reported being told that male family members could not transmit BRCA1 and 2 mutations to offspring and men were generally not invited for testing in high risk families. One deeply angry woman had been told the familial risk was on her 'father's side of the family' and thus would not apply to her, and then developed breast cancer. The constant information searching (theme 4) was used to double-check the information from their local doctors. The implications are troubling for patient care. For instance, inappropriate use of screening could hold costing implications if these women's experiences are shown in a wider study to reflect a common response.

While appropriate management of at-risk individuals can also involve the consideration of surgical prophylaxis,[4,8,31] in this study most participants tended to initially avoid breast surgery, opting instead for oophorectomy, while continuing a breast surveillance regime.[10,37.] However, breast surgery appeared to be more readily considered as time passed and concerns over personal risk continued. Chemoprevention (e.g. Tamoxifen) is another

route to prophylaxis, although the optimal dose and treatment duration is unknown, there are side effects,[35,36] and concerns efficacy may be compromised by the tumour's hormonal status.[9] However, chemoprevention was not reported by the women to have been considered. The New Zealand Guidelines Group recommends all such options be discussed with very high risk women i.e. BRCA1 and 2 mutation carriers.[8]

Even so, how adequately these prophylactic options might be conveyed to patients is a moot point given the incorrect understandings these women already exhibited regarding the purpose of screening. Similar problems of interpretation arose over the significance of test results and genetic counselling. Women with a confirmed mutation, for instance, indicated that it was difficult to comprehend the possibility of a gene mutation being present yet not expressed. Because prophylaxis only reduces risks for the individual, some women in this study were considering the possibility of either forgoing childbearing or using egg donors to remove the risk of the mutation being passed on to their children. These intentions highlight the concerns raised in themes 3, 6 and 7. Increasingly, in vitro fertilisation clinics offer preimplantation embryo testing for BRCA mutations and are discarding carrier embryos because of their associated predisposition for disease risk.[34] Such contemporary clinical practices (in the context of the declining BRCA1 and 2 risk estimates) convey the same thread of genetic fatalism (theme 3) that the women reported of themselves. Uncoupling risk from personal destiny and a mutation from its full expression would appear then to be a conceptual task required on both sides of the consultation desk.

In conclusion, these results, while not representative of the whole population, are still interesting as they provide an alternative to the predominant medical view of the usefulness of genetic knowledge to individual patients. The fatalistic emotional and intuitive experience of genetic risk which these women described as 'going-to-have-cancerness' coupled with the sense of failure of expected support from the health care system created a negative experience of anxiety, futility and guilt. In light of the downward numerical movement of risk calculations, this creates a moral imperative for health care providers to provide frank discussions of this currently confusing state of risk assessment and also to discover a means of keeping in touch with clients to update them of changes in their risk status. Careful enquiry into how people make sense of their risk status as time progresses is also needed. While a role exists for GPs in ongoing education and support of these women, as previously noted, this support needs to be factually correct, to avoid genetic fatalism, and (given these women's experiences) to be critically informed as to the benefits of not testing. Finally, the study suggests the value of a wider and systematic enquiry into the experiences of living with high personal or familial risk of BRCA1 and 2 mutations. In such a study, the views of medical practitioners on the management of such cases (e.g. referrals between primary, secondary and tertiary service providers) would also give a more complete understanding of the situation surrounding the long-term management of living with this genetic knowledge.

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COMPETING INTERESTS
None declared.