

Development of the Fertility and Cancer Project: An Internet Approach to Help Young Cancer Survivors

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Fertility preservation among young survivors of cancer is a vital area of quality of life (Dow, 1994; Partridge, 2008). For some young women, future childbearing is one their first concerns upon receiving a cancer diagnosis; for others, thoughts about fertility do not occur until well into or upon completion of treatment (Dow, 1994). Options for preserving fertility diminish rapidly with cancer treatment and advancing age (Murray, 2005; Oktay, Buyuk, Libertella, Akar, & Rosenwaks, 2005); thus, decisions about fertility preservation must be made relatively quickly following diagnosis. Yet many young survivors of cancer do not receive timely, high-quality information about the effect of cancer treatment on reproductive function (Dow & Kuhn, 2004; Duffy, Allen, & Clark, 2005).

Current evidence indicates that only about half of men and women of childbearing age with cancer receive information about reproductive health from oncology care providers (Canada & Schover, 2005). Although expecting oncologists to have the time required to engage in detailed discussions about fertility preservation and options is unrealistic, a practical alternative is for other oncology care providers, such as nurses and social workers, to address the topic of fertility and reproductive health (Canada & Schover, 2005). Innovative strategies to deliver reproductive patient education (e.g., computerized media, peer counseling, educational modules) would greatly aid oncology healthcare professionals in fulfilling this responsibility.

Many cancers affect young women, but breast cancer has the highest incidence in that population. In 2008, more than 42,700 women younger than 50 years were diagnosed with breast cancer in the United States (National Cancer Institute, 2005). The purpose of this article is to: (a) describe the development of the Fertility and Cancer Project (FCP), an Internet approach to provide young breast cancer survivors with supplemental information about fertility; (b) describe FCP participants, fertility knowledge, and Internet use; and (c) assess perceived information and support from the oncology team.

Purpose/Objectives: To describe the development of the Fertility and Cancer Project (FCP), an Internet approach to supplement information about fertility; describe FCP study participants' characteristics, fertility, cancer knowledge, and Internet use; and assess perceived information and support from the oncology team.

Design: Descriptive.

Setting: Internet, international.

Sample: 106 young survivors of breast cancer from eight countries.

Methods: FCP content was developed from the literature and interviews with breast cancer survivors, oncology professionals, and young women without cancer who were having fertility problems. Participants learned about the FCP through advocacy groups, cancer care providers, and Web searches. After enrollment, they completed five surveys: sociodemographic, breast cancer and health status, knowledge of fertility, Internet use, and the Medical Outcomes Study–Social Support Survey.

Main Research Variables: Sociodemographics, breast cancer, health status, fertility knowledge, Internet use, and social support.

Findings: Prior to diagnosis, most survivors had no fertility concerns, but more than 14% reported fertility problems. Following breast cancer diagnosis and treatment, 23 reported fertility problems. About half reported receiving little information about fertility options from the oncology team and were referred to a reproductive endocrinologist. Internet use to obtain support and health information was common. Most reported frequent computer use and Internet access in their homes. Participants were most knowledgeable of the general and treatment-related factors that could affect fertility; they were least knowledgeable of infertility treatment.

Conclusions: Results provide preliminary evidence about the demographic, cancer treatment, and support characteristics of young survivors of breast cancer who seek online information about fertility.

Implications for Nursing: The Internet is a promising format for engaging young cancer survivors who seek information about fertility and cancer. Future studies can evaluate FCP effectiveness in delivering education and support interventions.