

APHON Position Paper on Fertility Preservation for Pediatric and Adolescent Young Adult (AYA)

Cancer Patients

Authors

Lisa Bashore PhD, RN, CPNP, CPON®

Barbara Carr RN, PNP

Barbara Lockart RN, MSN, CPNP, CPON®

Deb Schmidt RN, MSN, CPNP

Kristin Stegenga PhD, RN, CPON®

Reviewers

Melody Ann Watral, MSN RN CPON®

Deborah Echtenkamp, MSN RN CPON®

Christina Baggott, MSN RN CPON®

Deborah A. Freiburg, MS RN

Kathleen B. Adlard, MSN RN CPNP CPON®

Mary Baron Nelson, MS RN CPNP

Jami Gattuso RN, MSN, CPON®

Cheryl Rodgers PhD, RN, CPNP, CPON®

Childhood cancer survival rates are now approximately 80% (Smith et al., 2010). As a result of these improvements in survival, consideration of late-effects of treatment 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, 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; Green et al., 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.

Childhood and Adolescent/Young Adult (AYA) cancer patients and their families should receive information about the risk of infertility 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, both established and experimental. Counseling all families prior to the initiation of treatment is ideal. 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 also might be at risk for infertility due to stem cell transplant or alkylating agents. This would include hematology patients undergoing stem cell transplant or rheumatology patients receiving cyclophosphamide as treatment.

Several studies report childhood and adolescent cancer patients are interested in learning about fertility preservation options, even experimental options. (Burns et al., 2008, Ginsberg et al., 2009) Families report that 85% of health 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, 2006) All patients and families should receive this information.

The impact of treatment on fertility may not be known for years as 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 institution but 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 there is no guarantee of success. Families should be aware of the costs associated with fertility preservation (including information about long-term storage 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) donation to science or 3) disposal in a manner respectful of families' wishes and religious beliefs.

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 health care team bias.
- Discussions regarding fertility preservation and reproductive health should begin before treatment and continue throughout treatment and survivorship.
- 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.

References

Burns, K.C., Boudreau C., Panepinto J.A. (2006). Attitudes regarding fertility preservation in female adolescent cancer patients. *Journal of Pediatric Hematology /Oncology*, 28(6) 350-4.

Ginsburg, J.P., Carlson, C.A., Lin, K., Hobbie, W.L., Nizo, E., Wu X., Brinster, R.L. Kolon, T.F. (2010). An experimental protocol for fertility preservation in prepubertal boys recently diagnosed with cancer: a report of acceptability and safety. *Human Reproduction*, 25 (1), 37-41.

Goodwin, T., Oosterhuis, B.E., Kiernan, M., Hudson, M.M., Dahl, G.V. (2007). Attitudes and practices of pediatric oncology providers regarding fertility issues. *Pediatric Blood Cancer*, 48, 80-85.

Green, D.M., Kawashima, T., Stovall, M., Leisenring, W., Sklar C.A., Mertens, A.C., Donaldson S.S., Byrne, J., Robison, L.L. (2009). Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*, 27, (16) 2677-2685.

Green, D.M., Kawashima, T., Stovall, M., Leisenring, W., Sklar C.A., Mertens, A.C., Donaldson S.S., Byrne, J., Robison, L.L. (2009). Fertility of female survivors of childhood cancer: a report from the childhood cancer survivor study. *Journal of Clinical Oncology*, 28, (2) 332-339.

Schover, L.R., Rybicki, L.A., Martin, B.A., Bringelsen, K.A. (1999). Having children after cancer: a pilot survey of survivors attitudes and beliefs. *Cancer*, 86, (4) 697-709

Smith, M.A., Seibel, N.C., Altekruise, S.F., Ries, L.A.G., Melbert, D.L., O'Leary, M., Smith, F.O., Reaman, G.H. (2010). Outcomes for children and adolescents with cancer: challenges for the twenty first century. *Journal of Clinical Oncology*, 28, (15) 2625-2634.