

Pediatric Oncology Nurses' Attitudes Related to Discussing Fertility Preservation With Pediatric Cancer Patients and Their Families

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This study explores nurses' attitudes toward the discussion of fertility preservation (FP) with pediatric cancer patients and their families. A cross-sectional survey was administered to attendees of a pediatric oncology conference. Of the 115 nurses who responded and comprised the study sample, most reported discussing risks of infertility or FP $\leq 50\%$ of the time. The 3 attitudinal factors most commonly rated by nurses to influence discussion of FP are the potential of upsetting patients' families, that boys younger than 18 years should not be given erotic materials during semen collection, and difficulty locating FP facilities. The 3 patient factors most likely to encourage the discussion of FP are the patient being recently married or engaged, the patient asking about FP, and availability of patient education materials. While the results indicate that nurses do not regularly discuss FP with their patients, nurses perceive such discussion as being within their scope of practice. Therefore, with appropriate intervention, nurses may play a key role in facilitating discussions regarding FP with patients and families.

Key words: *fertility preservation, nurses, pediatric cancer patients, survey, attitudes*

While cancer during childhood is relatively rare, it is one of the leading causes of death among children younger than 15 years of age (National Cancer Institute, 2002; Stiller, 2004). Fortunately, the survival rates for pediatric cancers have continuously improved over the past few decades, and currently, it is estimated

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that 5-year, event-free survival rates are greater than 75% (Bleyer, 1997; Mertens et al., 2001; National Cancer Institute, 2002). As many pediatric cancer patients transition into adulthood, the focus of care has expanded beyond the immediate goal of survival to include long-term quality-of-life issues (Hovatta, 2001).

Unfortunately, there are several adverse consequences of cancer treatment such as endocrine disorders, cardiac and pulmonary dysfunction, secondary malignancies, and psychosocial disorders (Wallace, Anderson, & Irvine, 2005). In addition, for many types of pediatric cancers, treatment options may impair future fertility. For example, among pediatric adolescent male patients, damage to the testes may result from either direct radiation of the testes or whole-body irradiation (Brydoy et al., 2005). For females being treated for cancer, irradiation of the whole body, pelvic region, or abdomen can damage the ovaries and impair the function of the uterus (Maltaris, Boehm, Dittrich, Seufert, & Koelbl, 2006; Maltaris et al., 2007). Many chemotherapy drugs have shown gonadotoxic effects among both males and females (Wallace et al., 2005). In addition to the damage that may occur from treatment, studies indicate the disease itself may also adversely affect fertility. For example, several studies have reported that the pretreatment sperm quality for patients with Hodgkin lymphoma was impaired in males (Agarwal & Allamaneni, 2005).

Although infertility may be an expected consequence of cancer treatment, there are some options for pediatric cancer patients to reduce the likelihood of lifetime infertility. The ability to preserve future fertility is an option for some patients, although it can be affected by a variety of factors such as age, type of cancer, and type of treatment (Wallace et al., 2005). Fertility preservation (FP) options for males in adolescence (semen cryopreservation) are more established than those for females. Cryopreservation of embryos is the only established option for females (Lee et al., 2006). Unfortunately, this may not be ideal for female pediatric cancer patients, as a sperm donor would need to be identified (Wallace et al., 2005). Cryopreservation of oocytes is considered experimental, and research into prepubertal methods of preserving fertility for both males and females (eg, cryopreservation and transplantation of either ovarian or testicular tissue) is still in an early phase (Brougham & Wallace, 2005; Konc, Kanyo, & Cseh, 2006; Marhhom & Cohen, 2007; Oktay & Sonmezer, 2004; Patrizio, Butts, & Caplan, 2005).

Future fertility is important to cancer survivors. Among women treated for cancer during their reproductive years, 51% reported they feared they would have impaired reproductive ability (Zanagnolo, Sartori, Trussardi, Pasinetti, & Maggino, 2005). Follow-up studies have demonstrated that pediatric cancer survivors who had their fertility preserved have since used assisted reproductive technologies to establish pregnancies (Meseguer et al., 2006). Studies of the offspring of cancer survivors have been reassuring, suggesting they are not at increased risk for congenital anomalies and other disorders (Green, 1997).

While FP among pediatric cancer patients is an important aspect of long-term quality of life (Lee et al., 2006), existing studies indicate this issue is not consistently discussed by health care providers with cancer patients and their families (Reebals, Brown, & Buckner, 2006; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002a). Oncology nurses play a key role in the care of pediatric cancer patients and their families (Cope, 2002), and compared to other health care providers (eg, physicians), nurses are more likely to have multiple interactions with patients prior to the initiation of treatment. Therefore, oncology nurses may be in an ideal position to discuss quality-of-life issues such as FP with patients and their families. This study explores attitudes among pediatric oncology nurses toward the discussion of FP with pediatric patients and their families.

Materials and Methods

Participant Recruitment and Data Collection

Attendees of the Florida Association of Pediatric Tumor Programs (FAPTP) 28th Annual Advances in Pediatric Hematology/Oncology Conference in Orlando, Fla, were invited to participate in a brief survey regarding their attitudes related to the discussion of FP with pediatric oncology patients and their families. The conference attendees were primarily nurses practicing in the field of pediatric oncology. We obtained a waiver of informed consent through the University of South Florida Institutional Review Board. A cover letter and survey were placed in the registration packets of each attendant. As an incentive for completing the survey, participants who returned the survey prior to the end of the conference were eligible for a raffle for 1 of 2 \$50.00 cash prizes.

Study Instrument

Based on a review of the literature, we identified 3 key content domains for the survey: practice characteristics and behaviors (Glaser, Wilkey, & Greenberg, 2000), provider attitudes toward the discussion of FP (Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002b), and provider attitudes toward patient factors that may affect the discussion of FP (Schover et al., 2002b). Where possible, survey items to assess key content domains were adapted from existing study instruments (Glaser et al., 2000; Schover et al., 2002b). If previous measures were either unavailable or incomplete in their assessment of a particular domain, new items were developed with the input of a pediatric hematologist oncologist. The items were further refined after review from content experts (2 oncology nurses and a social worker). The final instrument consisted of 45 items and took approximately 10 minutes to complete. All completed questionnaires were read by an optical scanner using Teleform (Verity Software), a high-accuracy content-capture system for automatically processing paper-based forms. If any response(s) could not be read by Teleform, data were entered manually.

The practice characteristics and behaviors section was adapted from an existing questionnaire and additional items developed by the study team (Glaser et al., 2000). Items in this section included location of primary position, professional background, institutional religious affiliation, and age of the patient population. Respondents also indicated the percentage of the following:

- time the risk of infertility was discussed with patients,
- time FP options were discussed with patients,
- patient's family members whom the respondent indicated were interested in finding out about FP, and
- time patients were seen prior to the initiation of chemotherapy and/or radiation.

To assess provider attitudes about discussion of FP with patients, we adapted 8 questions from an existing survey (Schover et al., 2002b) and developed 3 additional questions to assess whether the respondent felt that discussion of FP would upset the patient or family, whether it is only the physician's role to discuss FP, and whether respondents felt that nurses

and social workers should discuss FP with patients. Responses were based on a 5-point Likert-type scale (*agree strongly* to *disagree strongly*).

Last, respondents were asked to indicate how likely a series of patient characteristics such as marital status and HIV status may affect their willingness to discuss FP with patients. There were 3 possible response options: would be more likely to discuss, would not affect the discussion, and would be less likely to discuss. All these items were adapted from an existing instrument (Schover et al., 2002b).

Analysis

All descriptive analyses were performed using a standard statistical software package (SPSS, version 11.5).

Results

Response Rate

Of the 180 attendees of the 28th Annual FAPTP Conference, 126 (65%) completed the survey. Approximately 91% (n = 115) of the respondents were nurses (RN, ARNP), while the remaining 9% identified themselves as an oncologist, clinician, or "other." For the purposes of this analysis, responses were restricted to those who identified themselves as being a nurse, and thus, the final study sample consisted of 115 respondents.

Practice Characteristics and Behaviors

Most respondents indicated they were employed in Florida (47%), followed by 6.1% from Connecticut and Georgia. The remainder of the study population was distributed among 21 other states. Approximately 52% (n = 56) of respondents described the location of their primary position as a pediatric hospital, while 19% (n = 20) were located in an outpatient clinic, 17% (n = 18) described their location as a clinic (nonspecific), and 13% (n = 14) were located in either a medical hospital, cancer center/research institute, university, or other location type. About 47% (n = 48) of respondents had worked in oncology for 5 years or less, while 34% (n = 35) had worked for 6 to 15 years, and 19% (n = 20) had worked for more than 15 years. Only 15% of respondents indicated their institution had a

Table 1. Frequency of Practice Behaviors Related to Discussion of Fertility Preservation (n, %)

Practice Behavior	Frequency			
	0%-10%	11%-25%	26%-50%	51% or more
Percentage of time risks of infertility are discussed with these patients	70 (68)	10 (10)	6 (6)	17 (17)
Percentage of time fertility preservation options are discussed with patients	74 (73)	6 (6)	8 (8)	14 (14)
Percentage of the patients' families interested in finding out about fertility preservation	41 (42)	15 (15)	12 (12)	29 (30)
Percentage of the time patients are seen prior to initiation of chemotherapy/radiation	31 (31)	10 (10)	11 (11)	49 (49)

NOTE: Percentages may not add to 100 because of rounding. Totals may not sum to 115, as a small proportion of each item was missing data.

religious affiliation, 97% (n = 111) indicated they served a purely pediatric population, and 90% (n = 103) worked in oncology (data presented in this paragraph not shown in table format). Most respondents reported discussing either the risk of infertility (68%) or FP options (73%) $\leq 10\%$ of the time. Almost half of the nurses in our survey (49%) indicated that they see patients prior to the initiation of treatment $>50\%$ of the time (Table 1).

Provider Attitudes Toward Discussion of Fertility Preservation

A large proportion of respondents (93%) reported that they felt cancer patients at risk of infertility should be offered FP options (Table 2). In addition, 91% of nurses who completed the survey indicated they felt nurses and social workers should discuss FP options with patients. Attitudes among nurses varied with regard to semen collection procedures, with 47% indicating they felt that "boys under 18 should not be given erotic magazines or videos during semen collection unless parents agree." Nurses also provided a somewhat mixed response regarding the availability of FP options within their institutions, with 37% agreeing that "it is difficult to find convenient FP facilities for my patients" and 27% in disagreement. A large proportion of nurses (72%) disagreed with the statement that "patients under 18 years should not be told about fertility preservation unless parents give consent."

Impact of Patient Factors on Discussion of Fertility Preservation

Several patient factors increased the likelihood of having a nurse discuss FP. Patients who bring up the

topic of fertility and express the desire to have future children prompted 83% of nurses to indicate they would be more likely to discuss FP with those patients (Table 3). In addition, nurses would be more likely to discuss FP options with patients who were recently engaged or married (60% more likely to discuss vs 0% for less likely to discuss). Nurses also report they would be more likely to discuss FP options with patients if they had detailed educational materials about FP available for patients and families (32% more likely to discuss).

Overall, there was a large variation in reported likelihood (more likely, less likely, or neither more or less likely) of discussing FP among nurses by various patient characteristics. Whether a patient is younger than age 18 (73%) or single did not have a large effect on the likelihood of a discussion of FP. Nurses overwhelmingly (92%) indicated that patient access to health insurance would not affect a discussion of FP options.

Nurses reported a few patient factors that would make them less likely to discuss FP options. For example, a patient with a poor prognosis or an aggressive disease that requires immediate treatment appeared to make nurses less likely to discuss FP. Also, more than 3 times as many nurses indicated they would be less likely to discuss FP with homosexual patients (23%) versus 7% of nurses who indicated they would be more likely to discuss FP options with a homosexual patient. More than a third of the nurses (38%) indicated they would be less likely to discuss FP with an HIV-positive patient.

Discussion

The results of this survey indicate that most nurses see at least some patients who may be at risk for infertility because of their cancer treatment. However,

Table 2. Provider Attitudes About Discussion of Fertility Preservation (n, %)

Statement	Strongly Agree	Agree Somewhat	Neither Agree nor Disagree	Disagree Somewhat	Disagree Strongly
All cancer treatment patients at risk for loss of fertility should be offered fertility preservation	75 (65)	32 (28)	4 (4)	4 (4)	0
Nurses and social workers should discuss fertility preservation options with patients	40 (35)	64 (56)	7 (6)	4 (4)	0
Boys younger than age 18 should not be given erotic magazines or videos during semen collection unless parents agree	17 (15)	36 (32)	24 (21)	27 (24)	10 (9)
It is difficult to find convenient fertility preservation facilities for my patients	11 (10)	31 (27)	41 (36)	24 (21)	7 (6)
It is the role of only the physician to discuss fertility preservation	7 (6)	20 (17)	7 (6)	41 (36)	40 (35)
It is difficult to discuss fertility preservation with patients because it is an uncomfortable topic	6 (5)	35 (30)	18 (16)	34 (30)	22 (19)
Discussion of fertility preservation options may upset the patient or the family	6 (5)	61 (53)	24 (21)	19 (17)	5 (4)
I do not have time in a busy clinic to discuss fertility preservation adequately	5 (5)	29 (26)	30 (27)	19 (17)	28 (25)
Patients younger than age 18 should not be told about fertility preservation unless parents give consent	3 (3)	18 (16)	11 (10)	39 (34)	43 (38)
Fertility preservation options are affordable for most patients	2 (2)	12 (11)	37 (33)	38 (34)	24 (21)
The success rates of infertility treatments are too low to justify recommending them for patients	1 (1)	5 (4)	38 (33)	47 (41)	23 (20)

NOTE: Percentages may not add to 100 because of rounding. Totals may not sum to 115, as a small proportion of each item was missing data.

Table 3. Impact of Patient Factors on the Discussion of Fertility Preservation (n, %)

Statement	Would Be More Likely to Discuss	Would Not Affect the Discussion	Would Be Less Likely to Discuss
Patient brings up the topic of fertility and states he or she wants future children	93 (83)	19 (17)	0
Patient is engaged or recently married	67 (60)	44 (40)	0
Availability of detailed educational materials for patients and families about fertility preservation	35 (32)	65 (59)	11 (10)
Patient already has at least 1 child	25 (23)	79 (71)	7 (6)
Patient is younger than age 18	16 (14)	82 (73)	14 (13)
Patient has a very aggressive disease and needs rapid initiation of cancer treatment	16 (14)	55 (49)	41 (37)
Patient is not married	14 (13)	96 (86)	2 (2)
Patient is open about being homosexual	8 (7)	77 (69)	26 (23)
Patient does not have health insurance	5 (5)	102 (92)	4 (4)
Patient has poor prognosis of survival	5 (5)	76 (68)	31 (28)
Patient is HIV positive	4 (4)	64 (58)	42 (38)

NOTE: Totals may not sum to 115, as a small proportion of each item was missing data.

most nurses report discussing the risks of infertility or FP less than 51% of the time. In a study conducted by Goodwin, Oosterhuis, Kiernan, Hudson, and Dahl (2006) of physicians and nurses working in a single pediatric oncology clinic, more than 90% reported discussing the impact of cancer treatment on future fertility. These rates may be higher than our

population because the Goodwin et al. study respondents included physicians who may be more likely to discuss treatment and treatment-related side effects such as infertility with their patients. In addition, these providers were from a single institution, and the high rates may reflect a clinical practice policy supporting the discussion of FP in their practice setting.

The respondents in our study also perceived that patients' families were interested in learning about FP options less than 50% of the time. Nurses may perceive parents as focused solely on treating their child's cancer and as less concerned about the future impact of treatment. Yet in the study by Goodwin et al. (2006) of 16 physicians and 14 nurses, 86% reported "parents of patients often ask me about the effects of cancer treatment on their child's fertility." However, these results were not stratified by provider type. Therefore, it is difficult to discern if questions about FP are primarily directed at physicians rather than nurses, which may lead to nurses' perceptions of disinterest among patients' families.

Because infertility is a possible side effect of a cancer treatment, the optimal time to discuss FP is prior to the start of treatment. The nurses who responded to our survey reported seeing at least 50% of their patients prior to the initiation of chemotherapy or radiation. In addition, more than 90% of study respondents agreed that nurses and social workers should discuss FP options with patients and that all cancer patients should be offered FP. Only about 6% of respondents felt this was an issue that should be discussed only by physicians. Although current results indicate that nurses in our study are not discussing FP with their patients, they appear to be in a prime position to do so and feel that it is within their scope of practice. Thus, understanding factors that may serve as barriers or facilitators to this discussion may help to encourage conversations about FP between nurses and pediatric cancer patients and their families.

The top 3 attitudinal factors rated by nurses as having an impact on the discussion for FP were the potential for the topic of FP to upset patients' families, that boys younger than age 18 should not be given erotic materials during semen collection without parents' agreement, and difficulty finding convenient FP facilities. While it is critical that nurses are sensitive to the feelings of patients and their families, limited evidence suggests that parents (Goodwin et al., 2006; Lee et al., 2006) and young cancer patients (Schover et al., 2002a; Zebrack, Casillas, Nohr, Adams, & Zeltzer, 2004) do want to be given information about FP options. According to a literature review completed by the American Society of Clinical Oncology (ASCO; Lee et al., 2006), follow-up surveys of cancer survivors indicate that those who are infertile because of their treatment are at increased risk for emotional distress (Hartmann et al., 1999; Partridge et al., 2004; Rieker,

Fitzgerald, & Kalish, 1990; Schover et al., 2002a; Schover, Rybicki, Martin, & Bringelsen, 1999). The concept of providing erotic material to males younger than age 18 is a sensitive issue and is rated by nurses in our study as a possible factor that may influence the discussion of FP. This concern about the provision of such material has been corroborated in another study focused on nurses attitudes toward sperm banking for adolescent male cancer patients (Reebals et al., 2006). This becomes an issue of parental consent for providing visual materials in addition to consent for semen collection (Schover et al., 2002a). While this issue may continue to be debated by professionals and parents, clinicians may be able to implement alternatives that may be less sensitive. At one institution, women's swimsuit and clothing catalogues are available to adolescent males in the collection room instead of erotic materials (Marcia Leonard, personal communication), showing that this issue is not an insurmountable obstacle.

Another potential barrier identified in our survey was that more than one third of respondents agreed it was difficult to find FP facilities for their patients. In the Goodwin et al. (2006) study, 64% of respondents rated this as an obstacle to current fertility-related practices. This may be due to the difference in populations between the studies. In the Goodwin et al. (2006) study, all providers were from 1 institution and are therefore likely to have similar perceptions regarding the availability of FP resources in their area, whereas our study population included nurses practicing throughout the United States in a variety of practice settings. However, even for our study respondents, the issue remains that 1 of every 3 nurses in our survey would have trouble identifying local FP resources. The fertileHOPE organization has taken a first step toward addressing this issue by providing a national directory of FP resources (fertileHOPE, 2006a).

The 3 patient factors rated by nurses as making the discussion of FP more likely were the patient being recently married or engaged, the patient asking about FP, and the availability of patient education materials about FP. Partnership status was found to be an important factor in our study as well as in a qualitative study of adult oncology health care providers' perceptions of obstacles to sperm banking (Achille et al., 2006). In that study, health care providers perceived that having a parent or partner may influence an individual's use of sperm banking (Achille et al., 2006). While having a partner (as indicated by being recently married or engaged) may serve as a trigger for discussion about

FP, it is unlikely that most pediatric oncology patients will be in this situation. Therefore, using partnership status as a prompt for discussion of FP may result in most pediatric cancer patients' and families' interest in FP being missed.

Survey respondents indicated that if a patient raised the issue of FP, the nurses would be more likely to discuss it. Thus, one potential strategy for increasing discussion about FP may be to provide patients with resources to assist in initiating the conversation about FP. Both ASCO and the fertileHOPE organization have developed a series of questions for patients to ask their health care providers about the impact of cancer treatment on fertility and FP options (American Society of Clinical Oncology, 2006; fertileHOPE, 2006c).

In addition, nurses felt they would be more likely to discuss FP if appropriate patient education materials were available. Advocacy and professional organizations such as fertileHOPE, the Lance Armstrong Foundation, the American Cancer Society, and ASCO have developed educational materials about FP specifically for cancer patients and their families (American Cancer Society, 2006; American Society of Clinical Oncology, 2006; fertileHOPE, 2006b, 2006d; Lance Armstrong Foundation, 2006a, 2006b). Therefore, educating pediatric oncology nurses about the availability of these materials may help to facilitate the discussion of FP with cancer patients and their families.

The 3 primary patient factors that may decrease the likelihood of discussing FP were positive HIV status, poor prognosis, and the inability to delay treatment because of aggressive disease. In a study of nurses' attitudes toward sperm banking in male adolescent cancer patients, both HIV status and inability to delay treatment because of aggressive disease were ranked as important factors (Reebals et al., 2006). Similarly, in a qualitative study of adult oncology health care professionals, some health care providers indicated that they might not push the issue of sperm banking if the patient is in a critical state (Achille et al., 2006). Based on these results and ours, it appears that nurses might not discuss FP with patients who are at greater risk of mortality. In a qualitative study of male adult cancer patients, patients preoccupied with survival indicated they would be less likely to use sperm banking if it was presented as secondary to or would delay the initiation of treatment (Achille et al., 2006). Conversely, both the male cancer survivors and providers said an optimistic attitude toward survival

would influence the use of sperm banking (Achille et al., 2006). In addition, some health care providers suggested that raising the issue of sperm banking can encourage a more positive outlook on survival (Achille et al., 2006). Thus, it is possible that the desire for discussion about FP would be facilitated by the patient's attitude toward survival, which may be based on several factors other than prognosis. Therefore, at the very least, patients and families, regardless of prognosis, should be informed about FP options that may be relevant to them.

Although this study is among the first to assess the issue of discussion of FP for both male and female cancer patients among pediatric oncology nurses, there are some limitations that should be considered when interpreting study findings. First, this study was conducted among attendees of a nursing conference specific to pediatric oncology. It is possible that this represents a more motivated group of nurses who may be more likely to discuss FP with patients. Second, since the time this survey was administered, ASCO has issued clinical practice guidelines regarding the discussion of FP with cancer patients (Lee et al., 2006). Although these guidelines are targeted toward physicians, they were published in the *Journal of Clinical Oncology*, which has a readership that spans a variety of health professions, including nurses (<http://www.jco.org/misc/About.shtml#Readership>). Thus, the attitudes assessed at the time of our survey may have since changed as a result of the publication of these guidelines. However, our study does provide important baseline information that we and other researchers can use to assess whether attitudes toward the discussion of FP may have changed as a result of these guidelines. Furthermore, although the survey was anonymous, survey results still contain an inherent bias of response acquiescence, in that respondents may indicate they do or say what they perceive to be the norm among their peers. Finally, 11 of the 115 respondents answered "no" to the question "Do you work in the field of oncology?" (response options were yes and no). It is possible that because we did not include hematology as an option, individuals who attended who worked primarily in hematological malignancies (which are more common in the pediatric population) may not have viewed themselves as working in the field of oncology exclusively. However, we chose to include them in the analysis since their attendance at a conference specific to pediatric tumors demonstrated some interest in the issue. Despite these limitations, we

feel this is an accurate representation of the attitudes of nurses attending this conference and that the results aid in highlighting future directions for interventions to improve the quality and increase the frequency of discussion regarding FP.

Conclusions

The need to better understand the issues surrounding FP and pediatric cancer patients is moving to the forefront of the survivorship agenda. As the technology for effective fertility methods continues to improve at a rapid pace, understanding factors that may affect clinical adoption of these methods is vitally important. Oncology nurses are in a prime position to discuss these options with pediatric cancer patients and their families. The data from the study support the idea that nurses believe discussing fertility with patients is part of their role as a health care provider. Findings also indicate that nurses perceive difficulty in identifying FP resources for referring patients as well as patient education materials about FP. As noted by Achille et al. (2006), the need to improve communication is crucial: "Health Care Providers will be more effective in promoting (FP) if they come across as appealing communicators" (p. 3215). Such communication skill can result from gaining knowledge and confidence in one's ability. As such, it is imperative to create tools and educational materials that nurses can use to both increase their knowledge and confidence while satisfying the needs of patients and families.

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