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The complicated nature of genetic testing requires breast cancer medical professionals, and those diagnosed with breast cancer, to explore multiple outcomes with the understanding that optimal solutions may not be available, thus requiring them to select among satisfying options, and make good decisions based on incomplete information within the context of unknown and dynamic variables. Through the lens of bounded rationality, the findings reveal that complex decision-making evokes strong emotions, and requires those diagnosed with breast cancer to incorporate a combination of strategies and processes as they maneuver through both linear and non-linear paths for acquiring information, seeking alternatives, and making decisions.

Purpose

The purpose of this study was to explore how those diagnosed with breast cancer navigate the decision-making process associated with genetic testing.

Research Question: What are the main characteristics of rational choice among those who have been diagnosed with breast cancer (or are at a high risk for developing breast cancer) in situations where complexity precludes individual implications?

Descriptive Phenomenology

Phenomenology is both a philosophical practice and psychological scientific method. Grounded in the works of Kant & Hegel, Husserl became known as the modern-day founder. Phenomenological research acknowledges that there is a need for understanding a phenomenon in order to improve practice. Husserl asserts that the aim of phenomenology is the rigorous and unbiased study of things as they appear. It provides a deeper understanding of lived experiences by making evident the taken-for-granted assumptions of the phenomenon and allows the researcher to adopt an understanding of how the phenomenon presents itself to the participant’s consciousness. Specifically, descriptive phenomenology as an application is pre-transcendental and focuses on how human consciousness relates to the human world.

Data and Analysis

- Critical sampling
- Participants – Women diagnosed with breast cancer
- Open ended interviews, 60-90 minutes, Recorded and transcribed
- Delineating units of meaning
- Cluster and categorize themes
- Structural analysis and expressions
- Creating the essential structure
- Phenomenological reduction
- Bracketing
- Memo-ing
- MAXQDA

Findings:

1. Complex decision-making processes stem not only from the complexity of genetic testing, but also from the information (or lack thereof) that the person has at the beginning of the investigation, i.e., at the time of diagnosis.

2. Complex decision-making involves a shift or alteration in emotion. This is captured from all of the participants as they describe their experience from wanting genetic testing whole-heartedly, to the aftermath and long-term effects, i.e., living with knowledge of the results (which can’t be reversed).

3. Complex decision-making can be both linear and non-linear resulting from the outcome of the genetic test.

Themes:

Outcomes-Based Decision-Making
- Surgical Options; Impact on Family
- Group Decision-Making
  - Collaboration with spouse; Collaboration with doctors; Collaboration with offspring and relatives

Emotional Orientation
- Psychological, Emotional, Stressful, Unexpected

Procedural Strategies
- Collection of information; Processing of information

Findings in Relation to Design

Uncovering
- Consciousness
- 1st person’s point of view
- Capturing
- Participant
- Worldly Circumstances
- Transforming
- Lived Experiences
- Essential Structures

Findings in Relation to Theory

- I felt very much that if there’s anything else that’s here, like a genetic thing, I want my relatives to know so that they have full information and they can make whatever choices work for them in the context of that. (Participant E, 2020).

- So you have unknown information. So how do you make these choices and navigate that path, right? Like should you make lifestyle changes? Should you be proactive about something differently? Should you be doing something differently? Should you be proactive or not about something? Like what does this mean? So how are you coming to terms with that? (Participant F, 2020).

- So I decided that I’m going to have a double mastectomy. After I had more time to think about it and consulted with my gynecological oncologist. She said, we don’t know everything there is to know about PSM2 at this point. And we certainly don’t fully understand the PSM2 in breast cancer, but she was like, there is a connection, 50% of my patients that I see that have PSM2 have breast cancer. (Participant B, 2020).

Findings in Relation to Practice

- Assist medical professionals in understanding the interconnectivity of linear and non-linear processes associated with complex decision-making as they endeavor to advise their patients on genetic testing.
- Assist practitioners in understanding the emotional and psychological impact of genetic testing, and complex decision making, when perfect or complete information is not available.

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