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European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Medical consultations about fertility preservation with haematological patients of childbearing age: A qualitative study

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ARTICLE INFO

Article history:

Received 22 September 2014

Received in revised form

3 August 2015

Accepted 22 September 2015

Keywords:

Fertility preservation

Oncology

Physician–patient-communication

Qualitative research

Desire to have a child

Childbearing age

ABSTRACT

Purpose: Oncological treatments can cause serious long-term consequences, including effects on patients' fertility. Communication about possible fertility impairment is essential for cancer patients who want to have children. When oncologists initiate this discussion in a timely manner, patients can be referred to fertility specialists and avail themselves of fertility preservation methods. The oncologist plays a key role in this context.

Methods: 30 cancer patients of childbearing age (21–43 years) took part in semi-structured interviews between March 2011 and April 2012 about fertility and their desire to have children. Interview transcripts were thematically analyzed.

Results: Physician–patient consultations broached the issue as a central theme in almost all patients. A few consultations were patient initiated, and the majority took place before the beginning of treatment. Almost half of the patients were satisfied with their consultations and were referred to a fertility specialist. The ideal setting for these conversations is in the presence of the patient's partner, in a private space, before the beginning of treatment.

Conclusions: All patients should be informed about the possibility of their fertility being impaired due to treatments, even if they have not explicitly expressed wanting children. The oncologist is the first and most important contact for the patient and, hence, should bring up the issue of family planning and fertility. An interdisciplinary communication and collaboration between oncologists and fertility specialists can improve patient care.

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1. Introduction

Cancer is rather rare in younger adulthood; however, especially hematologic neoplasms can affect younger people. In Germany, around six percent people have a cancer diagnosis between 15 and 45 years (Robert Koch Institut, 2012). Approximately 13 percent of these diagnoses are hemato-oncological diseases, which often entail highly aggressive treatments to increase survival rates. These, however, can pose serious side effects such as fertility impairment (Nagel et al., 2009). But many patients have not finished family

planning at the time of diagnosis and reported a strong desire to have own children (Armund et al., 2014; Geue et al., 2014; Schmidt et al., 2014). According to this, information and discussion about fertility preservation with an oncologist are necessary.

Discussing the risk of infertility with cancer patients of childbearing age is, at least in Germany, still not standard practice although guidelines have been developed by special divisions of oncology like the German Society for Hematology and Oncology (DGHO) and recommended like the ASCO to discuss fertility preservation methods with every patient of reproductive age (Geue et al., 2011).

Furthermore, in 2006 the network “Fertiprotekt” was founded in Germany. This network is a collaboration of around 100 centers in Germany, Switzerland and Austria to pool the expertise of

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specialists in reproductive medicine, reproductive biology and oncology (Wolff et al., 2011). The aims of Fertiprotekt are to improve fertility preservation methods and to counsel all cancer patients before an oncological treatment. A registry was also developed which contains information of all treatments, complications, and pregnancies after fertility preservation.

There are a number of established fertility preservation methods that enable cancer survivors to have children. Fertility preservation treatments can only help however if patients are aware of them and are given access to reproductive medicine specialists. A study by Mancini et al. (2008) demonstrated that 30% of female and 13% of male patients had not undergone fertility preservation because they were unaware of its existence. Other studies have similarly documented the urgent need for young adult cancer patients to discuss their plans for parenthood, the possibility of infertility, and fertility preservation with their oncologists (Hill et al., 2012; Murphy et al., 2013; Niemasik et al., 2012).

Despite of these studies, Forman et al. (2010) showed that 95% of oncologists report that they routinely discuss the possible risk of infertility after treatment and 39% oncologists refer patients to reproductive endocrinologists. In a study of Armuand et al. (2012) 80% of males and 46% of females recalled having a discussion about fertility with an oncologist.

Quinn et al. (2015) investigated the documentation of fertility-related discussions at four cancer center institutions. The results indicated that only 26% discussions of infertility risks and 13% referrals to a fertility specialist were documented.

However, several studies have shown that patients do not feel that they are given enough information about possible fertility impairments resulting from planned treatments when they are first diagnosed (Penrose et al., 2012; Thewes et al., 2003; Yee et al., 2012). In a study of Ruddy et al. (2014), nearly one third of breast cancer patients do not remember discussing this issue with their oncologists.

The disclosure of barriers for not discussing fertility issues have been the subject of many studies. Shimizu et al. (2013) have shown that a high recurrence of cancer is the greatest barrier to avoid these discussions. In a study of Adams et al. (2013) 88% of the oncologists were influenced by a patient's poor prognosis. The urgent need of treatment, lack of time and knowledge about existing fertility preservation methods and socio-demographic factors such as partnership status, gender, insurance coverage or existing children represent other main barriers to address fertility preservation issues (Goodman et al., 2012; Joshi et al., 2014; Kumar et al., 2012). In contrast to the USA, health insurance is obligatory in Germany with a fee depending on income. Legal health insurances cover the administration of GNRH analogs and the transposition of ovaries. The collection and storage of gametes were not funded and must be paid by the patients themselves.

Due to the German Embryo Protection Act ("Embryonenschutzgesetz") which prohibits any manipulation such as freezing of human embryos, cryopreservation of oocytes and ovarian tissue is the only legal technique for storing gametes of women. This procedure is also not funded by health insurances.

Studies on patient consultations regarding fertility issues mainly come from the USA, UK, Australia or Canada. The present study provides an initial overview of the situation in a German sample based on the limited number of studies available that report on how physician–patient discussions about fertility take place in German oncological hospitals.

The following survey illustrates whether and in which way oncologists routinely discuss parenthood plans and fertility risks with their patients, which patients opt for fertility preservation treatments, and for which reasons. Additionally, the present study

will look into how an ideal consultation would best satisfy patients' expectations in this matter.

2. Methods

2.1. Procedure and sampling

Participants were recruited from three hospitals (two university medical centers and an urban medical center) in the German state of Saxony between February 2011 and May 2012. We contacted outpatients by post with a letter including written study information. Inpatients were recruited by health care staff during inpatient treatments.

We included patients aged 18–45 years with hematological malignancies (Hodgkin's and non-Hodgkin's lymphomas and leukemia) diagnosed within the previous three years who had plans to become parents at the time of diagnosis. Patients with chronic leukemia were excluded due to their specific disease pattern; other exclusion criteria included lack of knowledge of the German language as well as physical and mental incapacity. The patient group with hematological malignancies was chosen due to the higher prevalence rates in both sexes and across the whole age range. Furthermore, hematological neoplasms require medical treatments (such as total body irradiation) often predestined to affect fertility status (Wunder and Perey, 2012).

The recruiting process was documented only at the University Medical Center Leipzig. In this hospital, 120 patients were contacted, of whom 28 patients (23.3%) were eligible and consented to take part in the study. Two patients were recruited by other hospitals. Reasons for refusal were organizational considerations, lack of interest or the wish to forget the cancer disease.

All of the participants signed written informed consent forms before study entry.

We obtained approval (number 189-10-12072010) for the study from the local ethics committee at the University of Leipzig's Medical Faculty.

2.2. Interviews

We used a qualitative methodology to gain initial insight into physicians' consultations with hematological patients concerning parenthood and fertility in German clinical settings. A qualitative approach allowed a detailed analysis of this sensitive issue.

Participation entailed completing a semi-structured face-to-face interview. The interview was based on a guideline showing what questions need to be covered during the interview.

The interviewer follows the guide, but individual variations are also possible to explore particular themes or further responses when it is appropriate.

A researcher contacted patients willing to participate and arranged an appointment for the interview. The interviews were conducted by trained interviewers either at the hospital or at the patient's home. The interview guide was based on findings from previous studies and literature research. The guideline consisted of 30 self-developed questions and covered the following areas: initial diagnosis and course of treatment, attitude towards potential parenthood, consultation during oncological treatment about side effects regarding possible infertility, decision-making on fertility preservation, and ideal consultations about fertility.

2.3. Data analysis

Interviews were audio recorded and transcribed verbatim immediately afterwards. We used the qualitative content analysis according to Mayring, one of the best-established qualitative

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