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Chapter 7

ATTITUDES OF PHYSICIANS AND PARENTS TOWARDS DISCUSSING INFERTILITY RISKS AND SEMEN CRYOPRESERVATION WITH MALE ADOLESCENTS DIAGNOSED WITH CANCER

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ABSTRACT

Background. In pediatric 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 timeframe. In this chapter we determine attitudes and preferred roles of physicians and parents towards discussing sperm banking with male adolescents.


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.
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 (American Cancer Society 2007). 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 pre-treatment fertility (Fallat et al 2008; Lee et al 2006a; Schrader et al 2001; Wallace et al 2001). Most at risk are those who are intensively treated with a treatment modality encompassing successive multiple toxicity, like bone marrow transplantation.


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 (British Fertility Society 2003). 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 (Tournaye et al 2004). 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 (Hovav et al 2001; Schmiegelow et al 1998).

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 (Schover 1999; Crawshaw et al 2007). 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 (Müller et al 2000). 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 (Schover 1999). 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, not much data is available on the practice of discussing fertility preservation in the pediatric oncology setting. Most studies assessed the adult oncology setting (Green et al 2003; Quinn et al 2007). Previous reports on pediatric oncologists only concern their knowledge about infertility risks and fertility preservation techniques, and whether fertility issues are discussed before the start of treatment (Anderson et al 2008; Goodwin et al 2007). 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 (Van den Berg et al 2007), their concerns about fertility (Oosterhuis et al 2008) and their presence during initial discussions (Ginsberg et al 2008), 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 pediatric 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 (Zwaanswijk et al 2007).

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
Discussing infertility risks

informed-consent process for treatment after initial cancer diagnosis or after relapse. In this project we invited patients (aged 8-18 years) attending the pediatric 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 focused 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 had 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. These interviews generated not enough data for assessment in this study.

Figure 4 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 9.

The group of physicians comprised the entire medical staff of both pediatric oncology units. Physicians had a mean age of 42.1 years (range 32-52 years), worked in pediatric oncology for a mean of 7.6 years (range 1.5-20 years) and 7 (46.7%) were male. The project was approved by the medical ethics committees at the study sites. All parents gave written informed consent.

**Interview procedure and data collection**

All families were interviewed by the author of this thesis. The parent interviews lasted between 60 and 90 minutes 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 minutes. 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 9: characteristics of parents and their sons

<table>
<thead>
<tr>
<th>Parent number</th>
<th>Age patient (yrs)</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Parent interviewed</th>
<th>Age parent</th>
<th>Education parent</th>
<th>Marital status parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>11</td>
<td>ALL</td>
<td>chemotherapy</td>
<td>father</td>
<td>37</td>
<td>Middle level high school</td>
<td>married</td>
</tr>
<tr>
<td>2</td>
<td>12</td>
<td>AML</td>
<td>chemotherapy</td>
<td>father</td>
<td>36</td>
<td>Middle level high school</td>
<td>married</td>
</tr>
<tr>
<td>3</td>
<td>15</td>
<td>AML relapse</td>
<td>HSCT</td>
<td>mother</td>
<td>43</td>
<td>Advanced vocational</td>
<td>divorced</td>
</tr>
<tr>
<td>4</td>
<td>12</td>
<td>AML</td>
<td>chemotherapy</td>
<td>mother</td>
<td>39</td>
<td>Middle level high school</td>
<td>married</td>
</tr>
<tr>
<td>5*</td>
<td>13</td>
<td>MDS</td>
<td>HSCT</td>
<td>father</td>
<td>41</td>
<td>Lower level high school</td>
<td>married</td>
</tr>
<tr>
<td>6*</td>
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<td>HSCT</td>
<td>mother</td>
<td>39</td>
<td>Lower level high school</td>
<td>married</td>
</tr>
<tr>
<td>7</td>
<td>13</td>
<td>NHL</td>
<td>chemotherapy</td>
<td>father</td>
<td>49</td>
<td>Middle level high school</td>
<td>married</td>
</tr>
<tr>
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<td>17</td>
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<td>HSCT</td>
<td>father</td>
<td>50</td>
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<td>married</td>
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<td>16</td>
<td>Hodgkin relapse</td>
<td>HSCT</td>
<td>father</td>
<td>47</td>
<td>Middle level high school</td>
<td>divorced</td>
</tr>
<tr>
<td>10</td>
<td>14</td>
<td>Ewing sarcoma</td>
<td>chemotherapy</td>
<td>mother</td>
<td>46</td>
<td>Advanced vocational</td>
<td>married</td>
</tr>
<tr>
<td>11</td>
<td>15</td>
<td>Ewing sarcoma</td>
<td>chemotherapy</td>
<td>mother</td>
<td>41</td>
<td>unknown</td>
<td>married</td>
</tr>
<tr>
<td>12</td>
<td>14</td>
<td>Ewing sarcoma</td>
<td>chemotherapy</td>
<td>father</td>
<td>46</td>
<td>Middle level high school</td>
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<td>13</td>
<td>14</td>
<td>Ewing sarcoma</td>
<td>chemotherapy</td>
<td>father</td>
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<td>married</td>
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<td>Osteosarcoma</td>
<td>chemotherapy</td>
<td>mother</td>
<td>46</td>
<td>Advanced vocational</td>
<td>married</td>
</tr>
</tbody>
</table>

Abbreviations: ALL=acute lymphoblastic leukaemia; AML=acute myeloid leukaemia; MDS=myelodysplastic syndrome; NHL=non Hodgkin’s lymphoma; HSCT=haematopoietic stem cell transplantation

* Parent 5 and 6 were parent of the same child.
Data Analysis

All the interviews were audiotaped and transcribed verbatim. Data analysis was based on the constant comparative method (Malterud 2001; Strauss and Corbin 1998). The authors, MdV and EvL, independently coded the full transcripts by identifying and labeling 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 (Guest et al 2006; Denzin and Lincoln 2000).

We used qualitative software (Kwalitan 5.0, Peters 2000) 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.

RESULTS

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.

I think it’s our duty as oncologists to offer fertility preservation, because only before start of treatment is there the possibility to do so. Once they have had chemotherapy, it’s over. And maybe later on, when they are 25 years old they come back to me and ask: doctor, why didn’t you offer it to me? – Physician A8

1 For the quotes: physician numbers refer to the physician numbers in Table 3 (page 21). Parent numbers refer to the parent numbers in Table 9.
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Children 8-18 years with new diagnosis of cancer or relapse between 1-1-2006 and 1-9-2007 in two oncology centres

Male adolescents 11-18 years n = 25

Assessed for eligibility n = 24

NOT ASSESSED FOR ELIGIBILITY:
- Refusal by patient’s own physician because of psychosocial situation n=1

EXCLUDED (Total is 11):
1. Not Meeting Inclusion Criteria
   - child IQ < 75 n=1
   - critically ill * n=4
   - Unable to read/write Dutch n=2
2. Refusal by child or parents n=4

Total recruited n = 13 adolescents

DATA AVAILABLE FOR ANALYSIS:
- Interview one parent n=12
- Interview two parents n=1

14 parent interviews

Figure 4. Enrollment, eligibility and recruitment of parents.

* For critically ill adolescents, therapy had to start immediately and there was no time to cryopreserve semen
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.

I always first discuss it with the parents. Even with older adolescents I first talk to the parents and ask them whether they think that the boy is ready to discuss the topic and produce semen. Only after that I talk to the boy. – Physician A7

Physicians, however, knew from experience that parents cannot always correctly predict whether their child masturbates or has nocturnal semen emissions.

I remember one mother who had it completely wrong. She thought her son didn’t do anything yet, but he was [masturbating]! She just didn’t know and she was shocked to find out, because she thought she knew her child very well, but now found out that she didn’t. – Physician B4

We have been mistaken once or twice. Parents sometimes said that their child was not ready, but then we talked to the child alone, and it turned out that the child was ready. And that he was able to produce sperm for preservation. On such occasions we almost let a chance pass by because parents had said that the boy was not ready. I learned from those experiences that you always have to talk to the adolescent alone, and not leave the issue to the parents. – Physician B3

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.

If you think that a patient will become infertile from the treatment, and the boy has reached an age at which sperm can be preserved, then I think it’s your duty to do so. You can only do it once. I think it should be offered and I feel justified in passing over the parents. If I think the child is ready and parents doubt that, then I think it’s in the best interest of the child to go ahead. – Physician A3

Fourteen of the 15 physicians would even discuss the topic with the adolescent when parents straightforwardly refused them 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.

*Once, with a 14-year old boy, I first talked to the boy, without his mother knowing. Because I thought it was too delicate an issue to discuss with everyone present. The mother was furious when she found out. ‘It’s MY child and I have a right to know!’, she claimed. I replied that she had a right to know, but that the child had the right to know FIRST, because with this issue you enter a private domain.* – Physician B4

**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.

*What counted for us was the thought that, well, let’s suppose that he wants to start a family, that his future wife has a strong child wish, and we would have blocked the way. If you say no [to fertility preservation], then that’s final. That would be too much control from our side. In my opinion, that would be unwise.* – Parent 14

*For him to have a choice in the future to start a family or not, that was the reason why we made the decision to preserve semen. It is his life after all. And I don’t want to intervene in it. I don’t want to deny him choices in the future by deciding for him now.* – Parent 13

**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.

*He [the child] initially said that we [the parents] had to decide what to do. Well, that was something! I thought it was too much. We couldn’t decide over something that he might regret 10 years from now. So we talked it over with him. And he eventually cut the knot. And we supported him. He generally very easily passes the buck to us. As soon as he has to think something through, he makes us decide. But in this case that was not realistic. It’s about your life, I told him.* – Parent 14
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.

At one point I said to the nurse: ‘I want to protect him from this [fertility] conversation with the physicians. I will tell him myself what he needs to know’. – Parent 6

[Patient was approached first, without his mother knowing] Well, the fact that they approached him first, that they let him decide, I found it hard to come to terms with that. His whole life I've been responsible and the one people talked to concerning him. Of course we always discuss things, me and the children, but in the end, I’m the one with the most life experience. So I take the final decisions. But now, they approached the child directly. So I said to them [the physicians]: ‘I think the sequence is wrong. You should first contact me, when you want to discuss things with my child.’ – Parent 3

The main reason parents wanted control over the discussion was because they doubted whether their son was sexually mature.

We had to think about whether he already has ejaculations. I just knew this was not the case. I mean, he is almost 14 years old, but it's just not the case. Is it reasonable then to confront him with this side-effect? We told the physician not to mention it to him. – Parent 5

Three parents were reluctant to discuss the issue because they felt that the conversations were ill-timed and confronting due to the sensitive nature.

The evening before the start of the chemotherapy he [the child] was told about possible infertility and semen preservation. Later on we told them [the physicians] that the timing was really bad. For a child to be in such a big hospital and then to have to think about something like that. Even adults wouldn’t be able to do that. We felt it was mentioned too late. They should have mentioned it during the first conversation. (...) Because then the child has 2 or 3 weeks to think about it in his own environment. – Parent 11

That he had to think about whether he could produce semen or not, that was really shocking. He had to make such a leap in his development. Of course, to hear that you have cancer is also very shocking. But in a way that just happens to you. It’s just a fact. While for this issue we had a choice, we had a choice what to do. – Parent 13
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 pediatric 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 (Feinberg 1992; Davis 2001). 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 (Fallat et al. 2008; Davis 2001).

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 discussing 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 (Tates and Meeuwesen 2000, 2001). Literature shows that physicians normally deem this mode of communication acceptable (Levetown et al. 2008). Studies in pediatric oncology describe a general tendency from physicians to protect children from too much information (Young et al. 2003; Olechnowicz et al. 2002). 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. The future potential of fertility seemed too important to them and they wanted to discuss it with the child, even when the parents did not give consent. 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 parents and physicians at the outset of a long treatment relationship.
Discussing infertility risks

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 (Ross 1998). 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 (2002b) 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 (2008) showed that almost half of the male adolescents would have 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 (Bahadur et al 2002). 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) (British Fertility Society 2003; Sigman and O’Connor 1991; Committee on Bioethics 1995; Dickens and Cook 2005). 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 prioritize 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 (Lee et al 2006; Vadaparampil et al 2007). 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, communi-
ties, and families. Simon and Kodish (2005) therefore emphasize the danger of making assumptions based on ethnicity or socioeconomic factors, which may contribute to the omission of important information for 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 (Ginsberg et al. 2008). Two surveys suggest that lack of timely information is the most common reason for not banking sperm (Schover et al. 1999; Schover et al. 2002a). 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 (Nagel et al. 2008).

CONCLUSION

Discussing the storage of sperm of an adolescent with cancer is a challenging aspect of pediatric 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 (for example timeframe, use of erotic material, design of collection rooms). Since these topics turned out to be so sensitive for the adolescents, this research should be done anonymously (for example by using a questionnaire) or by a sexologist / andrologist to gain a better insight into their views.