

Original article

Fertility Preservation and Adolescent/Young Adult Cancer Patients: Physician Communication Challenges

Gwendolyn P. Quinn, Ph.D.^{a,b,*}, and Susan T. Vadaparampil, Ph.D., MPH^{a,b}

THE FERTILITY PRESERVATION RESEARCH GROUP^b

^aUniversity of South Florida, College of Medicine, Department of Oncologic Sciences, Tampa, Florida

^bH. Lee Moffitt Cancer Center & Research Institute, Department of Health Outcomes and Behavior, Tampa, Florida

Manuscript received March 14, 2008; manuscript accepted August 27, 2008

Abstract

Purpose: The doctor–parent–adolescent triad is a unique communication challenge, particularly in the area of fertility preservation for adolescents with cancer. This paper provides a preliminary exploration into the barriers experienced by physicians in discussing cancer related fertility issues with patients aged 12–18.

Methods: This study used a subset of the data from qualitative interviews with pediatric oncologists.

Results: The majority of physicians agreed that fertility preservation conversations were awkward because of limited options and resources for the technology as well as the existence of a fine line between establishing a sense of trust between doctor and patient, while not excluding parents.

Conclusions: Healthcare providers need training on how and when to broach fertility issues with patients, emphasizing open communication and early disclosure. © 2009 Society for Adolescent Medicine. All rights reserved.

Key words:

Fertility preservation; Adolescents and young adults (AYA); Physician communication challenges; Cancer survivorship

For clinicians, discussing the fertility of an adolescent with the added presence of a parent and a cancer diagnosis, may prove challenging for all involved. Sex, religion, illness, and death are difficult for any parent to discuss with an adolescent, but even more so in the presence of the cancer diagnosis [1]. In the past, communication literature primarily addressed the concerns of the doctor–parent dyad in cases of serious child illness. Given the complex nature of the topic of fertility preservation (FP) for the newly diagnosed adolescent cancer patient, a new focus should be directed to the triad

relationship which includes the physicians, parents and the adolescent/young adult [2].

The most recently available data indicate that in the year 2000, approximately 21,400 individuals between the ages of 15 and 29 were diagnosed with invasive cancer [3]. Given that cancer in the adolescent and young adult (AYA) population represents only about 2% of all invasive cancers in the United States [3], this group is generally not the focus of clinical care and research. However, this age group represents a unique clinical challenge because medical decisions, such as fertility, which will have life-long impact, are likely to be made using decision making models designed for pediatric patients (where parents are the decision makers).

Improvements in the survival statistics for this AYA population remain stagnant. More specifically, although younger children and older adults with cancer have benefited from a steady improvement in 5-year survival trends (over 1.5% per year), AYA patients have had *no change* in survival rates in the past 20 years [4].

The AYA patient 12–18 years of age may be receiving the best care for his or her cancer diagnosis, despite being in

This work is supported in part by the American Cancer Society, Atlanta, GA, RSGPB-07-019-01-CPPB, and in part by the Pediatric Clinical Research Center of All Children's Hospital and the University of South Florida, and the Maternal and Child Health Bureau, R60 MC 00003-01, Department of Health and Human Services, Health Resources and Services Administration, as well as supported in part by the Survey Methods Core Facility at the H. Lee Moffitt Cancer Center & Research Institute.

*Address correspondence to: Gwendolyn P. Quinn, Ph.D., 12902 Magnolia Drive, MRC CANCONT, University of South Florida/Moffitt Cancer Center, Tampa, FL 33647.

E-mail address: gwen.quinn@moffitt.org

a pediatric setting that is uncomfortable or juvenile (e.g., animal prints on the wall, cartoons on the television) [5]. This exemplifies the many ways the AYA cancer patient may be straddling the medical and psychosocial boundaries of childhood and adulthood.

The option of FP, or the banking and storing of sperm for males and eggs or embryos for females, is a technology that can afford the opportunity to become a biological parent in the future, particularly for cancer patients who may experience sterility or reduced fertility because of cancer treatment. Presently, discussions of FP are low in the adult oncology population [6]. Although recent studies suggest these discussions have greater priority among pediatric oncologists, less is known about the unique communication challenge this issue presents for young adults/adolescents who are not quite pediatric patients but not yet legal adults [7]. This paper provides a preliminary exploration into the barriers experienced by physicians regarding this topic, such as communication, consenting rights, and lack of FP training.

Physician Communication

Physicians tend to be older and more similar in age to a parent [8]. As a result, it may be easier for a physician to initiate a conversation with another adult and ignore the adolescent. The physician may initially talk with the adolescent to obtain information for diagnosis, but divert attention to the parent to discuss treatment [2,9]. Physicians tend to speak to adolescents in a jocular manner, while addressing the parents in a more professional manner [2], which may be because of the compassionate nature of the physician, with intentions of trying to ease the pain of an ill child [10]. Thus, the typical communication pattern of the oncologist may be seriously challenged when it comes to discussing this sensitive topic.

Parent Communication

The discussion of a patient's fertility is also challenging for many parents. FP discussions involve sensitive topics such as the chance of long-term survival and even the necessity of male patients using masturbation to collect a semen sample [11]. In some cases, parents may prefer that sexuality topics not be addressed [11]. Parents tend to be more focused on treatment options and survival and discussions of fertility often do not arise.

Barriers to Discussing FP with Adolescent Patients

In determining the barriers to communication in the doctor–parent–adolescent relationship, each individual's role should be examined, although boundaries sometimes intertwine.

AYA Barriers

Both males and females may experience emotional as well as physical barriers to using FP. Communication about sperm

storage may be difficult and embarrassing for the male teen. In some cases, young men are unprepared for the physical process of sperm banking and may need support from an interdisciplinary team of experts [12]. Although it has been suggested that females are more likely than males to have considered future desire for children, the physical process of FP is more complicated for women. The only established method of FP for females is embryo cryopreservation, which requires ovarian hyperstimulation and egg harvesting [13]. However, if females do not have a sperm donor or if they are uneasy about using a sperm bank, then embryo cryopreservation is not an option for them and they may have to consider freezing their eggs, which is a relatively new procedure and considered experimental [13].

Parent barriers

Parental communication barriers surrounding their teenager's cancer diagnosis include lack of knowledge about emotional development and cognitive processes of the adolescent/young adult, varying cultural values, and the reality that the wishes of minors do not carry much weight [14]. An additional barrier to communication is the parent's lack of information, which can mean the clinician is educating both the parent and patient at the same time [15]. The potential obstacle of needing to address the concerns of both the parents and the patient (which may be at odds) is an area in which many physicians lack the knowledge and training needed to effectively communicate with both parties.

Medical professionals' barriers

Schover et al's (2002) [16] study of oncologists regarding their knowledge, attitudes, and practices related to patients' sperm banking before cancer treatment reports that their knowledge is not up to date and many do not provide sufficient information on FP options during cancer treatment. Vadaparampil et al's (2008) [7] study of pediatric oncologists' knowledge, attitudes, and behaviors related to FP found that about half of the respondents reported they needed to learn more about FP, especially options for females. In addition, King et al's (2008) [17] study of oncology nurses' perceptions of barriers to the discussion of FP found that nurses had a general awareness of established FP options, but few were aware of resources.

Thus, existing literature shows that physicians tend to have unique communication patterns with adolescents about health in general. However, the added stress of a cancer diagnosis, combined with the emotional and educational issues for the adolescent and their parents, may pose additional challenges when communicating about FP in the AYA population. Pediatric oncologists play a key role in the care of AYA cancer patients and their families, as they are typically the principal provider, responsible for overseeing and coordinating the care of these patients. They generally interact with

patients prior to the initiation of any treatment, and as such, are in an ideal position to discuss long-term quality-of-life issues, such as FP, with patients and their families [18]. Available data, however, suggest that this discussion does not happen on a regular basis. This lack of discussion about FP may be partially because of the unique communication patterns physicians have with adolescents, the added stress of a cancer diagnosis, and/or the emotional and educational issues faced by AYA patients and their parents. However, no study to date has explored the unique communication issues present in the situation of AYA cancer patients and the discussion of FP.

Methods

This study used a subset of data from a larger study examining the knowledge, attitudes, and behaviors of pediatric oncologists [7]. We obtained approval to conduct this study by an institutional review board, and the procedures followed were in accordance with the ethical standards of the committee. Qualitative, semistructured, in-depth interviews with pediatric hematologist/oncologists practicing in the state of Florida were completed. Using multiple search strategies, 15 clinical centers in Florida treating pediatric cancer patients with a total of 59 pediatric hematologist/oncologists were identified.

The interview guide consisted of seven demographic and practice-related questions, six primary interview questions, and 14 possible probe questions. The interviewers reviewed and fully explained the informed consent document with each physician. All interviews were tape recorded and transcribed. The transcripts were read through and the content analyzed through intuitive analysis, whereby the research team reviews all the data and culls out those aspects most relevant to the research questions [19]. Through this analysis, key themes related to the barriers experienced by physicians in discussing cancer related fertility issues specifically with teen patients were identified.

Twenty-four oncologists participated in the study, representing 41% of pediatric oncologists in the state of Florida. The physician respondents worked across the state of Florida and were all board certified in pediatrics and pediatric hematology/oncology, except for four respondents who were board eligible. Although we list our response rate as 41%, our objective was not to attain a random sample, as in quantitative research, where power analysis is used to determine the necessary sample size for a representative sample. For this study and most qualitative research, to justify sample size, we used theoretical saturation, in which each new participant we recruited refined new theoretical constructs. Midway in the data analysis we ascertained no new information was emerging; thus, we perceived we had reached theoretical saturation and made no further attempts to recruit additional physicians with a second wave of communication [20].

Results

Primary healthcare system barriers to discussions of FP

Physicians were asked to respond to the primary system barriers that impacted discussions with teens about FP. The key themes and sample quotes are shown in Table 1. The most commonly reported barriers were issues related to insurance because FP is not covered and many families cannot afford this additional expense.

Our policy is that we offer them the possibility of banking, but since it is not paid for by insurance... it is expensive... and a big hassle for them and they end up not doing it.

The next most frequently discussed system barrier related to a combination of lack of resources and lack of training or guidelines for having discussions.

We don't have a clinic that offers cryopreservation for these teen patients and we don't have guidelines... we don't have training programs."

Physician perceptions of patient/family desire for FP information

Physicians were asked if they perceived that patients (or their families) wanted information about FP. About half of the physicians said the cancer diagnosis is such a shock that an issue like fertility is often put on the "back burner."

I think that part of what happens... is (parents)... don't give a damn about the rest of it. All they care about is if their kid (going to live).

The other half believed parents and teens do want this information but they are either embarrassed to discuss it or have no background on the topic and do not know how to begin a discussion. The embarrassment issue requires frank discussion about reproductive health, but there is sometimes an underlying feeling that it is too much to ask for their teenager to live and have children.

I've had teens who were very interested in (sperm banking) and they were devastated when they discovered they did not have viable sperm... and one said it was too much to ask to beat the cancer and maybe be a parent. That broke my heart.

There is a certain degree of embarrassment (with parents). It's hard in that kind of emotional situation... I've had parents say it's a good idea, I want you to go talk to my kid, and I don't want to be in the room.

Awareness of FP resources

Physicians were asked if they knew of FP resources within the healthcare system. About one-third were aware of sperm-banking facilities. The remainder said their facility either had none or they were unaware of resources for females, except for the procedure of oophoropexy (the practice of moving the ovaries out of the field of radiation for females

undergoing radiation treatment). A few said they distribute a brochure (produced through a nationally based organization, FertileHope), but this was not always relevant at the local level and needed improvement.

Patient characteristics that pose barriers to FP discussions

Respondents commented on their comfort level discussing FP. Although most were comfortable in a general sense and likened the conversation to “giving bad news,” many experienced barriers related to a patient’s specific diagnosis or socioeconomic situation. Patient barriers ranged from perceived cultural or religious differences, to knowing the family could not afford FP.

Some families have different beliefs or religions and we don't find out what the kid wants because the parents don't continue the discussion.

Kids with cancer are very different than adults with cancer. They can seem in bad shape 1 minute and recover very quickly, or they can go downhill very fast. It doesn't make sense to add insult to injury by discussing this with a family and kid who doesn't have a good shot at living.

Challenges related to discussions with AYA

Some physicians said the teen patient presents a unique challenge. For teens who have reached puberty, all physicians but one said this was an important issue to address. Some broached the conversation in a strict sense of the sterility that may be caused by treatment and felt more comfortable using this tactic. Others felt it was important to discuss what treatment meant in terms of fertility. Most agreed these conversations were awkward because resources were usually limited and there was a fine line between establishing a sense of trust with the patient, while not excluding parents.

It's important that you (the physician) not be embarrassed about it, but these days with regulations, you have to be very careful in terms of what you discuss with the patient of his sexual lifestyle and the risk for sexually transmitted diseases. He may already be sexually active but you can't bring any of that stuff into the discussion with the parents.

It's a liability issue if you don't discuss it (FP) but some parents don't want to deal with it. They don't want to think about their kid masturbating.

Some physicians mentioned having patients who became pregnant during their treatment, representing the greatest ethical challenge experienced. Most mentioned the need to counsel patients that although they may be infertile after treatment, they should not consider the treatment as birth control.

We've had a couple of teenagers who have been on chemotherapy and gotten pregnant. And that actually turns out to be a rather more emotional of an issue than this. Well, it's very hard to stay on intensive chemotherapy when you're pregnant. You know, frequently if you're gonna delay for 9 months, you've got a dead patient

and so you either have to vastly modify the therapy or recommend an abortion.

Discussion

This paper examined communication barriers regarding discussing FP among pediatric oncologist physicians and adolescents diagnosed with cancer. The primary challenges noted by physicians focus on their perceptions that the financial costs of FP were too high for most families. Other concerns centered on whether parents and patients thought FP was a priority given the nature of the cancer diagnosis. Related to issues of priority were the perceptions that the conversations about fertility were related to issues of sexuality, and this was a source of embarrassment for both the patient and parent. Furthermore, physicians typically had low levels of knowledge about resources to refer patients to for FP procedures or consultations.

A main barrier the physicians mentioned was the perception that the financial costs of FP were too high for most families. Schover et al's (2002) [16] study of oncologists' knowledge of sperm banking had similar results with 49% reporting concern FP would not be affordable to patients. Sperm cryopreservation typically costs \$1500, embryo cryopreservation is generally \$8000, and neither are usually covered by insurance [13,21]. However, FertileHope, a national, nonprofit organization dedicated to providing fertility information to cancer patients, offers a Sharing Hope program that provides FP discounts to cancer patients [22,23]. Patient surveys also conducted by Schover [24,25] found that patients typically do not cite cost as a reason patients do not sperm bank, which indicates that physicians incorrectly perceive this issue as a barrier.

Although the pediatric oncologists balance a precarious role between treating the young adult patient and involving parents, physicians must use caution to guard against paternalistic behaviors that negate the roles of parents and AYAs as active participants in the process of treatment and planning for survivorship [14]. Most physicians in the study were either unsure of or assumed that FP information was not desired by parents or patients. Improving patient–physician communication may help AYAs and their families to better understand, prepare for, and cope with their illness and its treatment. The development of communication tools to assess patient and parent knowledge of FP issues and to guide them toward thinking about the topic, may be useful in pediatric oncology practices.

Results also indicate that adolescents pose a unique challenge in terms of the FP discussion, causing embarrassment for the patient or parents. Although most adolescents may want their parents present during a cancer diagnosis [26], the presence of a parent may cause embarrassment when talking about issues of sexuality and fertility. The adolescent cancer patient is often the least empowered person in the physician–patient–parent triad. Although some adolescents

Table 1
Key themes and sample quotes

| Key themes | Sample quotes |
|---------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| System barriers that may impact discussions of FP | <p>“Our policy is that we offer them the possibility of banking, but since it is not paid for by insurance . . . it is expensive . . . and a big hassle for them and they end up not doing it.”</p> <p>“We don’t have a clinic that offers cryopreservation for these teen patients and we don’t have guidelines . . . we don’t have training programs.”</p> |
| Perception of parent/patient desire for FP information | <p>“I think that part of what happens . . . is (parents) . . . don’t give a damn about the rest of it. All they care about is if their kid (going to live).”</p> <p>“I’ve had teens who were very interested in (sperm banking) and they were devastated when they discovered they did not have viable sperm . . . and one said it was too much to ask to beat the cancer and maybe be a parent. That broke my heart.”</p> <p>“There is a certain degree of embarrassment (with parents). It’s hard in that kind of emotional situation . . . I’ve had parents say it’s a good idea, I want you to go talk to my kid, and I don’t want to be in the room.”</p> |
| Patient characteristics that may impact FP discussions. | <p>“Some families have different beliefs or religions and we don’t find out what the kid wants because the parents don’t continue the discussion.”</p> <p>“Kids with cancer are very different than adults with cancer. They can seem in bad shape 1 minute and recover very quickly, or they can go downhill very fast. It doesn’t make sense to add insult to injury by discussing this with a family and kid who doesn’t have a good shot at living.”</p> |
| Issues unique to adolescent patients | <p>“It’s important that you (the physician) not be embarrassed about it, but these days with regulations, you have to be very careful in terms of what you discuss with the patient of his sexual lifestyle and the risk for sexually transmitted diseases. He may already be sexually active but you can’t bring any of that stuff into the discussion with the parents.”</p> <p>“It’s a liability issue if you don’t discuss it (FP) but some parents don’t want to deal with it. They don’t want to think about their kid masturbating.”</p> <p>“We’ve had a couple of teenagers who have been on chemotherapy and gotten pregnant. And that actually turns out to be a rather more emotional of an issue than this. Well, it’s very hard to stay on intensive chemotherapy when you’re pregnant. You know, frequently if you’re gonna delay for 9 months, you’ve got a dead patient and so you either have to vastly modify the therapy or recommend an abortion.”</p> |

FP = fertility preservation.

may be developmentally mature enough to verbalize their desire for children in the future, some may not. It is not uncommon for a 12-year-old boy, who may be sexually mature enough to produce sperm, to regard being a parent as

“gross.” However, in 5 to 10 years that same boy may feel differently and regret his decision not to bank sperm. Physicians may misinterpret a patient’s embarrassment of the topic with actual embarrassment of discussing the topic in front of

a parent. Physicians should consider having FP conversations separately with parents and then the patient. Involving the patient in the decision-making process can give a sense of control [27].

Finally, the data indicate that physicians perceive there is an equal need to discuss general reproductive health issues along with FP for some adolescent patients, particularly young women. However, before strategies and interventions are developed to address these issues, more research is needed to determine the adolescent–patient point of view, particularly with regard to embarrassment, reproductive health, and whom should be present during discussions of a sensitive nature. It is also possible that this communication role may be better suited for a nurse or social worker who may often have more training in discussing sensitive topics. Other studies conducted by this research team indicate that allied health professionals see discussion of FP as their role and are willing to have extended conversations once the physician initially mentions it. [6,7,17,28–31].

Limitations

The results of this study should be interpreted carefully because of certain limitations. Because this is a qualitative study, the results can not be generalized to other pediatric hematology/oncology physicians or other populations. Also, the interviews were conducted with physicians practicing within the state of Florida. Consequently, our results may not be applicable to other states. The length of the interview may have limited the amount of in-depth discussion on any one topic. The physicians who responded to a request for an interview may have been more interested in the topic and more likely to engage in discussions about and/or encourage FP. Furthermore, although strategies and interventions have been suggested based on these data, we caution that more research is needed from the adolescent and parent perspective before such strategies are implemented.

Conclusions

To facilitate effective communication with adolescent patients, providers should (1) acknowledge patients' feelings, attitudes, and norms; (2) assist patients with development of skills they may need to achieve personal goals; (3) provide up-to-date sexual health information; and (4) be aware and respectful of their patients' sexual values and lifestyle [32]. One article recommends holding a separate session with the adolescent so that the parent does not intrude on the developing relationship between doctor–patient [33]. One researcher concluded physicians need to regulate a patient's access to information and help parents overcome their urge to protect by withholding information [34].

Healthcare personnel should be informed about the psychosocial problems and needs of the AYA patient [35]. Physicians need sensitivity training to help adolescents communicate their needs. They must take into account all

factors of communication, such as a patient's medical condition, mental and emotional development, perceived needs and concerns, their readiness and ability to communicate, and with whom they prefer to discuss concerns [36]. Ultimately, the responsibility for conveying information about fertility and childbearing in relation to the cancer diagnosis and treatment lies in the hands of the medical professionals. However, all physicians in this study reported they did not have adequate referral information about FP. This is consistent with the few studies conducted with physician populations indicating the majority have little to no knowledge of specialists to refer patients to and no formal training in the discussion [6–8,17,28,30,37]. Quinn et al's (2007) [29] study of oncologists' knowledge related to the discussion of FP found that knowledge was a key factor in determining whether and how physicians discussed FP.

To effectively improve the quality of life in AYAs as it relates to FP, new methods of communication between all parties must be examined and utilized. Healthcare providers need training on how and when to broach fertility issues with patients, emphasizing open communication and early disclosure. Depending on the age of the patients, parents must allow AYAs to assist in the decision making process. AYAs must be able to advocate for their future fertility in the midst of a cancer diagnosis.

References

- [1] Chesler MA, Paris J, Barbarin OA. "Telling" the child with cancer: parental choices to share information with ill children. *J Pediatr Psychol* 1986;11(4):497–516.
- [2] Tates K, Meeuwesen L. Doctor–parent–child communication. A (re-)view of the literature. *Soc Sci Med* 2001;52(6):839–51.
- [3] Bleyer A, O'Leary M, Barr R, Ries L, eds. *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 19 Years of Age Including SEER Incidence and Survival: 1975–2000*. Bethesda, MD: National Cancer Institute, 2006.
- [4] Burns KC, Boudreau C, Panepinto JA. Attitudes regarding fertility preservation in female adolescent cancer patients. *J Pediatr Hematol Oncol* 2006;28(6):350–4.
- [5] Albritton K, Stock W, Paulussen M. *Cancer at the Interface of Pediatric and Medical Oncology: Striving to Understand and Improve Outcomes*. Alexandria, VA: ASCO Educational Book, 2004. 587–64.
- [6] Quinn GP, Vadaparampil ST, Gwede CK, et al. Discussion of fertility preservation with newly diagnosed patients: oncologists' views. *J Cancer Survivorship* 2007;1:146–55.
- [7] Vadaparampil S, Quinn G, King L, et al. Barriers to fertility preservation among florida pediatric oncologists. *Patient Educ Couns* 2007; 1:146–55.
- [8] Crawshaw M, Glaser A, Hale J, Sloper P. Professionals' views on the issues and challenges arising from providing a fertility preservation service through sperm banking to teenage males with cancer. *Hum Fertil (Camb)* 2004;7(1):23–30.
- [9] Stewart TJ, Pantell RH, Dias JK, et al. Children as patients: a communications process study in family practice. *J Fam Pract* 1981; 13(6):827–35.
- [10] Mack JW, Wolfe J, Grier HE, et al. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *J Clin Oncol* 2006; 24(33):5265–70.

- [11] Schover LR. Psychosocial aspects of infertility and decisions about reproduction in young cancer survivors: a review. *Med Pediatr Oncol* 1999;33(1):53–9.
- [12] Chapple A, Salinas M, Ziebland S, et al. Fertility issues: the perceptions and experiences of young men recently diagnosed and treated for cancer. *J Adolesc Health* 2007;40(1):69–75.
- [13] Lee S, Schover L, Partridge A, et al. American Society of Clinical Oncology recommendations on fertility preservation in cancer Patients. *J Clin Oncol* 2006;24(18):2917–31.
- [14] Foley GV. Enhancing child–family–health team communication. *Cancer* 1993. 15;71(10 Suppl):3281–3289.
- [15] Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA* 2000;284(19):2469–75.
- [16] Schover LR, Brey K, Lichtin A, et al. Oncologists' attitudes and practices regarding banking sperm before cancer treatment. *J Clin Oncol* 2002;20:1890–7.
- [17] King L, Quinn G, Vadaparampil S, et al. Oncology nurses' perceptions of barriers to discussion fertility preservation with cancer patients. *Clin J Nurs Oncol* 2008;12(3):467–76.
- [18] Cope D. Patients' and physicians' experiences with sperm banking and infertility issues related to cancer treatment. *Clin J Oncol Nurs* 2002; 6(5):293–309.
- [19] Miles M, Huberman A. *Qualitative Data Analysis*. 2nd edition. Newbury Park, CA: Sage, 1994.
- [20] Auerbach CF, Silverstein LB. *Qualitative Data: An Introduction to Coding and Analysis*. New York City: NYU Press, 2003.
- [21] Oktay KH, Beck LN, Reinecke JD. One hundred questions and answers about cancer and fertility. Sudbury, MA: Jones and Bartlett, 2008.
- [22] FertileHope. *Cancer & Fertility Resource Guide 2006*. New York: FertileHope, 2006.
- [23] Clarke SA, Davies H, Jenney M, et al. Parental communication and children's behaviour following diagnosis of childhood leukaemia. *Psychooncology* 2005;14(4):274–81.
- [24] Schover LR, Brey K, Lichtin A, et al. Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors. *J Clin Oncol* 2002;20(7):1880–9.
- [25] Schover LR, Rybicki LA, Martin BA, Bringelsen KA. Having children after cancer. A pilot survey of survivors' attitudes and experiences. *Cancer* 1999;86:697–709.
- [26] Orr DP. Adolescents with cancer report their psychosocial needs. *J Psychosoc Oncol* 1984;2(2):47–59.
- [27] Spinetta JJ, Masera G, Jankovic M, et al. Valid informed consent and participative decision-making in children with cancer and their parents: a report of the SIOP Working Committee on psychosocial issues in pediatric oncology. *Med Pediatr Oncol* 2003;40(4):244–6.
- [28] King LM, Quinn GP, Vadaparampil ST, et al. Oncology social workers' perceptions of barriers to discussing fertility preservation with cancer patients. *Social Work Healthcare* 2008.
- [29] Vadaparampil ST, Clayton HB, Quinn GP, et al. Pediatric oncology nurses' attitudes related to discussing fertility preservation with pediatric cancer patients and their families. *J Pediatr Oncol Nurs* 2007; 24(5):255–63.
- [30] Clayton HB, Quinn GP, Vadaparampil ST, et al. Trends in clinical practice and nurses' attitudes about fertility preservation for pediatric patients with cancer. *Oncol Nurs Forum* 2008;35(2):1–7.
- [31] Vadaparampil ST, Quinn GP, Clayton HB, et al. Institutional availability of fertility preservation. *Clin Pediatr* 2008;47(3):302–5.
- [32] Association of Reproductive Health Professionals. Talking to patients about sexuality and sexual health. what you need to know. Available at: www.arhp.org/factsheets; 2005.
- [33] Masera G, Chesler MA, Jankovic M, et al. SIOP Working Committee on psychosocial issues in pediatric oncology: guidelines for communication of the diagnosis. *Med Pediatr Oncol* 1997;28(5):382–5.
- [34] Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *BMJ* 2003; 326(7384):305.
- [35] Lavigne JV. The pediatric hospital staff's knowledge of normal adolescent development. *J Pediatr Psychol* 1977;2(3):98–100.
- [36] Scott JT, Harmsen M, Prictor MJ, et al. Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database Syst Rev* 2003;(3). CD002969.
- [37] Goodwin T, Elizabeth Oosterhuis B, Kiernan M, et al. Attitudes and practices of pediatric oncology providers regarding fertility issues. *Pediatr Blood Cancer* 2007;48(1):80–5.