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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.

Development of the Fertility and Cancer Project

The FCP is a dedicated research project that focuses on electronically delivered education about reproductive health and fertility. Though the project is described briefly elsewhere (Dow Meneses & McNees, 2007), detail on the development of FCP content is provided in this article. FCP content was derived through literature review, clinical experiences, and extant research on fertility and pregnancy outcomes in young survivors of breast cancer. Sixteen informational themes were developed and presented within five major modules: (a) normal reproductive function, (b) factors affecting fertility, (c) assisted reproductive technologies, (d) elements of an infertility workup, and (e) alternative parenting options (see Figure 1). Informational themes and modules were revised through an iterative process in which content experts, including breast cancer survivors, young women with infertility problems, and oncology professionals, reviewed the information and provided feedback for clarity and improvement.

Methods

Recruitment

A descriptive research design was used to examine the main research variables. Following study approval from the institutional review board, investigators used a combination of traditional and electronic recruitment methods. First, a one-page study announcement that contained information about the FCP's purpose and registration process was developed for distribution by an advocacy group at its annual national meeting. Second, the one-page flyer was converted into an electronic announcement for inclusion on the advocacy group Web site and FCP home page. Keywords such as *fertility*, *breast cancer*, *child*, and *pregnancy* were added to the domain name. Third, the electronic announcement was e-mailed to more than 200 oncology professionals, who were asked to forward the announcement to breast cancer advocacy organizations, young breast cancer survivors, and other interested individuals.

Participant Eligibility and Inclusion

A checklist was developed to help potential FCP participants determine eligibility. Interested participants were required to check each eligibility requirement contained within an electronic box. Inclusion criteria included being aged 18–50 years, having a personal history of breast cancer, being able to communicate in English, and having access to the Internet.

Several scenarios of proxy personae were developed to address those inclined, though not eligible, to register and enroll in the FCP. The first proxy persona was an

Module Content

- Normal reproductive function
 - Female reproductive cycle
- Factors affecting fertility
 - Age and fertility
 - Weight and fertility
 - Smoking and other health problems
 - Breast cancer and fertility
- Assisted reproductive technologies
 - Fertility options before chemotherapy
 - Assisted reproductive technologies
 - Egg and sperm donation
 - Concerns with breast cancer
 - Pregnancy after breast cancer
 - Having children after breast cancer
- Elements of an infertility workup
 - The infertility workup
 - Selecting an assisted reproductive technology program
 - Infertility counseling
- Alternative parenting options
 - Surrogacy and gestational carriers
 - Adoption and child-free living

Web Site Sections

- Home page
- Questionnaires
- Patient education modules
- Bulletin board
- Ask the research team
- Glossary
- Online resources

Figure 1. Fertility and Cancer Project: Major Themes and Module Content

interested friend or relative. The researchers included a question-and-answer statement that if a person was a friend or loved one, he or she could forward the Web address directly to a loved one. A second proxy persona was a professional or clinician who might wish to examine FCP content and enroll as a subject.

Several oncology professionals (e.g., oncologists, nurses, social workers) expressed interest in reviewing the FCP Web site before they referred their patients to the project. The FCP technology team devised a strategy for professional review and referral, while at the same time ensuring confidentiality of FCP participants. This technique was premised on the development of a "mirror" site, which was an exact duplicate of the live electronic site that allowed professionals to examine the FCP and navigate through the educational content, but access to study questionnaires was restricted.

The third proxy persona was an individual surfing the Web. Though unlikely that a fertility and cancer Web site is at the top of any list for intentional havoc-wreaking, an "ethical caution" statement was created. The ethical caution statement contained strong language requesting that ineligible subjects refrain from registration and enrollment. It further stressed that educational resources provided by the FCP were designed to have beneficial impact and that fictitious or spurious data could harm

the chances that women would receive benefit from the research. The ethical caution strategy worked well; no incidents of inappropriate registration and enrollment are known or suspected.

Electronic Informed Consent and Enrollment

After participants determined their eligibility and agreed to the ethical caution, they gave electronic informed consent and received a unique user identification and password. They also had an opportunity to ask questions via e-mail or telephone. Participants then were asked to complete five self-report questionnaires. Upon completion, FCP participants could navigate through the educational content at their own pace and post questions and concerns to the FCP research team.

Outcome Measures and Instruments

Sociodemographic questionnaire: A descriptive questionnaire consisted of 10 items related to sociodemographics (e.g., residency, age, race, ethnicity) and the referral source for the FCP Web site.

Breast Cancer Treatment and Health Status Questionnaire (BCTHS): This questionnaire was developed by the investigators to gather descriptive information on breast cancer treatment, health, and fertility status. The BCTHS contained 20 multiple-choice questions relating to breast cancer (e.g., status, time since diagnosis), breast cancer treatment (e.g., type of surgery, chemotherapy), health status (e.g., weight, smoking status, health status), and self-reported fertility and children status (e.g., fertility concerns and options, natality).

Knowledge of Fertility Scale: This questionnaire was developed by the investigators to gather information about fertility knowledge prior to participation in the FCP. It contained 22 questions directly related to the five educational modules contained in the FCP. Items were scored on a scale of 1–3 (1 = a little, 2 = some, 3 = a lot) with regard to factors affecting fertility, infertility workup, and other options for parenting. Content validity of the questionnaire was established through literature and expert review. Internal consistency was high (Cronbach alpha = 0.89) in the FCP sample.

Computer Usage Questionnaire (CUQ): This 12-item questionnaire was developed by investigators to gather data describing general computer and Internet use, including the amount of time spent accessing cancer and fertility information and peer support. Content validity for the CUQ was established through interviews with young survivors of breast cancer and a literature review.

Medical Outcomes Study–Social Support Survey (MOS-SSS): This 20-item measure of perceived availability of social support (Sherbourne & Stewart, 1991) has been widely accepted as a valid and reliable instrument. The instrument contains four functional support scales (i.e., emotional/informational, tangible, affec-

tionate, and positive social interaction). Nineteen items are rated on a five-point Likert scale, with anchors of “none of the time” and “all of the time.” One item asks about the number of support people available. Possible scores range from 19–95. Higher scores are indicative of higher levels of perceived availability of social support. Subscale reliability is greater than $r = 0.91$.

Data Analyses

Questionnaire data were summarized. Exact confidence intervals for proportions of interest were calculated. Differences in reported time spent online for fertility issues versus cancer issues were tested with nonparametric methods (Wilcoxon signed-rank tests) because of the observed skewness of the distribution of reported times. Differences in reported experience using the Internet with respect to fertility issues versus cancer issues also were tested with nonparametric methods because of the ordinal yet limited range of responses. Use of Internet forums on fertility issues versus cancer issues was tested with McNemar’s test. Difference in overall MOS-SSS score between FCP participants and MOS participants was tested with a two-sample *t* test assuming unequal variances. The relationship between MOS-SSS subscale and overall scores and perceived emotional support from the oncology team was examined with reference-cell analysis of variance.

Results

The FCP enrolled 106 international participants (101 of which reported their countries of residence) representing eight countries (Australia [$n = 9$], Canada [$n = 4$],

Table 1. Age at and Time Since Breast Cancer Diagnosis

Characteristic	n	%
Age at diagnosis (years)		
20–25	6	6
26–30	16	16
31–35	57	57
36–40	16	16
41–44	5	5
Time since diagnosis (months)		
Less than 6 months	32	31
6–12 months	18	17
12–24 months	11	11
24–48 months	29	28
More than 48 months	13	13

Note. Study instruments were filled out online by study participants. Some participants filled out the entire set of instruments, whereas others completed only some instruments or skipped questions. Therefore, *n* values are item-dependent. Percentages correspond to those who answered each respective item.

Note. Because of rounding, not all percentages total 100.

Table 2. Participants' Reported Knowledge of Factors Influencing Fertility

Factor	A Little		Some		A Lot	
	n	%	n	%	n	%
Reproductive factors						
Female reproductive cycle	13	13	41	41	46	46
Follicular phase	63	63	24	24	13	13
Ovulatory phase	45	45	31	31	24	24
Luteal phase	72	72	16	16	12	12
General factors affecting fertility						
Age	12	12	38	38	50	50
Obesity	36	36	37	37	27	27
Smoking	24	24	24	24	52	52
Cancer-related factors affecting fertility						
Breast cancer	22	22	41	41	37	37
Chemotherapy	21	21	33	33	46	46
Radiation therapy	51	51	34	34	15	15
Hormonal therapy	46	46	33	33	21	21
Infertility treatment and resources						
Assisted reproductive technology	57	57	29	29	14	14
Infertility workup	71	71	19	19	10	10
Egg, embryo, and sperm donation	56	56	29	29	15	15
Surrogacy and gestational carriers	80	80	14	14	6	6
Adoption alternatives	62	62	22	22	16	16
Child-free living	69	69	20	20	11	11
Fertility online resources	62	62	30	30	8	8

N = 100

India [n = 1], Netherlands [n = 2], South Africa [n = 1], Taiwan [n = 1], the United Kingdom [n = 1], and the United States [n = 82; 81%]. Participants' mean age was 34.3 years (SD = 4.38; range: 25–45 years). The vast majority were Caucasian (n = 87; 86%) or Hispanic or Latino (n = 5; 5%) and had a college education (n = 89; 88%). Most were working full-time (n = 76; 75%), and almost two-thirds (n = 67; 66%) reported family incomes greater than \$50,000. Participants learned of the FCP through advocacy groups (n = 68; 67%), Web searches (n = 10; 10%), researchers (n = 8; 8%), and support people (n = 15; 15%).

Cancer Treatment, Health, and Fertility Characteristics

Age at time of diagnosis and time since diagnosis are summarized in Table 1. Mean time since diagnosis was 22.2 months (SD = 23.3 months; range = 1–95 months). Most participants were either currently receiving therapy (n = 41; 38%) or had completed treatment (n = 51; 48%). However, 15 (14%) were newly diagnosed and had not yet started treatment. Surgical treatment included mastectomy (n = 20; 19%), bilateral mastectomy (n = 25; 23%), and partial mastectomy (n = 51; 48%). About half (n = 54; 51%) reported having received radiation therapy. Chemotherapy with cyclophosphamide was common (n = 54; 51%). Of those who received

cyclophosphamide, 24% (n = 13) indicated no change in menstrual cycles, 48% (n = 26) had either irregular periods or amenorrhea, and 27.7% (n = 15) experienced menopausal symptoms. Thirty-eight (36%) received hormonal therapy with tamoxifen.

The majority (95%) reported excellent to very good health status. Weight gain was common, with more than half (n = 55; 53%) reporting weight gain during treatment. About one-third (n = 35; 33%) had a history of smoking tobacco, and 7 (7%) currently smoked. Of the 55 reporting weight gain, 26 gained 1–10 pounds, 17 gained 10–20 pounds, and 12 gained more than 20 pounds.

Prior to diagnosis with breast cancer, 30 (28%) had fertility concerns, and an additional 15 (14%) had fertility problems. Following diagnosis and treatment, 25 (23%) reported fertility problems. About half (n = 55; 53%) indicated that they were given "some" to "a lot" of information about fertility options by their oncology team, though only 22% (n = 23) were referred to a reproductive endocrinologist. Most (n = 72; 73%) did not have children before their breast cancer diagnoses. Of those who had children before breast cancer, 22 (76%) had one child, 6 (21%) had two children, and 1 (4%) had three children.

Knowledge of Fertility

In general, participants were knowledgeable about normal and cancer-related factors that could influence fertility, but less so of assisted reproductive technology. Table 2 summarizes participants' fertility knowledge at entry into the study.

Participants' Experiences Accessing Internet Information

Almost all participants (n = 99; 98%) reported computer use, with the vast majority (n = 94; 93%) having Internet access within their homes. Internet use to read about breast cancer (n = 85; 84%) was more common than use to read about fertility (n = 62; 61%) ($p < 0.001$). Participants' experiences accessing Internet health information are summarized in Table 3.

Perceived Information and Support

Although 24% (95% confidence interval = 15.5, 33.1) reported receiving sufficient emotional support from their oncology care providers, only 11% (95% confidence interval = 5.4, 18.3) believed that they received sufficient information about fertility preservation. Mean MOS-SSS scores

Table 3. Participants' Experiences Accessing Internet Information

Experience	Cancer Information		Fertility Information	
	n	%	n	%
Did not find relevant information	3	3	18	18
Found some information	23	23	59	58
Found most information; it was scattered and took long.	42	42	16	16
Found most information in one place but it took long.	11	11	3	3
Found most information in one place and fast	18	18	3	3
Found all information needed	4	4	2	2
N = 101				
Note. Because of rounding, not all percentages total 100.				

and MOS-SSS scores by perceived emotional support from the oncology team are listed in Table 4. Participants who perceived greater emotional support from oncology providers had significantly higher MOS-SSS scores on the overall scale ($p = 0.001$), as well as the emotional/informational ($p < 0.01$), affectionate ($p = 0.012$), and social interaction subscales ($p = 0.02$). Internet use was partially related to MOS-SSS scores. The researchers found no significant relationship between MOS-SSS scores and use of online forums or online experiences with fertility issues, but a significant association was found between overall MOS-SSS scores and online experiences with breast cancer issues. Participants with better experiences finding information and support online on breast cancer issues reported significantly higher mean overall MOS-SSS scores ($p = 0.01$), emotional/informational ($p = 0.03$), tangible ($p = 0.028$), and affectionate subscales ($p = 0.02$).

Discussion

Preliminary findings from the FCP contribute to the body of knowledge of young survivors of breast cancer and their experiences searching for health information about fertility. First, young breast cancer survivors actively use the Internet to seek fertility information. Despite being educated and having above-average incomes, many young survivors did not have ready access to fertility information through traditional sources. About three-quarters of participants learned of the FCP through online advocacy groups and Web searches, suggesting that young survivors of breast cancer frequently use the Internet to gain information and network with other cancer survivors. Unfortunately, though young women seek

information about cancer treatment and fertility, they often cannot access it readily.

Second, FCP participants seeking fertility information were doing so after treatment had ended. Ideally, the most beneficial time to receive health information is prior to treatment, when more fertility-sparing options are available (Jeruss & Woodruff, 2009). Participants' mean age was 34.3 years, an age in the general population of young women when advancing age has a strong influence on fertility outcomes (Raines, 2004). Though only 24% reported no change in menstrual cycle, most reported either amenorrhea or menopausal symptoms. For those receiving tamoxifen, pregnancy must be postponed for five years. Thus, some FCP participants are highly likely to experience infertility.

Third, the vast majority reported excellent to very good health status. However, major factors influencing

Table 4. Medical Outcomes Study–Social Support Survey Mean Scales

Scale ^a	Perceived Emotional Support From Oncology Team					p ^b
	All Participants (N = 98)		Little (n = 28)	Some (n = 47)	Sufficient (n = 23)	
	\bar{X}	SD	\bar{X}	\bar{X}	\bar{X}	
Overall	73.2	19.2	63.7	73.9	82.9	0.0013
Emotional or informational support	69	19.5	59.1	69.4	80.1	0.004
Tangible support	74.2	25.5	66.1	74.6	83.4	0.0522
Affectionate support	80.7	25.7	69.9	82.1	90.4	0.0117
Positive social interaction	75.3	22.6	66.1	77.1	82.6	0.023
N = 98						
^a Range = 0–100. Higher scores indicate greater perceived support.						
^b One-way analysis of variance						

fertility outcomes in any young woman are weight gain, obesity, and smoking status. More than half of the participants gained weight while on treatment, and about half of those women gained more than 10 pounds. Sustained post-treatment weight gain may increase the likelihood of poor fertility outcomes (Raines, 2004). Those currently smoking also are more likely to experience poor fertility and pregnancy outcomes (Raines, 2004).

Fourth, the incidence of infertility (approximately 14%) prior to breast cancer diagnosis is similar to the national average of 12% (American Society for Reproductive Medicine, 2006). Healthcare providers should acknowledge the possibility of preexisting infertility during any discussions with young survivors of breast cancer. On the positive side, about half of the participants indicated that they were given information about fertility options by the oncology team, though far fewer were referred to a reproductive endocrinologist. With the growing number of reproductive endocrinologists experienced in the care of cancer survivors, all young women would benefit from early referral when more reproductive options are available (Oktay et al., 2005).

Many of the young survivors in the FCP had already given birth to at least one child. An important clinical implication is that assumptions of the importance of fertility preservation should not be made based on prior obstetrics history. Rather, all young women should be provided with comprehensive health information to allow informed decisions regarding fertility preservation.

Fifth, FCP participants' knowledge about general (e.g., female reproductive cycle, smoking, weight gain, obesity) and cancer-specific (i.e., surgery, radiation therapy, chemotherapy, hormonal therapy) factors influencing fertility was good. Specific knowledge about assisted reproductive technologies and alternatives to child bearing (e.g., surrogacy, adoption, child-free living) was limited (see Figure 2). This knowledge gap could be filled through use of the electronic environment to engage young survivors of breast cancer in educational interventions that will supplement information provided by oncology healthcare professionals. Preliminary findings indicate that additional tangible information and support regarding fertility concerns are needed and actively sought by young survivors of breast cancer.

FCP participants derived social support from their oncology providers. Specifically, FCP participants who perceived greater emotional support from their oncology care providers had significantly higher MOS-SSS scores on the overall scale and across all subscales.

However, only 11% received sufficient information about fertility, indicating differences between types of social support and informational support.

Implications for Future Research

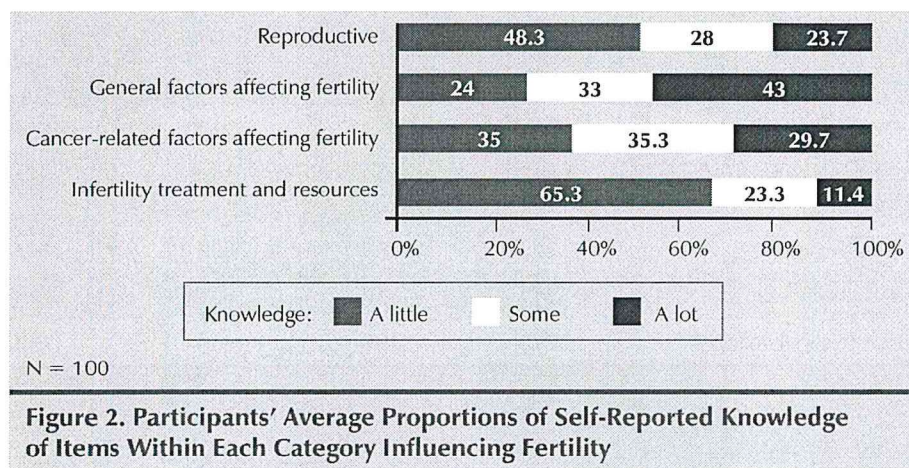
Innovative fertility education and support approaches clearly are needed for all young survivors of cancer. The FCP's Internet-based approach for young survivors of breast cancer may be a model for other fertility education directed to other young survivors.

The Knowledge of Fertility Scale performed well in this study. Additional testing in larger and more diverse populations is needed to further validate its use with other young survivors of breast cancer.

Young women are a population known to consistently use the Internet for health information and peer support (Bowen, 2003; Duffy et al., 2005; Mayer et al., 2007; Owen et al., 2005). Internet use to access health information has known benefits that include increased confidence to be an active participant in care and increased satisfaction with health care (Bowen, 2003; Mayer et al., 2007). Those using the Internet to gather health information are likely to be highly educated, to be Caucasian, and to have private health insurance (Canada & Schover, 2005; Mayer et al., 2007); findings from this study are similar. Future research examining barriers to Internet use by other populations of young survivors is needed to ensure equal access to this beneficial source for health information and peer support.

Resources for Practitioners

The most influential and trusted source for information during cancer treatment is the oncology healthcare team (van de Poll-Franse & van Eenbergen, 2008). Oncology care providers can meet the fertility preservation informational needs of young women through a comprehensive discussion of options and referral to an infertility endocrinologist when indicated. Providers can further supplement information with referral to other high-quality sources for



support and information, such as professional organizations and advocacy groups (see Figure 3).

Limitations

Findings are from a small, self-selected sample of young survivors of breast cancer who learned of the program through an advocacy organization. Nonetheless, the Internet is a viable medium for delivering high-quality health information to young cancer survivors. Second, FCP participants are similar to other cancer survivors using the Internet—largely Caucasian, well educated, and with economic resources. Furthermore, FCP participants comprise a sample of those who are motivated, have computer skills, and have Internet access. Generalization of findings to other young survivors is not possible.

Conclusion

High-quality information about fertility and fertility preservation is a vital area of concern for young survivors of cancer. Based on the knowledge about general fertility, factors affecting fertility, breast cancer and fertility, infertility workup, and other parenting options, more information directed to young survivors of breast

American Society for Reproductive Medicine
www.asrm.org
American Society of Clinical Oncology
www.asco.org
Fertile Hope
www.fertilehope.org
Young Survival Coalition
www.youngsurvival.org

Figure 3. Referral Resources

cancer is warranted. Evaluating the benefit of alternative means to provide this information, such as the Internet, may be helpful for future young survivors and oncology healthcare professionals.

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