

Title: “It’s not *if* I will get cancer, it’s *when*”: Exploring previvors’ management of uncertainty for hereditary breast and ovarian cancer in clinical encounters

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Why might a woman willingly cut off her breasts? On May 14, 2013 Angelina Jolie, an Oscar winning actress, director, and humanitarian, wrote in *The New York Times* that she “carr[ies] a ‘faulty’ gene, BRCA1, which sharply increases [her] risk of developing breast cancer and ovarian cancer” (par. 2). Having this gene mutation in addition to her family history of cancer means she has an 87 percent risk for developing breast cancer and a 50 percent risk for developing ovarian cancer during her lifetime. Because of this information, Angelina decided to “be proactive and to minimize the risk as much as [she] could” (par. 5) by undergoing a prophylactic double mastectomy—the surgical removal of one’s noncancerous breast tissue. Doing so reduced her risk for breast cancer from 87 percent to 5 percent (Jolie, 2013)!

Angelina Jolie is a previvor. A *previvor* refers to an individual who is highly predisposed to breast or ovarian cancer due to a genetic mutation called BReast CAncer1 (BRCA1) and BReast CAncer2 (BRCA2), commonly known as the “breast cancer gene” (Friedman, Sutphen, & Steligo, 2012; Roth Port, 2010). This gene is familial, meaning it is inherited and passed down from generation to generation. One’s risk ranges from about 44 to 87 percent depending on the type of genetic mutation the individual possesses as well as other risk factors such as gender, age, ethnicity, etc. (Friedman, Sutphen, & Steligo, 2012). Because of this genetic mutation, previvors live in a constant state of *uncertainty*—wondering not *if* they might get cancer but *when*—and thus must make certain preventative health decisions to reduce their cancer risk.

Research reveals that within medical encounters uncertainty cannot ever be entirely eliminated (Epstein & Street, 2007), and inadequately managed uncertainty can have detrimental psychosocial effects (Neville, 1998) and impair decision-making for patients (Mishel, 1999). As such, it is essential to understand previvors' health experiences.

To do so, thirty-four interviews were conducted with female previvors. Participants were recruited through Facing Our Risk of Cancer Empowered's (FORCE) social media pages. Interviews were recorded and transcribed. The constant comparison method was employed to code the interview transcriptions, and the transcripts' themes served as the units of analysis.

First, analysis revealed two main uncertainty sources for previvors—medical uncertainty and familial uncertainty. Medical uncertainty types include the unknown future, peaks and valleys associated with medical consultations, and personal cancer scares. Familial uncertainty encompasses traumatic family cancer experiences and being a mother and being present in children's lives. Second, four uncertainty management strategies—seeking clinicians as an informational source, seeking clinicians as a partner for decision-making, seeking clinicians as an emotional support, and seeking referrals from clinicians for emotional support—were identified as ways previvors try to manage their uncertainties. Ultimately, previvors' uncertainty sources and uncertainty management strategies impacted their health decision-making with preventative surgeries (e.g., prophylactic mastectomy) as the most common health decision.

In short, this research gains insight into previvors' uncertain health experiences, thus providing information to improve communication between previvors and clinicians and better previvors' health and well-being.

References

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