Adolescents and Young Adults With Cancer: Oncology Nurses Report Attitudes and Barriers to Discussing Fertility Preservation

Alexandra Nobel Murray, MA, Joan C. Chriessler, PhD, and Mark L. Robbins, PhD

**Background:** Fertility issues have been found to be an important topic for adolescents and young adults (AYAs) with cancer. Medical technology has made fertility preservation (FP) increasingly effective for postpubertal patients whose treatment course may inhibit their future ability to achieve biologic parenthood. Oncology providers’ recommendations have been shown to vary, potentially affecting patients’ decision-making processes regarding FP.

**Objectives:** This study was designed to assess oncology nurses’ recommendations for patients to consider FP options and to explore what patient-related factors may influence discussion of FP with AYAs with cancer.

**Methods:** 116 oncology nurses participated in this study and were randomized to read one of four vignettes about a patient whose proposed treatment course could affect his or her fertility. Participants’ recommendations to partake in FP were analyzed to test for differences by patient age and gender. Open-ended responses to questions about their experiences as oncology nurses were analyzed descriptively.

**Findings:** Nurses strongly recommended that all patients explore FP options before the start of treatment. Oncology nurses endorsed stronger opinions that young adult female patients should be given independent decision-making power to delay treatment for FP, compared to male and female adolescent patients and young adult male patients. Participants mentioned barriers to discussions that included concerns about exacerbating negative emotions and the decision-making capacity of young patients.

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Adolescents and young adults (AYAs) with cancer, as well as survivors, have noted that discussing treatment risks associated with fertility and fertility preservation (FP) options with the oncology treatment team is important (Gorman et al., 2014; Gupta, Edelstein, Albert-Green, & D’Agostino, 2013; Ruddy et al., 2014). Various professional associations have recommended that, because of the potential negative impact of chemotherapy or radiation therapy on reproductive functioning, the risks of treatment to fertility and FP options be communicated to all patients of reproductive age, regardless of diagnosis or treatment plan, prior to the onset of treatment (Hayes & Bubley, 2015; Sathyapalan & Dixit, 2012). However, what remains unclear is how these discussions are initiated, whether these discussions occur with all patients, and which members of the oncology team are responsible for communicating with patients about these risks and available options.

**Background**

Late effects of some cancer treatments have been associated with azoospermia (the absence of sperm) and premature ovarian failure (de Luyk et al., 2012; Green et al., 2009; van Dorp et al., 2012). Young adults with Hodgkin lymphoma (de Luyk et al., 2012), survivors of childhood Hodgkin lymphoma (van Dorp et al., 2012), and women treated with high doses
of alkylating agent chemotherapy and pelvic radiation therapy (Behringer et al., 2005; Harel, Fermé, & Poirot, 2011) have been found to have premature ovarian failure (i.e., premature menopause), reduced semen quality, or azoospermia.

Advances in medical technologies have provided many patients with cancer of reproductive age with increasingly effective options to preserve the function of reproductive cells, tissues, and organs that may be negatively affected by cancer treatments (Practice Committees of the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology, 2013). Standard FP methods include sperm and embryo cryopreservation (Dillon & Gracia, 2012; Ginsberg et al., 2008). The availability of FP options may vary by the age and gender of the patient, along with other personal and environmental variables (e.g., personal motivations, financial ability). The American Society for Reproductive Medicine (2012) reported that the number of healthy infants born following egg cryopreservation is now comparable to the number born following in vitro fertilization, lifting the “experimental” label from the procedure; this progress is particularly relevant for young female patients and/or those without a male partner.

Depending on the location of the nearest cryopreservation facility, cryopreservation of sperm or eggs may be significantly delayed. In addition, the process of preparing the female body with hormone stimulation, surgical removal of the ova, and cryopreservation requires two to three weeks (American Society for Reproductive Medicine, 2015); this timeline also depends on the availability of a physician to perform the procedure prior to beginning cancer treatment. Researchers found that sperm banking was available in 64 of 68 cancer centers across Europe and that egg cryopreservation was offered in only one-third of the 68 centers (Terenziani et al., 2014). Consequently, female patients may have a more difficult time accessing FP and/or may require a greater delay in treatment onset. Terenziani et al. (2014) also surveyed pediatric oncology/hematology department heads in hospitals across Europe and found that 42% of the participating institutions (N = 68) had established guidelines for their providers regarding FP discussions and recommendations. Oncologists practicing in hospitals without guidelines specific to discussing fertility risk and FP options have been found to be less likely to recommend FP to their patients (Louwé et al., 2013).

Many oncology providers endorse positive attitudes toward their patients’ engagement in FP if it is available to them in hopes of maximizing options for biologic parenthood after treatment (Louwé et al., 2013; Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). However, positive attitudes toward FP may not be sufficient; some researchers have found that oncologists’ and oncology nurses’ attitudes and knowledge about FP may not be related to reported practices of recommending FP to patients (Kotronoulas, Papadopoulou, & Patiraki, 2009; Loren et al., 2013; Quinn et al., 2009; Schover et al., 2002). Other factors may play a role in whether these providers recommend that patients pursue sperm, egg, or embryo cryopreservation.

Recommendations to engage in FP before treatment onset have been shown to vary based on patient age (Quinn et al., 2011) and gender (Köhler et al., 2011). These differences may be attributable to the relative ease of sperm banking for male patients and the more involved process of harvesting eggs for female patients. Providers’ recommendations appear to also be affected by various factors, such as stage of disease (Loren et al., 2013) and socioeconomic status (Letourneau et al., 2012). Currently approved FP options are available only to postpubertal patients, and some procedures, such as testicular tissue cryopreservation, are still considered to be experimental (Ethics Committee of the American Society for Reproductive Medicine, 2013; Revel & Mejia, 2010).

The questions of who is primarily responsible for FP discussions with patients and whether all providers receive ongoing education and training in this area remain unclear. Oncology nurses have reported feeling uncertain about their responsibility in communicating the risks of treatment to fertility and discussing FP options. In addition, many have contemplated whether specific medical team members should be specified as being in charge of these discussions to ensure that all patients are fully informed (Goossens et al., 2014). Nagel and Neal (2008) also found that the majority of oncology nurses surveyed felt unprepared for discussions of sperm banking with patients and desired more education about FP procedures and how to approach these discussions.

Oncology nurses play key roles in the emotional responses of their patients. Understanding oncology nurses’ attitudes and perceived barriers to FP discussions would better support patients in managing fertility and FP issues and better direct their care. The recommendations of healthcare providers, including oncologists and oncology nurses, may be significant in the decision-making process of a patient and his or her family. This study focused on oncology nurses’ perceptions of whether FP should be discussed with patients of specified ages and genders, as well as what patient-related factors may influence these discussions.

Methods
Design

An experimental design was used to test whether oncology nurses’ recommendations and attitudes toward FP varied among four patient conditions (adolescent, young adult, male, female) when the type of cancer, stage, and treatment protocol were held constant. Participants were asked how strongly they would recommend that the patient described explore FP options before the start of treatment.

Partly because of inconsistent research evidence, debate remains among medical ethicists (Piker, 2011) as to how healthcare providers and parents determine the emotional maturity of an adolescent and to what extent they should be involved in treatment decisions (McCabe, 1996; Quinn et al., 2011). In the current study, the authors hypothesized that adolescents and female patients would receive weaker recommendations to engage in FP because of reasons including the following: likelihood of longer treatment delays, procedural difficulties involved in FP for female patients, and uncertainty on the part of the provider about who to include in FP discussions for adolescent patients. Hypotheses included main effects for age and gender, as well as an interaction
TABLE 1. Sample Characteristics (N = 116)

<table>
<thead>
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<th>Characteristic</th>
<th>X</th>
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<th>Range</th>
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<tbody>
<tr>
<td>Age (years)*</td>
<td>44</td>
<td>11.83</td>
<td>22–74</td>
</tr>
<tr>
<td>Length of time in practice (years)*</td>
<td>12.84</td>
<td>–</td>
<td>0–39</td>
</tr>
<tr>
<td>Characteristic</td>
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<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td>Asian American/Asian/Pacific Islander</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino/Latina</td>
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<td></td>
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<tr>
<td>Male</td>
<td>6</td>
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<td>U.S. region*</td>
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<td>South or Southeast</td>
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<tr>
<td>Southwest</td>
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<td></td>
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<tr>
<td>Other</td>
<td>7</td>
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<td></td>
</tr>
<tr>
<td>Missing data</td>
<td>7</td>
<td></td>
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</tbody>
</table>

* Nine responses were missing.
+ Thirty responses were missing.
+ Participants who selected “other” did not practice full-time in the United States.

effect, with the weakest recommendations to partake in FP to be given to 14-year-old female patients.

The other aim of this study was to learn about oncology nurses’ attitudes toward FP based on their professional experience via descriptive analysis of responses to open-ended questions, including the impact of their personal values on FP recommendations and what barriers might exist in discussing FP with their patients. Because the quantitative analyses involved in this study focused on a hypothetical case, asking participants about their experiences with patients in care settings could enrich the discussion of attitudes regarding FP compared to actual behaviors.

Sample

Sample characteristics are listed in Table 1. Participants responded to an invitation, sent to a random sample of the Oncology Nursing Society (ONS) membership database, to participate in a study concerning ethical issues related to the treatment of AYAs with cancer to minimize bias toward providers who may have a more developed interest or knowledge of FP. The authors later asked ONS membership administrators to resend the invitation to a sample of pediatric oncology nurse specialists in hopes of reaching providers who regularly treat patients aged younger than 18 years.

Data Collection and Analysis

Participants were randomized to read one of four vignettes that described a 14- or 19-year-old female or male patient (i.e., 14-year-old female, 14-year-old male, 19-year-old female, and 19-year-old male) diagnosed with stage II Hodgkin lymphoma whose proposed treatment course would include high doses of chemotherapy and radiation therapy, which would pose significant threats to the patient’s fertility.

Participants were asked to respond with treatment recommendations pertaining to the patient in the vignette, including how strongly they would recommend that the patient explore FP options (including recommendations to discuss FP with a specialist and to partake in FP) before the start of treatment; this was rated on a Likert-type scale of 1 (strongly recommend against) to 7 (strongly recommend). What followed were various multiple choice and open-ended questions regarding their professional experience (e.g., whether they have witnessed minor patients and their families disagree about treatment decisions) and how their personal values and opinions regarding FP may affect discussions with patients.

Analysis of group differences was performed using SPSS®, version 21.0. Descriptive analysis of the open-ended responses was exploratory in nature, with the goal of enriching discussion of oncology nurses’ attitudes toward FP and how they understand their roles in discussing FP with patients. Responses to open-ended questions were read independently by two coders using an open coding approach prior to shared discussion and consensus of embedded themes.

Results

Group Differences

Recommendations by responding oncology nurses to participate in FP discussions were high across patient age and gender conditions (see Table 2). Although the mean recommendations trended in the hypothesized direction (with the lowest recommendations for a 14-year-old female patient), the strongest recommendations (for a 19-year-old male patient) were statistically equivalent to the lowest

TABLE 2. Strength of Recommendation to Explore Fertility Preservation Options: Assessment by Patient Characteristic

<table>
<thead>
<tr>
<th>Patient Characteristic</th>
<th>X</th>
<th>SD</th>
<th>F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>14-year-old female</td>
<td>5.4</td>
<td>1.83</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>14-year-old male</td>
<td>5.41</td>
<td>1.98</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>19-year-old female</td>
<td>5.73</td>
<td>1.93</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>19-year-old male</td>
<td>5.88</td>
<td>1.63</td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>Strength of recommendation by patient</td>
<td>–</td>
<td>–</td>
<td>0.52</td>
<td>0.67</td>
</tr>
</tbody>
</table>

Note. The “strength of the recommendation to explore fertility preservation” item is a composite of two items based on questions asked of all participants: “How strongly would you recommend that this patient speak with an endocrinologist and/or visit a fertility clinic before beginning treatment?” and “How strongly would you recommend that this patient partake in fertility preservation if it is available to them?” A Likert-type scale of 1 (strongly recommend against) to 7 (strongly recommend) was used, and the scores for each of the two items were averaged to create those for the composite item.
recommendations. A one-way analysis of variance showed no differences in strength of recommendations to explore FP options across patient conditions (F[3, 112] = 0.52, p = 0.67, with a small effect size, η² = 0.01). No significant main effects were noted for recommendation strength by patient age or gender.

Most participants (61%, n = 71) across conditions reported that patients, families, and oncology teams should collaborate to make the final decision of whether to delay treatment for FP. However, nurses who read the vignette describing a 19-year-old female patient were significantly more likely to report that the patient alone should have the final decision of whether to delay treatment to engage in FP (χ²[12, N = 116] = 33, p = 0.001). See Figure 1 for a more detailed description of participants’ responses regarding who should be involved in the decision-making process to engage in FP.

Sixty-five percent (n = 75) of participants stated that they have witnessed a minor patient disagree with his or her family on the course of treatment. Of those participants who noted that they have been involved in a minor’s treatment, 40% (n = 46) reported that a parent or legal guardian had asked them not to communicate information to the patient about the diagnosis, treatment course, or potential late effects of treatment (including, but not limited to, fertility problems).

A small percentage of participants (13%, n = 15) reported that they primarily work with the target age group of this study, indicating a potential limitation in accessing providers who work mostly with AYAs with cancer. Only nine participants and six participants said their average patient age groups were aged 13–17 years and 18–29 years, respectively. Forty-nine participants indicated that, in the past five years, their average patient age group was aged 30 years or older, whereas 45 participants said their average patient age group was aged 0–12 years. Seven participant responses were missing.

**Open-Ended Responses**

Seventy-six participants responded to one or more of the open-ended questions related to the patient described in the vignette, as well as to their professional experiences related to FP discussions and decision making. Open-ended questions were as follows:

- What other factors may play a role in how you approach the discussion of FP with the patient described in the vignette and would potentially affect your recommendation?
- Please explain the impact of your personal values as indicated above on these topics.
- Is there anything else about your experience as an oncology medical professional working with AYAs and/or FP issues that you would like to share with me to help me understand how medical teams navigate these issues in clinical practice?

Numerous themes emerged through independent coding followed by mutual discussion. See Figure 2 for selected responses by theme. Emphasis was placed on ensuring that the patient and his or her family are fully informed of the treatment risks, as well as the risks of delaying treatment to pursue FP. For example, one participant noted the necessity to make “sure they understood the risks associated with the delay and then follow whatever their informed decision might be.” Participants endorsed the necessity of supporting the decision of the patient and his or her family regarding engaging in FP once fully informed; one participant said, “If they demonstrate understanding, the final decision whether or not to delay should be the patient’s.”

Numerous participants shared the opinion that the oncologist is primarily responsible for initiating these discussions with patients and that they might recommend the patient “defer this conversation” until the oncologist can fully inform the patient of the options. Some noted that a patient’s mental and/or cognitive status would affect the discussion of FP. One participant responded that discussions may be affected by “emotional stability of the patient and family, their level of intelligence, and ability to comprehend risks and benefits of treatment.” Others discussed their concern with the experimental nature of some FP techniques and uncertainty about which procedures may be available to patients of different ages.

**Discussion**

The results of this study indicate that oncology nurses strongly recommend that male and female AYAs with cancer explore FP options before the start of treatment; however,
Ensuring patients are fully informed and supporting the family’s decision

“Ensure the family has full understanding of the outcomes of both options. Medical consequences may be related to delaying treatment, but personal/cultural impact may occur if fertility preservation does not occur. . . . The decision should remain with the family and be supported by the team.”

“Give the patient as much information regarding costs and what is involved in the preservation process, and explain the risks of delaying treatment and let the patient make [his or her] decision.”

“Advise rationale for treatment and urgency, listen as they explore their reasons, and make decisions together. Make sure they truly understand informed consent, pros and cons.”

Concerns regarding patients’ cognitive functioning and decision-making capacity

“If the patient had any cognitive disabilities preventing [him or her] from understanding fertility, it may not be appropriate to approach the patient with this information.”

“Is this someone who truly understands the risk of delay to eventual survival? What are his/her issues? Religious, societal, financial?”

“As long as he is conscious and mentally competent, he must be informed.”

Acknowledging the interpersonal context of decision making


“Family should only be included if the patient requires family involvement.”

Uncertainty about experimental nature of fertility preservation

“Children under the age of 18 are not in a situation to do this usually. Other strategies are to freeze unfertilized eggs or resect ovary tissue to freeze, but whether this will result in a future viable pregnancy is not known.”

Responsibility for fertility preservation discussions

“I would be sure the oncologist has completely discussed risks/benefits, and I would try to remove the barriers to getting the fertility issue resolved.”

“Defer this conversation to the primary oncologist to meet again with the patient and family.”

Involving outside providers and opinions of proper care

“Allow family to pursue options, but assist in making this as quickly as possible so treatment is not delayed. If child is in a life-threatening situation, I will consider involving child protective services.”

“Our facility has a representative from a youth cancer support group who can be contacted seven days a week . . . [to bring] in information regarding fertility preservation.”

“The question about responsibility to inform starts with the physician and continues with the oncology nurse, the nurse practitioner, and other physicians. The whole team should be involved, along with the patient and family.”

FIGURE 2. Embedded Themes in Response to Open-Ended Questions

confusion about nurses’ role in these discussions, as well as barriers to engaging in these discussions with all patients, continue. Although attitudes regarding engaging in FP appeared to be similar across age and gender groups, oncology nurses noted that female young adult patients should have the final decision to delay treatment for FP at a higher rate than other patient age and gender groups. Providers may hold different attitudes regarding the importance of fertility and preservation for young women, which may affect how they approach medical decision making with these patients.

Because of the unique experiences of AYA patients with cancer and the fact that survival rates of these patients have not increased as steadily as those of children or older adults, some healthcare professionals have proposed AYA oncology as a separate subspecialty in cancer care (American Cancer Society, 2012; Bleyer, 2011; Williams, 2013). Specialized training is needed in treating AYAs with cancer, emphasizing the importance of integrated healthcare teams (i.e., medical and mental health providers) to benefit patients, families, and medical providers alike.

Some participants’ responses to open-ended questions referred to the experimental nature of some FP methods, particularly for female patients. Ongoing education for oncology providers about FP is necessary to ensure that patients receive recommendations based on the latest scientific developments and available options. For example, after the current study was conducted, the Practice Committees of the American Society for Reproductive Medicine and the Society for Assisted Reproductive Technology (2013) concluded that egg cryopreservation should no longer be considered an experimental procedure because of technological advancements in this area.

Along with ongoing education about the evolving science of FP, providers may also benefit from continuing cultural competence training to assess for bias in their interactions with patients. For example, one participant noted that the lesbian, gay, bisexual, and transgender (LGBT) “community would need a different approach.” Little research has been done regarding FP discussions with patients with cancer who identify as LGBT. However, growing acceptance of LGBT individuals as parents may require updated guidelines for discussing FP with these and all patients. Researchers have found that FP options are discussed less often with Hispanic and Latino patients (Quinn et al., 2014), patients who identify as gay (Schover et al., 2002), and patients whose income is less than $30,000 a year (Letourneau et al., 2012). Assessment of oncology providers’ attitudes toward FP for patients of different demographic and cultural backgrounds, ages, and genders, as well as their tendencies of recommending FP across patients, could be of importance in increasing multicultural competence.

Participants in this study listed several barriers to providers’ discussion of FP. Patients’ maturity, demographic and socioeconomic factors, and emotional status were noted barriers that may prevent an oncology provider from discussing FP with a newly diagnosed patient with cancer and his or her family because of theoretically benevolent reasons (e.g., providers do not intend to cause harm to patients by withholding information about FP options). However, if the provider believes that this information (treatment risk to fertility and the existence of available FP options) should be shared with patients, then, ethically, this information should be shared universally, giving patients and families the option to participate and respecting their agency and decision-making capacities (Lee et al., 2006).
Patients and families have identified that learning about FP options is important and noted that, whether or not the banked sperm were viable, patients were satisfied with their decision to bank, even if a delay in treatment was necessary (Edge, Holmes, & Makin, 2006; Ginsberg et al., 2008). Researchers in Japan found that participating in FP increased hope for the future for young patients and their families, contrary to some oncologists’ opinions that it may be another burden to bear (Saito, Suzuki, Iwasaki, Yumura, & Kubota, 2005). More research is needed with multicultural and international patients, families, and oncology providers to assess the generalizability of these findings.

Limitations

The results of this study are limited by the possibility that participants’ recommendations may be more indicative of attitudes than actions related to past or future discussions of FP with their patients. The small sample of nurses in each vignette condition (n ranged from 26–33) may contribute to limited power in the analyses for the experimental element of the study. A significant limitation of this study is that only 15 participants reported that they had primarily worked with AYA patients (aged 13–29 years) in the past five years, indicating that the current sample was not fully representative of oncology nurses who are familiar with the unique psychosocial issues of these patients (e.g., individuation from parents, importance of school and peer relationships).

Conclusion

Oncology providers must be kept abreast of advancements in FP technology. Integrated care team members (physicians, oncology nurses, clinical health psychologists, social workers) should also feel competent and comfortable discussing these interventions with AYA patients and families and/or be aware of where to refer patients for more information. Findings from previous research indicated that oncology nurses are unsure of their role in communicating fertility risk and information about FP (King et al., 2008) and feel unprepared for these discussions (Nagel & Neal, 2008). The current study adds evidence to this research area by expanding on barriers that oncology nurses may perceive when deciding if and how to discuss FP with their patients. Oncology nurses play a vital role in patient care and are typically more available than oncologists to patients and families in inpatient and outpatient settings. Effective communication among providers and ongoing education in the rapidly advancing area of FP in cancer care appear to be important areas for future study to enhance quality of care and the quality of life and future fertility of AYAs with cancer.

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