

POSITION STATEMENT

Fertility Preservation for Pediatric and Adolescent Young Adult (AYA) Cancer Patients

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SUMMARY

Pediatric hematology/oncology nurses are an important source of information for patients and families regarding topics important to their quality of life, such as fertility preservation. It is APHON's position that discussions regarding fertility preservation occur with all patients and families as early in the treatment trajectory as possible (prior to treatment whenever possible). These discussions should continue throughout treatment and follow-up care as patients continue to grow and develop.

AUGUST 2012



ASSOCIATION *of* PEDIATRIC
HEMATOLOGY/ONCOLOGY NURSES

Background

Childhood cancer survival rates are now approximately 80% (Smith et al., 2010). As a result of these improvements in survival, consideration of treatment late effects and quality of life are important, in addition to cure of disease. *Infertility*, defined as the inability to achieve conception or produce offspring, is a known long-term consequence of some cancer treatment regimens, including alkylating agents, radiation (based on site), and myeloablative therapies.

Having children is an important decision and developmental milestone for the majority of adults. Greater than 75% of young adult cancer survivors report the desire to parent in the future (Schover, Rybicki, Martin, & Bringelsen, 1999). Two studies from the Childhood Cancer Survivor Study reported lower pregnancy rates in male and female childhood cancer survivors when compared to their siblings (Green, et al., 2009, 2010).

Culture, ethnicity, and religious beliefs may also influence the patient and family's approach to fertility preservation. Healthcare providers must be sensitive to these differences. Promoting an environment of open communication allows families to express their unique concerns regarding fertility and the desire for fertility preservation.

Children and adolescent and young adult (AYA) cancer patients and their families should receive information about the risk of infertility that is appropriate to their particular age and treatment. Pediatric hematology/oncology nurses are a vital source of information to families regarding infertility risk and available fertility preservation options that are both established and experimental. Counseling all families prior to the initiation of treatment is ideal, and information provided should be based on the patient's age, developmental stage, and desire for information. Fertility preservation should also be discussed with patients who do not have an oncology diagnosis but who also might be at risk for infertility from a stem cell transplant or alkylating agents, which would include hematology patients undergoing stem cell transplant or rheumatology patients receiving cyclophosphamide as treatment.

Several studies report childhood and AYA cancer patients are interested in learning about fertility preservation options, including those that are experimental (Burns, Boudreau, & Panepinto, 2006; Ginsberg et al., 2010). Families report that 85% of healthcare providers discussed fertility preservation with them, but less than 50% of nurses surveyed in the same study believed that families desire information about fertility preservation (Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007). All patients and families should receive this information.

The impact of treatment on fertility may not be known for years because individual responses to treatment vary. Factors such as pre-existing conditions, chronic health problems, and genetics influence the ability of survivors to have biological children. Therefore, it is important to maintain open communication and continued follow-up with patients and families as they move through treatment and into survivorship.

Males and females respond differently to cancer treatment and face different risks of infertility. The risk of infertility is a very real concern for patients and families and must be dealt with in a sensitive and timely manner. Given the complexity of the evaluation process, counseling patients and families should be done by a healthcare provider well versed in this topic.

Many pediatric facilities do not have the resources available to offer fertility preservation in their institutions, but they may partner with reproductive or adult centers that provide fertility preservation services. Coordination between the centers is vital for a successful experience for the patient, family, and healthcare team. Pediatric oncology nurses' expertise may be needed to provide adult healthcare providers with information about the unique psychosocial and developmental needs of childhood and AYA oncology patients and their families.

It is also important that patients and families be aware that many fertility preservation techniques are considered experimental and that there is no guarantee of success. Families should be aware of the costs associated with fertility preservation, including information about long-term storage to preserve specimens if appropriate, as well as factors such as frequently inadequate insurance coverage for this type of expense.

Still another difficult, yet important topic that must be discussed with families who decide to preserve specimens is what to do with the specimens in the event that their child does not survive their cancer diagnosis. Options

for disposition of preserved specimens includes 1) maintaining preserved specimens despite death, 2) donating preserved specimens to science, or 3) disposing of preserved specimens in a manner that is respectful of the family's wishes and religious beliefs.

Recommendations

It is the position of APHON that

- discussion regarding the risk of infertility secondary to treatment should be initiated with all patients and families prior to treatment, regardless of the patient's age, gender, culture, socioeconomic status, or healthcare team bias
- discussions regarding fertility preservation and reproductive health should begin before treatment and continue throughout treatment and survivorship in a manner appropriate to the patient's developmental stage at that time
- referral to appropriate fertility preservation specialists should be initiated at the patient and family's request
- the planning and referral process include decisions regarding disposition of preserved specimens in the event of the patient's death.

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