

Ways of approaching risk: The experiences of a group of New Zealand women

ALISON McEWAN

Abstract

The hereditary breast and ovarian cancer syndromes are rare hereditary conditions conferring a potentially high risk of cancer over a woman's lifetime. Technological developments over the past 15 years mean that it is now possible for some individuals to define their own cancer risk, and to take steps to manage this risk. International research has suggested that most women cope well with the knowledge of their risk in the long term. Qualitative, semi-structured interviews, and a narrative, thematic approach to the data analysis were used to explore the experiences and stories of thirty-two Pakeha New Zealand women who carry a BRCA mutation or who have a high risk based on their family history of cancer. 'Getting on with it' emerged as a dominant theme, as the way in which the majority of the participants in this study approached the risk. 'Getting on with it' appears to be a deeply entrenched social, cultural and gendered expectation in New Zealand, perhaps influenced by both neo-liberal governance and the women's movement. This article explores the way in which this group of women use the idea of 'getting on with it' as a coping strategy to manage their risk and live their lives.

Key words: breast cancer, ovarian cancer, BRCA, risk

Introduction

I always knew I was going to have the test done, but why did I? Because I wanted to know, I wanted to know because I watched Mum die and I thought yep I've got to know [29].

This woman is reflecting on her experience of deciding to have a genetic test that would tell her whether or not she had inherited a change (mutation) in a gene that is associated with an increased risk of developing breast and ovarian cancer. Her narrative, along with those of 31 other women, was drawn on in conducting a project seeking to explore the experiences of New Zealand women living with an increased chance of developing breast and ovarian cancer.

Why do women seek to clarify and understand their chance of developing breast and ovarian cancer? This woman states that, quite simply, she had to know. She frames this statement with the information that she had watched her mother die, with the unspoken implication that she did not want the same thing to happen to her. The test showed that she had inherited a BRCA¹ mutation and she went on to have her breasts and ovaries removed. The initial decision regarding genetic testing took her a year to make. Learning that she carried the familial BRCA mutation was so distressing that she was unable to drive home from the appointment. However, once the initial shock had passed, she almost immediately arranged to have a risk reducing salpingo-oophorectomy². The decision to have risk reducing mastectomy was made on the way home from the appointment to collect her results, although the surgery itself occurred many months later.

1 BRCA1 and BRCA2 are human tumour suppressor genes that have a role in DNA repair. When functioning, BRCA1 and BRCA2 are protective against the development of certain cancers including breast, ovarian and prostate cancer.

2 Salpingo-oophorectomy involves surgical removal of the ovaries and fallopian tubes. The surgery may be unilateral or bilateral.

Women who carry a mutation in a BRCA gene have a 50-85% chance of developing breast cancer and a 20-40% chance of developing ovarian cancer in their lifetime (Antoniou et al, 2003; Suthers 2007). The options for medical management of the risks include intensive surveillance utilising mammography, magnetic resonance imaging (MRI) and clinical breast examination aimed at the early detection of breast cancer, or risk reducing mastectomies to very substantially reduce the risk (Domchek et al, 2010; Evans et al, 2009; National Institute for Health and Clinical Excellence (NICE), 2006). The efficacy of screening for ovarian cancer is unproven, so the international medical recommendations suggest that these women should have their ovaries removed (risk reducing salpingo-oophorectomy) around age 40 (Domchek et al, 2010).

Women living with an increased cancer risk make many decisions as they seek to understand and manage their risk, communicate with their families and get on with their lives. Each woman brings different influences to bear in her decision making, influences such as her experiences of cancer in her family, her life stage, and her feelings about the different risk management options. This paper explores the ways in which the women approach their risk, and the societal, political and cultural discourses that influence their approach.

Literature review

A range of disciplines were drawn upon in recognition of the different fields where research has been performed that contributes to our understanding of living with an inherited cancer risk. Research has been undertaken in genetic counselling, social sciences such as anthropology, psychology and the biomedical sciences. Out of these varying disciplinary perspectives, particular concepts emerged as pivotal to this project. These include concepts of risk and the effects of late modernity on our thinking regarding risk, the social construction of gender, concepts regarding mothering in the twenty-first century and the importance of the local on the experiences of the women who participated.

In order to gain an understanding of the experience of living at increased risk of developing cancer, it is necessary to consider the meaning of the word risk and the way that this term has come to be used in the present day. The term risk is sometimes used as a synonym for 'harm' but is also a concept that relates to the management of future uncertainties (Giddens, 1991; Zinn, 2005). During late modernity individuals have become increasingly responsible for managing a range of risks (Alaszewski & Coxon, 2008). With the rise of neo-liberal thinking and governance there has been a concomitant rise in effecting governance through citizens who are responsible for managing themselves and their relationship to risk (Petersen, 1998; Petersen, 1999).

Response to uncertainty is grounded in an individual's experiences, cultural perceptions and dispositions (Alaszewski and Coxon, 2008). Living with an increased risk of developing ovarian and breast cancer creates uncertainty, uncertainty about whether a woman will develop cancer, when this may happen, uncertainty about the efficacy of surveillance and uncertainty about the effects of risk reducing surgery.

A number of studies of women in Western countries have identified the importance of being able to act to control the cancer risk, for example by undergoing risk reducing surgery. Women making decisions regarding risk reducing salpingo-oophorectomy have previously reported needing to feel in control of the possibility of developing cancer, with risk reducing surgery helping to provide peace of mind (Babb et al, 2002; D'Agincourt-Canning, 2006; Hallowell et al, 2004; Lim et al, 2004).

The discourse of personal responsibility is being discussed in a number of domains, including genetic counselling, sociology and public health (Hallowell, 1999; Koch & Svendsen, 2005; Petersen, 1998; Petersen, 1999; Steinberg, 1996). In writing about her own experience of breast cancer, Broom (2001) suggests that the 'achievement of health has become a kind of

social duty' (p. 254). Societal expectations are of health and vitality, with individuals expected to take responsibility for maintenance of their own well-being. This may be particularly so for women given their responsibilities as care-givers of both children and other family members. At the same time care-giving responsibilities may mean women are less able to engage with health-seeking activities, creating a double-bind in the project of health.

In an analysis of genetic consultations for hereditary breast and ovarian cancer, Hallowell (1999) reported that the clinicians presented the risk of cancer as something manageable and indicated that women have a responsibility to act in ways that will manage this risk. Several commentators have suggested that the discourse of the genetic clinic implies that the people who come to the clinic are responsible for taking steps to manage their risk (Petersen, 1998; Petersen, 1999; Steinberg, 1996). The application of this discourse can perhaps be seen most clearly in the familial cancer clinic³ where surveillance and risk reducing surgery are routinely discussed but the option of 'doing nothing' is seldom mentioned (Hallowell, 1999).

In considering women's experiences of prenatal screening in New Zealand, Donovan (2010) notes that there is an assumption that medical information is valuable. Women in her study critiqued this assumption, with some women choosing not to undergo prenatal screening. These women did not view their decision as 'doing nothing' however they were aware that they were making a choice that was not medically or socially sanctioned (Donovan, 2010). The prevailing discourse of personal responsibility may result in women experiencing implicit pressure to act, with women feeling as though they have little choice but to have genetic testing and to consider risk reducing surgery, particularly if they wish to access continued care through the public health system.

Client autonomy and informed decision making, within which ideas regarding personal responsibility are implicit, are central facets of genetic counselling practice. They have arisen and developed during a similar time period as the moves to reduce the patriarchal and paternalistic grip on medicine. While the feminist movement of the late 1960s and early 1970s was initially concerned with achieving equality within existing social structures, efforts were also made to reclaim women's bodies from the medical profession. Women started to educate themselves and each other about their own bodies and to reclaim natural processes such as menstruation, childbirth and menopause from a male dominated medical profession (Boston Women's Health Collective, 1971; Dann, 1985; Jarvilauma et al, 2003). The emergence of the field of bioethics and the influence of medical consumerism were also important in questioning long-standing paternalistic medical practices (Manning, 2009). In New Zealand, the Cartwright Inquiry in the late 1980s exposed the actions of Dr Herbert Green in conducting experimental medicine on women with cervical changes without their knowledge. The repercussions of one doctor's actions have reverberated through the health system in New Zealand, resulting in sweeping changes to the law and the development of practices regarding health consumer's rights and informed consent (Manning, 2009; Skegg, 2009).

The language that predominates in genetic counselling is a language that reinforces ideas of individual autonomy, informed choice and non-directiveness. Koch and Svendsen (2005) suggest that genetic counselling is now situated in a medical setting that promotes health. They argue that attending genetic counselling to acquire knowledge about one's personal risk is the first step in cancer prevention for at-risk individuals. Biesecker (2001) suggested that the goal of genetic counselling in familial cancer clinics is similar to the goal of other health education

³ Familial Cancer Clinics are part of Clinical Genetic Services. They are staffed by genetic counsellors and clinical geneticists and offer individuals and families who have a personal and family history of cancer risk assessment in some cases genetic testing. Recommendations regarding medical options for surveillance and risk reducing surgery are also provided.

programmes, in that the client develops an understanding of their disease risk and their options for health-promoting behaviours. The acquisition of information about cancer risk theoretically results in autonomous decisions regarding risk reduction and is viewed as an exercise in responsibility, both personal responsibility for one's own health and familial responsibility as the information will also be useful for one's genetic relatives (Koch & Svendsen, 2005).

Methodology

This project was conceived out of the recognition that understanding women's experiences is necessary for appropriate service and resource development. New Zealand women live their lives within a specific society, influenced by the time and period, political discourses and ideas about national identity. Central to this are ideas about being female in New Zealand. This project is under-pinned by feminist research theory, with the focus on allowing the voices of the women who participated to be heard and accepting that the findings of the project are the collective and shared experiences of the participants, resulting in an extension of existing knowledge (Alice, 1999; Richardson, 1990). The importance of using the findings to influence future service planning and delivery underpinned the research (Coy, 2006).

Feminist research epistemology does not seek to generalise women's experiences in the pursuit of an ultimate truth. Instead, it seeks to provide multiple, subjective understandings of ways of being a woman. In keeping with a postmodern approach to research, findings of a project like this are recognised as a narrative that provides a time and context bound illumination of the 'truth', 'a truth limited by the constructions and interpretations of both the researcher and researched...' (Grbich, 2004, p. 28). This project does not seek to make broad generalisations about the experience of living with and managing an increased cancer risk. Instead, it seeks to explore and describe the experiences of a group of thirty-two Pakeha New Zealand women, to begin to develop an understanding of what it is like for women living in New Zealand to have this risk. The study also seeks to add to the growing body of international literature about the experiences of living with risk.

Choosing a feminist methodology allows for the development and extension of knowledge through a collective and shared experience, recognising the impact of the position of the researcher on the development of knowledge (Coy, 2006). The findings in this study are the collective experiences of the women interviewed for the study, interpreted through the lens of a practitioner-researcher. The stories these women tell became collective as they were woven together with the many experiences of the women who I work with in my professional capacity as a genetic counsellor. The stories of the women I have met professionally became part of the greater story because of the approach I have taken to this research.

The study used semi-structured interviews with an interview guide. Given my position as a practitioner-researcher, an independent interviewer with previous experience working with families with inherited conditions was contracted to complete the interviews. The interviewer was a woman with experience in feminist research. The interviews were transcribed and returned to the participants for review prior to the analysis. Minor changes made to the order of the topics for discussion in the interview guide after the first eight interviews. A thematic approach to data analysis was taken.

Writing emerged as one of the central methods of inquiry in this project. Laurel Richardson (1994) describes the way that writing about a topic leads the researcher to discoveries about the material as we seek to develop the collective stories of our participants. In this project, writing created a way in which to organise the data and to explore and challenge assumptions regarding my initial impressions of the material.

Participants

The participants were recruited in collaboration with a gynaecologist who ran a hospital-based clinic for women with a family history of ovarian cancer. At the time that the invitation to participate was sent out, the women attending this clinic all identified as New Zealand European. Thirty-two women assessed as having an increased risk of developing breast and ovarian cancer agreed to participate and were interviewed. Fourteen women carried a mutation in a gene known to predispose to breast and ovarian cancer and two women carried mutations in genes known to predispose to colorectal, endometrial and ovarian cancer. The remaining 16 women had completed a familial risk assessment with Genetic Services and were ‘at potentially high risk’ due to their family history of breast and ovarian cancer.

The women all identified as New Zealand European/Pakeha. They were well-educated, with just over half having a tertiary qualification. Twenty-seven women were married or partnered. Almost all of these women were in heterosexual relationships, while two women identified as lesbian. The age range of the group was 25-66 years, with a cluster of women aged between their late thirties and early fifties. Twenty-five women were mothers at the time of the interview and another two women were planning to have children.

The available options for surveillance or risk reducing surgery were all represented by the respondents. Nine peri- or postmenopausal women had had a bilateral salpingo-oophorectomy, as had five women who were premenopausal at the time of surgery. Three premenopausal women were due to have surgery in the weeks following the interview and others were planning this when they had completed child-bearing. The majority of participants were undergoing surveillance aimed at the early detection of breast cancer; however four women aged in their 30’s and early 40’s had had bilateral risk reducing mastectomies, two women were actively planning this surgery and one woman was planning to have a contra-lateral risk reducing mastectomy.

As a consequence of the method of recruitment, the women who participated in this study are a homogeneous group. The homogeneous nature of the group of participants is a significant limitation of this study as it means that we continue to know little about the experiences of women who are outside the demographic of the majority of the participants.

In a study of the New Zealand experience of living with an increased cancer risk, it is disappointing that the participants were largely ethnically homogeneous. This limitation was present from the start of the study, with no Maori or Pacific women listed on the database that was used to invite study participation. The reasons for this are unclear, although it is likely to be a reflection of well reported disparities in access to medical care in New Zealand (Blakely et al, 2005; Priest et al, 2006; Sarfati et al, 2006). While these studies examining access to cancer screening services provide useful insight regarding disparity in accessing services by ethnic groups, at this stage access to Genetic Services has not been studied.

In this paper, the thematic analysis focuses on ways of approaching risk and how this was expressed by this group of women in a New Zealand context.

‘Getting on with it’: The emergence of a theme

I’m not going to make it my life [1].

I just got on with it [2].

I got on and did it... [10].

I just get on with it [19].

I just seemed to get on with it [21].

... you just sort of have to go oh okay just get on with it...it's something that's happened and it's not great but you just get on with it... you just get on with it and so yeah that's how we've always decided to deal with it [28].

Comments like this are found in the majority of the interviews, affirmations of these women's determination to do what they can to manage or reduce their risk of getting cancer and then to get on with living their lives because, in the words of one of these women, living is the purpose of life... It's that simple [9]. These women tell us that they want to live; they want to be there for their children, and they are prepared to make difficult decisions and go through major, sometimes disfiguring, surgery to make that happen.

The predominant approach to managing risk identified in this study is to 'get on with it', perhaps a way of approaching life that is familiar to many New Zealanders. As the above excerpts demonstrate, the interviews contained many individual comments that highlight a feeling of pragmatism, matter-of-factness, and desire to 'get on with it'; however, the overall tone and content of each interview was also used to define the approach of each individual woman.

'Getting on with it' and risk reducing surgery

While the overall tone of each interview indicated the woman's approach to risk, there are specific topics that arise in the majority of interviews where the pragmatism can be seen most clearly. Surveillance aimed at the early detection of ovarian cancer has not been proven to be effective so women may choose risk reducing salpingo-oophorectomy (removal of ovaries and fallopian tubes) to very substantially reduce the risk of ovarian cancer. When discussing this surgery, many of the women made very matter of fact observations. A woman who was perimenopausal at the time of her salpingo-oophorectomy says ... I didn't think I would really miss them... [4] of her ovaries. Another woman, in her early 40s at the time that she learnt that she carried a BRCA1 mutation says I just wanted those things out [29]. Other women describe the way in which pursuing the option of risk reducing surgery gave them a feeling of controlling the cancer risk:

I also wanted to be in control of when I had/have my surgeries not have to wait and develop cancer and then have to have surgery – it is then out of my control [16].

I mean it's all about balancing things up because the worst case scenario for me would be to get breast cancer in the other breast and have to go through chemotherapy again, have my lymph nodes impacted, whereas if I have it out, if I have my other breast off under my own terms it's in my own control in terms of timing, in terms of what I have done. [9].

The majority of the women interviewed appear to accept the dominant discourse of our larger society, the unwritten, unspoken 'rules' or 'expectations' about individual responsibility and agency, perhaps without conscious thought. These women voice their understanding of societal expectations in comments such as the one made by a young woman talking about options for managing her risk who says ...if there's something positive I can be doing then why wouldn't I go there? [3].

Fewer women had opted to have bilateral risk-reducing mastectomy. Four women had had this surgery and a further two women were due to have the surgery within a few months of the interview. Those who have opted to have risk reducing mastectomy also spoke about the decision in a pragmatic manner. They talk about how they ...didn't want to die of cancer... didn't want to live with that anxiety [16]. They also talk about wanting to be proactive and ... just to move on [27]. The desire to 'get on with' managing or reducing their cancer risk to save my life and move on suggested that many of these women approached their risk management with a future orientation. Women with young children expressed a strong motivation to see my kids grow up [19], a finding which may help provide an explanation for this orientation.

Struggling to 'get on with it'

Most of the women in this study appeared to be comfortable with the acquisition of risk information and with using this information to make decisions that will allow them to 'get on with' their lives. For a few women, the situation is more complex in that they appear to be willing to seek information regarding their risk and to understand the discourse around using the information to 'get on with' their lives, but actually putting this into practice is more difficult for them. These women struggle to talk about the risk and tears are more frequent during the interviews. They describe the fear and anxiety that permeates their daily lives. When asked about how she feels about the increased risk, one woman says it sits there, it sits there... [8] and another says yeah, so it's there all the time [31]. A young woman says I do feel very lucky to have that knowledge. It does feel heavy sometimes [13]. These women are describing a pervasive sense of unease that is present in their daily lives.

Several women described an overwhelming initial reaction to the test results:

I went up and she told me and spent about an hour with me and then I basically went to the toilets in the [name] hospital and had a cry. I went up by myself which was very silly. She did suggest bringing someone, I didn't really think about it... it hit really hard. It was hard. It hit really hard actually. Yeah I spent a few hours, I sat in the toilet and cried... I think I kind of spiralled down really and maybe I became depressed I don't really know but I certainly wasn't myself. I had, (pause) I had an interesting six months really [13].

I believe in the power of positive thinking. And my sister in [name of town] who had the test the same day as me, she had convinced herself she was positive and she rang me and she said no. I said oh. And I thought holy crap if you're not then there's a chance that I am. Now the big, big mistake about that day was and I don't know whether [genetic counsellor] said to me when you go and get your results take a support person. I don't know whether she said that or not but I didn't take anyone, I went by myself. I got my results. I was an absolute cot case and I couldn't drive myself home. I had to spend the day in [name of town] because I hadn't got myself together enough to drive home... So my GP her response really shocked me, because as soon as she got the results I said I'm not getting my breasts off and she was shocked. She said but you've got an 85% chance of getting breast cancer. She was shocked that I was not considering that surgery but by the time I got home that day I'd talked to a friend of mine about it and talked to her about it and by the time I got home I said to my husband, I think I'm going to consider having the breast surgery. [29].

Both women describe the huge impact of finding that they carried an inherited risk of cancer, and go on to describe quite different responses to the news. The first young woman found it difficult to make any decisions or to seek out support after receiving her response and spiralled down, while the second woman used the shock of the result and resolved to undergo risk reducing surgery. While the surgery did not occur for a number of months, the impact of her response on the day of her result appointment was a motivating factor in her decision regarding surgery. These two excerpts reflect the different approaches to risk that the women in this study described.

The differences among the women are evident not just in the tone of the interview, language that is used and the scarcity of matter of fact comments; the women who struggle with the increased risk appear to behave differently and to think about themselves and the health practitioners they encounter in a different way. Health practitioners are described as 'they', as being in some way other, disconnected from the woman, rather than being a person with whom they can have a meaningful interaction. One woman describes her healthcare as being up to them, up to them [5] and another mentions that she left it with [Genetic Counsellor]... I don't know where it's going [31]. These women talk in ways that suggest they view their healthcare as being in the hands of medical professionals. One of these women described feeling pretty powerless [31] and went on to say:

I just feel that I'm not a priority because I'm not showing symptoms or because I'm in a certain age bracket, that yeah they're not going to think seriously about it at all really. [31].

Another woman reported that she sees from the letter it should have been followed up; anyway it wasn't [23]. These comments indicate very real difficulty in accessing healthcare, with the women indicating that they do not feel valued by the healthcare professionals with whom they have been involved.

Discussion

This study examined the experiences of a group of New Zealand women living with an increased risk of developing cancer. As far as I am aware, it is the first study to explore the experiences of New Zealand women, although a number of studies have been conducted overseas. There is an increasing recognition that knowledge of an individual's genetic background will allow people to make lifestyle modifications pertinent to their risks for particular diseases, for example, certain types of cancer and cardiovascular disease. Given the complexities the women described with adjusting to and managing their cancer risk, the development of appropriate services and resources for people living with genetic risk is becoming increasingly important.

The women interviewed for this study appear to understand that 'getting on with it' is a dominant discourse in New Zealand society and that therefore the expectation is that they will 'get on with' managing their cancer risk. Other studies by and about women have identified 'getting on with it' as a way of approaching various life experiences, indicating that it may be a gendered expectation for women. For example, Kenen et al (2003) found that an attempt to 'get on with their lives' was common in women attending a genetic clinic due to a family history of cancer. British women report regarding menopause as a natural life stage that one just got on with (Darke, 1996). In another British study, 'getting on with it' appeared to help women cope with issues including selfhood, risk and uncertainty after a breast cancer diagnosis (Morris, 1999). Morris (1999) suggests that this attitude is part of a much larger health discourse regarding individual responsibility for managing one's own health risks. While Darke, (1996) suggested that 'getting on with it' may be a gendered expectation, I suggest that it is in fact not solely a gendered expectation. The relationship between the studies from the United Kingdom and the present New Zealand study encourage particular consideration of the overlay of cultural expectations along with gendered expectations.

The way that New Zealand women approach their risk is likely to be influenced by societal influences that are unique to New Zealand. Contributing factors include elements of our national identity and the shared history of New Zealand, elements of gender identity, aspects of New Zealand history and social and governmental policy that have contributed to the formation of gender identities in New Zealand, alongside expectations regarding personal responsibility at both a national and international level. New Zealanders, with our history as a nation of peoples who made long and dangerous voyages first from Polynesia and, much later, from the United Kingdom, to settle these islands, appear to think that 'getting on with it' is just what we do. More recently, we built on those early pioneering views about courage and strength in the face of challenge, when we became part of a massive 'social experiment' during the 1980s, when neo-liberal government was introduced (Kelsey, 1997). Neo-liberal governance holds at its heart ideas about individual responsibility, local and individual autonomy, with governance from a distance (Petersen, 1998; Petersen, 1999). The goal of neo-liberal governance is to create individuals who function autonomously, governing themselves and managing their own risks. During the same period that neo-liberal policies were introduced, the New Zealand healthcare system underwent a series of rapid reforms (Gauld, 2003). The influence of neo-liberal policies, along with global changes in thinking regarding paternalism in medicine, has resulted in a healthcare system with a significant emphasis on individual autonomy and responsibility.

Recent examples in the New Zealand media reflect the desire to ‘get on with it’. For example, in an interview about her movie ‘Home by Christmas’, Gaylene Preston comments that her parents’ generation ‘took one day at a time and just got on with it.’ (Thomson, 2010, p.13). The stories in Rachel Goodchild’s (2007) book about New Zealand women living on the land also contain a strong element of ‘getting on with it’, as women talk about their experiences of living in remote areas of New Zealand. The strength of the finding in this study that New Zealand women are ‘getting on with it’ may therefore be attributable to a combination of gender, cultural and societal expectations associated with being a New Zealander.

Almost all of the women make comments indicating an implicit awareness of sets of understandings within society that encourage them to behave in a particular way about their risk. This observation suggests that taking personal responsibility, in this case for one’s health and well-being, is a dominant discourse in our society. The ability to take responsibility for our own health is viewed positively in today’s society, both within New Zealand and in Western societies more generally. Petersen (1999) has suggested that, in order to understand what occurs in genetic counselling, an appreciation of the dominant, neo-liberal mode of governance is necessary. Neo-liberal governance places emphasis on local and individual autonomy, providing governance from a distance, with the goal of ‘creating’ individuals who operate autonomously (Petersen, 1999). Individuals are expected to govern themselves, and this includes managing their own risk (Petersen, 1998). In New Zealand, neo-liberal government policy was established in the 1980s and has included policies aimed at fostering self-reliance and personal choice in matters such as healthcare and education (Kelsey, 1997). Neo-liberal policies in public health result in imperatives about health promotion and are associated with efforts to persuade individuals to take greater responsibility for their own health (Petersen, 1999). Public health messages exhort individuals to take responsibility for maintaining a healthy lifestyle, to avoid risks and to participate in publicly funded screening programmes. While these messages predominate in New Zealand society, there is evidence from some of the women in this study of the difficulty in accessing and utilising services. In a health system that places responsibility on individuals to initiate follow up, the chance that some people will be lost to follow up and will have difficulty finding their way back into ‘the system’ is significant.

The expectation that women will ‘get on with it’ appears to be a deeply pervasive expectation. While the future orientation and the desire for a healthy future can be seen in several studies (Darke, 1996; Kenen et al, 2003), there is also a sense from some of the women in this New Zealand study and in the study by Morris (1999) that this attitude is socially expected. In order to be deserving of appropriate medical care and treatment, a woman must take personal responsibility for her own health and must be prepared to ‘get on with’ whatever treatments are deemed necessary. The women in the current study justify the acceptability of their risk management through a discourse of personal responsibility and a desire to reassert control.

A number of women spoke about their need to be in control of the timing of surgery and about the anxiety that came with feeling as though they were not in control. A desire for control is found more generally in the biomedical literature with both Birke (1999) and Jenner and Scott (2008) suggesting that control of one’s body – of one’s health – is a strongly felt imperative in Western societies. Jenner and Scott (2008) found that people with Hepatitis C were uncomfortable with the lack of certainty offered by some treatments and that undergoing sometimes gruelling biomedical treatments gave them a means of reasserting control. In much the same way, a preparedness to undergo risk reducing surgery gave some of these women a similar feeling of asserting control over their cancer risk, thereby allowing them to reclaim a healthy future.

An alternative reading of this material considers whether in fact the women who are ‘getting on with it’ are constructing themselves, or being constructed by the medical profession, as ‘good patients’ because they are compliant with the options available for medical management of their cancer risk. In this reading, the women who struggle to ‘get on with it’ may be seen as introducing dissent or resistance into their interactions with the medical profession, and therefore may be more empowered than it would appear on the first reading. The boundaries between the groups become blurred, with those who are ‘getting on with it’ perhaps complying with medical recommendations in a way that suggests they may not be as empowered as their discourse of ‘getting on with it’ suggests.

As a result of the Cartwright Report and the development of the New Zealand Code of Health and Disability Service Consumers Rights, healthcare in New Zealand is provided in an environment where there are expectations regarding adequate communication from practitioners, alongside informed consent from patients (Manning, 2009; Skegg, 2009). Healthcare practitioners are expected to respect the rights of patients to participate in their care and to make choices reflecting their own world views and experiences. The women in the group who are ‘getting on with it’ talk about their medical specialists in ways that suggest they have an interactive relationship, that they regard themselves as partners in seeking information and making decisions. They are more likely to use their doctors’ names than to refer to their doctors as ‘they’. Both their language and behaviour suggest that they have embraced the messages about rights and autonomy in healthcare and feel comfortable with this more equal relationship.

The indications from the women interviewed for this study are that some women, particularly those who are ‘getting on with it’, will seek the knowledge they require to make decisions both from their healthcare providers and from other sources such as the internet. For a small group of women, access to adequate information and education appears to be difficult, and consequently they may not receive appropriate risk management even though they sought this when they attended the genetic clinic initially. As familial cancer services develop and become integrated with public health services and dialogues, it will become increasingly important to identify the barriers that are currently limiting access to information and services. It may be that additional funding is required so that services are able to offer more than one appointment, allowing women to make return visits as they absorb complex information.

Conclusion

A strong desire to ‘get on with it’ is expressed by these Pakeha New Zealand women. Ways of approaching risk are likely to be strongly influenced by the period in which people are living, the political discourses that are predominant at the time and by societal ideas around national identity. New Zealanders are discussing issues such as the right to healthcare for all and the place of individual responsibility in accessing healthcare. Increasing options for surveillance aimed at early detection of cancer are altering the way that we think about health and at the same time altering the role of health practitioners, requiring them to persuade individuals to take responsibility for managing their own health risks (Hallowell, 1999). This broad shift in governance is reflected in the emphasis on autonomy, empowerment, informed choice, the right to know and non-directiveness in genetic counselling (Petersen, 1999). New Zealand women who have an increased risk of developing ovarian and breast cancer live in a society where neo-liberal policies have been systematically applied for over twenty years.

A number of the women in this study are now aged in their late thirties and early forties, and have lived with these policies and the resulting messages about self-responsibility for their entire adult lives. They have also grown up with the influence of the women’s movement and the

emergence of bioethics and medical consumerism questioning long-standing patriarchal medical practices and encouraging individuals to become active participants in their healthcare. That they may feel pressured at some level by societal expectations to use medical interventions to take responsibility for managing their risk is understandable. In the case of hereditary breast and ovarian cancer, taking responsibility may mean agreeing to risk reducing surgery.

Approaches to managing risk are influenced by societal and cultural messages as well as by an individual's perception of the risk. The majority of New Zealand women interviewed for this study approach their risk with a clear desire to 'get on with' their lives. I suggest that this desire is influenced by the women's identity as New Zealand women, with our recent history of neo-liberalism at governmental level contributing to a felt sense of personal responsibility for managing one's own risk within the context of a dominant medical model.

ALISON MCEWAN is a genetic counsellor working in Wellington. She recently completed a PhD through the University of Otago. Her research explores the experiences of New Zealand women living with an increased risk of breast and ovarian cancer. Alison is a current member and past chair of the Human Genetics Society of Australasia Board of Censors for Genetic Counselling.

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