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Reasons Why Young Women Accept or Decline Fertility Preservation After Cancer Diagnosis

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ABSTRACT

Objective: To understand young women's reasons for accepting or declining fertility preservation after cancer diagnosis to aid in the development of theory regarding decision making in this context.

Design: Qualitative descriptive.

Setting: Participants' homes or other private location.

Participants: Twenty-seven young women (mean age, 29 years) diagnosed with cancer and eligible for fertility preservation.

Methods: Recruitment was conducted via the Internet and in fertility centers. Participants completed demographic questionnaires and in-depth semi-structured interviews. Tenets of grounded theory guided an inductive and deductive analysis.

Results: Young women's reasons for deciding whether to undergo fertility preservation were linked to four theoretical dimensions: *Cognitive Appraisals, Emotional Responses, Moral Judgments*, and *Decision Partners*. Women who declined fertility preservation described more reasons in the *Cognitive Appraisals* dimension, including financial cost and human risks, than women who accepted. In the *Emotional Responses* dimension, most women who accepted fertility preservation reported a strong desire for biological motherhood, whereas women who declined tended to report a strong desire for surviving cancer. Three participants who declined reported reasons linked to the *Moral Judgments* dimension, and most participants were influenced by *Decision Partners*, including husbands, boyfriends, parents, and clinicians.

Conclusion: The primary reason on which many but not all participants based decisions related to fertility preservation was whether the immediate emphasis of care should be placed on surviving cancer or securing options for future biological motherhood. Nurses and other clinicians should base education and counseling on the four theoretical dimensions to effectively support young women with cancer.

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Increasing survival rates after cancer treatment have expanded the focus of care to include survivorship issues and quality of life concerns (American Cancer Society, 2014). For example, fertility preservation (defined as egg, embryo, or ovarian tissue cryopreservation) for young women with cancer who are at risk for fertility loss has gained wide acceptance, and egg and embryo cryopreservation are now considered standards in clinical practice (Loren et al., 2013; Practice Committees of the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology, 2013). Egg and embryo cryopreservation are typically performed in conjunction with ovarian stimulation before the onset of cancer treatment (Kasum, Beketić-Orešković, Peddi, Orešković, & Johnson, 2014; Trudgen & Ayensu-Coker, 2014). Ovarian tissue cryopreservation is an experimental option that, when performed within a research protocol, can be appropriate for young women who urgently need to undergo chemotherapy and/or radiation treatment (Practice Committee of the American Society for Reproductive Medicine, 2014). Worldwide, the number of fertility centers offering fertility preservation to young women with cancer is expanding (Ory et al., 2014).

In the United States, the number of women who delay pregnancy and childbearing until they are in their thirties and forties is increasing (Hamilton,

Many young women find they have not yet contemplated the significance of motherhood in their lives or their desire for biological children.

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Martin, Osterman, & Curtin, 2014), and as a result, many young women diagnosed with cancer have neither begun nor completed childbearing. In some cases, young women diagnosed with cancer have not fully considered whether they want to have children. In such situations, there is a critical need for nurses and other clinicians to provide effective education and support for these young women. The body of research on the underlying reasons why young women accept or decline fertility preservation, such as associated financial costs incurred during treatment, is small but expanding. However, the accumulating evidence is often conflicted or confounded by extraneous factors and is typically void of the explicit theoretical underpinnings that are needed to examine the phenomena of decision making within this specific context. Therefore, the purpose of this article is to provide insight into the reasons why young women accept or decline fertility preservation after cancer diagnosis to contribute to theoretical knowledge in this area.

Background

Limited research is available about the complex decisions young women with cancer make about fertility preservation, because there was not great interest in fertility and pregnancy among these women until the early 1990s. During this time, researchers reported survival rates for young women with cancer and began to show that those who experienced naturally occurring pregnancies after cancer had the same prognosis as young women who did not experience pregnancy (Danforth, 1991). Then, in a groundbreaking study published in 2004, Partridge and colleagues found that of 657 young women surveyed who survived breast cancer, an overwhelming majority (73%) indicated they were concerned about loss of fertility. Many women in this study who voiced concern about their fertility wanted children or more children. However, 36% of the women reported they did not want children in the future or were unsure about future childbearing because they thought a future pregnancy would increase the risk of cancer recurrence, a concern that was also expressed by other young cancer survivors (Avis, Crawford, & Manuel, 2004; Connell, Patterson, & Newman, 2006; Klock, Zhang, & Kazer, 2010). Some cancer survivors who did not want to become pregnant also expressed feelings of selfishness about having children when their own lifespans could be compromised (Connell et al., 2006), or they indicated that the financial cost associated with fertility preservation was a barrier (Kim et al., 2013; Klock et al., 2010; Mersereau et al., 2013).

As more young women with cancer become aware of fertility preservation, the effect of clinical counseling (Bastings et al., 2014; Goodman, Balthazar, Kim, & Mersereau, 2012; King et al., 2008) on their decisions, including processes related to the exchange of information with clinicians, is being examined (Balthazar et al., 2012; Jukkala, Azuero, McNees, Bates, & Meneses, 2010). In a poignant example, Peddie et al. (2012) explored factors that affected decisions regarding fertility preservation for women and men. They found that women declined this option because their clinicians often stressed the urgent need for cancer treatment. We and other investigators found that young women's decisions about fertility preservation were influenced by lack of clinician encouragement, lack of information, and low referral rates for fertility counseling (Hershberger, Finnegan, Altfeld, Lake, & Hirshfeld-Cytron, 2013; Hill et al., 2012; Mersereau et al., 2013; Peate et al., 2011; Thewes et al., 2005).

Kim and colleagues (2013) further explored the reasons why American women accepted fertility preservation, and the most reported were desire for future children and wishes of the women's partners. Among those women who declined fertility preservation, the top reasons were lack of desire for future children, financial costs, and length of time needed for treatment. However, Peate and colleagues (2011) demonstrated that neither having a definite desire for more children nor being in a committed relationship predicted Australian women's intentions to pursue fertility preservation. The various social, political, and cultural contexts that occur in the countries where these studies were completed add to the difficulty in understanding why young women chose fertility preservation.

Although findings from these studies are helpful to identify why young women choose fertility preservation, most investigators have not linked findings to theoretical constructs. Recently, scientists and scholars specializing in decision making have suggested that more explicit use