When Bad Genes Ruin a Perfectly Good Outlook: Psychological Implications of Hereditary Breast and Ovarian Cancer via Narrative Inquiry Methodology

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Images
Cammi Clark, Ph.D. is a 2019 graduate of the PHD Program in Leadership and Change at Antioch University.

Dr. Clark at her Dissertation Defense.
L-R: Dr. Piri Welch, Committee Member, Dr. Elizabeth Holloway, Committee Chair, Dr. Jon Wergin, Committee Member.

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Abstract
Scientists debunked the belief that breast cancer is always viral with the mid-90s discovery of the first hereditary genetic mutation linked to a significantly higher-than-average chance of breast and ovarian cancer. This genetic condition, called Hereditary Breast and Ovarian Cancer (HBOC), passes the mutation from generation to generation in a family. Thousands of variations of such mutations exist, and carriers account for 10 to 15% of all breast cancer, and up to 20% of ovarian cancer (Childers et al., 2017). In addition, genetic testing uncovered a rapidly rising number of healthy people (never had breast/ovarian cancer) who are also carriers, flooding healthcare providers seeking potential options to reduce their elevated risk. Those prophylactic measures are invasive, permanent and can cause physical—and emotional—scarring. As a newer medical phenomenon, few, if any, studies address the potential psychological implications, which include fear, anxiety, guilt, family tension, and more. Using narrative inquiry methodology, this study analyzes the authentic lived or felt experiences of individuals when they learn that they have inherited a mutation that significantly increases their risk.
of breast, ovarian and related cancers, and their choices that directly affect their effort to outrun a cancer that may never come. This dissertation is accompanied by the author's MP4 video introduction and is available in open access at AURA: Antioch University Repository and Archive, http://aura.antioch.edu/ and OhioLink ETD Center, https://etd.ohiolink.edu/

Comments

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With roots in journalism and storytelling, Cammi Clark has been a longtime communications expert. Her approach is to bring voice to those who need to be heard. With her background in building content-driven publications and experience in connecting through narrative, Clark creates a compelling space filled with comprehension and compassion, aimed at educating.

Clark’s work with Hereditary Breast and Ovarian Cancer carriers began more than six years ago when she first discovered that her family was deeply affected by such a gene mutation. She recognized that the research into this newer medical phenomenon was primarily scientific and left little room for carriers who ache to be heard, to tell their personal stories of what this means and how they make sense of it all. It is through the stories and experiences of others that Clark will work to transform the quality of health care worldwide.

Clark currently leads a team of specialists that focus on communicating science through story at Florida Atlantic University’s Division of Research.

Recommended Citation


Standardised incidence ratios (SIRs) for ovarian, breast, and corpus uteri cancer among 225 786 women who underwent assisted reproduction in Great Britain, 1991-2010, stratified by various factors*. View this table: View popup. When tumours were classified as invasive or borderline, significant excesses of both were noted (264 observed v 188.1 expected cancers, standardised incidence ratio 1.40 (95% confidence interval 1.24 to 1.58), absolute excess risk 3.4 cases per 100 000 person years (95% confidence interval 2.0 to 4.9) and 141 v 103.7, 1.36. Early investigations of common genetic risk factors for breast cancer focused on candidate gene and candidate variant studies using hundreds of breast cancer cases and unaffected controls. The majority of candidate variants associated with breast cancer in these studies have subsequently failed replication and have therefore been excluded as risk factors for breast cancer (8). Only a coding variant (D302H) in the caspase 8 gene (CASP8) has consistently shown associations with breast cancer, and ongoing studies have recently identified multiple independent risk–associated signals in this locus. Soon after the groundbreaking publication by Easton and colleagues, additional evidence quickly accumulated implicating the FGFR2 locus in breast cancer risk (11–15). Breast cancer is a disease in which breast cells become abnormal and multiply to form a malignant tumor. Breast cancer is the most common form of cancer and the second most common cause of death from a neoplastic disease affecting women. One in 8 women will develop breast cancer in her lifetime in the developed world [1, 2]. There are a number of recognized risk factors for breast cancer development including hormonal, reproductive, and menstrual history, age, lack of exercise, alcohol, radiation, benign breast disease, and obesity [3]. Nevertheless, the key factor to breast cancer development... Genes with high-penetration mutations. Hereditary breast/ovarian cancer syndrome. BRCA1 (17q12–21). Female breast, ovarian cancer. 40–80%.