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## Education for Pediatric Oncology Nurses on Fertility Preservation of Pediatric Oncology Patients

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### Recommended Citation

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EDUCATION FOR PEDIATRIC ONCOLOGY NURSES ON FERTILITY PRESERVATION  
OF PEDIATRIC ONCOLOGY PATIENTS

by

ELYSE BREIT

A thesis submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Nursing  
in the College of Nursing  
and in the Burnett Honors College  
at the University of Central Florida  
Orlando, Florida

Spring Term 2014

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## Abstract

Although the survival rate of childhood cancer is high, nearly two thirds of these survivors experience negative long-term secondary side effects from cancer treatments. Infertility is one such side effect that can have a prominent impact on quality of life as the patient ages. It is important for nurses working with pediatric oncology patients to provide the patient and family with education about risk for infertility and fertility preservation (FP) in order to allow families to make decisions about FP before cancer treatment starts. However, pediatric oncology nurses report being uneducated about FP guidelines and are hesitant to broach this subject with families. The purpose of this HIM thesis is to review nurse perceived barriers related to educating patients and their families about the risk for infertility following cancer treatments and FP and to make recommendations for improving communication between nurses and families about FP. A search was performed using CINAHL, PreCINAHL, PsychINFO, PsychARTICLES, and Medline databases and examined peer-reviewed quantitative and qualitative research studies. Key terms used in the database searches were ped\* OR child\*, onco\* OR cancer\*, fert\*, and nurs\*. Findings indicated that there were many barriers for pediatric oncology nurses, which inhibited the discussion of FP with patients and families such as lack of knowledge and resources, provider attitudes toward FP, and patient factors. Based on the findings, the researcher identified several interventions to aid pediatric oncology nurses in overcoming these barriers to FP discussion.

## **Dedication**

My family has always encouraged me to have high aspirations and I am fortunate that they are also some of the most amazing role models in my life. I would like to thank my parents, siblings, and extended family for their endless and unconditional support throughout all of my endeavors.

Additionally, I would like to thank Dr. Jean Leuner for being the most amazing mentor. I am so thankful for your guidance and support throughout my time in nursing school.

## **Acknowledgments**

Dr. Loerzel, you are an amazing and inspiring woman to look up to. You believed in me from the beginning and I could not have completed this without your continual support, guidance, and encouragement. I am forever thankful for this experience - I am so lucky to have had you as my chair for this past year.

I would like to thank my wonderful committee members who have provided me with invaluable input and have guided me throughout this process: Dr. Victoria Loerzel, Mrs. Charlotte Neubauer, and Dr. Ana León.

A special thank you to Orlando Health for awarding me the Orlando Health Nursing Honors in the Major Scholarship.

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## **Introduction**

Cancer is one of the leading causes of disease-related death in children. According to the American Childhood Cancer Organization [ACCO] (2011), approximately 13,400 children, infant to 19 years, are diagnosed with cancer each year. The most predominant types of childhood cancers include leukemia, brain and central nervous system tumors. Medical advances have led to increased cancer survival rates for pediatric patients and the National Cancer Institute [NCI] (2008) reports that 79.6% of survivors of childhood cancers now survive at least five years past their diagnosis.

Although the survival rate of childhood cancer is high, cancer treatments such as alkylating chemotherapy agents, radiation, and surgery can lead to undesirable long term side effects. The American Childhood Cancer Organization (2011) states that negative secondary effects of cancer treatment are experienced by approximately two-thirds of childhood cancer survivors. These effects include, but are not limited to: secondary cancers, psychological issues, cognitive and developmental issues, organ malfunction including heart and lung damage, chronic hepatitis, and infertility (Davis, 2005; ACCO, 2011).

A study done on oncology nurses perceptions regarding fertility preservation (FP) showed that many nurses considered FP to be of high importance to discuss with patients, however they felt that other immediate issues such as the patient's treatment and cure took priority over everything else (King et al., 2008). Nevertheless, the issue of compromised fertility as a long term side effect of cancer treatments can have a pronounced impact on the patient's quality of life, both physically and psychologically (Davis, 2005).



Many cancer therapies may have adverse effects on fertility in both male and female patients (King et al., 2008). One study suggests that up to one-third of childhood and adolescent cancer survivors have suspected infertility (Balcerek, Reinmuth, Hohmann, Keil, Borgmann-Staudt, 2012). Treatments that are considered high risk in males and females include alkylating agents, pelvic radiation, cranial radiation in conjunction with chemotherapy, and pelvic and genitourinary surgery (Davis, 2005). These treatments can adversely affect the reproductive organs which can then alter pubertal development, hormone regulation, sexual function, and ultimately fertility (Metzger et al., 2013). According to the Children's Oncology Group (2008), these treatments can lead to delayed or early puberty, gonadal damage and failure, hypogonadism, infertility, premature menopause, and adverse pregnancy outcomes later on in life.

In males, sperm are produced in the testes and can be produced throughout a male's entire lifetime. Infertility occurs when sperm production is low or nonexistent or when sperm are damaged beyond repair. It can also be defined as the inability to conceive after a year of intercourse which results in the inability to father a child (Fertile Hope, 2013). Cancer treatment can also damage the Leydig cells in males which produce the male hormone testosterone. Low testosterone levels cause diminished sex drive and sexual functioning (Goodwin & Oosterhuis, 2006). The American Society of Clinical Oncology (ASCO) recommends sperm cryopreservation, also known as sperm banking, as an established method for FP in postpubertal males. Experimental options include testicular tissue cryopreservation, spermatogonial cryopreservation, and testis xenografting. Although these methods are experimental, they may be the only options available to prepubertal males (Loren et al., 2013).

On the other hand, females are born with a finite number of oocytes, which are more commonly known as egg cells. The number of oocytes diminishes as the female ages in a process called atresia. As a result, atresia leads to menopause later on in life as a result of the decrease in the number of oocytes. Unfortunately, chemotherapy and radiation can cause infertility and can accelerate atresia leading to premature menopause in patients (Davis, 2005). This is significant for pediatric and adolescent patients because it can shorten the number of reproductive years or eliminate the possibility of reproduction altogether. Established methods of FP for postpubertal females, presented by ASCO, include embryo cryopreservation and oocyte cryopreservation. Other investigational methods do exist for postpubertal females such as ovarian transposition, ovarian suppression through the GnRHa hormone, ovarian stimulation, conservative gynecologic surgery to help preserve the reproductive organs as much as possible, and ovarian tissue cryopreservation. Ovarian tissue cryopreservation is considered experimental but is the only current option for prepubertal females (Loren et al, 2013). Unfortunately there is limited research regarding the FP of prepubertal children and all of the current methods for FP in this patient population are experimental.

Guidelines published by ASCO regarding FP aids healthcare providers on advising their patients about different fertility preservation options available to them (Loren et al., 2013). These guidelines mainly focus on FP options for adults. However, this information can also be used as a guide when discussing FP with a postpubertal adolescent. It briefly covers the effects of chemotherapy and radiation on the male and female reproductive system and it provides an overview about fertility preservation options indicated for males and females. Additionally, it covers topics that should be addressed when discussing fertility preservation.

The Children's Oncology Group (2008) published long-term follow-up resource guidelines, which provide recommendations to clinicians for screening and management of late effects that may occur in pediatric cancer survivors as a result from therapeutic treatments for pediatric cancers and malignancies. It lists risk factors and high risk factors associated with an increased risk of developing a potential complication from these treatments. These include: host factors (i.e. age, sex, race, and genetic predisposition), treatment factors (i.e. dose of the therapeutic agent, route of administration, and whether a combination of treatments were involved), medical conditions (pre- or co-morbid conditions), and health behaviors (lifestyle choices such as diet, alcohol use, and tobacco use). Host factors are objective and include age, sex, race, and genetic predisposition.

This survivorship guideline has a section which specifically focuses on the treatment effects of radiation and its impact on the male and female reproductive systems. Therefore, it provides information to patients and their family as to whether a treatment puts them at risk for fertility or reproductive issues. It discusses the potential late effects, risk factors, and high risk factors associated with radiation treatment. Periodic follow-up evaluations (physical development, health history, and lab test screenings related to the reproductive system) are recommended. Additionally, the guideline provides further recommendations on health counseling, resources (Fertile Hope and the American Society for Reproductive Medicine), and information on additional tests that may be indicated for the patient.

The Children's Oncology Group (COG) also wrote "Health Links" documents that provide a more comprehensive and in-depth explanation of the effects of therapeutic cancer agents on the body. The two indicated for the reproductive system are titled "Male Health Issues

after Treatment for Childhood Cancer” and “Female Health Issues after Treatment for Childhood Cancer.” A third “Health Link” could apply to this population regarding precocious puberty.

Ultimately, it is up to the health care provider to discuss FP with their patient and/or patient’s family at the time of diagnosis because it can affect the patient’s quality of life in the future. It is the responsibility of the health care provider to give their patient a referral to a professional who can provide education on FP if they have inadequate knowledge on the topic. There are many factors that must be taken into consideration when the topic of future fertility is discussed. This would include age, gender, prognosis, cost, family factors, guideline awareness, and lack of knowledge (Clayton et al., 2008; King et al, 2008).

Lack of knowledge of FP by the health care provider is a recurring issue in many studies. Studies have shown that health care providers lack knowledge on FP and that this knowledge is not up to date with current practices. Therefore, they may not be able to adequately discuss FP with patients (Achille et al., 2006; Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007). A study conducted in 2006 that surveyed nurses attending a pediatric oncology meeting, found that 96% of the nurses surveyed were unaware of the ASCO guidelines on FP (Clayton et al, 2008). Research conducted by a multidisciplinary team has also identified the need for further education and increased awareness of resources regarding FP (Nagel, Cassano, Wizowski, Neal, 2009). Additionally, adult survivors of childhood cancer express that fertility is a main concern. Upon diagnosis, many were unaware of the risk that cancer treatments pose to fertility and many wish they had been given more information on the subject prior to treatment (Crawshaw & Sloper, 2011).

## **Problem**

Overall, patients and their family need more education about FP and a crucial step in providing this information is to first educate health care providers, specifically pediatric oncology nurses. A study that surveyed pediatric oncology nurses found that 81% of the nurses believed it was their responsibility to discuss FP with their patients and patient's family (Clayton et al, 2008). Nurses may be more favorable, compared to physicians, to address the topic of FP and discuss it with their patient and patient's family because they have more time with their patients in the clinical setting (Clayton et al., 2008). However, many nurses express that they do not feel knowledgeable enough on FP to adequately discuss it with patients (King et al., 2007; Nagel & Neal, 2006). Therefore, nurses need more education and training on the topic in order to provide their patients with proper care.

## **Purpose**

The purpose of this literature review is to (1) review nurse knowledge of FP and attitudes toward FP, (2) review nurse perceived barriers of educating pediatric oncology patients and their families about the side effect of infertility following cancer treatments and FP and (3) provide recommendations and strategies for pediatric oncology nurses who will educate parents and patients of various ages and developmental stages about infertility and FP.

## **Method**

An initial literature review search was done using CINAHL, Medline, and Academic Search Premiere databases using key terms fert\*, nurs\*, ped\* OR child\*, and onco\* OR cancer\*. The results were limited to peer reviewed research articles published no earlier than the year 2005. Additional inclusion criteria included English language, human, nursing subset, and have at least one age subset specified at 18 years and younger which narrowed down articles dealing with pediatrics. Articles were excluded from the search if they did not relate to fertility preservation (consisting of fertility preservation, sperm and ova banking, cryopreservation), pediatric oncology patients, and pediatric oncology nurses.

The first search using the key terms and databases listed above yielded 75 results. After inclusion criteria were taken into consideration, only eight articles remained. In these findings, only three studies were related to pediatric oncology nurses. The other four articles were excluded because they did not relate to pediatric oncology nurses, pediatric oncology patients, and fertility preservation.

After a thorough review of the three articles, a second literature search was performed because the findings were so low. The same databases and inclusion criteria were applied in this review. This search did not include the key terms ped\* OR child\*. These terms were replaced with the key term barrier\*. Other key terms were: fert\*, nurs\*, and onco\* OR cancer\*. Therefore, this opened up research to fertility preservation related to oncology nurses and oncology patients of all ages. Articles were excluded if they did not relate to oncology nursing, oncology patients, and fertility preservation. Studies were included in review if the sample

population included oncology nursing in addition to another health care profession. This search yielded ten results but none of the articles fit the inclusion criteria.

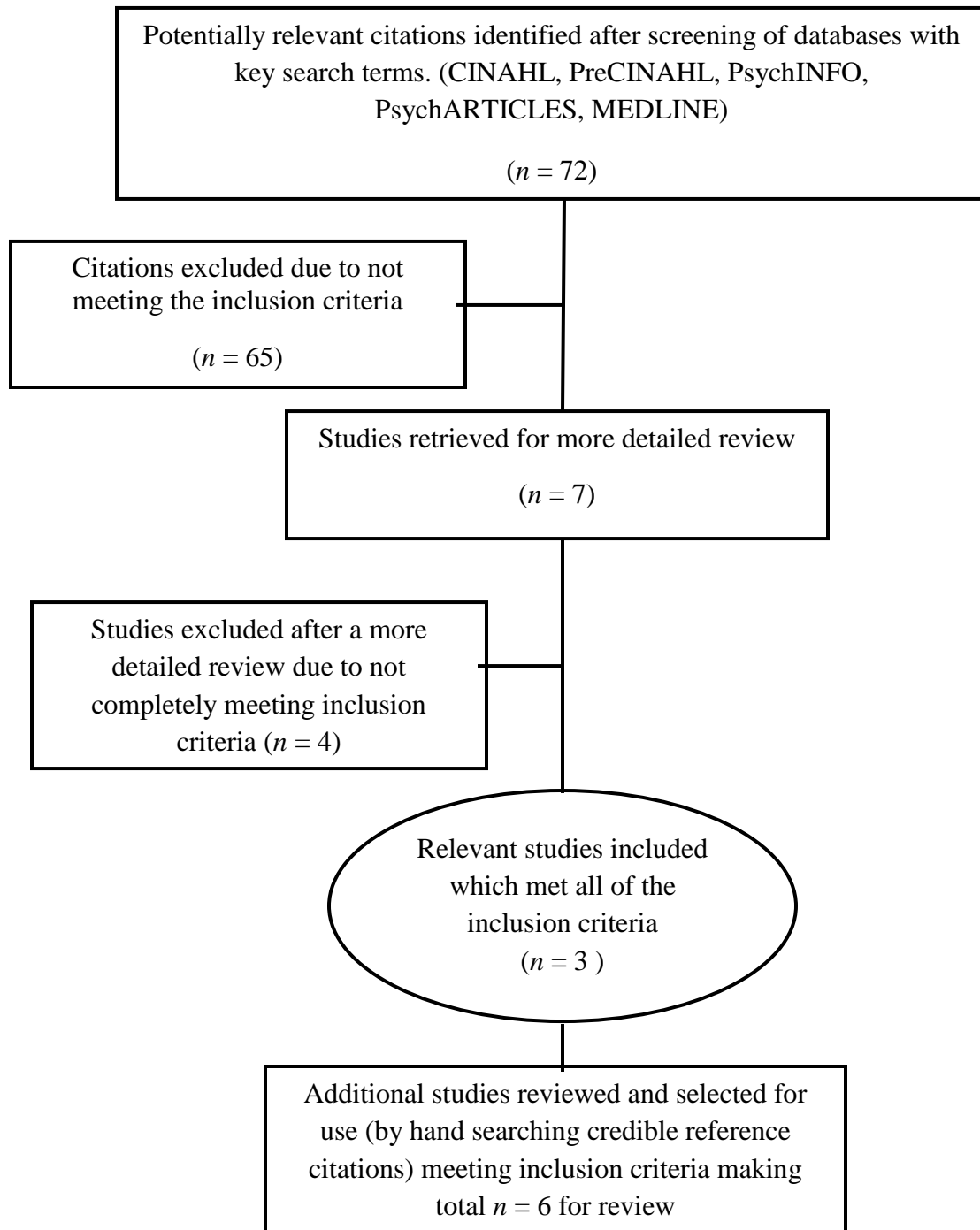
A third search was performed examining the grey literature of the three articles included in the literature review. From this search, three articles fit the inclusion criteria and were added to the literature review. Regardless of practice setting, there is limited research on this topic.



Figure 1: Selection Method of Literature

Key Search Terms = (ped\* OR child\*) AND fert\* AND (onco\* OR cancer\*) AND nurs\*

Inclusion Criteria = Publication date 2005 – current, peer reviewed, research articles, English language, human, Nursing subset, Age specified 18 and younger



## **Summary of Literature**

A total of six studies met inclusion criteria for the literature review. This was composed of two qualitative studies and four quantitative studies. Both qualitative studies (King et al, 2008; Nagel & Neal, 2008) used individual interviews and one qualitative study (King et al., 2008) additionally conducted a focus group to explore aspects of fertility preservation discussions such as knowledge, attitudes, and behaviors. All of the studies established validity. Only one of six studies established reliability (King et al., 2008).

Three of the quantitative studies (Reebals, Brown, & Buckner, 2006; Vadaparampil et al, 2007; Clayton et al, 2008) used a general survey adapted from a 2002 study by Schover and colleagues. The instrument was designed to assess the attitudes and practice of oncologist's views on sperm banking prior to cancer treatment and also assessed oncologist's knowledge of sperm banking. The studies in this review adapted this tool for assessing the nurse's views instead of those of physicians and it was additionally modified to fit their individual respective research. In the Schover instrument, attitudes were measured using a Likert scale with choices of "agree", "disagree", and "do not know/neither". Factors that affect nurse discussion were also measured on a Likert scale with choices of "more likely", "less likely", and "would not affect". Knowledge was assessed using 15 true/false questions.

The studies are grouped based on topic regarding general nurse perceptions of fertility preservation, nurse knowledge and attitudes specific to sperm banking, and provider knowledge and attitudes of fertility preservation.

## **General Nurse Perception of Fertility Preservation**

Vadaparampil and colleagues (2007) examined the attitudes of pediatric oncology nurses towards discussing fertility preservation (FP) with pediatric oncology patients and families. This survey used a modification of the instrument developed by Schover and colleagues to assess nurse attitudes and patient factors, as well as an adaptation of a survey developed from Glaser, Wilkey, and Greenberg (2000), which measured practice characteristics and behaviors. A 45-item survey measured three content domains: practice characteristics, provider attitudes towards the discussion of FP, and patient factors such as age, prognosis, and marital status. The survey was distributed to the attendees of the 2005 Florida Association of Pediatric Tumor Programs Annual Advances in Pediatric Hematology/Oncology conference; 115 pediatric oncology nurses (registered nurses and advanced registered nurses practitioners) participated.

Of the respondents (n=115), 47% of nurses were employed in Florida and 90% indicated working in oncology. The majority of nurses (97%) worked exclusively with the pediatric population. Nurses reported working in a pediatric hospital (52%), outpatient clinic (19%), or other medically based institution (17%). Approximately 47% of nurses worked in oncology for 5 years or less and the remaining worked for six to fifteen years (34%) or more than fifteen years (19%).

Unfortunately, 31% of participants reported seeing pediatric patients and families prior to the start of treatment less than 10% of the time. During these meetings, discussion of FP was inconsistent. Nurses reported rarely (less than 10% of the time) discussing the risk of infertility following cancer treatments (68%) and FP options with clients (73%). In addition, only 30% of

nurses felt that clients were interested in knowing about FP on a regular basis (51% or more of the time).

Most nurses (93%) agreed that patients at risk for fertility loss due to cancer treatment should be offered FP. However, some nurses (24%) thought that physicians were the only ones responsible for FP discussions with clients. Most participants (91%) agreed that nurses and social workers should discuss FP with patients.

In addition, nurses reported barriers to having FP conversations with clients. The majority of nurses (58%) agreed that FP discussions might upset the patient or family. Some nurses (35%) agreed that discussing FP with patients was uncomfortable for the nurse. Time was an important factor; 31% of nurses said they were too busy to discuss FP with clients. Only 14% of nurses thought that FP options were affordable for their patients and 37% of nurses reported that it was difficult to find FP facilities for patients. However, nurses believed that patients younger than 18 years of age should be told about FP regardless if parents give consent (72%).

Instances or situations that would make nurses less likely to talk about FP with clients include if the patient had aggressive disease (37%), HIV positive status (38%), and a pediatric patient being open about their homosexuality (23%). On the other hand, nurses would be more likely to discuss FP with patients if educational materials were available (32%), and if the patient brought up the topic themselves for discussion (83%). Few nurses were more likely to discuss FP with patients who already had children (23%). Only 5% of nurses were likely to discuss FP with patients with a poor prognosis. Additionally, nurses thought that some factors would not affect discussion such as if the patient was recently engaged or married (40%) or not married (86%).

In a 2006 follow up study, Clayton and colleagues (2008) examined trends in the attitudes and behaviors that pediatric oncology nurses had regarding FP through a cross-sectional study of the same 45-item survey conducted in 2005. The study used the same survey instruments to measure the same content domains (practice characteristics, provider attitudes towards the discussion of FP, and patient factors). This quantitative study also evaluated the nurses' awareness of FP guidelines published by ASCO in 2006 and institutional barriers regarding FP discussion between nurses and their patients. The survey was distributed to the attendees of the 2006 Florida Association of Pediatric Tumor Programs Annual Advances in Pediatric Hematology/Oncology conference. The sample in this study included 95 pediatric oncology nurse conference attendees in 2006 and 115 oncology nurse conference attendees from the Vadaparampil et al study in 2005 for a total sample size of 210. While the author of this article focused on trends, only two years of data was reported and the sample may have been biased as participants may or may have not participated in the study for both years.

Practice characteristics in the 2006 survey were similar to those in 2005 and statistically non-significant. However, nurses who saw their patients less than 10% of the time before treatment increased from 31% in 2005 to 41% in 2006. Overall, attitudes toward FP discussion did not vary much between 2005 and 2006. The majority of nurses agreed that all patients at risk for fertility loss due to cancer treatments should be offered FP (93% in 2005, 94% in 2006) and agreed that nurses and social workers should discuss FP with patients (91% in 2005, 81% in 2006). However, the percentage of nurses who thought that only physicians were responsible for FP discussion increased from 24% in 2005 to 32% in 2006.

A few significant changes occurred between the 2005 and 2006 studies regarding patient factors that impact the discussion of FP. The percentage of nurses who reported that they were more likely to have a conversation about FP with a patient with poor prognosis increased from 5% in 2005 to 22% in 2006 ( $p<0.001$ ). The proportion of nurses who were more likely to discuss FP with patients who already had children increased from 23% in 2005 to 39% in 2006 ( $p=0.03$ ). Approximately 69% of nurses in 2006 indicated that a patient who was not married would not affect the discussion of FP. This was a decrease from 86% in 2005 ( $p=0.007$ ). However, an increase of nurses in 2006 indicated that a patient who was recently engaged or married would not affect discussion of FP (40% in 2005, 55% in 2006,  $p=0.03$ ). Given that this study may not have used the same sample in both years, change in attitude is not measured. This study is simply presenting data from two years of data collection.

Institutional barriers were highlighted in the follow-up study from 2006, which presented survey data from both 2005 and 2006. There were no significant changes between 2005 and 2006. Regardless of year, results indicated an overall lack of resources. Less than 14% of nurses reported working in a facility that discussed or had guidelines on sperm and ova conservation. Only up to 30% of nurses responded that their facility had an established link with a sperm collection or preservation service and an even smaller percentage of nurses reported that there was an established link with an ova collection or preservation service (no more than 8%). Additionally, approximately 37% of nurses reported that their facility offered counseling regarding fertility issues. An overwhelming majority of nurses (at least 83%) did not distribute any educational materials to clients about FP. Only 4% of nurses were aware of the 2006 ASCO FP guidelines.

King and colleagues (2008) conducted a qualitative pilot study that consisted of both focus groups and individual in-depth interviews. Fifteen nurses participated in the study; seven nurses participated in the focus group and eight nurses had individual interviews. The participants were composed of registered nurses (RN), nurses with a bachelor's of science in nursing (BSN), and one master's degree in nursing. Each nurse was purposefully selected based on the fact that she/he had discussed FP with a minimum of five patients of childbearing age per year. The interview was composed of seven demographic questions and thirteen primary interview questions. The goal of this study was to evaluate the nurses FP discussion with their patients and to explore their attitude, behaviors, and knowledge related to that topic.

Lack of knowledge, lack of educational materials, and role questionability were found to be barriers for nurses in FP discussion in this study. Nurses reported an overall lack of knowledge related to FP. All of the nurses were aware of basic FP for men (sperm banking) and women (embryo cryopreservation), however many were unaware of the more experimental options such as ovarian or testicular tissue cryopreservation. None of the nurses had knowledge of institutional or national guidelines for FP nor had they received any training on FP. A small amount of nurses had provided educational materials on FP for their patients and few knew of fertility clinics to refer their patients to.

Overall, nurses believed that FP was a topic that should be addressed in the discussion with patients undergoing cancer treatments, however the treatments and cure were considered to be of higher importance. Most of the participants believed that it was part of their role as a nurse to discuss FP with patients, but thought that the physician should initiate the discussion. The majority of nurses reported being comfortable talking about FP with patients, but felt that they

needed more education on the topic in order to facilitate these discussions. Lack of time, patient age, prognosis, and patient interest in FP was considered to be a factor to whether nurses discussed FP with their patients and families. Patient prognosis was deemed to be an ethical issue for the nurses. Nurses were more hesitant to discuss FP with patients whose chances for survival were low. Cost was reported by the nurses to be a possible barrier for patients, however it would not make them less likely to discuss FP. Most nurses reported only discussing FP with patients who had voiced interest in the practice.

### **Nurse Perceptions of Sperm Banking**

Reebals, Brown, and Buckner (2006) conducted a quantitative survey with the purpose of identifying nurse practice issues that have an effect on determining whether sperm banking is discussed with adolescent male cancer patients in the pediatric oncology setting. The sample population consisted of 27 hematology/oncology nurses and nurse practitioners, who work in pediatric hospital in the southeastern United States or outpatient clinic, and who typically treat hematology/oncology patients from fourteen to eighteen years old.

Assessment of knowledge, provider attitudes and patient factors regarding sperm banking in young males with cancer were measured using questions adapted from the previously discussed instrument developed by Schover and colleagues.

Findings indicated that nurses and nurse practitioners had a knowledge deficit related to sperm banking. Only one participant answered all questions correctly; the mean score of all participants was 63%. At least 51% of nurses were not aware that infertility after cancer treatment is more common for males than females. Approximately 92.6% of nurses did not know the cost of sperm banking; falsely believing that general costs were over \$2000. In general, over



half of the nurses were not aware of the practices regarding sperm banking including the fact that some males can have low sperm count upon diagnosis of cancer (77.8%) and the amount of semen samples needed to be banked before cancer treatment (70.4%). Also, 51.9% of nurses falsely believed that an increased risk of birth defects occurred from semen collected during the first week of cancer treatments.

Most nurses agreed that all male patients undergoing cancer treatment should be offered sperm banking (96.3%) and should have advanced directives for banked sperm (96.3%). Approximately 37% of nurses felt uncomfortable discussing sperm banking with patients and 14.8% thought that adolescent males should only be told about sperm banking if their parents allow the topic to be addressed. Only 18.5% of nurses agreed that sperm banking was affordable for patients. Some nurses thought that the cost of infertility treatments were too high to justify banking sperm (7.4%). However, none of the nurses agreed that success rate of FP was too low to justify banking sperm. Interestingly, 51.9% of nurses did not know if it was difficult to find sperm banking facilities.

Nurses were more likely to discuss sperm banking with patients who brought up the topic of fertility (85.2%) and if educational materials were available (66.7%). Nurses determined that the following factors would not affect discussion of sperm banking: the patient is not married (96.3%), recently married or engaged (63%), already had a child (63%), openly homosexual (63%), had no health insurance (85.2%), needed immediate cancer treatment due to aggressive stage of disease (48.1%), and had poor prognosis (74.1%). Only 14.8% of nurses would be more likely to discuss sperm banking with patients under the age of nineteen. Nurses were less likely to discuss sperm banking with patients who were HIV positive (77.8%).

Nagel and Neal (2008) conducted a cross-sectional qualitative study examining nurse discussion with adolescent male patients with cancer and their families regarding sperm banking and any barriers that affected that discussion. A total of twenty-one nurses from the McMaster Children's Hospital and the Hamilton Health Sciences Center for Reproductive Care in Ontario, Canada participated in the survey. Seventeen nurses worked in oncology and the remaining three were reproductive health nurses. Only nurses who had interacted with the patient prior to undergoing cancer treatment were able to participate in the study. The survey consisted of open-ended questions aimed at determining the nurses' knowledge of sperm banking process, the incidence of sperm banking discussion with patients, and what did or did not facilitate the discussion.

The results of this study highlighted four major barriers that affected the discussion of sperm banking. Nurses (1) did not know if it was their role to initiate the discussion, (2) felt unprepared for discussion, (3) expressed a lack of knowledge in the subject area, and (4) reported lack of educational materials to distribute to patients.

First, nurses were unsure of their role in the process of sperm banking. They were unclear as to whether it was their role or the doctor's role to discuss this topic with patients. Secondly, the majority of nurses felt unprepared to talk about sperm banking with their patients and many nurses reported that they did not even have these discussions with their patients. Those that did talk with their patients about sperm banking noted that the discussion was awkward and uncomfortable for the nurse, patient, and family. One nurse stated that it was difficult to talk about sperm banking with one particular patient and therefore did not discuss the subject at all.

Knowledge about sperm banking was reported as a third barrier for nurses. Nurses expressed the need for more education on about sperm banking. All of the nurses reported that they did not feel prepared to discuss this topic with patients due to lack of knowledge about the process and therefore would be unable to discuss it and answer any questions that the patient and family might have. Lastly, all nurses agreed that there were not enough educational materials on sperm banking to distribute to patients and families. They concluded that an increased availability of these materials would benefit sperm banking discussions between them and their patients.

### **Provider Perception of Fertility Preservation**

Goodwin and colleagues (2007) conducted a quantitative study with the aim of understanding the practice and attitudes of pediatric oncology providers regarding fertility issues related to cancer treatments in pediatric oncology patients. A total of thirty healthcare providers (HCPs) that worked in pediatric hematology/oncology medical institutions responded to the survey. Sixteen of the participants were physicians and the remaining fourteen participants were comprised of nurses and nurse practitioners. The researchers created their own survey instrument that assessed provider knowledge, practices, obstacles to practice, patient perceptions, and future practices related to FP. The survey was reviewed by a pediatric oncology physician with experience in survey design to establish validity and ensure that survey questions were clear and appropriate. Knowledge was assessed if the provider was aware or not aware of each statement. Subsequent sections consisted of questions that the provider agreed or disagreed with. The results of the physicians and nurses were reported collectively because there was no statistically significant difference between groups.

Over 90% of participants were aware that alkylating agents were linked to infertility, abdominal and pelvic radiation were linked to infertility, and that cancer treatments have a risk to delay puberty and induce early menopause. However, only 50% of participants were aware that infertility risks related to cancer treatment were higher in boys than girls. Additionally, only half of the participants were aware of more current evidence and experimental options regarding FP. HCPs were unaware that pre- and post-pubertal girls can undergo ovarian tissue cryopreservation (46.7%) and that this experimental option has resulted in successful pregnancy following chemotherapy (50%).

Providers reported that they customarily talk to patients about the impact of cancer treatments on fertility (92.8%). However, only 63.3% reported that they caution patients going through cancer treatments about the potential side effect of infertility. Around 25% of providers did not address fertility with patients with a poor prognosis and few participants reported that they consult with specialists about infertility (34.6%). The family's economic status had a minimal impact on whether FP was discussed (3.8%).

Overall, 64.3% of HCPs indicated that it is challenging to find FP facilities and specialists for their patients. Few providers agreed that the cost of infertility treatment was too expensive to justify FP for males (7.1%) and females (14.8%). A limited proportion of providers also agreed that the success rate of FP is too low to justify FP for males (10.3%) and females (34.4%). Findings indicated that there were more obstacles to FP for female patients.

How the HCP perceived the beliefs and attitudes of their patients regarding fertility was also examined. HCPs agree that parents of patients are more likely to ask about the effect of cancer treatment on fertility than patients (85.7% and 57.2%, respectively). Providers believe

that older patients and families are more likely to be concerned about fertility than their younger counterparts (79.5%). Only 22.4% of participants believed that female patients and families were more concerned with fertility than males and thought that patients of lower socioeconomic status were less worried about fertility (23.3%).

Lastly, the survey assessed HCPs desires for practice improvements. The majority of providers responded that they wanted to consult with an infertility specialist in the future (92.8%) and discuss FP options with patients at risk for infertility due to cancer treatment (96.6%). Most importantly, 96.6% of HCPs responded that there should be a training session on infertility risks and FP for all providers and agreed that patients should be given more information on infertility issues and FP. The majority (86.7%) believed that all developmentally apt children should be included in FP discussions. Approximately half providers thought that it appropriate to address fertility issues at the patient's consent for treatment appointment.

### **Summary of Patient Factors and Provider Attitudes about discussing Fertility Preservation**

Tables 1 and 2 are compilations of the results of the three quantitative studies: (A) Reebals, Brown, & Buckner, 2006, (B) Vadaparampil et al., 2008, and (C) Clayton et al., 2007. These studies used a modification of the survey tool developed by Schover and colleagues on patient factors affecting nurse discussion of FP and provider attitudes towards FP (2002).

Table 1: Patient Factors Affecting Nurse Discussion of FP with Patients (%)

	More Likely			Would Not Affect			Less Likely		
	A	B	C	A	B	C	A	B	C
1. Patient is not married.	0	13	22	96.3	86	69	3.7	2	10
2. Patient is recently engaged or married.	37	60	44	63	30	55	0	0	1
3. Patient already has at least one child.	22.2	23	39	63	71	58	11.1	6	3
4. Patient is openly homosexual.	0	7	15	63	69	68	33.3	23	17
5. Patient is 18 years old or younger.	14.8	15	18	74.1	73	70	11.1	13	12
6. Patient has no health insurance.	3.7	5	10	85.2	92	84	11.1	4	7
7. Patient brings up the topic of fertility or FP.	85.2	83	74	14.8	17	26	0	0	0
8. Patient has poor prognosis.	3.7	5	22	74.1	68	51	22.2	28	27
9. Patient is HIV positive.	3.7	4	11	18.5	58	52	77.8	38	38
10. Patient has an aggressive stage of disease and needs immediate initiation of cancer treatment.	11.1	14	16	48.1	49	46	40.7	37	38
11. Educational materials are available.	66.7	32	38	33.3	59	51	0	10	11

- Nurses were asked about what patient factors would affect their discussion of FP with patients and families. Choices were “more likely”, “less likely”, or “would not affect” discussion.
- Studies: (A) *Reebals, Brown, & Buckner, 2006*. (B) *Vadaparampil et al., 2007*. (C) *Clayton et al., 2008*.
- Study (A) *Reebals, Brown, & Buckner, 2006*, specifically examines sperm banking discussion rather than general FP.

Table 2: Provider Attitudes Toward FP Discussion (%)

	Agree			Disagree			Neither/Do Not Know		
	A	B	C	A	B	C	A	B	C
1. Physicians are responsible for FP discussion.	-	24	32	-	71	55	-	6	14
2. Nurses and social workers should discuss FP.	-	91	81	-	4	14	-	6	5
3. All patients at risk for fertility loss due to cancer treatments should be offered FP.	96.3	93	94	3.7	4	1	0	4	5
4. Nurses don't have enough time to adequately discuss FP.	33	31	42	62.9	92	35	3.7	27	23
5. Discussing FP is uncomfortable.	37	36	30	62.9	49	52	0	16	19
6. Success rates of FP are too low to justify recommending them to patients.	0	5	6	74	61	63	25.9	33	32
7. FP is affordable for patients.	18.5	12	9	51.8	55	61	29.6	33	30
8. It is difficult to find convenient FP clinics.	33.3	37	31	14.8	27	31	51.9	36	38
9. Patients under 18 years should not be told about FP without parental consent.	14.8	18	16	85.2	72	68	0	10	16
10. Boys under 18 years old should not be given erotic materials during sperm collection without parental consent.	48.1	47	44	48.1	33	44	3.7	21	13
11. Discussing FP will upset the patient and family.	-	58	56	-	21	22	-	21	23
12. The expense of FP is too high to justify recommending it to patients.	7.4	-	-	77.7	-	-	14.8	-	-
13. Patients should have advanced directives for banked sperm	96.3	-	-	3.7	-	-	0	-	-

- Provider attitudes toward FP were measured. Participants were asked the degree to which they agreed or disagreed with attitude statements.
- Studies: (A) *Reebals, Brown, & Buckner, 2006*. (B) *Vadaparampil et al., 2007*. (C) *Clayton et al., 2008*.
- The (-) symbol signifies that the question was not included in the respective survey.
- Study (A) *Reebals, Brown, & Buckner, 2006*, specifically examines sperm banking discussion rather than general FP.

## **Discussion**

Overall, studies suggest that pediatric oncology nurses/providers are not discussing FP very often with their pediatric patients (King et al., 2008; Nagel & Neal, 2006; Vadaparampil et al., 2007). This review highlighted several barriers that inhibit discussion of FP between pediatric oncology nurses, providers and their pediatric patients. These barriers include lack of knowledge and resources, provider attitudes towards FP and sperm banking, and individual patient factors.

### **Lack of Knowledge and Resources**

Overall, these studies showed a general lack of pediatric oncology nurse/provider knowledge about FP and a lack of resources (Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007; King et al, 2008; Nagel & Neal, 2008; Reebals, Brown, & Buckner, 2006). Some providers were unaware of fertility risks of cancer therapies, FP practices, costs, and practice guidelines. Knowledge disparities between male and female infertility or fertility preservation options were also evident (Clayton et al, 2008; Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007; Reebals, Brown, & Buckner, 2006). The findings in the study conducted by Schover and colleagues (2002) also showed a general lack of knowledge for oncologists regarding the same topics (fertility risks of cancer treatment, FP practices, costs, and gender disparity). Although the remaining studies did not specifically focus on assessing knowledge, the results also suggested an overall knowledge deficit of pediatric oncology nurses and other oncology providers on FP.

Knowledge of FP guidelines was also lacking. Clayton and colleagues (2008) showed that the majority of their participants had no knowledge of the 2006 ASCO guidelines on FP. King and colleagues (2008) also demonstrated lack of guideline knowledge, although not



specific to the ASCO guidelines. Within individual institutions, nurses reported that their facility did not have nor discuss any FP guidelines for them to refer to (Clayton et al., 2008; Vadaparampil et al., 2007).

Lack of resources was also a barrier. Resources were lacking for pediatric oncology nurses and providers. Some nurses did not have any educational materials to provide to patients (Clayton et al., 2008). While there was an overall lack of education materials to give to patients and families, there were even fewer resources available for female patients compared to male patients (Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007). This discrepancy between sexes is also evident in the fact that there is a wider availability of FP options for males than females, both pre- and post-puberty. Overall, studies showed that oncology nurses and providers would be more likely to discuss FP if these resources were available.

Many providers reported being unfamiliar with fertility resources to refer their patients to (Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007; King et al., 2008; Reebals, Brown, & Buckner, 2006; Vadaparampil et al., 2007). Many oncologists thought that it was challenging to locate sperm banking clinics (Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Some studies also showed that nurses and providers did not have an established link with a fertility clinic or specialist (Clayton et al., 2008; Goodwin, Oosterhuis, Kiernan, Hudson, & Dahl, 2007; King et al., 2008; Reebals, Brown, & Buckner, 2006). The lack of knowledge or appropriate clinics is a huge barrier for pediatric oncology nurses/providers as it may inhibit conversations with patients, especially if they do not know how to help them follow up on FP advice.

### **Provider Attitudes towards Fertility Preservation Discussions**

Provider attitudes were also a barrier. The majority of participants believed that it was part of their role as a nurse to discuss FP with their pediatric patients and that patients undergoing cancer therapy that risks fertility should be offered FP (Clayton et al., 2008; King et al., 2008; Vadaparampil et al., 2007). However, some pediatric oncology nurses thought that the doctor should bring up the topic of FP first (King et al., 2008). In addition, there was also varied feedback regarding comfort level of discussing the topic, which would affect whether these discussions even occurred. In general, the quantitative studies showed that nurses did not think discussing FP was uncomfortable whereas the qualitative studies stated that comfort level was a barrier. This difference could be due to depth of knowledge and experience with this practice.

In comparison, few oncologists thought that discussing sperm banking with patients was uncomfortable (Schover, Brey, Lichtin, Lipshultz, & Jeha, 2002). Some participants expressed that they were uncomfortable discussing FP because they did not feel knowledgeable on the topic or if the patient and family seemed uncomfortable. In the study conducted by King and colleagues (2008), nurses said they would feel more comfortable if they had more knowledge and information about FP resources for patients. Additional barriers were provider's belief that FP was an important topic, however, treatment and cure of the cancer always had priority over fertility discussions.

### **Patient Factors**

Patient factors seemed to guide discussion about FP. Studies suggest that pediatric oncology nurses and providers are picking which patients they want to discuss FP with and which patients they think are more interested in learning about FP instead of offering it to all

patients. Some patients may be completely unaware that FP could be a potential option for them. Providers are possibly leaving out pediatric patients and families who may really want information on FP. The decision to undergo FP should ultimately be up to the patient and family and should not be determined based on the provider's decision to discuss it.

## **Limitations**

There are several limitations in the review of the literature. There is limited research examining pediatric oncology nurses perceptions regarding FP for pediatric oncology patients. Additionally, there is limited research examining oncology nurses views of FP for oncology patients. However, all studies showed similar findings, which is a launching point for further research and interventions.

Second, the six studies were comprised of different samples. The samples were a mix of staff nurses, advance practice nurses and physicians. Therefore, these findings only apply to the sample that participated in each study and cannot be generalized to all pediatric oncology nurses and providers.

Lastly, the validity of the modified survey tool adapted from Schover and colleagues used in the studies is questionable. The original tool was developed to examine the attitudes and practices of oncologists regarding sperm banking in adults prior to cancer treatment. More recent studies used this tool to measure attitudes and knowledge of nurses and providers who work with pediatric patients with cancer. This tool is not pediatric specific and some questions may not apply to the pediatric population and nurses who treat pediatric patients. For example, some questions referred to patient's marital status, prior fertility history, sexual orientation, and HIV status. It is possible that most pediatric oncology patients are not married, do not have prior children, may be too young to have sexual identity, and/or do not have to worry about HIV status.

## **Recommendations**

### **Education**

The research demonstrates that education on fertility risks and FP is needed for pediatric oncology nurses and oncology HCPs who care for patients undergoing cancer treatments. If oncology nurses and HCPs were provided better education about FP, they may feel more comfortable discussing the topic and initiating the conversation in order to better educate and care for their patients and families.

Many organizations provide information regarding these topics such as the American Society for Clinical Oncology (ASCO), Children's Oncology Group (COG), American Cancer Society (ACS), National Cancer Institute (NCI), American Society for Reproductive Medicine (ASRM), Livestrong, and Fertile Hope. These organizations can provide educational materials to providers and patients on how cancer treatment can affect fertility and FP options before and after treatment for both pre- and post-pubertal men and women. Pediatric oncology nurses and providers should also familiarize themselves with guidelines regarding FP for patients with cancer including both those published by COG (pediatrics) and ASCO (adult and pediatrics), which was most recently updated in 2013 (Loren et al.). These guidelines provide the most up to date research and information on FP and will help to advise healthcare providers on discussing fertility risks and FP options with their patients.

A continuing education class or in-service learning opportunity on FP should be held for both inpatient and outpatient pediatric oncology nurses in the hospital. Online webinars or learning modules should also be considered to ensure that nurses are able to learn the material at

a time that best suits their schedule. A pre- and post- test can be used to evaluate effectiveness of the intervention.

Additionally, a brief introduction of FP could be included in undergraduate and graduate nursing education classes so that students could have basic knowledge of the topic before they go into practice.

Lastly, it is difficult to discuss such personal and intimate topics, such as fertility and FP, with patients and families. Multidisciplinary staff training, which includes nurses, nurse practitioners, and physicians, is needed on how to initiate and hold discussions with pediatric oncology patients and families about fertility risks and FP options. As part of this training, simulation and role-playing workshops should be developed in order to help pediatric oncology nurses and providers practice having these discussions and to ease their comfort level with the topic. These types of workshops will allow pediatric oncology nurses and staff to refine their therapeutic communication skills.

### *Resources*

Finally, staff must be educated on the resources available to them. There is an abundance of resources available for pediatric oncology nurses and other oncology HCPs that can be easily accessed on the Internet. Nurses, health professionals, and patients and families can easily locate fertility clinics based on their zip code by using websites such as [fertilityguide.com](http://fertilityguide.com).

Additionally, providers can access and order free educational materials for themselves and to give patients on the Internet. Fertile Hope is an organization that provides reproductive information and resources for patients undergoing cancer treatments that put their fertility at risk. For health professionals, such as pediatric oncology nurses, Fertile Hope provides free

educational brochures, in both English and Spanish, to give to patients and their families. Patients can access these documents online, however these brochures can be ordered online by health professionals in greater quantities so that they can be readily available in offices, hospitals, and clinics when needed. It also has a free pre-prepared presentation on FP that health professionals can order.

Fertile Hope provides information on up to date research and research trials and provides comprehensive information on fertility risks for male and female oncology patients with separate sections that focus on the pediatric population and specific types of cancer. It also provides further informational links to other organizations such as COG, ASRM, and ACS. Fertile Hope also has a fertility risk calculator for males and females based on their cancer type or treatment regimen. An options calculator can be used to gauge fertility preservation options for patients based on age, treatment stage, and types of treatments. The site also provides recommendations for support groups and financial assistance. All pediatric oncology nurses and providers need to know about these resources in order to direct patients and families to it and to help explain everything to them.

An interactive web and compact disk program regarding male fertility and cancer treatment is being developed called “Banking on Fatherhood” with two versions, one specifically to educate the healthcare professional and a second version to educate the patient and family. This educational tool is free of cost to both the healthcare professional and patient. It is encouraged by the researcher that more online programs like this be created for staff education not just on sperm banking, but also on matters of fertility preservation for females.

Tables 3 and 4 located in Appendix B highlight online links that provide beneficial information to both the patient and provider.

## **Practice**

First, pediatric oncology nurses need to gain knowledge on FP in order to provide optimal care to their patients and families. Once this is achieved, facilities should devise a plan on discussion of FP. Facilities should come up with their own FP guidelines and plan for practice so that all staff members are educated on the topic and are all on the same page. The multidisciplinary staff, especially nurses and physicians, needs to have meetings to determine the process of FP discussion. It is imperative to identify which healthcare team member will initiate and follow-up FP discussion with oncology patients since this has been shown to be an issue throughout multiple research studies. Periodic meetings between the healthcare team should be held to determine the effectiveness of FP protocol and FP discussions in order to make necessary adjustments to refine the process.

This plan should also consist of developing a standard protocol for offering FP to all patients and families. This will aid in avoiding bias based on patient factors. As part of protocol, facilities should create an informational packet on FP, individualized for the patient based on gender and pre- or post-pubertal developmental stage, to distribute to the patients and families. Additionally, a list of fertility clinics in the area should be included in the informational packet for patients and families. This will encourage pediatric oncology nurses and providers to make connections with fertility clinics so that patients interested in FP can be referred to a specialist.



## **Research**

This literature review has established that there are barriers to discussing FP with pediatric oncology and oncology patients and their families and has addressed the need to overcome these barriers. The next step is to create interventions to overcome these barriers. Research is needed to directly examine the effectiveness of educational and practice interventions, like training programs, for the pediatric oncology nurse and providers involved in the FP process. Additionally, an assessment tool could be developed which would evaluate FP discussions with patients and families. This tool could focus on all aspects of the discussion including patient and family interest, comfort level, what was discussed, how the discussion went, and outcome of the discussion such as whether the patient and family decided to further pursue or undergo FP or not.

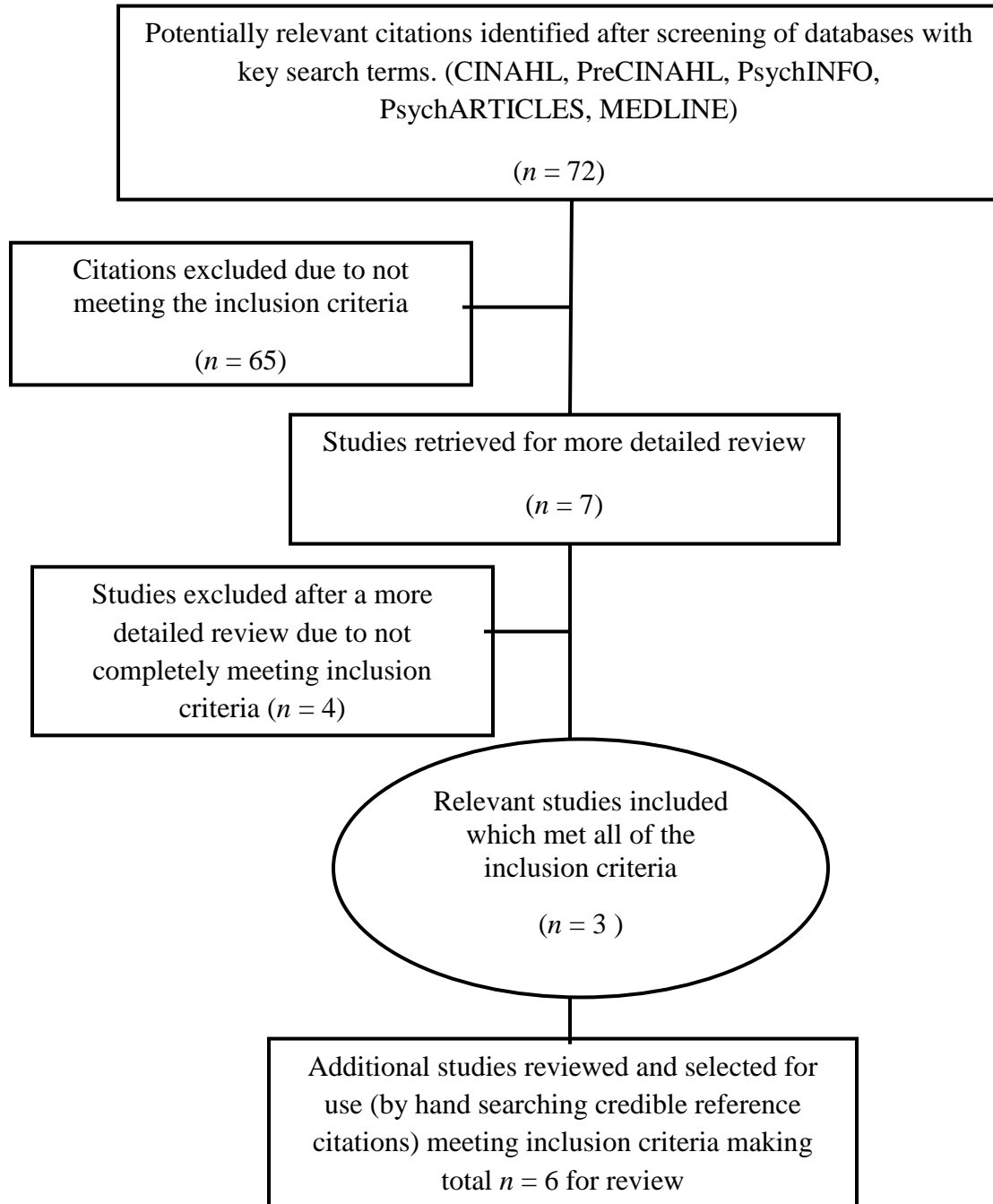
Lastly, future research could also examine various cultural perspectives and implications of discussing fertility preservation in the pediatric oncology population, which may vary in different cultural groups.

## **Appendix A: Selection Method of Literature**

**Figure 1: Selection Method of Literature**

Key Search Terms = (ped\* OR child\*) AND fert\* AND (onco\* OR cancer\*) AND nurs\*

Inclusion Criteria = Publication date 2005 – current, peer reviewed, research articles, English language, human, Nursing subset, Age specified 18 and younger



## **Appendix B: Online Links on Fertility Preservation Information**

**Table 3: Fertility Preservation Links for Nurses and Healthcare Providers**

Organization	Link Name and Description	Website Link
ASCO	Practice Guidelines: Recommendations on FP on Cancer Patients	<a href="http://jco.ascopubs.org/content/early/2013/05/24/JCO.2013.49.2678.full.pdf+html">http://jco.ascopubs.org/content/early/2013/05/24/JCO.2013.49.2678.full.pdf+html</a>
COG	COG Long-Term Follow-Up Guidelines for Survivors on Childhood, Adolescent, and Young Adult Cancer	<a href="http://www.survivorshipguidelines.org/pdf/ltfuguidelines.pdf">http://www.survivorshipguidelines.org/pdf/ltfuguidelines.pdf</a>
Fertile Hope	Educational Materials for both health professionals and patients	<a href="http://www.fertilehope.org/learn-more/publications/print-materials.cfm">http://www.fertilehope.org/learn-more/publications/print-materials.cfm</a>
Fertile Hope	Free electronic Cancer and FP presentation	<a href="http://www.fertilehope.org/healthcare-professionals/professional-education/request-a-kit.cfm">http://www.fertilehope.org/healthcare-professionals/professional-education/request-a-kit.cfm</a>
Fertile Hope	Patient Triage: an algorithm on how to address and process cancer patients for fertility preservation	<a href="http://www.fertilehope.org/healthcare-professionals/clinical-tools/patient-triage.cfm">http://www.fertilehope.org/healthcare-professionals/clinical-tools/patient-triage.cfm</a>
Fertile Hope	Risk Calculator: calculates risk of fertility based on cancer type or treatment regimen	<a href="http://www.fertilehope.org/tool-bar/risk-calculator.cfm">http://www.fertilehope.org/tool-bar/risk-calculator.cfm</a>
Fertile Hope	Options Calculator: FP options for patients undergoing cancer treatment	<a href="http://www.fertilehope.org/tool-bar/options-calculator.cfm">http://www.fertilehope.org/tool-bar/options-calculator.cfm</a>
NCI	“Banking on Fatherhood” Educational CD-ROM on banking sperm before cancer treatment	<a href="http://sbir-cancercontrol.cancer.gov/sbir/viewProduct.do?prodId=56385">http://sbir-cancercontrol.cancer.gov/sbir/viewProduct.do?prodId=56385</a>

**Table 4: Fertility Preservation Links for Patients**

Organization	Link Name and Description	Website Link
ACS	Fertility and Men with Cancer	<a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-041228-pdf.pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-041228-pdf.pdf</a>
ACS	Fertility and Women with Cancer	<a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-041244-pdf.pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-041244-pdf.pdf</a>
The Oncofertility Consortium at Northwestern University	Patient Education Resource	<a href="http://www.myoncofertility.org">http://www.myoncofertility.org</a>
Fertile Hope	Financial Assistance	<a href="http://www.fertilehope.org/financial-assistance/index.cfm">http://www.fertilehope.org/financial-assistance/index.cfm</a>
Live: On	At-home sperm banking kit. Sponsored by Fertile Hope and Livestrong	<a href="http://www.liveonkit.com/index.cfm">http://www.liveonkit.com/index.cfm</a>

## **Appendix C: Table of Evidence**

**Table of Evidence**

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
Clayton, H., Quinn, G., Lee, J., King, L., Miree, C., Nieder, M., & Vadaparampil, S. (2008). Trends in clinical practice and nurses' attitudes about fertility preservation for pediatric patients with cancer. <i>Oncology Nursing Forum</i> , 35(2),	To examine trends in FP attitudes and behaviors of PON and evaluate their awareness of the FP guidelines published by ASCO in June 2006	Cross-sectional quantitative study of a 45 item survey conducted in 2005 and 2006.  The survey measured: practice characteristics, provider attitudes toward FP discussion, and patient factors.	N= 210.  115 pediatric oncology nurses (PON) in 2005 and 95 nurses in 2006 who attended the annual meeting of the Florida Association of Pediatric Tumor Program.	<ul style="list-style-type: none"> <li>• The number of nurses who believed it was their role to discuss FP with patients decreased from 91% in 2005 to 81% in 2006</li> <li>• Nurse awareness of ASCO guidelines was less than 5%</li> <li>• FP discussion by nurses was more likely to occur with patients who had at least one child or who had poor prognosis.</li> </ul> <p><u>Nurse Perceived Barriers:</u></p> <ul style="list-style-type: none"> <li>• Institutional: availability of guidelines, established links with FP providers</li> <li>• lack of guideline awareness</li> <li>• lack of education materials available</li> <li>• questionable role responsibility</li> </ul>	<ul style="list-style-type: none"> <li>• Increased knowledge of FP guidelines may help promote FP, which may help lead to the spread of that knowledge and implementation of training programs focusing on ASCO FP guidelines.</li> <li>• Nurses are imperative in survivorship discussions for pediatric oncology patients and their families.</li> </ul>



Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
249-255					
Goodwin, T., Oosterhuis, B., Kiernan, M., Hudson, M., & Dahl, G. (2007). Attitudes and practices of pediatric oncology providers regarding fertility issues. <i>Pediatric Blood &amp;</i>	To understand the practice and attitudes of pediatric hematology/oncology providers regarding fertility issues related to patient care	44-item survey assessing provider knowledge, practices, obstacles to practice, perceptions of pt differences, and future practice improvements regarding FP	N = 30 healthcare providers (HCP) in a pediatric hematology/oncology department at the Lucille Packard Children's Hospital at Stanford's University Medical	<ul style="list-style-type: none"> <li>Overall, there was no statistically significant differences between the responses from physicians and nurse, so the data was reported collectively.</li> </ul> <u>Knowledge of FP:</u> <ul style="list-style-type: none"> <li>50% HCPs aware that infertility risks are higher for males</li> <li>in general, only 50% of participants were up to date with more current/advanced/experimental options for FP</li> </ul> <u>FP Practices:</u> <ul style="list-style-type: none"> <li>92.8% HCPs agree that they regularly talk to pts about impact of cancer treatments on fertility</li> <li>63.3% HCPs agree that all pts going</li> </ul>	<ul style="list-style-type: none"> <li>knowledge deficits about FP suggest remedial and further education on FP is needed</li> <li>behavioral changes also needed by HCPs in order to better treat pts</li> <li>better links with infertility specialists need to be established</li> </ul>

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
<i>Cancer</i> , 48(1), 80-85.			Center. 16/30 participants were physicians and 14/30 participants were NPs or RNs	<p>through cancer treatment are warned about infertility as a potential side effect</p> <ul style="list-style-type: none"> <li>• 34.6% HCPs consult with a infertility specialist</li> <li>• 3.8% agree that cost determines whether FP is discussed</li> <li>• 25% do not discuss FP with patients with poor prognosis</li> </ul> <p><u>Obstacles to FP:</u></p> <ul style="list-style-type: none"> <li>• 64.3% HCPs agree it is challenging to find FP facilities and specialists for pts</li> <li>• cost of infertility treatment too high to justify for males (7.1%) and for females (14.8%)</li> <li>• success rate of FP is too low to justify FP treatment for males (10.3%) and for females (34.4%)</li> </ul> <p><u>Beliefs and Attitudes:</u></p> <ul style="list-style-type: none"> <li>• 85.7% HCPs agree that parents of pts ask about fertility effects on their child following cancer treatment</li> <li>• 57.2% HCPs agree that pts ask about effect of cancer treatment on their fertility</li> <li>• 79.5% agree older pts more likely to be</li> </ul>	<ul style="list-style-type: none"> <li>• greater research on fertility outcomes of pediatric cancer survivors needed in order to better inform pts, families, and HCPs on potential late side effects cancer treatments have on fertility</li> <li>• HCPs need to stay up to date on current research and medical advancements regarding FP</li> <li>• greater referral to specialists for better care</li> </ul>

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
				<p>concerned about fertility than younger patients</p> <ul style="list-style-type: none"> <li>• 22.4% HCPs agree than female pts are more concerned about future fertility than male pts</li> <li>• 23.3% HCPs agree families of lower socioeconomic status are less worried about future fertility</li> </ul> <p><u>Future practice improvements:</u></p> <ul style="list-style-type: none"> <li>• 92.8% HCPs want to consult with infertility specialist in the future</li> <li>• over 95% HCPs want to: discuss FP with pts at risk undergoing cancer treatment, desire a training session on FP for all providers of oncology pts, believe that pts should be given more information on fertility issues</li> <li>• 86.7% agree children, regardless of age, should be included in FP discussions</li> <li>• 58.6% think best time to talk to pts about FP is during their appointment for consent of treatment</li> </ul>	

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
King, L., Quinn, G., Vadaparampil, S., Gwede, C., Miree, C., Wilson, C., ... Perrin, K. (2008). Oncology nurses' perceptions of barriers to discussion of fertility preservation with patients with cancer. <i>Clinical Journal of Oncology Nursing</i> , 12(3), 467-476.	To explore knowledge, attitudes, practice behaviors related to nurses' discussion of FP with oncology patients.	Qualitative, cross-sectional pilot study using a focus group and in depth interviews.  7 demographic questions and 13 primary interview questions served as a guide.	N = 15  Purposeful selection of nurses who have discussed FP with at least five patients of childbearing age per year.  7 nurses participated in the focus group and 8 nurses participated in in-depth interviews	<ul style="list-style-type: none"> <li>50% on the nurses discuss FP with patients even though most believe that FP discussion with patients is part of their role.</li> <li>majority of nurses who discussed FP with pts, only discussed it because the pt initiated the conversation</li> <li>nurse consensus determined that there was a need for professional education on FP</li> </ul> <u>Nurse Perceived Barriers:</u> <ol style="list-style-type: none"> <li>Lack of knowledge of FP procedures, fertility institutes and clinics, resources for pts, and practice guidelines.</li> <li>Attitudes: difficulty finding facilities, time constraints, role, comfort level, ethical issues, financial considerations, pt characteristics.</li> <li>Behaviors: pt initiation, physician behaviors, pt characteristics, timing.</li> </ol>	<ul style="list-style-type: none"> <li>Barriers could be overcome through: providing educational materials for pts, and training in FP as continuing education for nurses</li> <li>Need for increased knowledge and information on FP for nurses to ease in FP discussion with pts</li> <li>Need for educational interventions and practice guidelines aimed at oncology nurses</li> </ul>

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
doi:10.1188/08.CJON.467-476					<p>to facilitate FP discussions with pts</p> <ul style="list-style-type: none"> <li>• Need for further research to generate testable hypotheses among representative samples of nurses regarding FP discussion</li> </ul>
Nagel, K., & Neal, M. (2008). Discussions regarding sperm banking with adolescent and young adult males	1. To determine the number of nurses who interacted with adolescent and young adult males undergoing cancer chemotherapy	Cross-sectional qualitative survey	<p>N=21.</p> <p>17 oncology nurses and 3 reproductive health nurses from the McMaster Children's</p>	<p><u>Nurse Perceived Barriers:</u></p> <ol style="list-style-type: none"> <li>1. Nurses felt unprepared for discussion on sperm banking with patients and families</li> <li>2. Identification of staff member to initiate discussion</li> <li>3. Staff education on sperm banking was needed</li> </ol>	<ul style="list-style-type: none"> <li>• Nurses need further education and information about FP options to help them discuss this with their patients</li> </ul>

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
who have cancer. <i>Journal Of Pediatric Oncology Nursing</i> , 25(2), 102-106.	treatments who had participated in discussions about sperm banking.  2. Determine barriers to discussion of sperm banking and to assess if educational materials would benefit nurses.		hospital and the HHS Center for Reproductive care.  Only nurses who were with the pt prior to treatment were invited to participate	4. Educational materials on sperm banking were needed to provide to patient and families	
Reebals, J., Brown, R., & Buckner, E. (2006). Nurse practice issues regarding sperm banking in	Identify the nurse practice issues in determining whether sperm banking is discussed with adolescent male cancer patients	Quantitative survey assessing provider knowledge, attitudes, and patient factors regarding sperm	N= 27 hematology/ oncology nurses and nurse practitioners who work in a southeastern	<u>Knowledge:</u> <ul style="list-style-type: none"> <li>• 1 participant answered all questions correctly; the mean score was 63%</li> <li>• 22.2% of nurses knew that young men with cancer have low sperm count and motility at diagnosis</li> <li>• 48.1% nurses falsely believed that risk of birth defects increases in children conceived one week following cancer therapy</li> </ul>	<ul style="list-style-type: none"> <li>• Need to provide education to nurses about sperm banking in order to aid in discussions with patients.</li> <li>• More educational materials are</li> </ul>

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adolescent male cancer patients. <i>Journal Of Pediatric Oncology Nursing</i> , 23(4), 182-188.	in the pediatric oncology settings	banking	United States pediatric hospital or outpatient clinic and typically treat hematology/oncology patients 14-18 years old.	<ul style="list-style-type: none"> <li>• 7.4% nurses were aware of the cost of sperm banking</li> <li>• 29.6% nurses falsely believed that 3-6 semen sample collections were needed prior to initiation of cancer treatment</li> <li>• 48.1% nurses knew that infertility is more common for males than females following cancer treatments</li> </ul> <p><u>Attitudes about Sperm banking:</u></p> <ul style="list-style-type: none"> <li>• Agree: pts should be offered sperm banking (96.3%), pts should have advanced directives for banked sperm (96.3%)</li> <li>• Disagree: do not have time to discuss (62.9%), sperm banking is affordable for pts (51.8%), too low success rates to justify banking sperm (74%), too costly and not worthwhile (77.7%), uncomfortable to discuss (62.9%), need consent from parents before telling boys under 19 about sperm banking (85.2%)</li> <li>• Did not know: difficult to find sperm bank facilities (51.9%)</li> </ul> <p><u>Patient Factors affecting sperm banking discussion:</u></p>	needed on sperm banking to provide to patients and families which would help to facilitate discussions.

Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
				<ul style="list-style-type: none"> <li>• More likely to affect: patient brings up fertility (85.2%), educational materials available (66.7%)</li> <li>• Would not affect: pt not married (96.3%), pt recently engaged or married (63%), pt already has children (63.0%), pt openly homosexual (63%), pt under age 19 (74.1%), no health insurance (85.2%), poor prognosis (74.1%), pt has aggressive disease and needs immediate treatment (48.1%)</li> <li>• Less likely: pt is HIV positive (77.8%)</li> </ul>	
Vadaparampil, S., Clayton, H., Quinn, G., King, L., Nieder, M., & Wilson, C. (2007). Pediatric oncology nurses' attitudes related to	To explore nurses' attitudes toward the discussion of FP with pediatric oncology pts and their families	Cross-sectional quantitative study of a 45 item survey conducted in 2005 and 2006.  Using five-point Likert-type scale, the survey measured: practice	115 pediatric oncology nurses (PON) in 2005 who attended the annual meeting of the Florida Association of Pediatric	<ul style="list-style-type: none"> <li>• less than 51% of nurses reported actually discussing risks of infertility or FP</li> <li>• nurses perceive FP discussion to be within their scope of practice</li> <li>• 72% of nurses disagreed that "pts under 18 yrs of age should not be told about FP unless parents give consent"</li> <li>• 83% of nurses more likely to discuss FP with pts who expressed interest for future family or brought up topic of fertility</li> <li>• 60% more likely to discuss with recently engaged or married</li> <li>• more than 90% of study respondents agreed that nurses and social workers should</li> </ul>	<ul style="list-style-type: none"> <li>• Need for appropriate educational material for pts</li> <li>• Need for FP education for PONs to help facilitate discussion</li> <li>• study provides important baseline information that we and other</li> </ul>



Articles	Purpose	Method and Design	Sample	Findings	Implications for Nursing Practice
<p>discussing fertility preservation with pediatric cancer patients and their families.</p> <p><i>Journal Of Pediatric Oncology Nursing</i>, 24(5), 255-263.</p>		<p>characteristics and behaviors, provider attitudes toward FP discussion, and provider attitudes toward pt patient factors that may affect discussion of FP</p>	Tumor Program.	<p>discuss FP options with patients and that all cancer patients should be offered FP.</p> <p><u>Nurse Perceived Barriers:</u></p> <ol style="list-style-type: none"> <li>1. Attitude: potential to upset pts family, difficulty locating FP facilities, boys younger than 18 yrs should not be given erotic material during semen collection</li> <li>2. Pt factors: pt recently married or engaged, pt asking about FP, availability of pt education materials</li> <li>3. 3 primary pt factors that may decrease the likelihood of discussing FP: positive HIV status, poor prognosis, and the inability to delay treatment because of aggressive disease.</li> </ol>	<p>researchers can use to assess whether attitudes toward the discussion of FP may have changed as a result of these guidelines</p>

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