

Attitudes of Physicians and Parents Towards Discussing Infertility Risks and Semen Cryopreservation With Male Adolescents Diagnosed With Cancer

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Background. In paediatric oncology, the risk of infertility due to treatment constitutes an important problem. For sexually mature male adolescents, sperm cryopreservation is an option, but discussing the topic is complex because of the sensitive nature and the limited time frame. In this article, we determined attitudes and preferred roles of physicians and parents towards discussing sperm banking with male adolescents. **Methods.** Qualitative multi-centre study, using in-depth semi-structured interviews with 14 physicians and 15 parents of male adolescents undergoing cancer treatment. **Results.** Although physicians and parents agreed that infertility would have a major impact on the future quality of life, they sometimes disagreed on whether the topic should be discussed with adolescents. Physicians always wanted a separate discussion with adolescents because of the sensitive nature and the experience that

parents sometimes misjudged the stage of maturity of their son. Parents, however, wanted control over whether physicians discussed the topic with their child and what was said. Physicians did not accept this control and, when necessary, were willing to bypass the parents and discuss the topic with the adolescent even when parents refused consent. **Conclusions.** Physicians face the difficult task of balancing between their ideas of what is in the (future) interest of the adolescent and accommodating parental wishes. We argue that, because of the private character of sexuality and the potentially inadequate maturity assessment by parents, semen cryopreservation should be discussed separately with adolescent and parents. In addition, there should be an open communication with parents to address potential discomforts. *Pediatr Blood Cancer* 2009;53:386–391. © 2009 Wiley-Liss, Inc.

Key words: adolescent; cancer treatment; ethics; fertility; sperm banking

INTRODUCTION

Children treated for cancer are increasingly likely to survive. For all childhood cancers 5-year overall survival has improved markedly over the past 30 years, from less than 20% to nearly 80%, due to improved treatments and better supportive care [1]. However, long-term survivors may face serious long-term side effects, including damage to the reproductive system. Rates of compromised fertility after cancer treatment vary and depend on many factors, like the chemotherapeutic agent or radiation field, the dose, dose-intensity, method of administration, disease, age, sex and pretreatment fertility [2–5]. Most at risk are those who are intensively treated with a treatment modality encompassing successive multiple toxicity, like bone marrow transplantation.

The inability to father genetically own children has a high impact on the future quality of life [3,6–10]. Both male and female cancer survivors report a large degree of stress regarding fertility [9,11,12].

In male adolescents with a risk of infertility, sperm banking can be offered, provided that the adolescent is sexually mature. Cryopreservation of semen for eligible adolescent boys is a well established and proven technique which should be considered routine [13]. The availability of ICSI makes it worthwhile to cryopreserve almost all semen samples, even when the sperm has extremely poor characteristics of count, motility and morphology [14]. In adolescents who are at risk for infertility and have had spontaneous nocturnal ejaculations, but are unable to produce semen by masturbation, transrectal electro-ejaculation under general anaesthesia is an option [15,16].

Notwithstanding the technical possibilities, semen collection in male adolescents can be complex because of communication difficulties. Discussing sperm banking involves sensitive topics like body changes and developing sexuality, the grief of confronting infertility as a side effect, the necessity of using masturbation to collect a semen sample and the use of pornographic materials as an aid [17,18]. Eligible patients and their parents must consider preserving fertility during the stressful period after having received a potentially

fatal diagnosis. Usually the time frame until cancer treatment starts is short, which further adds to the experienced pressure.

Because of the large variation in the stage of maturity among teenage boys, it is difficult to select the boys eligible for cryopreservation. Not only the Tanner stage is important in assessing possible success, but also whether the boy has spontaneous nocturnal semen emissions and/or masturbates. To gain insight in the stage of maturity, this sensitive topic is often discussed with parents first and subsequently with the patient [19]. The decision to initially talk with the parents requires ethical consideration. Talking to the parents first may be embarrassing for adolescents, because they value their privacy in this matter. But parents of teenagers may be protective and may prefer to have topics such as sexuality and reproduction not addressed without their consent. This may pose a dilemma for the oncology team about who to talk to first [17]. This dilemma raises special concern because of the need to balance the extent to which adolescents are able to participate in the discussion and the extent to which parents are able to judge the stage of maturity of their sons.

To date, few data are available on the practice of discussing fertility preservation in the paediatric oncology setting. Most studies

Additional Supporting Information may be found in the online version of this article.

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assessed the adult oncology setting [11,20]. Previous reports on paediatric oncologists only concern their knowledge about infertility risks and fertility preservation techniques, and whether fertility issues are discussed before the start of treatment [21,22]. There are no data on how the topic is discussed and on physicians' ideas about who should be present during the discussion. With regard to parents, there are publications on their knowledge about the infertility risks for their child [10], their concerns about fertility [23] and their presence during initial discussions [24], but none about the preferred roles of parents in the discussion about this topic.

The purpose of the present study was to clarify the attitudes of parents and physicians concerning various aspects of discussing fertility issues. Specifically, this study was conducted to: (1) assess the current communication practice of paediatric oncologists regarding fertility preservation, with emphasis on role delineation of physician, parents and adolescent; (2) explore the experiences of physicians and parents regarding their roles in fertility preservation communication; and (3) explore the ethical issues involved. Insight into the attitudes of physicians and the discomforts and preferences of parents may contribute to successful communication, and thereby positively affect parental satisfaction with communication [25].

METHODS

Participants and Design

Our sample was drawn from data collected as part of a larger qualitative multi-centre project in which we explored patients', parents' and physicians' experiences with the informed-consent process for treatment after initial cancer diagnosis or after relapse. In this project we invited patients (aged 8–18 years) attending the paediatric oncology units of two Dutch university hospitals, their parents and their physicians to participate in semi-structured interviews about the informed-consent process.

The present study is based on the interviews with the subgroup of parents of male adolescents ($n = 14$) and their physicians ($n = 15$). Since we only focussed on fertility preservation techniques available in the two clinics where the study was conducted (cryopreservation of semen collected through masturbation (both

clinics) or electro-ejaculation (one clinic)), we did not use the interview data of the parents of prepubertal male patients or female patients. We hoped to also include an analysis of the interviews with the male adolescents, but most of them were reluctant to talk about semen cryopreservation in the context of the broader research project.

Figure 1 shows eligibility and recruitment of parents. Parents had a mean age of 42.8 years (range 36–50 years). Their sons had a mean age of 13.8 years (range 11–17 years). The parents' occupations varied indicating social diversity. All families were of Dutch origin. Demographic and clinical characteristics of the parents and their sons are given in Table I.

The group of physicians comprised the entire medical staff of both paediatric oncology units. Physicians had a mean age of 42.1 years (range 32–52 years), worked in paediatric oncology for a mean of 7.6 years (range 1.5–20 years) and seven (46.7%) were male. The project was approved by the Medical Ethics Committees at the study sites. All parents gave written informed consent. The interviews were carried out between January 2005 and August 2007.

Interview Procedure and Data Collection

All families were interviewed by Martine C. de Vries, one of the authors. The parent interviews lasted between 60 and 90 min and were conducted at the hospital. The interview topics covered general characteristics of the patient; the history of the disease; discussions with physicians about the recommended treatment and possible side effects like infertility; parents' attitudes to these discussions; and the perceived role of parents in decision making regarding cancer therapy and related treatments, like fertility preservation options.

Each physician was interviewed in their office. The interview lasted between 30 and 60 min. The in-depth interview topics covered work experience; general goals of childhood oncology; the physician–patient–parent relationship, especially concerning decisions regarding therapy and related treatments, like fertility preservation options, patient and parent autonomy and physician's ideas on what is in the best interest of a child.

TABLE I. Characteristics of Parents and Their Sons

Parent number	Age patient (years)	Diagnosis	Treatment	Parent interviewed	Age parent	Education parent	Marital status parent
1	11	ALL	Chemotherapy	Father	37	Middle level high school	Married
2	12	AML	Chemotherapy	Father	36	Middle level high school	Married
3	15	AML relapse	HSCT	Mother	43	Advanced vocational	Divorced
4	12	AML	Chemotherapy	Mother	39	Middle level high school	Married
5 ^a	13	MDS	HSCT	Father	41	Lower level high school	Married
6 ^a	13	MDS	HSCT	Mother	39	Lower level high school	Married
7	13	NHL	Chemotherapy	Father	49	Middle level high school	Married
8	17	NHL relapse	HSCT	Father	50	Middle level high school	Married
9	16	Hodgkin relapse	HSCT	Father	47	Middle level high school	Divorced
10	14	Ewing sarcoma	Chemotherapy	Mother	46	Advanced vocational	Married
11	15	Ewing sarcoma	Chemotherapy	Mother	41	Unknown	Married
12	14	Ewing sarcoma	Chemotherapy	Father	46	Middle level high school	Married
13	14	Ewing sarcoma	Chemotherapy	Father	39	Advanced vocational	Married
14	13	Osteosarcoma	Chemotherapy	Mother	46	Advanced vocational	Married

ALL, acute lymphoblastic leukaemia; AML, acute myeloid leukaemia; MDS, myelodysplastic syndrome; NHL, non-Hodgkin lymphoma; HSCT, haematopoietic stem cell transplantation. ^aParents 5 and 6 were parent of the same child.

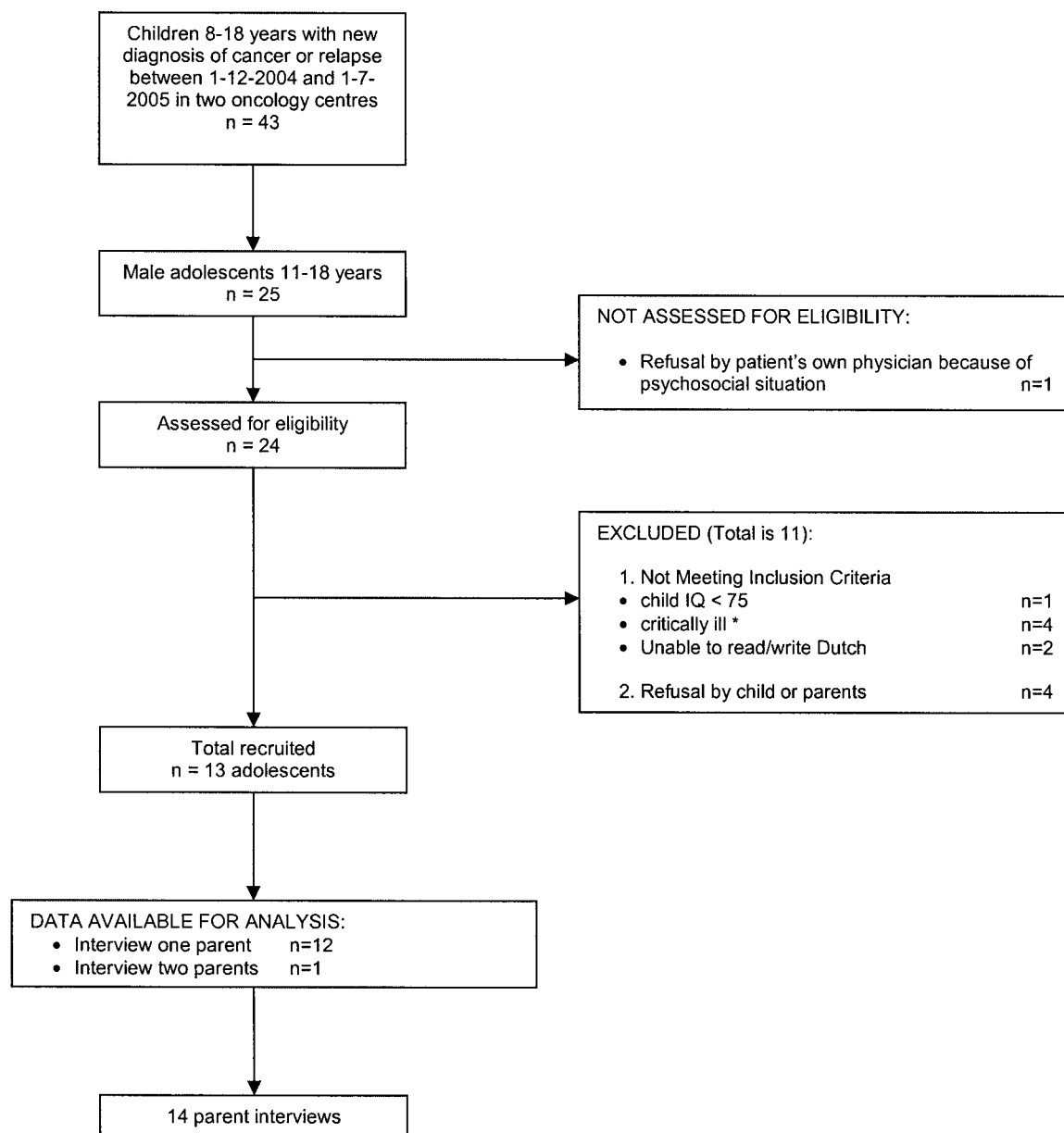


Fig. 1. Enrollment, eligibility and recruitment of parents. *For critically ill adolescents, therapy had to start immediately and there was not time to cryopreserve semen.

Data Analysis

All the interviews were audio taped and transcribed verbatim. Data analysis was based on the constant comparative method [26,27]. The authors, Martine C. de Vries and Evert van Leeuwen, independently coded the full transcripts by identifying and labelling discrete units of texts that referred to one or more concepts relevant to the study. Through comparison across transcripts, the open codes were developed into higher order themes to provide a framework for coding subsequent transcripts. The simultaneous inclusion of parents and physicians enabled comparison of themes between the two groups. An independent researcher coded two transcripts to check for consistency and adequacy of the framework. When no new thematic content was found in the parent interviews, subject

enrolment was stopped. This process, called thematic saturation, is a well-described qualitative method to avoid unnecessarily large and repetitive data sets [28,29].

We used qualitative software (Kwalitan 5.0) [30] for multiple text management, including coding, locating and retrieving key phrases. Finally, representative quotations from parents and physicians were chosen to demonstrate the themes identified. These quotations are listed in Supplemental Appendix A.

RESULTS

The quote numbers between brackets refer to the quotations in Supplemental Appendix A. We identified four central themes from the interviews: concerns about the future quality of life, child

participation, parental control, and timing and approach for fertility discussions. We discuss these themes for physicians and parents separately.

Attitudes of Physicians on Communicating Fertility Issues

Concerns about the future quality of life. For all physicians, infertility was seen as having a major impact on the future quality of life of patients. All physicians, therefore, felt a duty to bring up the issue and offer cryopreservation (quote 1).

Child participation and parental control. There was unanimity among physicians that children should participate in the decision-making process. Most of the times physicians talked to the parents first to find out their thoughts on the sexual development of their child. Subsequently, the opinion of the child was sought (quote 2).

Physicians, however, knew from experience that parents cannot predict always correctly whether their child masturbates or has nocturnal semen emissions (quote 3). Because of the alleged inability of the parents to make reliable predictions on this topic, and the importance of the issue, the physicians always talked to the adolescent, even if parents doubted whether the issue should be discussed with their son (quote 4).

Fourteen of the 15 physicians would even discuss the topic with the adolescent when parents straightforwardly refused to give permission to talk to their son. Only one physician said she would then follow the preferences of the parents. Because of the delicate issues to be discussed, physicians in fact sometimes talked to the adolescent alone, without the parents knowing (quote 5).

Experiences of Parents

Concerns about the future quality of life. Just like the physicians, many parents were thinking of the future quality of life of their son when pondering over the fertility issue (quote 6).

Child participation and parental control. In contrast to the physicians, there was no unanimity among parents with respect to their views on the participation of children in the decision-making process. Some parents were explicit in their views that it is eventually the child who decides what happens, because it relates to his own future (quote 7).

Many parents (8 of 14), however, doubted whether the issue should be discussed with their son. They wanted to protect their child from this information, or at least wanted control over what was being discussed with their child (quote 8).

The main reason parents wanted control over the discussion was because they doubted whether their son was sexually mature (quote 9). Three parents were reluctant to discuss the issue because they felt that the conversations were ill-timed and confronting due to the sensitive nature (quote 10).

DISCUSSION

Unanimity existed among parents and physicians with respect to the impact of possible infertility on the future life of the child. The child's best interest in the context of treatment was seen as to include both its present interests in surviving and future interests such as fertility preservation. Maintaining future options is a well-known theme in paediatric ethics, and various authors have argued that physicians and parents act unethical if they make choices that limit a

child's range of future options [31,32]. A child's right to fertility preservation is acknowledged in bioethical literature as a right in trust. If the medical risk is acceptable, it seems that parents have an ethical right to ask for fertility preservation and an ethical duty not to constrain the choices of their children regarding future reproduction [2,32].

Although physicians and parents agreed that infertility would have a major impact on the future quality of life of their child, they sometimes disagreed on how the topic should be discussed. Physicians always wanted a separate discussion with adolescents because of the sensitive nature of the topic and the experience that parents can misjudge the stage of maturity of their son. Some parents, however, felt that there were barriers to discuss the topic with their son because they felt he was too immature and under pressure of time. Discussing infertility with adolescents was a sensitive topic for parents and they wanted control over whether physicians discussed the topic with their child and what was said. In the literature, this control over physician-child communication has been described before and termed strategic control. Parents tend to filter and modulate what children are told by their physicians, relegating children to a passive role in medical decision making [33,34]. Literature shows that physicians normally deem this mode of communication acceptable [35]. Studies in paediatric oncology describe a general tendency from physicians to protect children from too much information [36,37]. Parents and physicians jointly discuss the ways to encounter the child, whether to involve the child in the decision-making process and the information given to the child. The parents in our study wanted to exert strategic control in fertility issues as with other topics. The physicians we interviewed, however, did not accept this strategic control when fertility preservation was involved. This confronts physicians with the difficult task of finding a balance between their view of the future interest of the adolescent and accommodating parental wishes. Most physicians in our study were ultimately willing to bypass the parents. This could potentially lead to an undesirable situation of conflict between the parents and the physicians at the outset of a long-treatment relationship.

Because of the potential differences in opinion between parents and physicians, fertility preservation can be used as an example case to discuss the limitations of parental discretion to regulate information disclosure to their child. In general, parents want to promote the welfare of their children. It is this intention that makes parents the presumed decision makers for their children and legitimises parental discretion to act as they think is best for them [38]. In the delicate issue of fertility discussions, however, the parental role can become problematic and it could be assumed that the adolescent is the most appropriate discussion partner and does not need a custodian. After interviewing young cancer survivors, Schover et al. [39] came to the conclusion that the fertility topic should first be raised with the adolescent in private and then be discussed separately with the parents. The patients in the study by Schover et al. reported that it was acutely uncomfortable to be informed about sperm banking in front of their parents. Ginsberg et al. [24] showed that almost half of the male adolescents would preferred to have initial discussions without their parents present. One study suggested that male adolescents may be more successful at masturbation if a parent does not accompany them to the sperm bank [40]. Various guidelines and protocols state that adolescents can, in some circumstances, be considered mature enough to give or refuse informed consent for medical procedures, without the need

for parental involvement, especially when reproductive health services are at stake (so-called mature minor doctrine) [13,41–43]. Strategic control from parents, therefore, seems inappropriate concerning fertility discussions.

There can be many reasons not to discuss fertility preservation with an adolescent, like the inclination to prioritise discussions about treatment and its immediate side effects, emotional discomfort with discussing fertility issues, lack of time or the prediction that the adolescent is probably not mature enough [3,44]. The ease with which physicians can discuss fertility issues also depends on the existing practice of educating teens about sexuality, which may differ from country to country. However, if we want to preserve future reproductive choices for adolescents and if we take the adolescents' ability to discuss their own sexual development and behaviour seriously, these reasons do not relieve physicians and parents of the obligation to initiate early discussions with adolescents in private about conservation of future fertility potential.

It should be noted that communication, especially on a potentially difficult topic such as fertility, is culturally sensitive. A basic knowledge of the norms and values about sexuality and fertility associated with specific groups is helpful for this purpose. On the other hand, we need to be aware that there is also a great diversity *within* groups, communities and families. Simon and Kodish [45], therefore, emphasise the danger of making assumptions based on ethnicity or socioeconomic factors, which may contribute to the omission of important information for the families.

In our study, 3 of 15 parents were surprised by the late announcement of fertility problems and cryopreservation options. Other studies show that adolescents and parents want information regarding sperm cryopreservation early (within a week of diagnosis) in order to have the opportunity to think about it and to avoid unnecessary delays in treatment [24]. Two surveys suggest that lack of timely information is the most common reason for not banking sperm [7,8]. Therefore, fertility preservation should be mentioned as early as possible, and should not be delayed because of the sensitive nature or a feeling of inappropriateness during a time of emotional stress. An educational brochure answering key questions could help facilitate discussion in a time of medical urgency and initial lack of relationships of trust between physicians, adolescents and parents [46].

CONCLUSION

Discussing the storage of sperm of an adolescent with cancer is a challenging aspect of paediatric oncology care. Because of the private character of the issue and the potentially inadequate assessment by parents of the stage of maturity of the adolescent, semen cryopreservation deserves to be discussed with the adolescent in private. In addition, there should be timely, open communication with parents, in which it is made clear that the issue is private and deserves separate discussion with their child. Addressing potential discomforts of parents about approaching their child may contribute to parents' eventual satisfaction with communication.

Future research should address adolescents' opinions on timing and approach for fertility discussions, as well as how to proceed once an adolescent wants to bank sperm (e.g., time frame, use of erotic material and design of collection rooms). Since these topics

turned out to be so sensitive for the adolescents, this research should be done anonymously (e.g., by using a questionnaire) or by a sexologist/andrologist to gain a better insight into their views.

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