



Original article

The Desire for Children and Fertility Issues Among Young German Cancer Survivors

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 A B S T R A C T

Purpose: For young cancer patients, family planning is not always completed at the time of cancer diagnosis. This study investigated young cancer patients' desire to have children, its intensity, and their discussion with oncologists and fertility specialists about fertility. Furthermore, gender differences, differences between childless patients and patients with children, and correlations with psychological distress were analyzed.

Methods: A total of 149 cancer patients (range, 18–45 years of age) answered a self-developed questionnaire. Psychological distress was measured with the Patient Health Questionnaire.

Results: Seventy-four percent of patients had a desire to have children at the time of diagnosis. Whereas the intensity of the desire for children increased pre- to post-treatment in childless patients, it decreased in patients who already had children. A total of 55 patients who wanted a child (50%) needed supportive care concerning this issue; 60% of the total sample had discussed fertility aspects with their oncologists and 20% with fertility specialists. Patients reported higher levels of satisfaction with their discussions with fertility specialists than with their discussions with oncologists. Men (56%) underwent fertility preservation more often than did women (31%). Female sex was the only variable predicting psychological distress, whereas parenthood, fertility preservation, and desire for children had no significant impact.

Conclusions: The desire to have children and the fertility issues involved are important for young cancer patients. Reasons for not discussing fertility aspects with oncologists and the cause of low referral rates to fertility specialists should be explored in future studies. The implementation of structured psychosocial supportive care might address the needs of highly fertility-distressed patients.

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 IMPLICATIONS AND
 CONTRIBUTION

The desire to have children and fertility aspects are essential for young cancer patients. These aspects should be considered appropriately in patients who are treated for cancer, and the possibility of fertility preservation should be addressed more often. Specified interventions, including fertility issues, should be offered to young cancer patients.

A cancer diagnosis and the resulting medical treatments in young adulthood can lead to restricted fertility or even infertility. In general, the number of young people who survive cancer is increasing. Currently, the 5-year survival rate for this age group

(15–39 years) displays a heterogeneous distribution ranging from 23% for stomach cancer to 99% for thyroid cancer, with an overall average of 80% [1–3]. As such, most young cancer survivors end up living with the effects of cancer for a long time. Because restricted fertility can be among these long-term effects, patients' life plans of family planning may have to be reconsidered, adapted, or developed anew.

Because up to 70% of young cancer patients want to have a child [4–6], fertility is an important topic for them [7–10]. At the same time, several studies have shown that the probability of

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young cancer patients having children is reduced in contrast to the general population. Women are more affected than men [11–13]. Fertility preservation is often the only possibility for cancer patients with a high risk of infertility to have children in the future [14,15].

In 2006, FertiPROTEKT, a network of 80 university-based, hospital-based, and private infertility and oncology centers was established in Germany [16,17]. The goal of the network is to provide fertility preservation to all cancer patients who want it, which is currently the best method of enabling future parenthood. All centers have to document their cases; every year, statistics from the registry are published, including details of treatments given, complications, and pregnancies. To date, patients in Germany have to cover the costs of fertility preservation themselves. Only the costs of gonadotropin-releasing hormone (GnRH) agonists are financed by health insurance companies. Cryopreservation of fertile eggs costs about 3.000€ (4.050 USD), cryopreservation of sperm about 350€ (470 USD), and storage of either about 250€ (335 USD) a year. The costs are thereby comparable to those in the United States [18].

Prompt and adequate discussion concerning possible fertility reduction as a result of cancer and/or medical treatment is necessary to protect patients' fertility options. Tschudin and Bitzer [19] concluded in their review that young patients were not sufficiently informed about their fertility risks and the possibilities of fertility preservation. In our overview [20] of conversations between physicians and patients, we found that only about half of young patients discuss fertility aspects with oncologists. The American Society of Clinical Oncology asserted that discussing fertility leads to improved quality of life and decreased distress in all cancer patient populations [21]. The German Society of Hematology and Medical Oncology published the *Guideline for Adolescents and Young Adults* in 2011. This guideline acknowledges that information about infertility risks should be part of the patient–physician conversation before starting treatment [2]. However, there is no directive dictating what information patients should receive. For more details, patients in Germany can obtain information on the Home page of the Web site www.fertiprotekt.eu, or from the brochure *Having Children After Cancer*, from the German Cancer Aid [22]. Most clinics are able to refer patients directly to fertility specialists. Barriers mentioned in the British study by Gilbert et al. [23], such as great distances, long waits, and high levels of bureaucracy, may be less of an issue in Germany.

Fertility issues and the frequency of referrals to fertility specialists of young cancer patients were analyzed in previous studies. However, there is no information regarding young patients in Germany. The aim of the present study was to fill this gap. In the current study, patients' subjective perception of their desire for a child, their fertility, and their prospective parenthood were examined. As a result, we explored the need for support of young cancer patients in relation to their desire to have a child. Furthermore, we defined differences between patients with and without children, gender differences, and correlations between the desire to have a child and psychological distress.

Methods

Design

This was a cross-sectional study of cancer patients between 18 and 45 years of age, who completed acute medical treatment. The patients were recruited between September 2011 and April

2012 and surveyed at a single time point. Every participant signed a written informed consent form. The study was approved by the local Ethics Committee of the University of Leipzig (Medical Faculty).

Procedure

We used several methods, with the aim of recruiting a high number of patients.

Method 1. A total of 139 patients at the University Medical Center Leipzig, between 18 and 45 years of age, were contacted, informed about the study, and invited to participate. Patients who agreed to participate were sent a questionnaire by post. Forty-nine patients remained unresponsive after several unsuccessful phone contact attempts. Reasons for nonparticipation were: deceased ($n = 6$), address unknown ($n = 12$), and no interest in the study ($n = 5$). The response rate was 59.4% ($n = 79$).

Method 2. Patients at the breast cancer center at the Westend Hospital in Berlin were recruited during aftercare visits, which took place every 3 months. Study information was given via flyers and face-to-face with the physicians. Each patient between 18 and 45 years of age was asked to participate; none refused (response rate, 100%). Thirty-two patients were given the questionnaire directly by the hospital staff and returned the questionnaire by mail using the attached stamped, addressed envelope.

Method 3. Patients who were in rehabilitation between January and April 2012 in Bad Oeynhausen and Bad Oexen (German specialized rehabilitation clinics for cancer patients between 18 and 32 years of age) were informed about the study and given the flyer. Patients interested in participating were then given the study materials. Participants delivered the completed questionnaire in a closed envelope to the clinics. This effort yielded 30 completed questionnaires.

Method 4. We also reached out to patients via local press releases and relevant Web pages. Interested patients ($n = 8$) contacted us and were sent the study materials.

Instruments

In addition to assessing sociodemographic and illness-related medical information (Table 1), various self-developed questions were administered. A standardized questionnaire to measure psychological distress was also used.

The self-developed questions rated on 2- or multiple-point scales the desire to have children, the intensity of the desire for children, discussions with physicians and fertility specialists, and fertility preservation. Table 2 presents the items used and their response formats.

We measured psychological distress using the Patient Health Questionnaire. The ultra-brief screener combines two validated two-item screeners for depression and anxiety. A total score is determined by adding together the scores for all four items. Scores are rated as normal (0–2), mild (3–5), moderate (6–8), and severe (9–12). Internal consistency is acceptable ($\alpha = .78$) [24,25].

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