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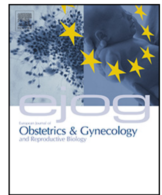

Characteristics and attitudes of women in relation to chosen fertility preservation techniques: a prospective, multicenter questionnaire-based study with 144 participants

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ABSTRACT

Objective: What are the patients attitudes about their fertility and about the counselling process at the time when fertility preservation counselling is performed?
Study design: A survey regarding fertility concerns and counselling performance in relation to the chosen fertility preservation procedure such as no treatment, GnRH agonists, and freezing of ovarian tissue or oocytes/zygotes was prospectively conducted in four university centres and one private centre, all belonging to the network *Ferti*PROTEKT in Germany and Switzerland.
Results: All women ($n = 145$) received a questionnaire at the first counselling appointment. The mean age of the patients was 30 years (±5.8, range 17–43 years). 91% were referred by their treating oncologists.

Single patients preferred invasive strategies, such as freezing of oocytes/zygotes (44.3%) or freezing of ovarian tissue (36%), whereas only 19.7% opted for no treatment/GnRH agonists. In married couples, the proportions were 28.9%, 31.1% and 40.0% respectively. Women without children also opted more frequently for invasive strategies, such as freezing of oocytes/zygotes (84.5%) or freezing of ovarian tissue (74.1%), and less frequently for no treatment/GnRH agonists (63.3%). Physical and psychological status, current and future fertility concerns and satisfaction with the counselling process were equal in all treatment groups.
Conclusion: As fertility concerns and attitudes about the counselling process were independent from the fertility preservation procedure chosen, the preferred treatment can hardly be predicted and therefore all women should be counselled about all possible fertility preservation techniques.
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Introduction

Q2 Due to recent progress in reproductive medicine, fertility preservation techniques now allow realistic chances to generate a pregnancy after gonadotoxic therapy. Reproductive physicians therefore recommend that all women up to the age of 40 years who undergo gonadotoxic therapy should be counselled about fertility preserving techniques by specialized physicians [1].

In contrast, several studies have revealed that firstly, only a limited proportion of women in their reproductive years are counselled at all by a specialist [2], and secondly, that information given to patients is often perceived as being inadequate or untimely [3,4]. The reasons for this deficit seem to be manifold. Due to the time pressure and the frightening diagnosis of a life

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threatening disease, infertility might assumed to be of secondary interest and relevance [5]. Furthermore, the knowledge about the different fertility preservation techniques, their time requirements and efficacy is limited [2] in spite of several national and international easily accessible guidelines [1,6–8].

Several studies have revealed that women who have been counselled on fertility preservation techniques have retrospectively regarded this as being useful and satisfying [9,10]. However, most of these studies have several limitations. Firstly, the number of analyzed patients was small, secondly the studies were performed at single institutions and thirdly, the surveys was initiated some considerable time after the counselling. These limitations, which have critically been discussed in the papers, might have led to a selection bias. In addition, the studies neither reflected the attitudes of the patients in the stressful situation at the time of the counselling just before the start of the gonadotoxic therapy, nor did they reliably allow a separate analysis of women who opted for or against fertility preserving procedures. Furthermore, detailed data about the attitudes of patients not wishing to undergo a fertility preservation technique, or choosing specific ovary protecting treatments such as gonadotrophin releasing hormone agonists (GnRHa), or gamete conserving therapies such as cryopreservation of ovarian tissue or cryopreservation of unfertilized or fertilized oocytes, still do not exist. However, such data would possibly allow the oncologist as well as the reproductive physician to better guide the individual patients through the counselling process.

We therefore set up a prospective multicenter study, involving five centres from the multinational German, Swiss and Austrian network for fertility preservation, *Ferti*PROTEKT [11], which offers the main common fertility preservation techniques according to the network's recommendations [1]. All women who were counselled were asked to participate in a questionnaire-based survey, irrespective of their decision towards the fertility preservation procedure at the time of the counselling process.

Material and methods

Participating centres

Five centres belonging to the *Ferti*PROTEKT network participated in the study. *Ferti*PROTEKT is a non-profit oriented network of around 95 university and private centres in the three German speaking countries of Germany, Switzerland and Austria which offer fertility preservation before gonadotoxic therapy. The network centres perform around 1000 counselling sessions per year [11]. All centres are obliged to participate in annual conferences to assure that fertility preservation treatments are performed according to state of the art knowledge. Furthermore, centres offer all current fertility preservation techniques such as GnRHa, freezing of ovarian tissue and ovarian stimulation followed by freezing of unfertilized oocytes or zygotes. In case they do not offer one of the techniques, they are required to cooperate with other centres. The counselled and treated patients are included in the network's register which is accessible to the public [12]. The centres follow the diagnostic and therapeutic guidelines of the network published elsewhere [1].

Only centres which performed a high number of counselling sessions per year, offered all the mentioned treatments and were part of a local oncology network participated in the study. The participating centres could thereby be expected to represent the network *Ferti*PROTEKT and the average spectrum of cancer cases recommended for fertility preservation counselling.

Ethics committee approval was obtained from each participating centre, and all women gave their written informed consent.

Patients and methods

All female patients counselled for fertility preservation between January 2012 and December 2013 were approached regarding participation at the end of the first counselling appointment. Patients were included if they were between 18 and 43 years of age, and if they were German speaking. As the study design did not allow a power analysis to determine the required number of participating patients to be performed, a time frame of 24 months for the patients' recruitment was defined.

A questionnaire was given to the patients at the first or the second counselling consultation, and they were allowed to complete it directly or at home and send it back before the onset of the gonadotoxic therapy. The questionnaire was developed empirically by the Division of Psychosomatics in Gynaecology, Bonn, Germany (A. Rohde). The questionnaire was first tested by the institute before it was accepted for the study.

The questionnaire included 43 items on patients' characteristics (Table 1), on their current health condition (Table 2), self-evaluated future pregnancy chances (Table 3), motivation to accept fertility preservation (Table 4) and on the satisfaction with the counselling procedure (Table 5). Most of the items are shown in the tables provided in the paper.

The items shown in Tables 2–5 were designed with a rating scale to allow semiquantitative analysis and comparison of the analyzed patient groups.

After finalizing the counselling process, data about the performed fertility preservation therapy was provided by the participating centres to allow data analysis in relation to the chosen therapy.

Statistical analysis

If women underwent double treatments such as such as "Freezing ovarian tissue" plus "Freezing oocytes/zygotes", they were included in each group, resulting in higher total group numbers than the group "Freezing tissue or oocytes/zygotes". Accordingly data in the group "Freezing ovarian tissue" and "Freezing oocytes/zygotes" were not disjunct, and could therefore not be statistically analyzed separately. Therefore only the group summarizing these both procedures were compared statistically with the group "No treatment or only GnRHa".

Differences in age were analyzed by independent two-sample t-test and the other variables by Fisher's exact test.

Results

Participating centres

The centres each recruited 51 patients (Heidelberg), 36 patients (Tuebingen), 35 patients (Berne), 14 patients (Hamburg) and 9 patients (Freiburg). One questionnaire could not be allocated to one of the centres, and had been excluded from the analysis. The counselling outcome in Heidelberg, Tuebingen, Berne, Hamburg and Freiburg was "No treatment or only GnRH agonists" in 26%, 19%, 49%, 57% and 33% of cases, "Freezing ovarian tissue" in 52%, 58%, 26% and 22% of cases and "freezing of unfertilized oocytes/zygotes" in 43%, 50%, 34%, 43% and 44% of cases, respectively. The five participating centres counselled 7.1% percent of all 2049 counselled patients within the network *Ferti*PROTEKT in 2012 and 2013 [12].

Patient characteristics

The mean age of the three treatment groups "No treatment or only GnRHa" and "Freezing tissue or oocytes/zygotes" were not

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