"Getting on with it": New Zealand Women's Experiences of Living with an Increased Risk of Breast and Ovarian Cancer

McEwen, Alison

Abstract:
This thesis explores the experiences of a group of New Zealand women living with an increased risk of hereditary breast and ovarian cancer. The experience of living with increased cancer risk has been explored overseas; however this is the first study examining the experiences of New Zealand women. The study aimed to investigate the experience of living with an increased risk of breast and ovarian cancer, the ways in which women make decisions regarding genetic testing and risk management, and the impact of risk reducing salpingo-oophorectomy and mastectomy on body image and sexuality.

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.

Decision making is an integral part of the experience of living with an increased risk of breast and ovarian cancer, as shown by earlier studies. This process begins with the decision to investigate the family history of cancer. Women go on to make a number of decisions regarding genetic testing, surveillance and surgical risk management. The influences on the decisions they make include the information they obtain, their perception of risk, their family experiences and their perceived responsibilities to their families. Decision making emerges as fluid, with decisions influenced by the woman's specific circumstances and change over time.

“Getting on with it” has emerged as a dominant theme, as the way in which most of these Pakeha New Zealand women are approaching their risk. “Getting on with it” appears to be a deeply entrenched social, cultural and gendered expectation in New Zealand, perhaps influenced by our history as a settler society and the more recent influences of neo-liberal governance. Neo-liberal governance holds at its heart ideas regarding individual responsibility. These women, who are prepared to undergo significant, life-altering and potentially disfiguring surgery in order to be there to fulfil their family responsibilities, are living out dominant social and political expectations that we will each take responsibility for our own health and well-being.

Women choosing to have risk reducing salpingo-oophorectomy and mastectomy face the removal of body parts that are central to their identity and femininity. In particular, mothering is central to the identity of many of the participants. Many of the women with young children describe using their desire to “be there” for their children as they grow up, as the motivation to undergo risk reducing surgery. I argue that choosing to undergo the removal of healthy body parts in order to reduce risk and remain alive to fulfil role expectations provides a symbolic and gendered representation of women as carers and nurturers.

The implications of the findings for clinical practice in New Zealand are considered. Possible means of addressing issues identified by this group of women include greater use of multi-disciplinary clinics, development of more effective means of information provision and exploring the role of genetic counselling with whanau (family) groups.

Date: 2011
Advisor: Robertson, Stephen; Kirkman, Allison
Degree Name: Doctor of Philosophy
Women also have an increased risk of endometrial and ovarian cancer. It is caused by inherited mutations in the PTEN gene. Hereditary nonpolyposis colon cancer. Women with this syndrome have a very high risk of colon cancer and also have an increased risk of developing cancer of the uterus (endometrial cancer) and ovarian cancer. Many different genes can cause this syndrome. They include MLH1, MLH3, MSH2, MSH6, TGFBR2, PMS1, and PMS2. The reduction in risk of ovarian cancer associated with oral-contraceptive use. The Cancer and Steroid Hormone Study of the Centers for Disease Control and the National Institute of Child Health and Human Development. N Engl J Med. It doesn't mean you are guaranteed to get cancer – your genes only partly influence your future health risks. Other factors, such as your medical history, lifestyle and your environment, also play a role. Risk-reducing surgery means removing all the tissue (such as the breasts or ovaries) that could become cancerous. Carriers of a faulty BRCA gene may wish to consider a preventative mastectomy. Women who have risk-reducing mastectomies reduce their risk of developing breast cancer by around 90%. The risk of ovarian cancer in women who carry a BRCA gene fault does not begin to rise significantly until about the age of 40. Therefore, carriers of the faulty gene who are younger than 40 usually wait to have this operation. Telling close relatives. Risk of ovarian cancer in women taking HRT returned to normal within a few years of stopping treatment. 'Worrying'. Lead researcher, Professor Valerie Beral - director of Cancer Research UK's epidemiology unit at the University of Oxford - said: "The results of this study are worrying because they show that, not only does HRT increase the risk of getting ovarian cancer, it also increases a woman's risk of dying of ovarian cancer. "Considering this alongside the increases in risk for breast and endometrial cancer, women should think very carefully about whether to take HRT. "And women who choose to take HRT should aim do so for clear medical need and for the shortest possible time."