Research Promoting Better Patient Education on Reproductive Health After Cancer

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Although research on cancer survivors’ experiences and attitudes about infertility is relatively new, existing literature suggests that only about half of men and women of childbearing age receive the information they need from their health care providers at the time of diagnosis and treatment planning. Thus, better patient education strategies are needed. Although the ideal would be to have oncologists conduct detailed discussions of options to preserve or restore fertility with all interested patients, this standard is unrealistic. A more practical alternative is to train nonphysician providers such as nurses and social workers to address this topic. In addition, innovative strategies of direct patient education could be helpful, including use of computerized media, peer counseling, or special educational modules tailored to a particular age group or cancer site. [J Natl Cancer Inst Monogr 2005;34:98–100]

INTRODUCTION

Increasing attention has been given to fertility as an important aspect of quality of life after cancer; however, a substantial proportion of young men and women report that they were not informed about the potential effects of their cancer treatment on the ability to father or bear children. In two surveys of survivors diagnosed with cancer in young adulthood (1,2), less than 60% of respondents were able to recall someone from their medical team discussing cancer-related infertility. Other topics that had not been addressed with female survivors included pregnancy as a health risk after cancer (two-thirds of women were not able to recall a discussion) and potential pregnancy complications related to cancer treatment (47% could not recall a discussion). Birth defects in children born after cancer treatment and lifetime cancer risks for children were also areas of concern in both surveys, but less than half of the survivors had discussed these issues with a physician.

These data are compatible with another recent survey of 657 women diagnosed with localized breast cancer before the age of 40 years (3). Infertility was an important concern at the time of treatment disposition for 57% of the women, and it actually affected treatment decisions for 29%. At the time of the survey, the median time since diagnosis was 1–2 years for this predominantly Caucasian (90%) and college-educated (76%) sample. Although 72% had discussed infertility with their physician, and 17% had consulted an infertility specialist, only 55% were satisfied that their concerns about childbearing had been addressed.

PHYSICIAN-INITIATED INFERTILITY COUNSELING

Encouraging oncology health care providers to initiate discussions of cancer-related infertility with all potentially affected
patients is one obvious way to remedy the lack of information exchange. However, given the complex demands to provide new information to patients in oncology clinics, this is not very realistic. Studies of outpatient visits to primary care physicians show an average duration of only 9–12 minutes, with much more time spent on the physical examination and treatment planning than on health education and behavioral counseling (4,5). In fact, a survey of 162 oncologists in two major cancer centers showed that although over 90% agreed that all men whose fertility could be impaired by cancer treatment should be offered an opportunity to bank sperm, almost half of the physicians never or rarely addressed this topic with their eligible patients (6).

A more practical solution is to train oncology nurses or social workers to address the topic of infertility with all new patients as well as to assess ongoing needs for information at follow-up visits with those interested in having future children. These health care providers can also refer patients to educational materials such as pamphlets, books, or computerized media and can facilitate timely referrals for cryopreserving gametes or gonadal tissue before cancer treatment or considering other fertility-sparing treatment modifications.

DIRECT PATIENT EDUCATION

It is also important to use innovative ways of providing information directly to newly diagnosed young men and women and to longer-term survivors who are ready to make decisions about becoming parents. Our group has been working on several projects designed to educate patients and families about reproductive issues after cancer.

Computerized Interactive Media: Banking on Fatherhood After Cancer

As discussed above, although most oncologists agree that sperm banking should be offered to all eligible men (7–12), few oncologists report attaining this standard in practice (6). Furthermore, even though a significant number of younger males desire to parent as cancer survivors, less than a quarter of eligible men actually bank sperm, even in sophisticated cancer centers (1,2). One of the most common reasons men give for failing to bank sperm is that they did not receive needed information on the topic before starting cancer treatment (1,2). To provide a better resource, we have created a computerized, interactive, educational tool for patients, families, and physicians called Banking on Fatherhood after Cancer. It will be viewable on CD-ROM or over the Internet.

Computer-based interventions can be accessed by English-speaking all over the world; can help health providers and patients understand emotionally charged issues such as semen collection, advance directives for stored gametes, cost–benefit ratios, and cultural or religious norms about assisted reproductive technology (13); and can save provider time in a busy medical clinic setting. Justification for use of this media with patients includes research findings that computer-based interventions are more effective than traditional print in promoting knowledge about health and in overcoming barriers to learning such as low literacy levels (14–16) and can be more easily tailored than traditional printed and graphic media to answer individuals’ specific questions (17–20).

Peer Counseling: Sisters Peer Counseling in Reproductive Issues After Treatment

For the 25% of women whose breast cancer is diagnosed before menopause, cancer treatment brings concerns about infertility, health of offspring, and risk of cancer recurrence with pregnancy. Decisions about childbearing after breast cancer can be complex and emotionally painful (21,22). African-American survivors may be particularly vulnerable to reproductive stressors after breast cancer. Before age 45 years, they have a higher incidence of the disease than any other ethnic group (23), yet they are less likely to seek help for fertility problems (24). Economic hardship and lack of access to medical care may limit the amount of information and services regarding reproductive health received by African-American breast cancer survivors (25). Because African-American women are more likely to consult female family members than health professionals for advice on women’s health issues (26), we have designed a peer counseling intervention focused on the African-American breast cancer survivors. This project is being conducted in partnership with the Sisters Network, a national advocacy organization of African-American breast cancer survivors, from whose membership we have recruited and trained volunteer peer counselors. The intervention itself consists of structured, individual counseling sessions, guided by the content of a workbook designed specifically for this study. The workbook includes information and coping strategies related to menopause, sexuality, fertility, safety of pregnancy after breast cancer, health of offspring, and recognizing inherited breast cancer in a family. A successful pilot trial has been completed, and a national randomized trial is in progress.

Targeted Patient Education: The Adolescent and Young Adult Study

Aggressive multimodal therapies for cancer have become increasingly successful in preserving life in the adolescent and young adult population. Along with such progress, however, there is growing concern about the delayed effects of treatment on the physical, psychological, and social development of survivors. Although cancer in adolescence/young adulthood is not associated with unusual rates of emotional disorders (27–30), there is some indication that the cancer experience may present both physical and psychosocial threats to healthy sexual development (31–34). Failure to address such threats may lead to long-term difficulties with sexual self-image and future roles (e.g., marriage and parenthood) (35).

We have created and are currently evaluating a brief counseling intervention to address this need. The Adolescent and Young Adult Study includes education, dialogue, and support relevant to cancer and the physical, emotional, and social aspects of sexuality and fertility. As in the Sisters Peer Counseling in Reproductive Issues after Treatment project, participants receive an educational workbook designed specifically for the study, but with the teens, the counseling sessions are conducted by a clinical psychologist. The research design involves random assignment of participants—young men and women ages 15–25 years old who have been diagnosed with cancer within the last 5 years—to receive the intervention immediately or to be placed on 3-month wait-list, after which time they receive the intervention. Preliminary results indicate that fertility is the most salient concern in this population, especially
for females, and that the intervention is able to decrease associated distress.

CONCLUSION

As cancer survivors become more assertive about their medical care, ignoring the risk of infertility will no longer be acceptable in oncological practice. Whether information is delivered via health care providers or directly by media geared to educate patients and healthcare professionals. Patient Educ Couns 1999;36:99–105.


Psychosocial Issues of Adolescents and Young Adults with Cancer. Soc Work Health Care 1998;27:3–18.


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