Knowledge Gaps, Barriers, and Facilitators to Fertility Preservation Counseling Among Oncology Nurses Managing the Care of Newly Diagnosed Cancer Patients

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Knowledge Gaps, Barriers, and Facilitators to Fertility Preservation Counseling Among Oncology Nurses Managing the Care of Newly Diagnosed Cancer Patients

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Abstract

Newly diagnosed cancer patients are inconsistently counseled about the infertility risks associated with oncologic treatments and the fertility preservation options currently available. Oncology nurses are placed in a unique position to introduce fertility topics with oncology patients; however, several barriers prevent counseling on this subject. The purpose of this paper is to determine the knowledge gaps, barriers, and facilitators of counseling newly diagnosed reproductive-aged cancer patients about fertility issues before cancer treatments among oncology nurses. An anonymous web-based, cross-sectional survey was accessed from August 2018-November 2018 and completed by oncology nurses employed in the medical oncology and infusion centers of a large multicenter cancer institution. The survey consisted of five elements: study consent, demographic information and general fertility questions, the American Society of Clinical Oncology (ASCO) 2013 clinical practice guideline questions, a validated knowledge tool to assess general fertility knowledge, and a validated oncology fertility preservation survey to determine barriers and facilitators to counseling patients about fertility issues. Thirty-eight participants completed the survey in its entirety, and the collected data were reviewed and analyzed. The majority of participants were full-time, Caucasian oncology nurses with an oncology experience of 1-5 years or 6-10 years. All of the participants were female. The majority of oncology nurses reported that they were unfamiliar with the clinical guidelines related to fertility preservation and oncology patients. The average baseline knowledge score using the validated knowledge tool was 7.1 (out of 13 questions). The higher domain scores in self-awareness, confidence, and external barriers from the fertility preservation survey indicated that self-perceived barriers and self-related preparedness hindered oncology nurse counseling on fertility topics. The findings suggest that oncology nurses would benefit from comprehensive
training about fertility issues that impact oncology patients to adequately and confidently counsel these patients on this topic. Presenting these topics to patients who are interested in future fertility and those that are physiologically stable enough to pursue fertility preservation options will allow them the opportunity to make informed decisions about their future fertility and quality of life before possible sterilizing treatments.

*Keywords*: fertility preservation, counseling, cancer patients, oncology nurse
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Knowledge Gaps, Barriers, and Facilitators to Fertility Preservation Counseling Among Oncology Nurses Managing the Care of Newly Diagnosed Cancer Patients

Women are born with a limited number of oocytes for utilization in future fertility endeavors, and with a diagnosis of cancer, the potential impact on fertility can be detrimental. Based on surveillance data from the Surveillance, Epidemiology, and End Results (SEER) program, women of reproductive age account for about 10% of new cancer cases with an impact of approximately 87 per 100,000 in the United States each year (Angarita, Johnson, Fader, & Christianson, 2016). Cancer treatment regimens that are necessary to improve cancer survival involve the use of chemotherapy and radiotherapy, which are often toxic to ovarian tissue precipitating ovarian failure (Roberts, Ronn, Tallon, & Holzer, 2015). Research has indicated that healthcare providers do not consistently counsel patients about the risks of iatrogenic fertility decline, or the options currently available to assist with fertility preservation (Angarita et al., 2016; Roberts et al., 2015; Shnorhavorian et al., 2015). It is important that newly diagnosed cancer patients be counseled about the risks associated with cancer treatment regimens and be provided with information regarding the current options available to optimize future fertility potential. The purpose of this paper is to discuss the current fertility related clinical guidelines that impact newly diagnosed cancer patients, explore the research regarding how these patients are counseled about fertility issues, and investigate the knowledge gaps, barriers, and facilitators to general patient fertility education in a select population, oncology nurses. The majority of the research included in this paper pertains to female fertility preservation since research has indicated disparities in fertility preservation counseling for women and because women have had limited options available until the experimental label was removed from oocyte cryopreservation in 2012 (Lawson et al., 2017). The results of this quality improvement project, however, can be
applied to both male and female oncology patients. Determination of the best strategies for educating the healthcare team about fertility issues, disseminating the information to newly diagnosed cancer patients, and providing adequate referrals to a reproductive specialist can aid in the development of an educational program to assist patients in the decision-making process.

**Problem Statement**

Healthcare providers do not consistently educate patients about the impact of cancer treatment regimens on future reproductive success, or the options currently available to assist with fertility preservation (Angarita et al., 2016; Loren et al., 2013; Roberts et al., 2015; Shnorhavorian et al., 2015). Lack of adequate counseling can deprive patients of the opportunity to make informed decisions about their future fertility before undergoing possible sterilizing treatment. Oncology nurses are uniquely positioned to counsel patients about fertility issues; however, several barriers prevent counseling on this topic (Grabowski, Spitzer, Stutzman, & Olson, 2017).

**Background and Significance**

Fertility preservation treatments for women are dependent on age, medical diagnosis, type of cancer treatment or medications utilized, whether the patient has a partner or willing to use donor sperm, the time available for treatment, and the severity of disease (Angarita et al., 2016; Loren et al., 2013; McLaren & Bates, 2012). A referral to a reproductive specialist precipitously after an initial cancer diagnosis is a critical component in the fertility preservation process (Loren et al., 2013). The current most effective treatment options available for women are oocyte and embryo cryopreservation (Loren et al., 2013; McLaren & Bates, 2012). Other less successful and experimental treatments for female patients include radical trachelectomy, ovarian transposition, ovarian tissue freezing, and ovarian suppression (Loren et al., 2013). Use
of donor eggs, donor embryos, surrogacy or adoption, are also reasonable alternatives if patients are amenable to not having a genetic link to the offspring (Loren et al., 2013). Embryo cryopreservation, although the most established fertility preservation option, has some limitations in that women must have a current partner, or be willing to use donor sperm for egg fertilization and subsequent embryo banking. Women who are single or unwilling to use donor sperm have the option of oocyte cryopreservation. When oocyte preservation was introduced in the 1980s, it was deemed experimental due to the technical issues related to manipulation of oocytes and low pregnancy outcomes (Argyle, Joyce, & Davies, 2016). Research has steadily progressed, and oocyte preservation has been validated as a noteworthy fertility preservation option for reproductive-aged women newly diagnosed with cancer (Loren et al., 2013). In 2012, the American Society of Reproductive Medicine (ASRM) with support from the American Society of Obstetricians and Gynecologists (ACOG) removed the experimental label from oocyte cryopreservation and recommended its use as a standard practice option in the treatment of newly diagnosed female cancer patients of reproductive age desiring to preserve future fertility (ACOG, 2014; Loren et al., 2013).

Newly diagnosed cancer patients are a vulnerable population, and with the amount of information disseminated during initial contact, the patient must learn how to adapt very quickly to this serious life event and be capable of making informed decisions regarding their health. This diagnosis necessitates prolonged interactions with the healthcare team, an environment uncommon and unfamiliar to a newly diagnosed cancer patient (Loren et al., 2013). The impact of cancer can be challenging and devastating for women in their reproductive years, and healthcare professionals caring for newly diagnosed cancer patients must develop a process for providing fertility preservation information in an already stressful environment. Psychological
counseling and support may also help guide patients through this process. It is crucial that the healthcare team discusses the potential detrimental effects of cancer treatment regimens and the options available for fertility preservation; if they are not knowledgeable, then the patient should promptly be referred to a reproductive specialist. As mentioned in the American Nursing Association (ANA) code of ethics, nurses working through interprofessional and multidisciplinary collaborations are imperative in ensuring the best possible outcomes for the patient (McCaffrey, 2012; p. 90). A thorough understanding of the knowledge deficits among oncology nurses managing the care of newly diagnosed cancer patients to facilitate developing an educational plan that would be beneficial in aiding with the informed decision-making process in this patient population is vital for quality care among this patient population (Grabowski et al., 2017).

**Clinical Question**

Among oncology nurses managing the care of newly diagnosed cancer patients, what are the knowledge gaps, barriers and facilitators to counseling patients about iatrogenic fertility decline and fertility preservation options before cancer treatment?

**Review of Literature**

**Search Strategy and Results**

A review of the literature using Cumulative Index of Nursing and Allied Health Literature (CINAHL), Pubmed, and ScienceDirect was completed to review current information regarding fertility preservation and the impact of cancer treatment among newly diagnosed female cancer patients. The following search terms were used: fertility preservation, cancer, and female. Counseling was also a topic of interest and was examined within the selected articles. All articles included all search terms listed and were additionally limited to women of
reproductive age, publications from January 2012-December 2017, and to the English language. The initial search criteria yielded 487 research articles for review. An evaluation of the titles, abstracts, and reference lists further limited the article count to 45 for additional review. A second database search was completed using CINAHL, Pubmed, and ScienceDirect to obtain information about barriers and facilitators to counseling for oncology nurses. The search items used were oncology, nursing, and fertility preservation. Additional limitations were English language and publication from January 2012-December 2017. Counseling was assessed within the selected articles. The search yielded 12 articles and after review of the titles, abstracts and reference lists, five articles were selected for additional review. A total of 19 articles from both searches were selected for inclusion in this paper. The appraisal of guidelines for research and evaluation II (AGREE II) instrument was utilized to assess the quality of clinical practice guidelines listed in the evidence matrix table (AGREE, 2009). The evidence hierarchy and quality guide were used to determine the level and strength of evidence. A review of the literature found that many of the articles ranked from III-V on the evidence triangle but were ranked as medium to high importance to use for analysis of the data. The majority of the articles were clinical guidelines, observational, correlational, and qualitative studies with few randomized control studies.

**Fertility Preservation for Women**

Providing newly diagnosed cancer patients with options to preserve fertility has been of considerable concern over the last decade, and several articles reviewed the current data related to oocyte cryopreservation which is a significant component of fertility preservation for women. With the transition of oocyte cryopreservation from experimental to standard treatment for select groups of patients, this has opened the doors for utilization of this method for women who had
limited alternatives to preserve fertility. The American Society of Reproductive Medicine (ASRM) and the Society for Assisted Reproductive Technology (SART), through joint efforts, published committee guidelines for oocyte cryopreservation after reviewing current data (ASRM, 2013). In 2014, the American College of Obstetricians and Gynecologists (ACOG) released a committee decision joining ASRM in recommending the use of oocyte preservation for newly diagnosed cancer patients and adopting the new guideline (ACOG, 2014). The oocyte cryopreservation guideline was primarily intended to assist providers in counseling patients with illnesses that could impact fertility; it was not intended as a solution for evading the natural aging process in healthy women delaying childbirth (ACOG, 2014). In two studies performed in infertile couples, implantation rates ranged from 17%-41% and clinical pregnancy rates per transfer ranged from 36%-65%, suggesting that outcome for in vitro fertilization (IVF) and intracytoplasmic sperm injection (ICSI), were similar between fresh and cryopreserved oocytes (ACOG, 2014). Nagy, Anderson, Feinberg, Hayward, & Mahony (2017) confirmed the use of oocyte cryopreservation as a recommended method for fertility preservation in women with new-onset cancer and provided data for 204 patients that utilized oocyte cryopreservation (Nagy et al., 2017). Based on ovarian reserve functionality and age, success rates for embryo banking is respectable with around 30-40% of transfers resulting in live births (Loren et al., 2013). Although less data is available for oocyte cryopreservation in cancer patients, current rates (36-61% clinical pregnancy rate per transfer) are similar to infertility patients undergoing in-vitro fertilization procedures (Argyle, Harper, & Davies, 2016). Based on current research from observational studies and clinical trials comparing reproductive outcomes after IVF using cryopreserved oocytes versus fresh oocytes, it was determined that implantation and pregnancy rates were similar (ACOG, 2014; ASRM, 2013). More research is needed to determine if this
information is generalizable to other populations and to verify findings once larger cohorts of
cancer survivors begin utilization of their cryopreserved embryos or oocytes (ACOG, 2014;
ASRM, 2013).

In 2012, the American Society of Clinical Oncology (ASCO) reviewed additional key
literature and updated the 2006 clinical guidelines regarding fertility preservation for patients
with cancer for implementation into practice (Loren et al., 2013). A list of critical questions was
investigated, and practice guideline recommendations were refined based on these results (Loren
et al., 2013). The questions evaluated were whether patients were interested in fertility
preservation interventions; what healthcare providers could do to provide information regarding
the impact of treatment on fertility and the preservation options available; what is the quality of
evidence supporting current and upcoming fertility preservation options; what is the role of the
healthcare providers in advising patients about options; and special considerations for pediatric
patients (Loren et al., 2013). Fertility preservation options recommended for discussion for
women were embryo and oocyte cryopreservation (first line therapy), ovarian transposition,
conservative gynecologic surgery, and radiation therapy when possible, along with less
documented treatments such as ovarian tissue cryopreservation and ovarian suppression (Loren
et al., 2013). Updated recommendations included the integration of oocyte cryopreservation as a
standard practice guideline, expanding the list of healthcare providers that should counsel
patients regarding the impact of treatment and fertility preservation options and encouraging
early referral to reproductive specialists before cancer treatment initiation (Loren et al., 2013).
More research is needed to determine the best method to provide fertility preservation
information to patients, and the ideal time to speak with patients about these options, however
referrals to infertility specialists should be made as soon as possible preceding patient treatment
(Loren et al., 2013). Of note, it was recommended that no patient be excluded from fertility preservation discussions based on ethnicity, the severity of disease, parity, age, socioeconomic status or any other reason (Loren et al., 2013). The ASCO guidelines were important in expanding the roles of healthcare providers who interact with newly diagnosed cancer patients so that counseling can be performed at any point during the patient's transitioning throughout treatment. This expansion places the oncology nurse in the forefront due to daily direct care provided to cancer patients, so it is especially important for nurses to be knowledgeable about fertility consequences related to oncologic treatments, fertility preservation options, and resources available to aid patients in the fertility preservation process. Oncology nurses, if provided the necessary educational resources and referral systems can act as a liaison and relay patient’s needs to the healthcare team.

Chin, Howards, Kramer, Mertens, and Spencer (2016) investigated the factors associated with 1116 young women newly diagnosed with cancer and their receipt of fertility counseling information (Chin et al., 2016). Based on the data, it was found that women who had at least one child, less educated women, low income, and unmarried women were less likely to receive information about the impact of cancer treatments on future fertility (Chin et al., 2016). About 60% of women reported receiving fertility counseling at the time of cancer diagnosis; however, only 13% reported referral to a fertility specialist for further fertility preservation discussions (Chin et al., 2016). Women with reproductive cancers and women with higher graded cancers were more likely to receive fertility preservation counseling; however, about 20% reported no fertility counseling (Chin et al., 2016). Since fertility preservation options are cost prohibitive for some patients, it is essential that providers are knowledgeable about financial resources available to help defer costs for patients with insufficient resources (Chin et al., 2016).
limitation of the study was that the outcomes were based on study participants relying on recall of events 7 years earlier, however, after chart review of documented fertility counseling, it was found that about 80% of patients who recalled counseling actually had this information noted in the chart (Chin et al., 2016). Health care provider collaboration, dissemination of fertility preservation information, rapid referral to reproductive specialists, and organized treatment plans will create a well-coordinated strategy to assist women in making informed decisions regarding their future fertility (Chin et al., 2016).

Kim et al. (2012) evaluated predictors that determine the use of fertility preservation in women diagnosed with breast cancer (Kim et al., 2012). Participants included 108 patients with breast cancer that pursued fertility preservation and 77 patients that did not pursue fertility preservation between 2005-2010 (Kim et al., 2012). The study found that administering neoadjuvant chemotherapy was an independent risk factor for not pursuing fertility preservation due to a restriction on the amount of time available (Kim et al., 2012). Based on the combined study information women that pursued fertility preservation were older, wealthier, and had a lower cancer stage, while women that did not pursue fertility preservation had elevated BMI, lower income, and higher cancer stage (Kim et al., 2012). Some of these indicators were similar to those depicted by Chin et al. (2016), however, while Chin et al. (2016) found that higher graded cancers were more likely to receive fertility preservation education it is unclear the percentage that pursued fertility preservation. Kim et al. (2012) noted that women with higher cancer stage tended to not pursue fertility preservation because of perceived limited time (Kim et al., 2012).

Goldfarb et al. (2016) examined the knowledge and preferences regarding fertility preservation among female reproductive-aged newly diagnosed breast cancer patients before
initial oncology provider consult (Goldfarb et al. 2016). Sixty women aged 18-45 participated in a cross-sectional observational study between May-September 2011 by completion of a survey collecting data on reproductive history, fertility knowledge and fertility preservation options (Goldfarb et al., 2016). Only 9% of women reported receiving information about fertility issues before provider consult; which gives us and indicator that there is a substantial lack of knowledge about fertility issues at the time of diagnosis. The oncology team is in the best position to introduce fertility topics before impending oncologic treatment and refer patients as needed so that individualized treatment plans can be developed to guide care.

Benedict, Thom, and Kelvin (2015) evaluated the psychological impact of decision regret on newly diagnosed cancer patients between 2010-2012 (Benedict et al., 2015). The selected participants were men and women 18-45 years old, but data was restricted to women age 18-39 years of age at the start of cancer treatment (Benedict et al., 2015). Participants completed an investigator-designed survey which included research-based literature and clinical expertise as well as the decision regret scale (Benedict et al., 2015). Participants (N=159) were the average age of 33, primarily non-Hispanic Caucasian (76%), well-educated with at least one-year post-treatment (Benedict et al., 2015). The majority of the women (89%) stated that fertility preservation was discussed with an oncologist before cancer treatment and 42% were provided referral information for fertility specialist (Benedict et al., 2015). Women without children were more likely to be referred for fertility preservation counseling. Among women who elected not to pursue fertility preservation, 61% were comfortable with the decision, 26% were regretful, and 19% would not make the same decision compared to women who pursued fertility preservation (84%, 10%, and 6% respectively) (Benedict et al., 2015). The primary reasons for not undergoing fertility preservation included a perceived lack of time before cancer treatment, cost,
and not wanting any more children (Benedict et al., 2015). Findings address the need for providers to discuss fertility issues and provide counseling with psychosocial interventions to decrease regret (Benedict et al., 2015). Although the study findings may not be generalizable, the importance of multidisciplinary collaborations and patient-centered care is evident. Hersberger, Finnegan, Pierce, and Socca (2012), evaluated the decision-making process of women newly diagnosed cancer regarding fertility preservation via a qualitative study of 27 women, primarily well-educated (63%), Caucasian (78 %), with a mean age of 29 (Hersberger et al., 2012). The study reiterated the importance of multidisciplinary collaboration and the impact of comprehensive psychological counseling in women after a cancer diagnosis. The amount of information provided in this setting can be overwhelming for many patients, and it is important for healthcare professionals to allow time for patients to reflect on this information so that they can make informed decisions regarding their care and future fertility needs. Letourneau et al. (2012) studied post-treatment quality of life impacts on 1041 women between aged 18-40 diagnosed with cancer who received infertility counseling before cancer treatment (Letourneau et al., 2012). The study was similar to Benedict et al. (2015) who noted that women who received counseling about the potential impact of cancer treatment and fertility preservation information were less likely to have regret regarding choices related to fertility (Letourneau et al., 2012). Shnorhavorian et al. (2015) utilized qualitative methodology to evaluate the extent to whether health care providers discussed fertility preservation information with patients (Shnorhavorian et al., 2015). The study included 459 adolescent and young adults from age 15-39 with cancer diagnosed between 2007-2008 from seven breast cancer registries (Shnorhavorian et al., 2015). About 75% of women noted that infertility risks were discussed, while about 45 % noted that fertility preservation was discussed (Shnorhavorian et al., 2015). This article continues to
highlight the inconsistencies in counseling and the need to counsel all patients with a new cancer diagnosis.

**Nursing Barriers and Facilitators**

Few articles examined the barriers and facilitators of oncology nurses managing newly diagnosed cancer patient. Krouwel et al. (2016) used an anonymous cross-sectional survey, web-based and in-person, to evaluate the knowledge of oncology nurses and barriers to discussing fertility issues with newly diagnosed cancer patients (Krouwel et al., 2016). The questionnaire was completed by 421 Dutch oncology nurses from various departments across the country. Findings reported that about a third (31%) of oncology nurses confirmed adequate knowledge about fertility issues, about a third (28%) reported limited or no knowledge and about a third (32%) stated that fertility issues were discussed with patients the majority or all of the time (Krouwel et al., 2016). Common barriers to patient discussions included knowledge deficit, poor patient prognosis, and insufficient time (Krouwel et al., 2016).

Grabowski, Spitzer, Stutzman, and Olson (2017) developed a survey instrument to examine the attitudes of oncology nurses about discussing fertility issues with newly diagnosed cancer patients (Grabowski et al., 2017). The survey was developed over four phases which ranged from initial survey development to implementation in the oncology nursing community. Oncology nurses completed the surveys in phases 3 and 4 with study sizes of 67 and 230 respectively. Phase 4 represented the validated survey to be used in future studies in evaluating oncology nurses about their attitudes regarding fertility issues. Barriers were similar for both the Krouwel et al. (2016) and the Grabowski et al. (2017) studies and included knowledge deficits, patient poor prognosis, time constraints, lack of access to fertility specialists, financial obligations, and personal religious or moral values related to patients or the use of assisted
reproductive technology (Grabowski, et al., 2017; Krouwel et al., 2016). Although these studies may not be generalizable to the general population, developing protocols to assist oncology nurses in the implementation of an educational intervention for newly diagnosed cancer patients is a vital component of managing their care. Additional research is needed to determine the best strategy for educating and providing support for oncology nurses so they can integrate patient education into daily routines to improve patient knowledge about fertility issues (Grabowski et al., 2017).

**Conceptual Framework**

Many nursing scholars believe that theoretical and conceptual frameworks provide insight into the function of nursing in society, guides nursing practice, and is necessary to establish "best-practice interventions to improve patient outcomes" (McCaffrey, 2012, p. 66). In 2006 Graham and his team members developed the Knowledge to Action (KTA) Conceptual Framework to expedite the translation of research (knowledge) into use in the clinical setting (action) to improve patient outcomes (Graham et al., 2006). Their concern was that the research was taking too long to be approved and integrated into practice thus denying the patients proven beneficial treatment (Graham et al., 2006). The KTA model consists of two concepts; knowledge creation and action (Graham et al., 2006). The knowledge creation concept is further delineated into knowledge inquiry, knowledge synthesis, and knowledge tools or products (Graham et al., 2006). Knowledge-inquiry refers to the initial broad spectrum of knowledge that is identified early in the research process, while knowledge synthesis involves further delineation and refinement of the research to identify and focus on the topic of interest. Knowledge tools and products refer to the practice guidelines utilized in the specific focus area, decisional aids, and a method of presenting this knowledge succinctly and comprehensively to influence practice and
facilitate knowledge uptake and application (Graham et al., 2006). The action phase consists of the steps necessary to apply the knowledge to the practice setting, is influenced by the knowledge creation phases, and involves planning activities directed toward changing behavior and attitudes to impact outcomes (Graham et al., 2006). Action steps may or may not be sequential and can begin at any point of the action cycle (Graham et al., 2006). Components of the action phase include the identification of the problem, determining the current knowledge level and knowledge deficits, and the identification and review of the selected knowledge (Graham et al., 2006). Once learning has been achieved, this knowledge must be adapted to the local context, and barriers and facilitators to knowledge use should be assessed. With the data collected from the assessment phase, interventions can be tailored to implement practice changes based on identified barriers. Once the interventions are in place, staff knowledge must be monitored to ensure adoption and to determine if the knowledge is sufficient to maintain practice changes (adaptation). Evaluation of the outcomes can provide insight as to whether the practice changes have made a difference in patient outcomes and whether these changes are sustainable (Graham et al., 2006).

The relationship of the research project to the KTA model begins with the knowledge creation phase which involves performing an extensive literature search regarding the problem and tailoring the literature selected to the topic of interest to identify barriers and implement future interventions. A component of the KTA action phase involves identification of the problem; the lack of consistent education of newly diagnosed cancer patients about the infertility risks associated with oncologic treatments and the fertility preservation options currently available can deprive patients of the opportunity to make informed decisions about their future fertility. Oncology nurses are placed in a unique position to provide information about fertility
issues; however, several barriers prevent this population from educating patients. Determining the current practices, knowledge gaps and barriers, as well as the attitudes that exist among oncology nurses regarding counseling interested patients about fertility issues can aid in the development of an interventional program to improve patient outcomes and quality of care regarding this issue. Practice guidelines encourage all members of the healthcare team to discuss fertility issues with newly diagnosed cancer patients interested (or ambivalent) in fertility preservation and provide referrals to a reproductive specialist for further discussions regarding the current options available (Loren et al., 2013). It is important to determine if once practice guidelines are reviewed, whether oncology nurses will feel this is appropriate and useful for their patient population and if prioritization will be established based on patient diagnosis. Due to the severity of some cancer diagnoses, it may not be possible to proceed with fertility preservation treatment; however, the patient can still be counseled on fertility options depending on their future fertility goals. Future research should focus on analyzing the data collected to tailor programs to increase oncology nurse awareness about fertility issues. Knowledgeable oncology nurses can determine the best strategies for the adoption of an educational program for newly diagnosed cancer patients to allow them to make informed decisions about their future fertility needs and improve quality of care. Sustainability of this program is also an essential aspect of the intervention since as treatment options improve for cancer patients, infertility issues have become more of a concern. The Knowledge to Adaptation Conceptual Model provides a guide to evaluating the challenges facing oncology nurses regarding fertility counseling, investigating the barriers and facilitators to adapting educational materials in their daily routine, and determining whether this education is considered necessary in a patient population where the severity of disease and timeliness of cancer treatment takes precedence.
Adaptability to the multiple environmental stressors will be an important first step in transitioning to decisions that could improve future reproductive outcomes. According to McCaffrey (2012), "Approaching care using a theoretical framework directed toward best-practice interventions to improve patient outcomes and create positive changes in health behaviors would enhance the management of complex clinical situations by providing holistic and comprehensive care" (McCaffrey, 2012, p. 66). The KTA Conceptual Framework can be utilized to provide insight and direction and as a good source of reference for research initiation to improve patient care practices and overall patient health through evidence-based practice. In an ever-changing healthcare environment, it is important to utilize the skills necessary to determine the needs of the population, evaluate current research, develop interprofessional collaborative relationships, and through a team approach define the best strategy to integrate the knowledge into current practice to improve patient outcomes.

Methodology

Participants

The oncology nurse is placed in a unique position to at least introduce the topic of fertility and gain insight regarding patient perspectives. Oncology nurses often spend more hours with the patients than the physician or any other staff member; this makes this population the ideal population for this quality improvement project. After interviewing stakeholders at each of the facilities, it was determined that all oncology registered nurses potentially have contact with reproductive-aged male patients, female patients, or both; therefore, the study population consisted of all oncology registered nurses employed in the ambulatory medical oncology and infusion centers. Participants were eligible if they were employed as a registered nurse in the ambulatory setting and managed the care of at least one male or female newly diagnosed
reproductive-aged oncology patient in the last year. Participants were ineligible if they were not a registered nurse or did not manage the care of a female or male newly diagnosed reproductive-aged oncology patient in the last year. The target sample size was the total number of oncology nurses employed in the ambulatory medical oncology and infusion centers of the cancer institute; approximately 120 potential participants.

**Setting**

The quality improvement project was conducted in the medical oncology and infusion centers of five ambulatory facilities of a large multicenter cancer institute located in a large metropolitan area in the southeast region of the United States. The multicenter comprehensive cancer institute manages the care of over 17,000 oncology patients yearly; which makes this site an ideal location for the recruitment of oncology nurses employed in the ambulatory setting for participation in this quality improvement project. While the total percentage of reproductive-aged cancer patients is unknown, oncology nurses have confirmed that this patient population is frequently seen in the clinic. Approximately 120 oncology nurses are employed in the combined areas of this multicenter cancer institute.

**Instruments and Tools**

The oncofertility survey is a web-based anonymous cross-sectional, convenience sampling survey designed to investigate the knowledge gaps, barriers, and facilitators to providing fertility counseling to newly diagnosed cancer patients. The Qualtrics® survey system was selected for survey data collection to allow the oncology nurses the flexibility to complete the survey at any time. Qualtrics® is a web-based survey tool used to develop and distribute surveys and collect and analyze data.
The survey took approximately 30 minutes and consisted of five elements; study consent (1 question), demographic information and general questions regarding fertility (17 questions), the American Society of Clinical Oncology (ASCO) clinical practice guideline questions (10 questions), the author approved Validated Knowledge Tool (13 questions) (Appendix A), and the author approved Validated Oncology Fertility Preservation Survey (15 questions) (Appendix B).

Demographic information included general information about the participant including age, gender, education, and years of practice experience and general fertility questions were asked along with short answer questions to allow the participant to provide expanded feedback. The clinical practice guideline questions pertained to the 2013 ASCO practice guidelines which were used to determine how familiar the oncology nurses were with these guidelines; a 5-point Likert scale ranging from all of the time to none of the time or not familiar with guidelines. The questions were used to determine how often specific fertility topics were addressed with oncology patients and was developed by the author based on the ACSO practice guidelines.

The Validated Knowledge Tool was developed by Balthazar, Deal, Fritz, Kondapalli, Kim, & Mesereau (2012) to assess comprehension of fertility preservation options currently available (Balthazar et al., 2012). This tool consisted of true or false answers and was used with the infertility patient population in the Balthazar et al. study (2012) but was used with the oncology nursing population in this quality improvement project. The content validity of the knowledge instrument was ascertained by collaboration with experts in reproductive endocrinology and infertility and item analysis, and item-rest correlations were performed (Balthazar et al., 2012). Content validity refers to whether the questions in the instrument measures the topic of interest (Polit & Beck, 2017, p. 337). In item analysis the participant
responses are examined on an individual and a group basis to determine the quality of the items individually and the test in its entirety interest (Polit & Beck, 2017, p. 340).

The Oncology Fertility Preservation Survey was developed by Grabowski, Spitzer, Stutzman, & Olson (2017) using a multiphase instrument development study and exploratory factor analysis as an aid for instrument refinement (Grabowski et al., 2017). This 15-question survey consisted of a 5-point Likert scale ranging from strongly agree to strongly disagree; 3 of the questions were inversely scored based on further review of the study questions. Factor analysis is a statistical method used for reducing the number of variables in an instrument to focus on the core dimensions to be studied (Watson & Thompson, 2006). Five key dimensions were identified which provided information about confidence, self-awareness, external barriers, time barriers and perceived treatment barriers for oncology nurses (Grabowski et al., 2017). Information regarding the reliability of the two tools, the Knowledge Tool or the Oncology Fertility Preservation Survey, for the collection of data, was not mentioned in articles and is unknown to date. A lack of evidence about use of these tools in the oncology nurse population warrants a reliability analysis upon data completion.

**Intervention and Data Collection**

Newly diagnosed cancer patients of reproductive age are interested in discussing fertility topics and how oncologic treatments may impact their fertility (Loren et al., 2013). The student investigator visited each of the five clinical sites to discuss the details of the quality improvement project, relay the importance of discussing fertility topics, and recruit participants to complete the survey. The survey was accessed between August 2018 and November 2018. Internal review board (IRB) approval was obtained from the Georgia State University and the multicenter cancer institute review board. The web-based survey was anonymous, password protected upon
entry into the survey, and the data collected was stored securely in the password protected Qualtrics system.

Study flyers with survey access information were delivered to each of the clinical sites by the student investigator and management was also asked to assist with the distribution of flyers to oncology nurses. Once the online survey was accessed, the participant was required to consent to participation before progression through the survey. The consent consisted of a description of the quality improvement project, contact information for the investigators in case the participant had any questions, benefit and risk information, and reinforced that participation was elective. For those participants who did not consent, the survey automatically ended.

No incentives were used to increase compliance; however, the anonymous web-based survey could be completed at any time which added some convenience. The completed survey was designed to achieve the following objectives: determine whether oncology nurses feel that fertility counseling is of high priority, assess the current knowledge, knowledge gaps, barriers, and facilitators among oncology nurses, and determine if oncology nurses were familiar with the ASCO guidelines regarding fertility recommendations for newly diagnosed cancer patients. The anonymous data was stored in the password-protected Qualtrics system. The information obtained from oncology nurses will be utilized to develop a comprehensive educational plan for oncology nurses so that they can educate and distribute information to oncology patients in the future.

Components of Analysis and Statistical Tests

The Qualtrics data collection system was utilized to collect, organize and secure the data. The Qualtrics data was converted directly into SPSS version 25 for data analysis. Similar research articles in which attitudes of oncology nurses were examined utilized SPSS for
statistical analysis (Krouwel et al., 2017 & Vadaparampil et al., 2016). Descriptive statistics and frequency distributions were used to analyze the data for reporting purposes. Statistical consulting was provided by faculty with expertise in statistics and research methodology.

**Results**

Of the 65 participants who initiated the survey, 38 participants completed the survey in its entirety, and this data was reviewed and analyzed. Only female oncology nurses completed the survey with the majority having an oncology experience of 1-5 years (42.1%) and 6-10 years (26.3%) (Table 1). The majority were Caucasian (65.8%) and were employed full-time (84.2%) (Table 1). Many of the oncology nurses (63.2%) had not attended an educational session regarding fertility issues in oncology patients, and of those that had attended an informational session (36.8%), 21.1% had not changed any aspect of their practice after attendance (Table 1).

The first objective of the quality improvement project was to determine if oncology nurses perceived fertility counseling as a high priority. Of the 38 oncology nurses who completed the survey, 71% felt the discussion of fertility issues was of high importance, but 58% were unsure if the provider they worked with addressed the topic (Figure 2). Of the 13% in which the provider addressed the topic, 24% reported that the provider addressed the topic most or all of the time. The majority of oncology nurses (61%) felt that both the oncologist and the oncology nurse should be responsible for educating newly diagnosed cancer patients about fertility issues; none of the oncology nurses believed that they had the sole responsibility of educating the patient.

The second objective was to determine if the oncology nurses were familiar with the 2013 ASCO guidelines, which were available at the time of this survey development. Recently, the 2018 ASCO guidelines were published with a recommendation for further clarifications
related to recommendations 3.5 and 3.6, ovarian suppression and ovarian tissue cryopreservation and transplantation and recommendations 3.2 and 3.7 concerning fertility preservation were combined; the other guidelines were updated for clarification, but essentially remained unchanged (Oktay et al., 2018). Although many oncology nurses, 84%, reported that they were not familiar with the ASCO guidelines (Figure 3), some of the guidelines were being followed (Figures 4A & 4B). Referrals to a reproductive specialist (36.9%) and psychosocial providers (36.9%) appeared to be the guidelines that were followed most or all of the time (Figure 4A & 4B). The ASCO guideline instrument for this population appears to be acceptable with a reliability coefficient of 0.938 suggesting the items have high internal consistency.

The third objective was to identify barriers and facilitators to providing fertility counseling to patients. The Validated Oncology Fertility Preservation Survey developed by Grabowski et al. (2016) provided a method to measure barriers and facilitators to providing fertility counseling to newly diagnosed cancer patients. The Grabowski tool for this population appears to be acceptable with a reliability coefficient of 0.738 suggesting the items have average internal consistency. Based on the results, the scores were elevated in all areas representing that many oncology nurses had “more self-perceived barriers and less self-rated preparedness” with a confidence score of 9.5 (range: 4-20), a self-awareness score of 20.4 (range: 5-25), an external barrier score of 7.4 (range: 2-10), a time barrier score of 5.6 (range: 2-10), a perceived treatment barrier of 6.6 (range: 2-10) and a combined score of 49.6 (range: 15-75) (Table 3) (Grabowski et al., 2017). To further delineate the information provided in the survey, many nurses reported knowledge deficits (76.3%) or comfort level concerns (55.3%) which limited their ability to bring up fertility topics (71.1%), however, 57.9% of nurses reported that sexuality concerns or problems were routinely addressed (Figure 5). Many nurses did not feel that ethical issues
(81.6%), attitudes about patient financial issues (76.3%), attitudes about patient and family comfort level (76.3%), personal religious beliefs (86.8%) limited their ability to bring up the topic, however, the majority of nurses (89.5%) felt that awareness of campus resources would increase the likelihood that the topic would be discussed (Figure 6). The majority of nurses (60.5%) did not believe that physician behaviors or family behaviors (68.5%) limited their ability to bring up fertility topics (Figure 7). Many nurses (55.3%) felt that time constraints and the ability to time fertility education (52.6%) limited their ability to bring up the topic (Figure 8). Several nurses (50%) felt that fertility preservation limited treatment options and 36.8% felt that fertility preservation slowed down treatment options for patients (Figure 9).

The fourth objective was to assess the current knowledge and identify knowledge gaps. The Validated Knowledge Tool was utilized to determine the baseline knowledge of oncology nurses related to fertility issues. Oncology nurses scored highest on questions 2 (94.6%) and question 8 (88.6%) which focused on embryo freezing and its process (table 3). Participants also scored high on question 9 (86.1%) which referred to cancer risks (table 3). Valid percentages were used due to the missing data. The remainder of the survey scores was <75% indicating that nurses would benefit from comprehensive education about fertility issues. The Balthazar et al. (2012) tool had a relatively low-reliability coefficient of 0.446 suggesting that this may not be an acceptable tool for this particular population. Additional factors affecting the coefficient include the low number of participants, missing data, and that the tool was originally used and tested in a patient population in which comprehensive education was provided before administration of the test.

Short answer questions were asked on the survey regarding how the oncology and fertility clinics could improve its services. The overall consensus was that oncology nurses are
not provided the education they need to introduce the topic of fertility to newly diagnosed reproductive-aged cancer patients. Both clinics should document fertility counseling in electronic medical records (EMRs) so that team members are aware of these conversations. Patients should be provided general fertility preservation information in the form of handouts or flyers to review in the clinical oncology areas to raise awareness. The fertility center should be more visible in the oncology center and provide staff educational sessions so that the oncology nurses can feel more confident in delivering this needed information to oncology patients. Although primary healthcare decisions pertain to cancer survival, the health care team must work collaboratively and be diligent about counseling patients about the potential implications of oncologic treatments and its impact on fertility and the fertility preservation options currently available.

**Discussion**

Research has indicated inconsistencies in counseling patients about the negative impact of oncologic treatments on fertility and fertility preservation options. National guidelines extend the responsibilities of educating patients to other healthcare professionals involved in the daily management of oncology patients (Loren et al., 2013). Oncology nurses are well-positioned to provide fertility information to newly diagnosed cancer patients if the topic has not been addressed and offer referrals to specialists if needed. The aims of the research project were to determine whether oncology nurses considered fertility counseling as a high priority, assess current knowledge and knowledge gaps regarding fertility issues, identify barriers and facilitators to providing fertility counseling and identify the level of knowledge about clinical practice guidelines. The majority of oncology nurses believe that counseling newly diagnosed cancer patients about fertility should be of high importance.
Developing a comprehensive training plan for oncology nurses will give them the tools needed to have the confidence to provide fertility information to patients. The Balthazar et al. (2012) was originally intended to measure fertility preservation knowledge of patients after undergoing comprehensive fertility preservation counseling; however, the instrument was selected to assess baseline fertility preservation knowledge of oncology nurses in this quality improvement project (Balthazar et al., 2012). Survey scores of <75% for the majority of questions indicated that oncology nurses would benefit from comprehensive training to improve fertility preservation knowledge. Grabowski et al. (2017) used an instrument for measuring the attitudes of oncology nurses regarding counseling newly diagnosed cancer patients and SAS version 9.4 was utilized for statistical analysis (Grabowski et al., 2017). In this oncology nursing population, the self-awareness domain had the highest score which indicated there was more self-perceived barriers or less self-rated preparedness to presenting fertility preservation options to patients (Grabowski et al., 2017). As Grabowski suggested, the comprehensive education for oncology nurses can initially address the domains in which scores were markedly elevated before moving to domains which have a lesser impact (Grabowski et al., 2017). The majority of oncology nurses had limited knowledge of clinical practice guidelines regarding fertility issues; awareness of these guidelines can aid in further development of a comprehensive training plan for oncology nurses.

Implementation of effective strategies that integrate fertility preservation counseling into routine care for newly diagnosed cancer patients may be useful in assisting these patients in making informed decisions about their fertility and improving quality of care. Although not all patients will be able to proceed with fertility preservation treatment due to the severity of disease, or no interest in future fertility, it is important that patients that are interested receive
counseling early in the cancer diagnosis to allow these patients the opportunity to make informed decisions about their future fertility before potentially sterilizing treatments. Determining barriers and facilitators to the dissemination of fertility information to these patients can assist in achieving the goal of developing interventions to improve counseling to prevent missed opportunities for patients with potential risks of future infertility.

This study had several limitations; only about 30% of the oncology nurses completed the survey, feedback from the majority of the nursing staff may add additional insight regarding the best strategies needed to improve patient education. Integrating alerts into electronic medical records may be an option to decrease or eliminate missed opportunities for reproductive-aged oncology patients desiring fertility preservation treatment. This alert may need to begin at the provider level since not all patients are candidates for fertility preservation due to the severity of disease and the timing necessary for treatment regimens, especially in female cancer patients. Providers can specify patients that are candidates for fertility preservation and oncology nurses can continue the process of patient fertility education where warranted. Interprofessional collaboration is important in this process. The Balthazar et al. (2012) tool was utilized to determine baseline fertility knowledge of oncology nurses which was not the intent of the original instrument (Balthazar et al., 2012). Utilization of the instrument in this manner may have been a reason for lower scores, especially since the instrument was not tested with this population. Lower scores, however, may reflect the need for integration of fertility preservation training for oncology nurses. More research is needed to determine if the survey can be utilized in populations other than the population in which the tool was developed.

Implications to Practice
Due to the complexity of managing cancer patients requiring fertility preservation treatment, interprofessional collaborations, a critical component of the nursing essentials, are necessary to implement patient care effectively and recruit the additional expertise needed to improve patient outcomes (McCaffrey, 2012 p. 10). In a collaborative relationship, it is important to foster an environment of mutual respect in which research ideas can be shared freely to determine the best ways to implement research into practice. The goal of the collaborative relationship is to break down long-established barriers between practitioners and researchers and promote a shift from the traditional roles of each in the research process (Baumbusch et al., 2008). Collaborative relationships should be initiated early in treatment when dealing with newly diagnosed cancer patients. Referral systems should be in place so that treatment can be initiated as soon as possible after fertility preservation intent has been established (Loren et al., 2013). Collaborative discussions should include information regarding the target population who would benefit from treatment, when (how soon) should patient discussions be initiated after diagnosis, the risks associated with chemotherapy or radiotherapy, and the impact on future fertility success (Shnorhavorian et al., 2015). Standard quality of care dictates that the patient is educated about the options available so that treatment protocols can be discussed to facilitate patient-centered outcomes.

Newly diagnosed cancer patients, as a vulnerable population, must learn how to interact with their health care team during this serious life event. It is important for the health care team to discuss the potential detrimental effects of cancer treatment regimens and the options available for fertility preservation. As mentioned previously, success rates for embryo banking is reasonable with around 30-40% of transfers resulting in live births, and although less data is available for oocyte cryopreservation in cancer patients, current rates (36-61% clinical pregnancy
rate per transfer) are similar to infertility patients undergoing in-vitro fertilization procedures (Argyle, Harper, & Davis, 2016; Loren et al., 2013). This recent data is encouraging; however, additional research is needed to verify findings once larger cohorts of cancer survivors begin using their cryopreserved embryos or oocytes for pregnancy attempts (ACOG, 2014). It is important that patients are aware of the potential implications related to cancer treatment and infertility, the research currently available regarding fertility preservation options, and the likelihood of future fertility success with embryo or oocyte cryopreservation to make informed decisions regarding their treatment. Collaborative efforts with open-communication and reciprocity of ideas with the entire healthcare team would be a component of the educational process to determine the specific patient needs, establish acceptable guidelines, and formulate an action plan for implementation and integration into practice. The management of this process requires a multidisciplinary team approach to implement a seamless educational intervention that would avoid treatment delays and improve patient outcomes. As mentioned in the ANA code of ethics, nurses working through interdisciplinary and multidisciplinary collaborations are imperative in ensuring the best possible outcomes for the patient (McCaffrey, 2012; p. 90). Determining the oncology nursing knowledge gaps and barriers to patient education can assist in the development of a comprehensive educational program to assist nurses in educating oncology patients. Strategies would include education of providers, nurses, and the health care team about fertility issues including the impact of oncologic treatments on fertility, current fertility preservation options available, and process for providing referrals to a reproductive specialist. Developing a method to integrate fertility preservation alerts into the electronic medical record system, may be an effective method of consistently managing the care of reproductive-aged
cancer patient who are candidates for fertility preservation and who are interested in pursuing this option.
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KNOWLEDGE GAPS, BARRIERS, AND FACILITATORS


Table 1

Baseline Characteristics of Oncology Nurses

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (range) or n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N=38</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>21-25</td>
<td>1 (2.6%)</td>
</tr>
<tr>
<td>26-30</td>
<td>6 (5.8%)</td>
</tr>
<tr>
<td>31-35</td>
<td>9 (23.7%)</td>
</tr>
<tr>
<td>36-40</td>
<td>6 (15.8%)</td>
</tr>
<tr>
<td>&gt;40</td>
<td>16 (42.1%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>38 (100%)</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>10 (26.3%)</td>
</tr>
<tr>
<td>Registered Nurse with Master’s</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>Registered Nurse with Oncology Certification</td>
<td>22 (57.9%)</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>32 (84.2%)</td>
</tr>
<tr>
<td>Part-time</td>
<td>6 (15.8%)</td>
</tr>
<tr>
<td><strong>Oncology Experience (years)</strong></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>16 (42.1%)</td>
</tr>
<tr>
<td>6-10</td>
<td>10 (26.3%)</td>
</tr>
<tr>
<td>11-15</td>
<td>7 (18.4%)</td>
</tr>
<tr>
<td>&gt;15</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>25 (65.8%)</td>
</tr>
<tr>
<td>Black</td>
<td>8 (21.1%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (5.3%)</td>
</tr>
<tr>
<td>Asian</td>
<td>2 (5.3%)</td>
</tr>
<tr>
<td><strong>Practice Area (multiple answers)</strong></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>7 (18.4%)</td>
</tr>
<tr>
<td>Lung</td>
<td>7 (18.4%)</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>Gynecological</td>
<td>3 (7.9%)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>7 (18.4%)</td>
</tr>
<tr>
<td><strong>Personal History of Cancer</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (13.2%)</td>
</tr>
<tr>
<td>No</td>
<td>33 (86.8%)</td>
</tr>
<tr>
<td><strong>Ever Attended Educational Session on Fertility Issues</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (36.8%)</td>
</tr>
<tr>
<td>No</td>
<td>24 (63.2%)</td>
</tr>
<tr>
<td><strong>Changed Aspects of Practice Since Attending Educational Session</strong></td>
<td></td>
</tr>
<tr>
<td>Yes—6 (15.8%)</td>
<td></td>
</tr>
<tr>
<td>No—8 (21.1%)</td>
<td></td>
</tr>
</tbody>
</table>
Table 2

*Nursing Barriers and Facilitators to Discussing Fertility Topics with Newly Diagnosed Cancer Patients*

<table>
<thead>
<tr>
<th>Factor/Domain</th>
<th>Average</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidence</td>
<td>9.50</td>
<td>3.39</td>
<td>4-20</td>
</tr>
<tr>
<td>Self-awareness</td>
<td>20.44</td>
<td>2.93</td>
<td>5-25</td>
</tr>
<tr>
<td>External Barriers</td>
<td>7.44</td>
<td>1.75</td>
<td>2-10</td>
</tr>
<tr>
<td>Time Barriers</td>
<td>5.57</td>
<td>2.43</td>
<td>2-10</td>
</tr>
<tr>
<td>Perceived Treatment Barriers</td>
<td>6.63</td>
<td>1.75</td>
<td>2-10</td>
</tr>
<tr>
<td>Combined Scores</td>
<td>49.58</td>
<td>7.43</td>
<td>15-75</td>
</tr>
</tbody>
</table>

Note: “Higher scores indicate more self-perceived barriers or less self-rated preparedness to present fertility preservation options to patients” (Grabowski, Spitzer, Stutzman, & Olson, 2016, p. 500).
<table>
<thead>
<tr>
<th>Correct Average: 7.1/13 N/Valid Percentages*</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A doctor can accurately predict the effect that cancer treatment will have on someone’s chance of becoming pregnant in the future. (False)</td>
</tr>
<tr>
<td>2. IVF with embryo freezing is an established treatment used for people with infertility (True)</td>
</tr>
<tr>
<td>3. Frozen embryos have more than a 90% chance of resulting in pregnancy in the future (False)</td>
</tr>
<tr>
<td>4. Ovarian tissue cryopreservation is a FP specific treatment. (True)</td>
</tr>
<tr>
<td>5. Egg freezing has the same chance of future pregnancy as embryo freezing (False)</td>
</tr>
<tr>
<td>6. Chemotherapy increases the risk that future children will have birth defects (False)</td>
</tr>
<tr>
<td>7. Egg freezing can be done in less than 1 week (False)</td>
</tr>
<tr>
<td>8. Embryo freezing requires ovarian stimulation (True)</td>
</tr>
<tr>
<td>9. Women who have fertility treatments before cancer treatment are at increased risk for recurrence of their cancer in the future (False)</td>
</tr>
<tr>
<td>10. Frozen eggs have more than a 50% chance of resulting in pregnancy in the future (False)</td>
</tr>
<tr>
<td>11. More than 100 babies have been born to women who had ovarian tissue freezing (False)</td>
</tr>
<tr>
<td>12. A patient who experiences ovarian failure after cancer treatment can become pregnant in the future (True)</td>
</tr>
<tr>
<td>13. A patient who has had an ovary removed is less likely to become pregnant in the future (False)</td>
</tr>
</tbody>
</table>


*Valid Percentages were used due to missing data
Figure 1: Believe Counseling Newly Diagnosed Cancer Patients About Fertility Issues is of High Importance (n=38)
Figure 2: Does The Provider You Work With Discuss Fertility Issues (n=38)?
Figure 3: Aware of 2013 ASCO Guidelines (n=38)

- Yes: 84%
- No: 16%
KNOWLEDGE GAPS, BARRIERS, AND FACILITATORS

**Figure 4A: ASCO Guidelines (n=38)**

<table>
<thead>
<tr>
<th>Action</th>
<th>All/Most of the time</th>
<th>Some of the time</th>
<th>None of the time</th>
<th>Not Familiar with guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discuss risk of infertility and fertility preservation options with oncology patients anticipating treatment</td>
<td>13.2</td>
<td>31.6</td>
<td>34.2</td>
<td>34.2</td>
</tr>
<tr>
<td>Discuss fertility preservation with patients of reproductive age if infertility is a potential risk of therapy</td>
<td>34.2</td>
<td>21.1</td>
<td>34.2</td>
<td>34.2</td>
</tr>
<tr>
<td>Refer patients who express interest to a reproductive specialist</td>
<td>36.9</td>
<td>13.2</td>
<td>21.1</td>
<td>23.7</td>
</tr>
<tr>
<td>Address fertility preservation as early as possible before treatment starts</td>
<td>21</td>
<td>31.6</td>
<td>31.6</td>
<td>28.9</td>
</tr>
</tbody>
</table>

**Figure 4B: ASCO Guidelines (n=38)**

<table>
<thead>
<tr>
<th>Action</th>
<th>All/Most of the time</th>
<th>Some of the time</th>
<th>None of the time</th>
<th>Not Familiar with guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Document fertility preservation discussions in medical record</td>
<td>15.8</td>
<td>21.1</td>
<td>36.8</td>
<td>28.9</td>
</tr>
<tr>
<td>Answer basic questions about whether fertility preservation may have an impact on successful cancer treatment</td>
<td>28.9</td>
<td>18.4</td>
<td>36.9</td>
<td>31.6</td>
</tr>
<tr>
<td>Refer patients to psychosocial providers if they experience distress about potential infertility</td>
<td>36.9</td>
<td>36.9</td>
<td>18.4</td>
<td>31.6</td>
</tr>
<tr>
<td>Encourage patients to participate in registries and clinical studies</td>
<td>34.2</td>
<td>34.2</td>
<td>15.8</td>
<td>21.1</td>
</tr>
</tbody>
</table>

DISCUSS RISK OF INFERTILITY AND FERTILITY PRESERVATION OPTIONS WITH ONCOLOGY PATIENTS ANTICIPATING TREATMENT

DISCUSS FERTILITY PRESERVATION WITH PATIENTS OF REPRODUCTIVE AGE IF INFERTILITY IS A POTENTIAL RISK OF THERAPY

REFER PATIENTS WHO EXPRESS INTEREST TO A REPRODUCTIVE SPECIALIST

ADDRESS FERTILITY PRESERVATION AS EARLY AS POSSIBLE BEFORE TREATMENT STARTS

DOCUMENT FERTILITY PRESERVATION DISCUSSIONS IN MEDICAL RECORD

ANSWER BASIC QUESTIONS ABOUT WHETHER FERTILITY PRESERVATION MAY HAVE AN IMPACT ON SUCCESSFUL CANCER TREATMENT

REFER PATIENTS TO PSYCHOSOCIAL PROVIDERS IF THEY EXPERIENCE DISTRESS ABOUT POTENTIAL INFERTILITY

ENCOURAGE PATIENTS TO PARTICIPATE IN REGISTRIES AND CLINICAL STUDIES
Figure 5: Attitudes Regarding Fertility Preservation Counseling: Confidence (n=38)
Figure 6: Attitudes Regarding Fertility Preservation Counseling: Self-awareness (n=38)
Physician behaviors limit ability to bring up fertility preservation topic.

Family behaviors limit ability to bring up topic.

**Figure 7: Attitudes Regarding Fertility Preservation Counseling: External Barriers (n=38)**
Figure 8: Attitudes Regarding Fertility Preservation Counseling: Time Barriers (n=38)
Figure 9: Attitudes Regarding Fertility Preservation Counseling: Perceived Treatment Barriers (n=38)
Appendix A

Approval for Survey Use

RE: Use of Survey
Mersereau, Jennifer Ellen <jennifer_mersereau@med.unc.edu>
Wed 3/14, 4:09 PMLutissa Nash Parker

Sure, you are welcome to use it! Thanks for checking with me. The questions are actually in Table II of the attached paper.

Let me know if you have any questions.

Best,

Jenny

Jennifer E. Mersereau, MD
Associate Professor, Department of OB-Gyn
Reproductive Endocrinology and Infertility
University of North Carolina

7920 ACC Blvd. Suite 300
Raleigh, NC 27617
Office: (919) 908-0000 | Fax: (919) 966-5214
www.UNCFertility.org

This electronic message may contain information that is confidential and/or legally privileged. It is intended only for the use of the individual(s) and entity named as recipients in the message. If you are not an intended recipient of this message, please notify the sender immediately and delete the material from any computer. Do not deliver, distribute or copy this message, and do not disclose its contents. Thank you.

From: Lutissa Nash Parker [mailto:lparker36@student.gsu.edu]
Sent: Monday, March 12, 2018 7:24 PM
To: Mersereau, Jennifer Ellen <jennifer_mersereau@med.unc.edu>
Subject: Use of Survey

Letter Seeking Permission to Use Survey/Questionnaire Tool

Date: 03/12/2018

Name: Lutissa Parker

Institution: Georgia State University
Department: School of Nursing

Address: 33 Gilmer Street SE, Atlanta, GA 30303

Dear Sir/Madam:

I am a doctoral student from Georgia State University writing my DNP research project titled Fertility Preservation Counseling in Newly Diagnosed Cancer Patients, under the direction of my dissertation committee chaired by Dr. Michelle Nelson, who can be reached at 404-413-1214/ mnelson18@gsu.edu. The IRB approval is pending.

I would like your permission to use your PROACT survey to assess fertility preservation information provided to newly diagnosed cancer patients and their decision making process.


I would like to use and print your survey under the following conditions:

- I will use the surveys only for my research study and will not sell or use it with any compensated or curriculum development activities.
- I will include the copyright statement on all copies of the instrument.
- I will send a copy of my completed research study to your attention upon completion of the study.
- I would also like permission to omit questions based on the relevancy to the study population.

If these are acceptable terms and conditions, please indicate by forwarding a copy of the survey and responding to me through e-mail: lparker36@student.gsu.edu.

Sincerely,

Lutissa Parker, WHNP-BC

Doctoral Candidate
Appendix B

Approval for Tool Use

RE: Seeking Permission to use Survey
Maria Grabowski <Maria.Grabowski@UTSouthwestern.edu>
Sat 3/31, 2:40 PMLutissa Nash Parker;ONFEditor@ons.org

Dear Lutissa,

Thank you for you email. Please feel free to use as you have outlined below. I wish you the very best and look forward to reading your outcomes. Maria

Full permission granted.

From: Lutissa Nash Parker <lparker36@student.gsu.edu>
Sent: Saturday, March 31, 2018 9:24 AM
To: Maria Grabowski <Maria.Grabowski@UTSouthwestern.edu>
Cc: ONFEditor@ons.org
Subject: Seeking Permission to use Survey

Letter Seeking Permission to Use Survey/Questionnaire Tool

Date: 03/31/2018

Name: Lutissa Parker

Institution: Georgia State University

Department: School of Nursing

Address: 33 Gilmer Street SE, Atlanta, GA 30303

Dear Ms. Grabowski,

I am a doctoral student from Georgia State University writing my DNP research project titled Fertility Preservation Counseling in Newly Diagnosed Cancer Patients, under the direction of my dissertation committee chaired by Dr. Michelle Nelson, who can be reached at 404-413-1214/ mnelson18@gsu.edu. The IRB approval is pending.

I would like your permission to use your fertility survey to assess fertility preservation knowledge and information provided by oncology nurses who manage the care of newly diagnosed cancer patients.

I would like to use and print your survey under the following conditions:

- I will use the surveys only for my research study and will not sell or use it with any compensated or curriculum development activities.
- I will include the copyright statement on all copies of the instrument.
- I will send a copy of my completed research study to your attention upon completion of the study.
- I would also like permission to omit questions based on the relevancy to the study population.

If these are acceptable terms and conditions, please indicate by responding to me through e-mail: lparker36@student.gsu.edu.

Sincerely,

Lutissa Parker, WHNP-BC

Doctoral Candidate

UT Southwestern
Medical Center
The future of medicine, today.