Exploring the Experiences of BRCA1 and BRCA2 patients: The potential benefit of therapeutic supports throughout the treatment journey.

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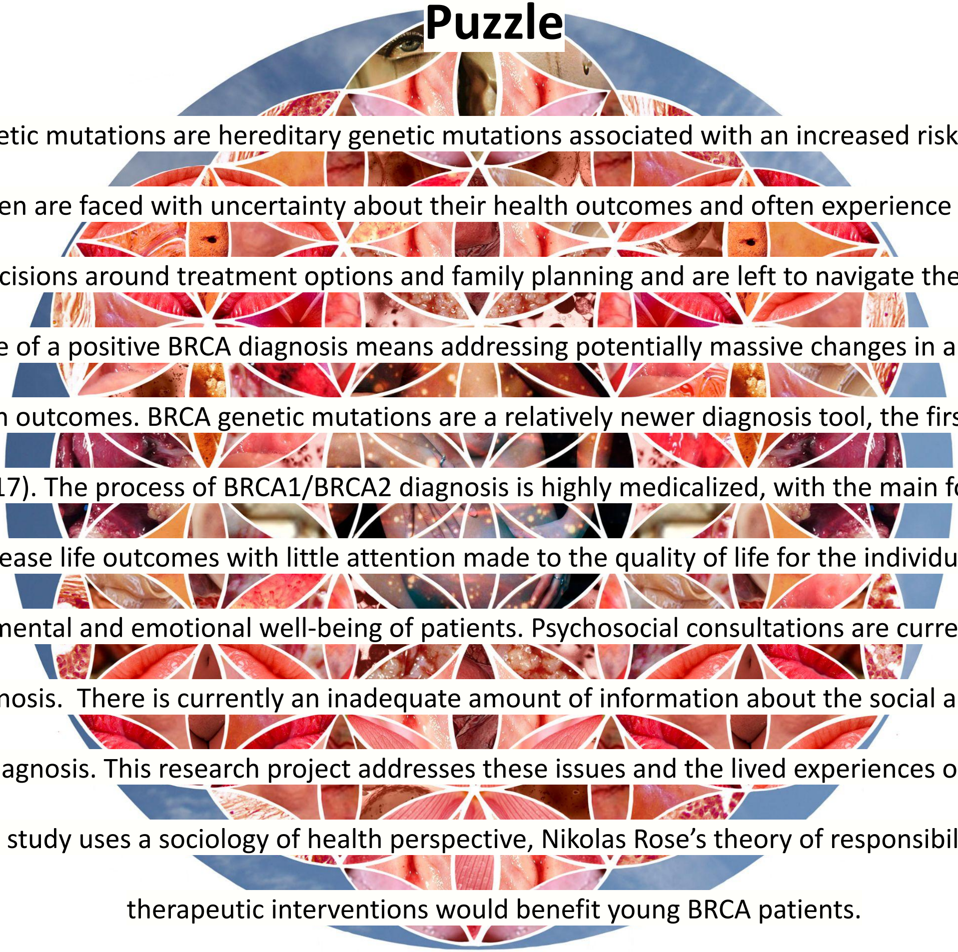
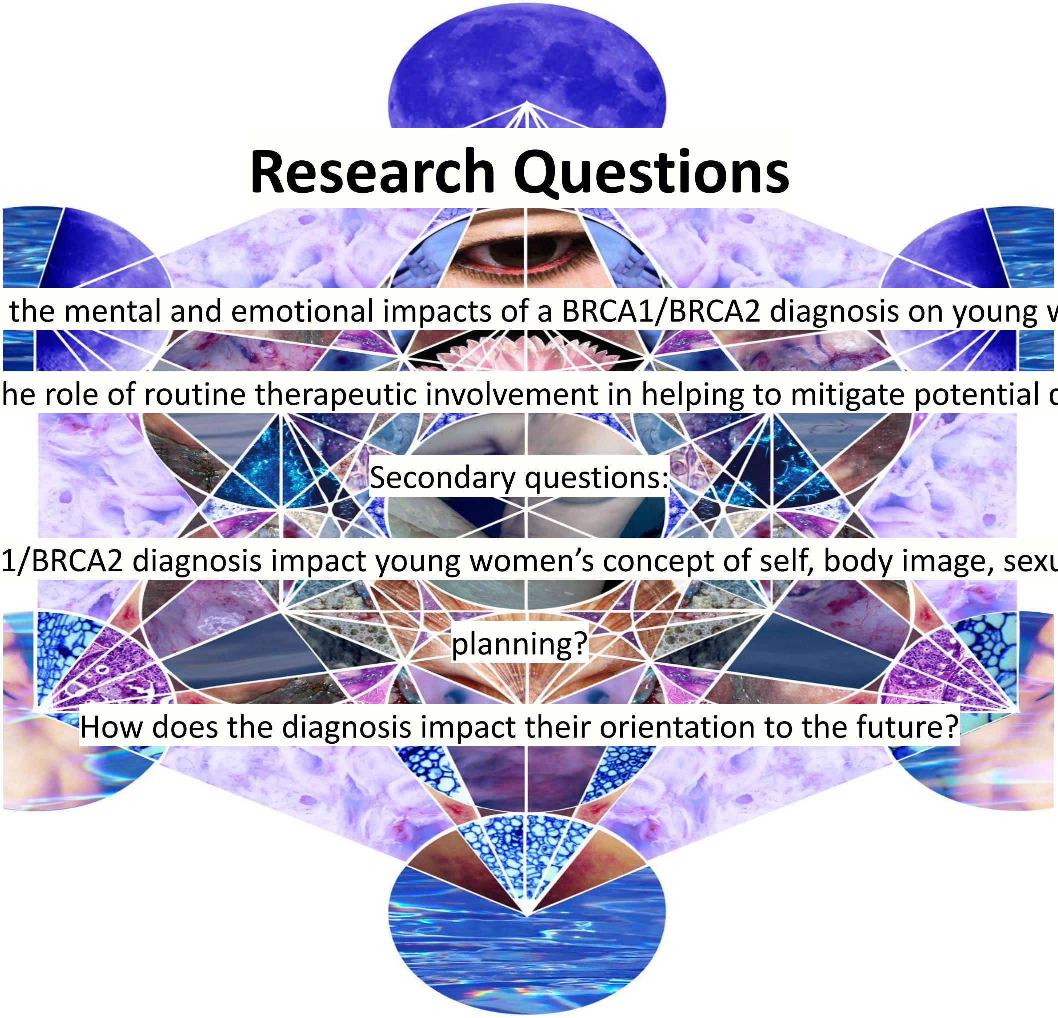
Honours Thesis

Puzzle



BRCA1 and BRCA2 genetic mutations are hereditary genetic mutations associated with an increased risk of developing breast and ovarian cancers. After diagnosis, women are faced with uncertainty about their health outcomes and often experience heightened health anxiety. BRCA positive women face difficult decisions around treatment options and family planning and are left to navigate their mental and emotional wellbeing independently. The outcome of a positive BRCA diagnosis means addressing potentially massive changes in an individual's life, self-concept, relationships, sexuality, and health outcomes. BRCA genetic mutations are a relatively newer diagnosis tool, the first active BRCA screening tool became available in 1996 (Nilan, 2016, p.17). The process of BRCA1/BRCA2 diagnosis is highly medicalized, with the main focus being on statistical information and preventative surgeries to increase life outcomes with little attention made to the quality of life for the individual after a positive diagnosis. There is even less attention paid to the mental and emotional well-being of patients. Psychosocial consultations are currently not recommended by medical practitioners at the time of diagnosis. There is currently an inadequate amount of information about the social and psychological impacts on young women with a BRCA1 or BRCA2 diagnosis. This research project addresses these issues and the lived experiences of young women (ages 25-40) from an interdisciplinary perspective. This study uses a sociology of health perspective, Nikolas Rose's theory of responsibilization, and psychology to explore if therapeutic interventions would benefit young BRCA patients.

Research Questions



What are the mental and emotional impacts of a BRCA1/BRCA2 diagnosis on young women?

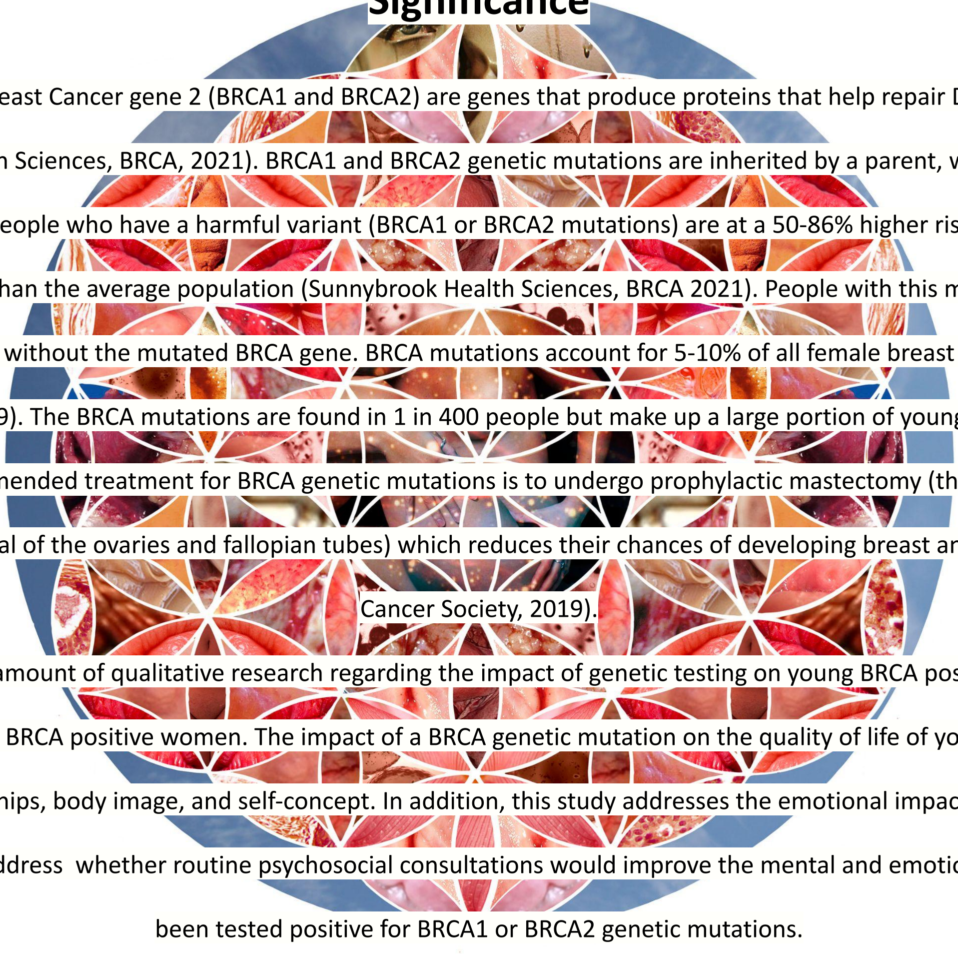
What is the role of routine therapeutic involvement in helping to mitigate potential distress?

Secondary questions:

How does a BRCA1/BRCA2 diagnosis impact young women’s concept of self, body image, sexuality, and family planning?

How does the diagnosis impact their orientation to the future?

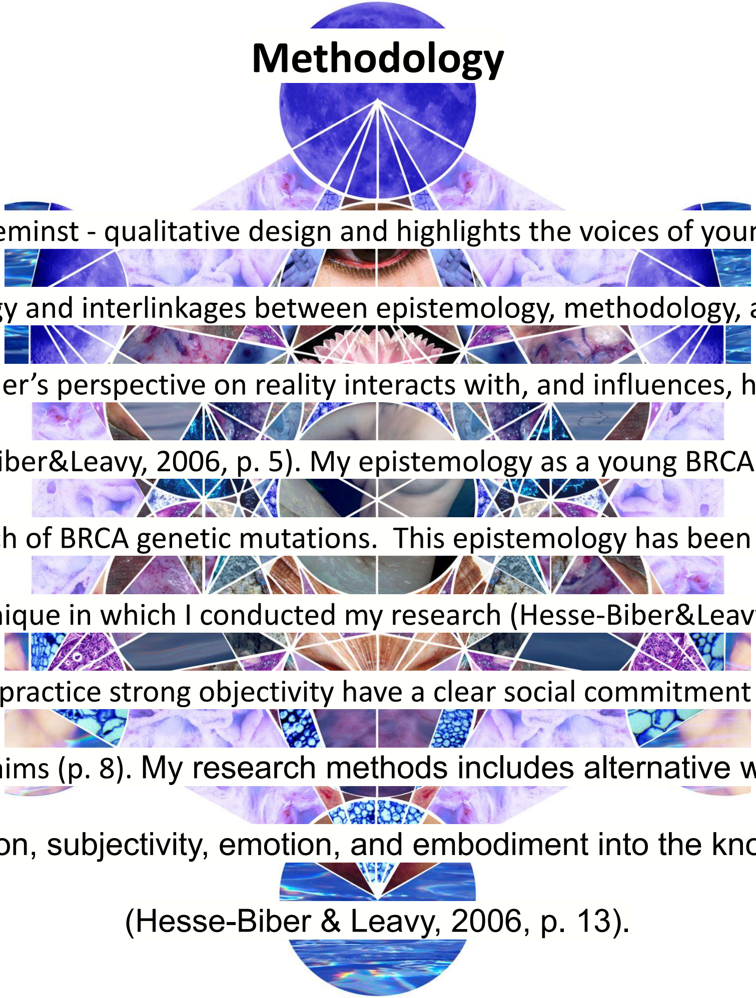
Significance



BReast Cancer gene 1 and BReast Cancer gene 2 (BRCA1 and BRCA2) are genes that produce proteins that help repair DNA, when changes occur to the gene, cancer can develop (Sunnybrook Health Sciences, BRCA, 2021). BRCA1 and BRCA2 genetic mutations are inherited by a parent, who has a 50 percent chance of passing the mutated gene on to their child. People who have a harmful variant (BRCA1 or BRCA2 mutations) are at a 50-86% higher risk of developing certain cancers, most notably breast and ovarian cancers, than the average population (Sunnybrook Health Sciences, BRCA 2021). People with this mutation are also at risk of developing cancers at a younger age than people without the mutated BRCA gene. BRCA mutations account for 5-10% of all female breast cancers and 15-20% of familial breast cancers (American Cancer Society, 2019). The BRCA mutations are found in 1 in 400 people but make up a large portion of young women diagnosed with breast cancer under the age of 40. The recommended treatment for BRCA genetic mutations is to undergo prophylactic mastectomy (the removal of both breasts) and a salpingo-oophorectomy (the removal of the ovaries and fallopian tubes) which reduces their chances of developing breast and ovarian cancer by 90% (American Cancer Society, 2019).

There is currently a limited amount of qualitative research regarding the impact of genetic testing on young BRCA positive women. This study explores the first-hand experiences of young BRCA positive women. The impact of a BRCA genetic mutation on the quality of life of young woman; how they navigate decision-making, disclosures, relationships, body image, and self-concept. In addition, this study addresses the emotional impact of a BRCA diagnosis and what it takes to heal. The outcome of the study is address whether routine psychosocial consultations would improve the mental and emotional health of young women who have been tested positive for BRCA1 or BRCA2 genetic mutations.

Methodology



This research was grounded in feminst - qualitative design and highlights the voices of young women interviewed. Feminist researchers emphasize the synergy and interlinkages between epistemology, methodology, and methods and are interested in the different ways that a researcher's perspective on reality interacts with, and influences, how she goes about collecting and analyzing her data (Hesse-Biber&Leavy, 2006, p. 5). My epistemology as a young BRCA1 positive woman shape my assumptions about the research of BRCA genetic mutations. This epistemology has been rooted in my decision process, choice of theory, and the technique in which I conducted my research (Hesse-Biber&Leavy, 2006, p. 5). Hesse-Biber and Leavy state that researchers who practice strong objectivity have a clear social commitment to strengthening the truthfulness and objectivity of knowledge claims (p. 8). My research methods includes alternative ways of thinking, and focus on incorporating interpretation, subjectivity, emotion, and embodiment into the knowledge-building process (Hesse-Biber & Leavy, 2006, p. 13).

Recruitment

This study involved the recruitment of young women through an online Facebook group. After gaining approval from the group's administrator, I posted a recruitment poster on the Facebook group page. The participants were required to reach out to the researcher if interested in participating in the project. Seventeen women responded to the BRCA Sisterhood Facebook recruitment post, from which six were selected based on specific criteria, to participate in an interview. I conducted four interviews in total with female-identified individuals between the ages of 25-40 years old, who reside in Canada, and who have been diagnosed with either BRCA1 or BRCA2 genetic mutation.

The recruitment and interviews were held entirely online through online social platforms such as Facebook, Zoom, and email.

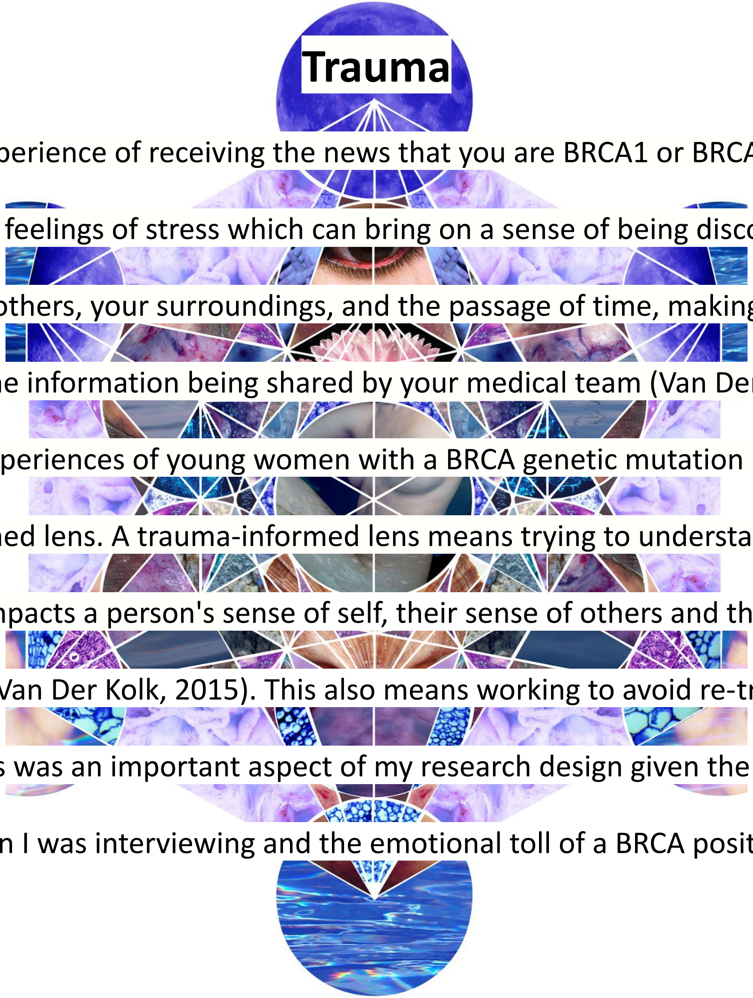
I gained consent from the participants via email including an informed consent form as an attachment. The participants were required to return a signed copy of the consent form via email. Included in the email with the consent form was a list of resources and the questions for the interview. The duration of each interview was between 60-90 minutes. Interview questions were open-ended and semistructured, guided by a prepared outline. All interviewees were assigned a pseudonym by the researcher.

Each woman involved in this study is at a different stage of their BRCA treatment journey which allows for an interesting exploration of the emotional impact at each stage of the treatment journey. All four women received their BRCA diagnosis prior to our interview, with an average of roughly one year since diagnosis.

Responsibilization

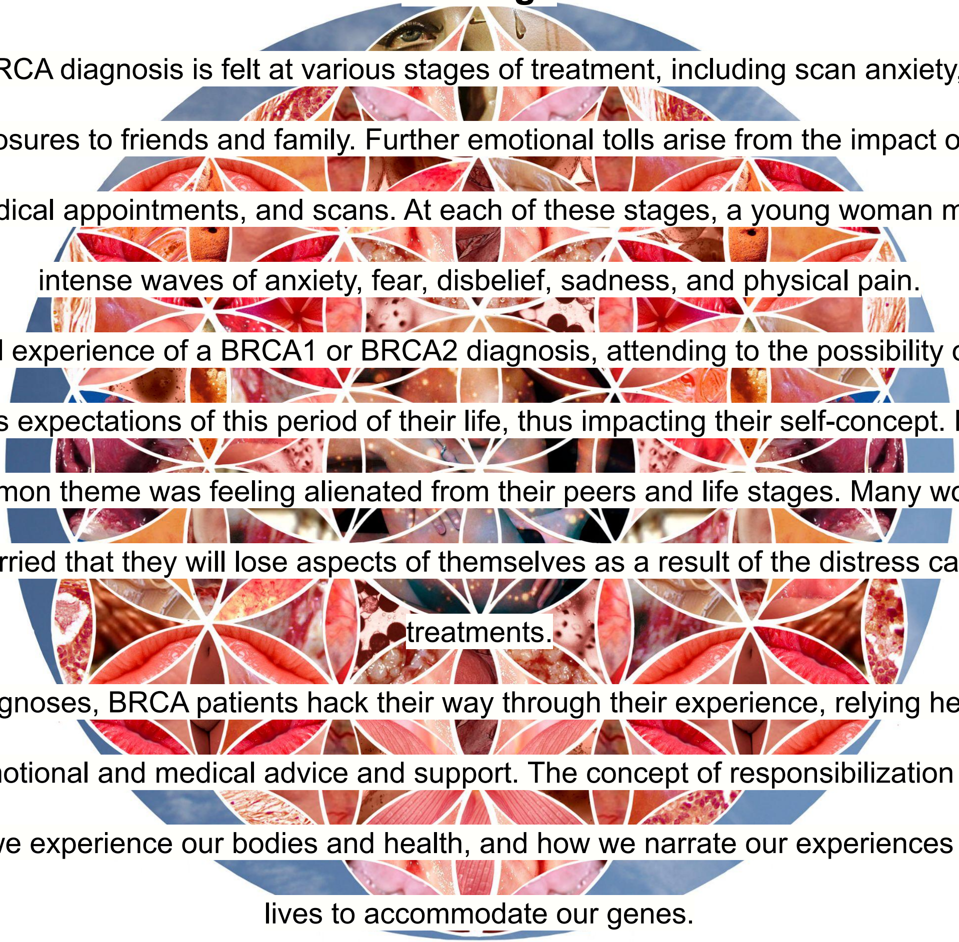
A BRCA diagnosis brings seemingly healthy young women under the medical gaze, creating new concepts of what it means to be at-risk. Nikolas Rose’s “contemporary biopolitics theory” states that the politics of health is “concerned with our growing capacities to control, manage, engineer, reshape, and modulate the very vital capacities of human beings as living creatures…of life itself” (Rose, 2008, p.16). Genetic testing is one way in which the governance over life itself has been engineered and is creating new ways of understanding what it means to be a healthy individual.Patient responsibilization refers to the personalized risk-surveillance of the body to maintain health and avoid illness (Annadale, 2014, p. 217). Responsibilization creates the concept that a “responsible citizen should want to know about their genetic history in order to manage health uncertainties and optimize medical treatments to be a ‘healthy’ citizen” (Annandale, 2014, p. 217).In advanced liberal democracies, genetics takes its salience within a political and ethical field in which individuals are increasingly obligated to formulate life strategies, to seek to maximize their life chances, to take action or refrain from action in order to increase the quality of their lives, and to act prudently in relation to themselves and to others” (Rose, 2008, p. 116). Not only do BRCA patients have to make sense of their lives in accordance to their genetics, but they also have adjust to new ways of being, and according to new values about who we are, what we must do, and what we can hope for (Rose, 2008).Technologies of life not only seek to reveal these invisible pathologies, but intervene upon them in order to optimize the life chances of the individual, becoming pre-patients, or in BRCA medical terminology previvors (Rose, p. 32). Previvor is a term used in the genetic mutation discourse as a way to describe BRCA patients who do not have a personal history of breast or ovarian cancer.

Trauma



The experience of receiving the news that you are BRCA1 or BRCA2 positive can create intense feelings of stress which can bring on a sense of being disconnected from yourself and others, your surroundings, and the passage of time, making it difficult to remember the information being shared by your medical team (Van Der Kolk, 2015). Exploring the experiences of young women with a BRCA genetic mutation required using a trauma-informed lens. A trauma-informed lens means trying to understand the ways in which trauma impacts a person's sense of self, their sense of others and their beliefs about the world (Van Der Kolk, 2015). This also means working to avoid re-traumatizing individuals. This was an important aspect of my research design given the vulnerability of the population I was interviewing and the emotional toll of a BRCA positive diagnosis.

Findings

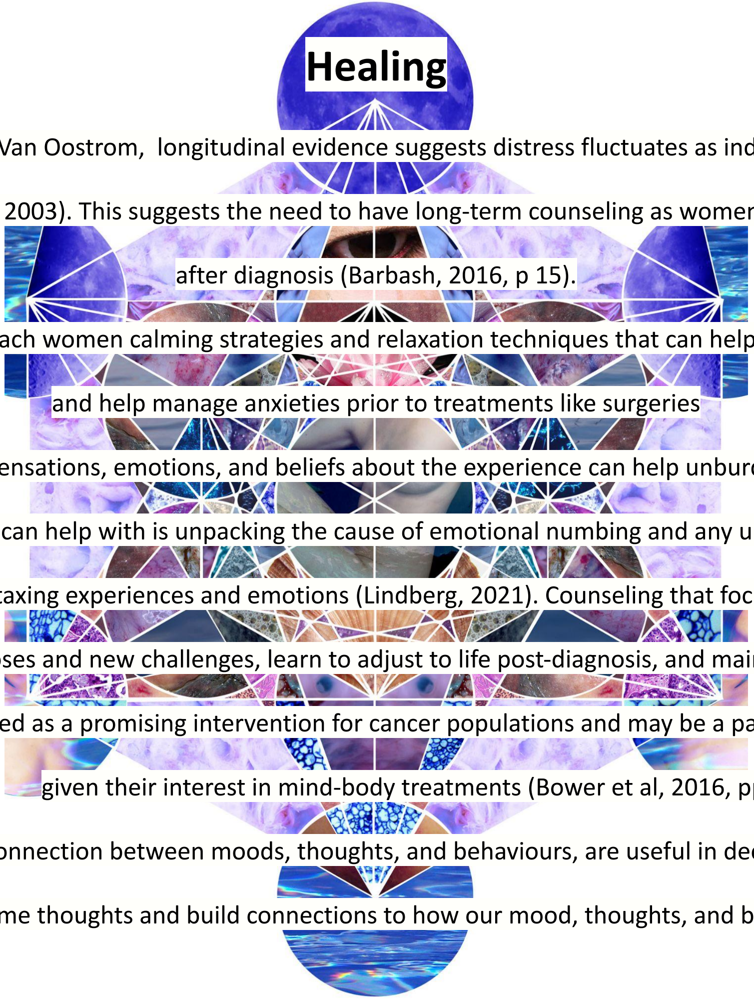


The emotional toll of a BRCA diagnosis is felt at various stages of treatment, including scan anxiety, fear around surgeries and body changes, physical pain, and disclosures to friends and family. Further emotional tolls arise from the impact of the disruption in young women’s lives as a result of surgeries, medical appointments, and scans. At each of these stages, a young woman may feel triggered and experience intense waves of anxiety, fear, disbelief, sadness, and physical pain.

In addition to the emotional experience of a BRCA1 or BRCA2 diagnosis, attending to the possibility of a life-threatening illness is out of sync with many young women’s expectations of this period of their life, thus impacting their self-concept. Many women discussed feeling different from their peers. A common theme was feeling alienated from their peers and life stages. Many women discuss wanting to feel like themselves again or feeling worried that they will lose aspects of themselves as a result of the distress caused by diagnosis and ongoing treatments.

As with many medical diagnoses, BRCA patients hack their way through their experience, relying heavily on peer support and shared knowledge to fill in the gaps of emotional and medical advice and support. The concept of responsibilization and gratitude shifts our narratives about who we think we are, how we experience our bodies and health, and how we narrate our experiences of disease, and how we adapt our lives to accommodate our genes.

Healing



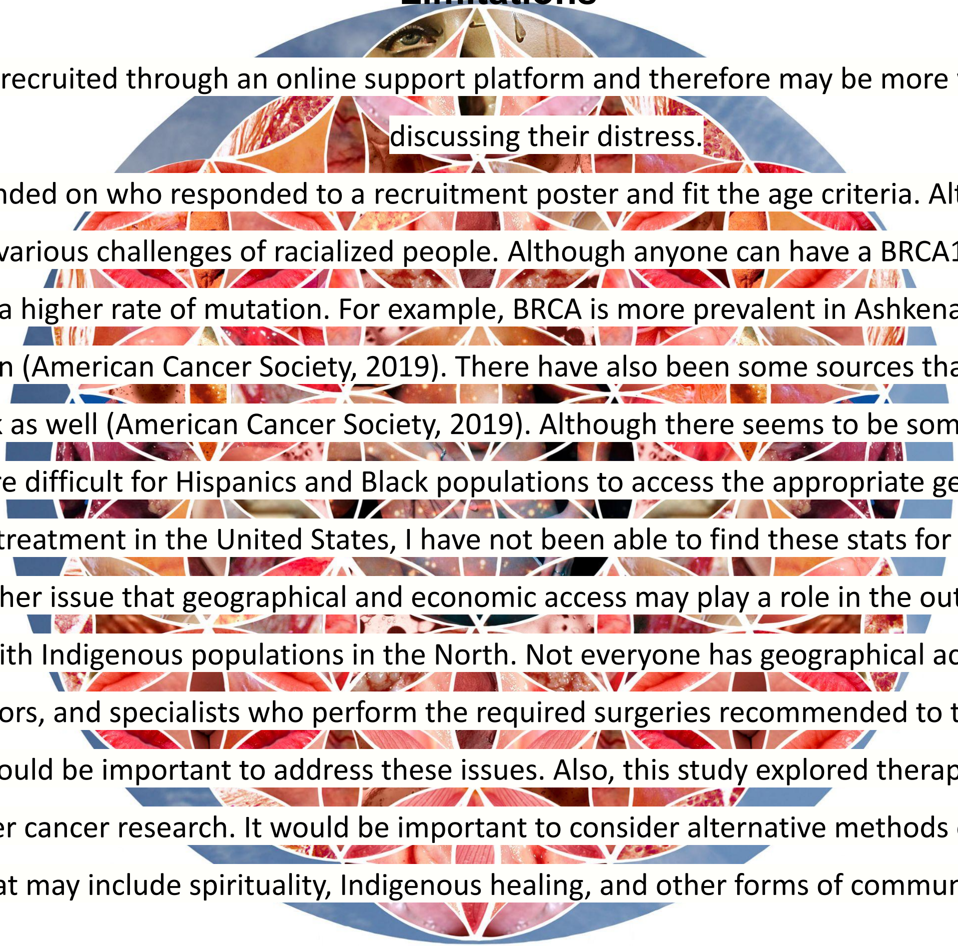
According to a study conducted by Van Oostrom, longitudinal evidence suggests distress fluctuates as individuals struggle to integrate genetic testing information into their life (van Oostrom et al., 2003). This suggests the need to have long-term counseling as women learn to integrate their changing self-concept after diagnosis (Barbash, 2016, p 15).

Speaking to a counselor can help teach women calming strategies and relaxation techniques that can help them stay present in medical appointments and help manage anxieties prior to treatments like surgeries

Having a safe space to unpack the sensations, emotions, and beliefs about the experience can help unburden some of the fear associated with a BRCA diagnosis. One of the first things a therapist can help with is unpacking the cause of emotional numbing and any underlying emotional reactions and together, come up with better ways to deal with overtaxing experiences and emotions (Lindberg, 2021). Counseling that focuses on the grieving process can help young women accept their diagnoses and new challenges, learn to adjust to life post-diagnosis, and maintain connects with others.

- Mindfulness meditation has emerged as a promising intervention for cancer populations and may be a particularly good option for younger survivors given their interest in mind-body treatments (Bower et al, 2016, pp. 2).
- CBT strategies, which focus on the connection between moods, thoughts, and behaviours, are useful in decreasing the thoughts associated with painful experiences. CBT can help to reframe thoughts and build connections to how our mood, thoughts, and behaviour interact (Greenberger et al, 2016)

Limitations



- Participants were recruited through an online support platform and therefore may be more willing to seeking support or discussing their distress.
- The interviews depended on who responded to a recruitment poster and fit the age criteria. Although not intended, this study does not address the various challenges of racialized people. Although anyone can have a BRCA1 and BRCA2 mutation, there are populations that have a higher rate of mutation. For example, BRCA is more prevalent in Ashkenazi Jewish women with about 1 in 40 having the mutation (American Cancer Society, 2019). There have also been some sources that state that Hispanics and Blacks may be at a higher risk as well (American Cancer Society, 2019). Although there seems to be some counter thought to this finding because it may be more difficult for Hispanics and Black populations to access the appropriate genetic supports due to the cost of testing and treatment in the United States, I have not been able to find these stats for Canadian populations.
- This leads me to another issue that geographical and economic access may play a role in the outcome of the findings, especially geographical access with Indigenous populations in the North. Not everyone has geographical access to hospitals, genetic testing sites, genetic counselors, and specialists who perform the required surgeries recommended to treat BRCA patients. If this study were to continue it would be important to address these issues. Also, this study explored therapeutic modalities that have been written about in larger cancer research. It would be important to consider alternative methods of mental and emotional health that may include spirituality, Indigenous healing, and other forms of community supports.