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Fertility preservation in pediatric and adolescent cancer patients in Switzerland: A qualitative cross-sectional survey

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ABSTRACT

Fertility preservation (FP) is an important topic of discussion in the field of oncology, particularly in pediatric oncology. Despite the awareness of severe impact of infertility on quality of life and different guidelines available in this area, the options in FP are not routinely discussed with the pediatric cancer patients and their parents. To the best of our knowledge, this is the first survey report concerned to FP counseling and procedures in pediatric and adolescent cancer patients in Switzerland. This survey was conducted from June 2014 to October 2014 on the counseling and procedures performed between 2009 and 2013; the questionnaire was completed by one of the professional from hematology/oncology centers in Switzerland. Currently, only four out of nine centers have a program for FP. In 2013, 45/301 (15%) patients received FP counseling and 36/301 (12%) underwent an FP procedure. The most commonly performed procedures from 2009 to 2013 were administration of gonadotropin releasing hormone agonist (3%) and cryopreservation of ovarian tissue in females (3%) and cryopreservation of sperms in males (6%); the most frequently cited reason for the absence of FP counseling was lack of time (55%). Therefore, this survey should help to develop and harmonize practices with respect to FP counseling and procedures in Switzerland, and to establish FP as a standard of care during cancer treatment.

1. Introduction

Fertility preservation (FP) has become an important topic of discussion in the field of oncology, particularly in pediatric oncology. This increasing importance is due to the progress in cancer research leading to the long-term survival of children and adolescents and advances in reproductive medicine, along with the significant impact of infertility on quality of life in cancer survivors. In developed European countries, the current 5-year overall survival rate for childhood cancer is approximately 80% [1]. This progress is largely due to the use of multimodal therapies and improvement in supportive care strategies. In Switzerland, approximately 230 new cases of childhood cancer (children and adolescents) have been diagnosed during 2013–2014 (www.Kinderkrebsregister.ch). All of these patients undergo treatment in one of the nine specialized centers belonging to *Schweizerische Pädiatrische Onkologie Gruppe (SPOG)*. According to the statistics, approximately 180 patients are expected to survive cancer each year.

However, cancer treatment can be harmful particularly to the gonads, leading to the impairment of pubertal development and/or causing infertility. Infertility may result in psychosocial distress, anxiety, depression, and low self-esteem thereby affecting quality of life in cancer survivors [2]. Therefore, fertility impairment during cancer treatment has been acknowledged by several groups worldwide, thus prompting different guidelines to be published over recent years concerned to FP counseling and procedures [3–6]. Despite these recommendations, data show that FP is considered or offered only in 40% of the eligible patients [7].

Herein, we present the results of our survey investigating FP counseling and procedures performed on pediatric and adolescent

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cancer patients registered for cancer treatment in Switzerland. To the best of our knowledge, this is the first survey report on FP counseling and procedures in Switzerland. The aim of this survey was to evaluate the different practices in FP performed on children and adolescents, and to identify unmet needs in this field.

2. Methods and statistics

All nine Swiss pediatric hematology/oncology centers were contacted to participate in this survey, which was conducted from June 2014 to October 2014. "Five of the 9 centers were university hospitals, performing allogeneic or autologous HSCT. In these centers a network of oncologists, pediatricians, gynecologists, and endocrinologists was present. Four of them had SOPs for FP which were predominately similar. The 4 remaining centers were tertiary hospitals where mostly the pediatrician and the gynecologist only performed the consultation. A questionnaire was sent by mail and e-mail to the head of each of the nine pediatric hematology/oncology departments in Switzerland. The questionnaire, which was filled by one physician from each center, consisted of 24 items divided into the following four sections: [1] the principal characteristics of the center, [2] the availability of FP counseling and/or a standard operating procedure (SOP) in FP counseling including the time point at which counseling is offered and the person/team responsible for it, [3] the FP procedures offered to maintain fertility, and [4] the physician's own view of FP. Questions seeking opinions on the relevance of FP, coverage of costs, and suggestions for improvement were also included. Furthermore, the physicians were given opportunity to provide the number and type of FP methods available at their center during the period of 2009–2013, according to cancer type. Most of the questions required an answer of either "yes" or "no". Certain topics required a response using a scale of 1–10 (low relevance to high relevance).

In this study, the survey population included children and adolescents aged below 18 years at the time of diagnosis either with a malignant disease, who were treated with radio-/chemotherapy or who underwent hematopoietic stem cell transplantation (HSCT), or with a nonmalignant disease who underwent an HSCT procedure. Patients who had undergone a cancer treatment or an HSCT procedure prior to 2009 were excluded. An ethical approval was obtained to perform this survey.

An exploratory analysis of the data was performed to evaluate the information provided by the pediatric hematology/oncology Swiss centers. Data were summarized in tables according to the principal characteristics of the center, such as the existence of an SOP. In addition, data were assessed visually using scatterplots, bar graphs, box plots, and maps to identify patterns, trends, and outliers. All analyses were performed using software R.

3. Results

All nine Swiss pediatric hematology/oncology centers agreed to participate in the survey and completed the questionnaire. Department characteristics and the number/proportion of counseling/procedures available during 2013 are described in Table 1. There were 308 new cases reported each year (including relapses); of them, 47 (16%) patients underwent an HSCT procedure as part of their therapy. An SOP for FP counseling and procedures was available in four out of nine (44%) centers (two for pre and postpubertal patients and two for postpubertal patients alone). These SOPs were in-house protocols based on the guidelines of American Society of Clinical Oncology (ASCO) (2006) or British Fertility Society (2004) and were written in collaboration with the university-based fertility team. The four centers that reported having an SOP were those with a larger number of treated cases (Table 1). In general, the use of SOPs was implemented recently (2010, 2011). Nevertheless, four out of five centers without an SOP performed FP counseling.

In the four centers with an SOP, counseling was performed by an interdisciplinary team consisting of a hematologist/oncologist, a pediatric endocrinologist, and a specialist in reproductive medicine, or at least by the hematologist together with the specialist in reproductive medicine. In three of the centers without an SOP, the hematologist performed FP counseling. In case of timing of counseling provided, in seven out of nine centers (four with an SOP), an FP counseling was conducted at the beginning of the treatment or procedure. However in three out of nine centers (all with an SOP) the FP counseling was conducted before performing HSCT procedure.

In 2013, out of 308 reported new cases, 36 (12%) patients underwent an FP procedure, whereas between 2009 and 2013, a total of 77 females and 75 males underwent an FP procedure. The most frequently used procedures in females were the use of a gonadotropin releasing hormone agonist (GnRHa) (42%) and ovarian tissue cryopreservation (47%) (Fig. 1A). In males, sperm cryopreservation (88%) was the most common procedure performed (Fig. 1B). Testicular sperm extraction was performed in three postpubertal males. No centers performed a cryopreservation of spermatogonial stem cells. Table 2 lists different procedures performed according to the type of cancer.

Table 3 summarizes the data on FP reimbursement for the year 2013. Costs were primarily covered by parents/patients (88%) and health insurance (66%). Some cases were subsidized by charitable institutions such as the Swiss cancer league.

According to the questionnaire, the study centers reported that parents and patients were indeed interested in discussing FP options (parents: 88% of prepubertal and 100% of postpubertal

Table 1
Demographic characteristics of centers and number/proportion of counseling/procedures in 2013.

Institution	New cases per year[a]	SOP	Counseling total	Procedure total
Zürich (including Chur)	77	Yes (post)	13/77 (17%)	13/77 (17%)
Lausanne	50	Yes (pre + post)	4/50 (8%)	4/50 (8%)
Berne	35	No	7/35 (20%)	7/35 (14%)
Geneva	32	Yes (pre + post)	3/32 (9%)	1/32 (3%)
Basel	32	Yes (post)	4/32 (12%)	4/32 (12%)
St. Gallen	30	No	7/30 (23%)	1/30 (3%)
Lucerne	25	No	0/25 (0%)	0
Aarau	15	No	4/15 (27%)	4/15 (27%)
Bellinzona	12	No	3/12 (25%)	2/12 (17%)

Note: pre = prepubertal; post = postpubertal; SOP: standard operating procedure.
[a] Including relapses.