

An Integrative Review of the Role of Nurses in Fertility Preservation for Adolescents and Young Adults With Cancer

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PROBLEM IDENTIFICATION: Adolescents and young adults (AYAs) with cancer commonly report future fertility as an important issue in care. Despite longstanding guidelines on fertility counseling and the trusting relationship between nurses and patients, little is known about the nurse's role in fertility preservation (FP) for AYAs with cancer.

LITERATURE SEARCH: The authors conducted a literature search of articles published through 2020 focused on nursing involvement in FP for AYAs with cancer.

DATA EVALUATION: 85 studies were identified. In total, 11 articles met inclusion criteria and were critically appraised in the review.

SYNTHESIS: Although well positioned to improve FP care among AYAs with cancer, nurses currently have a minimal role because of provider, institutional, and patient-related barriers.

IMPLICATIONS FOR PRACTICE: Interventions to enhance nurses' knowledge about FP, improvements in electronic health record documentation, and facilitation of institutional support are needed to support the nurse's role in FP for AYAs with cancer.

KEYWORDS oncology; adolescent and young adult; fertility preservation; oncology nursing; oncofertility
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In the United States, about 89,500 new cancer diagnoses among adolescents (ages 15–19 years) and young adults (ages 20–39 years) (AYAs) were estimated in 2020 (American Cancer Society [ACS], 2020). Although the incidence rates for AYAs are rising at a rate greater than other age groups, the five-year survival for AYAs ranges from 83% to 86%, compared to 84% for children and 66% for adults (ACS, 2020). There are more than 1.6 million cancer survivors of reproductive age (ACS, 2019). With the growing survival rates among AYAs, patient-centered care that addresses treatment and survivorship care needs is becoming more relevant.

Although AYAs with cancer identify fertility as a top concern of cancer care, many often face infertility as a common treatment side effect (Benedict et al., 2015; Klosky et al., 2014; Su et al., 2018). Fertility concerns remain highly prevalent at diagnosis and throughout survivorship (Su et al., 2018), with AYAs commonly prioritizing their fertility over home ownership and wealth (Klosky et al., 2014). For both sexes, infertility alone often leads to distress and diminished quality of life (QOL), affecting one's emotional well-being, sexuality, and relationships (Duffy & Allen, 2009). Fertility preservation (FP) is not always prioritized for adolescents because of age-related challenges; adolescents may not possess the maturity level to appreciate future fertility and often defer to parental support (Anazodo, Ataman-Millhouse, et al., 2018). The impact of infertility on QOL is even greater for those who did not receive adequate information prior to treatment initiation (Goossens et al., 2015; Vadaparampil & Quinn, 2013). AYAs affected by infertility are twice as likely to experience depression (Duffy & Allen, 2009). Therefore, it is imperative that clinicians identify patients of reproductive age and incorporate discussions about fertility in the plan of care.

To meet AYA fertility needs, numerous national healthcare organizations, including the American Society of Clinical Oncology (ASCO), American Society for Reproductive Medicine, American College of Obstetricians and Gynecologists, National Comprehensive Cancer Network, and American Academy of Pediatrics have issued FP practice guidelines. In 2018, ASCO issued clinical practice guidelines for healthcare providers to address fertility risks as early as possible and document FP discussions in the electronic health record (Oktay et al., 2018). However, evidence suggests that many providers do not disclose the risks of treatment-related infertility or do so inadequately (Lee et al., 2006; Quinn et al., 2009, 2015; Su et al., 2018). A referral to a reproductive specialist is also recommended by ASCO to facilitate FP procedures, given that many oncology providers report being unaware of or uncomfortable discussing FP with patients (Oktay et al., 2018). Standard FP procedures for males consist of sperm cryopreservation, and standard FP procedures for females include oocyte and embryo cryopreservation (Fernbach et al., 2014; Oktay et al., 2018).

Despite long-standing guidelines on fertility counseling, a significant gap remains in fertility care of AYAs with cancer (Flink et al., 2017). Intervention and implementation studies to improve FP education for AYAs are in their infancy and limited in scope (Johnson & Kroon, 2013; Su et al., 2018). To meet practice guidelines and to improve outcomes for AYAs with cancer, healthcare systems must intentionally improve access to FP throughout cancer treatment. Accordingly, the 2013 ASCO guidelines on FP have incorporated a variety of healthcare providers, including RNs, to their list of those capable of FP education (Loren et al., 2013). RNs have an important role within the oncology care team and are uniquely positioned to provide FP education and counseling (King et al., 2008). They generally have more consistent and prolonged contact with patients during their hospitalizations as compared to physicians (Douw et al., 2015; Romero-Brufau et al., 2019), and nursing has been rated the most trusted profession for the past 19 years (Reinhart, 2020). To successfully implement FP guidelines for AYAs with cancer, there is an urgent need to leverage the role of nurses. To the authors' knowledge, little is known about the nurse's role in FP for AYAs with cancer. Therefore, this integrative review sought to summarize and evaluate the existing quality of evidence on oncology nurses' role in FP for AYAs and to provide recommendations to increase nurses' involvement to improve AYA FP outcomes.

Methods

The authors conducted the literature search for this integrative review using methodology and analysis criteria relevant to nursing research (Whittemore & Knaf, 2005). To address the problem of identifying the role of nursing in AYA fertility preservation in cancer, a literature search was conducted. The initial database search was conducted in September 2019 and was updated in February 2021. A reference librarian was consulted prior to conducting the literature search to discuss search strategies and identify key terms relevant to the focus of integrating theory and research in nursing practice in AYA FP. A comprehensive search was completed using CINAHL®, PsycINFO®, PsycArticles®, Academic Search Ultimate, and MEDLINE®. Keywords included AYA, adolescent, young adult, YA, teen, cancer, oncology, neoplasm, tumor, tumour, malignancy, fertility, fertility preservation, onco-fertility, education, nurse, nursing, nurse practitioner, advanced practice registered nurse, NP, and APRN. The reference lists of all identified articles were also searched for relevant articles.

FIGURE 1. PRISMA Flow Diagram

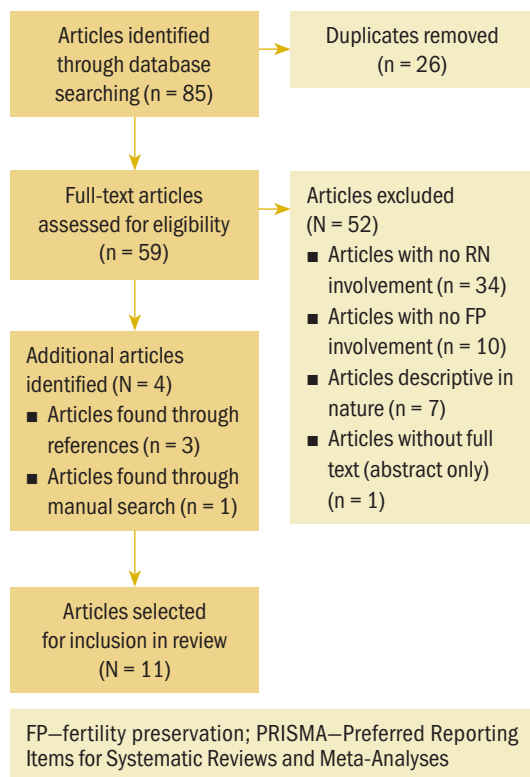


TABLE 1. Characteristics of Eligible Studies Evaluating the Role of Oncology RNs in FP (N = 11)

Study	Purpose and Sample	Methods	Findings	Recommendations	Nursing Involvement
Clayton et al., 2008	To examine trends in FP attitudes/behaviors of pediatric oncology RNs and evaluate their awareness of FP ASCO guidelines; 115 pediatric oncology RNs (in 2005) and 95 RNs (in 2006) were recruited at annual meetings of the Florida Association of Pediatric Tumor Programs.	A cross-sectional quantitative survey was distributed to conference attendees in 2005 and 2006. Survey instruments were adapted from Schover et al. (2002) and Glaser et al. (2004).	The majority felt that FP should be discussed, but knowledge was a barrier. Less than 15% reported awareness of guidelines at their facility. 96% were unaware of ASCO guidelines. Discussions are more likely to occur with patients who are parents or have a poor prognosis. Lack of insurance, poor prognosis, HIV-positive status, homosexuality, young age, and marital status do not affect the likelihood of FP discussion.	RNs play a key role in survivorship discussions and are in an ideal position to discuss FP. Improvements in RNs' knowledge about FP guidelines may help increase implementation of educational training programs.	Most RNs feel a sense of responsibility in engaging in FP discussions, regardless of patient factors. RNs are not knowledgeable about national guidelines.
Covelli et al., 2019	To understand clinicians' perspectives of barriers to discussing infertility and FP with young women with cancer; 22 clinicians were recruited from various cancer centers and community hospitals in Canada.	This cross-sectional qualitative study consisted of telephone interviews using a semi-structured interview guide from 2014 to 2015. Thematic analysis was used to discern nature of barriers.	Despite guidelines and standards of care, FP discussions are not standard in practice. Medical education has not kept up with current FP technologies, leaving clinicians uninformed. Creating resource tools for patients can improve levels of FP discussions.	Interprofessional communication, identification of local opinion leaders/champions, society endorsements, continuing medical education opportunities, dedicated FP programs, referral networks, and decision support are needed to help incorporate ASCO guidelines into clinical practice. Creating resource tools for patients can improve levels of FP discussions.	Of the 22 clinicians, 3 were oncology NPs or CNSs. There were no emerging themes based on NP and CNS perspectives.
Graham et al., 2017	To assess pediatric oncology providers' perceptions of FP options for female AYA patients and examine factors that influence their DM about FP discussions; 167 pediatric oncology HCPs identified through the Children's Oncology Group membership list were recruited via email in 2012 to complete an online survey.	Cross-sectional quantitative survey that included a 26-item measure	Providers felt comfortable discussing FP options but more comfortable discussing surgical relocation of ovaries than GnRH agonist therapy or embryo tissue cryopreservation. Diagnosis and risk of mortality were influential in FP DM; FP discussion was not considered unless risk of disease progression was low.	Improved collaborative care is needed between FP specialists and oncology providers. Consider incorporating reproductive specialists into interprofessional care clinics and tumor board meetings and having dedicated FP navigators.	Pediatric oncology RNs were included in this study, but it is unclear how many and their role was not specifically mentioned.

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TABLE 1. Characteristics of Eligible Studies Evaluating the Role of Oncology RNs in FP (N = 11) (Continued)

Study	Purpose and Sample	Methods	Findings	Recommendations	Nursing Involvement
Keim-Malpass et al., 2018	To assess the perspectives regarding current practice, the perception of role in fertility counseling and FP, and barriers to FP services among oncology RNs in an academic center; 52 RNs at an outpatient National Cancer Institute-designated cancer center	Cross-sectional descriptive survey using open-ended and Likert-type scale (mixed methods)	89% needed more information about FP options. 92% said fertility counseling and referral services are needed within their institution. 73%–77% rarely/never discuss the impact of cancer treatment or FP on fertility. 77%–85% rarely/never provide educational materials regarding the effects of cancer treatment on fertility or FP materials. 85% rarely/never use ASCO guidelines on FP.	Find innovative ways to embed more concepts of FP options within chemotherapy certification standards and CE. Case studies can be used to promote comfort in content delivery. More research is needed to understand system, educational, and institutional culture considerations. Interprofessional care is paramount to delineating roles and developing interventions specific to practice contexts.	Most RNs display a lack of knowledge about FP, have a need for FP counseling at their facility, and rarely engage in FP discussions, provide educational materials, or feel comfortable initiating FP discussions. However, most recognize that patients of reproductive age should be offered FP education. Most feel it is ultimately the responsibility of the physician/NP.
King et al., 2008	To explore RNs' knowledge, attitudes, and practice behaviors related to their discussions of FP with patients with cancer; 15 oncology RNs were recruited from outpatient clinics at a cancer center in the southeastern United States.	Qualitative cross-sectional pilot study that consisted of a focus group and in-depth interviews with a semistructured interview guide	Only half of RNs discuss FP methods with patients, yet most believe that FP discussion is part of their role. Factors relating to FP discussion include knowledge, attitudes, and behaviors.	Barriers involving lack of comfort because of decreased knowledge of resources can be addressed with training offered through CE. Discussion should be created among RNs relating to their role in FP discussion. Educational interventions and practice guidelines for oncology RNs should be developed.	Oncology RNs' knowledge, attitudes, and practice behaviors were examined in this study. Results demonstrate that RNs are capable of involving themselves in FP discussions and believe that it is part of their role but require further education.
Murray et al., 2016	To assess oncology RNs' perceptions and recommendations of FP discussions with AYA patients with cancer and to explore patient-related factors that may influence the discussions; 116 oncology RNs were recruited from the Oncology Nursing Society membership database.	Cross-sectional experimental study; participants were randomized to reading vignettes with various clinical characteristics and completing quantitative and open-ended questions thereafter.	RNs strongly recommend that all patients explore FP options prior to the initiation of cancer treatment. RNs strongly voiced that YA female patients should be granted independent DM authority to delay treatment for FP in comparison to male and female adolescent patients and young adult male patients.	Oncology providers should be knowledgeable about advances in FP technology. Oncology team members should feel competent and comfortable discussing FP interventions and knowledgeable about where to refer when further information is warranted. Future research should focus on effective communication among providers.	RNs are likely to initiate FP discussions and feel strongly that all patients of reproductive age should explore FP options. Barriers related to patient factors include maturity and emotional fragility.

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TABLE 1. Characteristics of Eligible Studies Evaluating the Role of Oncology RNs in FP (N = 11) (Continued)

Study	Purpose and Sample	Methods	Findings	Recommendations	Nursing Involvement
Norton & Wright, 2020	To explore and interpret nurses' experiences, feelings, and associated meanings attached to undertaking fertility-related discussions with teen/YA patients with cancer aged 13–24 years to advance understanding of factors that facilitate or hinder such discussions; 11 oncology RNs were recruited from a Teenage Cancer Trust unit in England.	Cross-sectional qualitative study; participants completed in-depth, semistructured interviews.	Parents/families of teens/YAs were experienced as self-appointed informal gatekeepers who controlled access to the patient. This dynamic was a barrier to engaging in private FP-related conversations with the patient. RNs adopted a supportive role, which was enhanced by positive relationships created with teens/YAs.	RNs need to be sensitive to parental involvement if teens/YAs are to make informed decisions. Further research is needed to explore ways to successfully engage with parents to ensure that patient views are considered. Clearer roles are needed in FP discussion to ensure that teens/YAs are referred to FP specialists before treatment initiation.	RNs had an ongoing supportive role in the FP process. They recognized that many families were not open to discussing FP initially and would have questions that evolve over time. In addition, they recognized that the relationship between the RN and patient/family develops over time.
Panagiotopoulou et al., 2017	To assess the prevalence and influential factors of FP discussion barriers among pediatric and adolescent oncology HCPs; 48 pediatric/adolescent oncology healthcare workers were recruited from Principal Treatment Centre in the United Kingdom.	Cross-sectional survey that included a 12-item survey; participants were identified by the site research coordinator. The survey consisted of closed- and open-ended questions regarding FP discussion barriers.	All participants reported at least one barrier to FP care. The most commonly reported barriers related to patient characteristics. The least reported barriers related to organizational barriers.	Educational support and interventions for RNs and allied health professionals can improve interprofessional collaboration and FP discussion with patients and families.	31 participants (65%) were oncology RNs. RNs reported knowledge as a barrier more than physicians.
Vadapampil et al., 2007	To explore RNs' attitudes toward the discussion of FP with pediatric patients with cancer and families; 115 pediatric oncology RNs were recruited at the Florida Association of Pediatric Tumor Programs 28th Annual Advances in Pediatric Hematology/Oncology Conference in Orlando, FL.	A 45-item cross-sectional survey, included in registration packets, was given to participants. The survey focused on practice characteristics and behaviors, provider attitudes toward FP discussion, and attitudes toward patient factors that may affect FP discussion.	Attitudinal factors most likely to influence FP discussions involve the potential of upsetting patients' families, that boys aged younger than 18 years should not be provided erotic materials, and challenges with locating FP facilities. Patient factors likely to encourage FP discussions include being recently married/engaged, patient inquiry of FP, and availability of patient education materials.	Understanding factors that may serve as barriers or facilitators to this discussion may help to encourage conversations about FP between RNs and pediatric patients with cancer and their families. Tools and educational materials are needed that RNs can use to increase their knowledge and confidence while satisfying the needs of patients and families.	Pediatric oncology RNs felt it was within their scope to engage in FP discussion but did so less than 50% of the time because of numerous barriers. RNs are capable of playing a key role in FP discussions with the help of further educational interventions.

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TABLE 1. Characteristics of Eligible Studies Evaluating the Role of Oncology RNs in FP (N = 11) (Continued)

Study	Purpose and Sample	Methods	Findings	Recommendations	Nursing Involvement
Vadaparrampil et al., 2016	To describe/assess the impact of ENRICH, a web-based communication skill-building curriculum for oncology RNs regarding AYA fertility and other reproductive health issues; 77 oncology RNs who provide care for AYA patients were recruited through oncology conference promotions and professional organizations.	Participants completed an eight-week course that incorporated didactic content, case studies, and interactive learning. Modules focused on infertility, FP options, sexuality, alternative family bonding, and skill building; pre- and post-test assessing knowledge and a six-month follow-up survey assessing learner behaviors and institutional changes	Practice improvements reported post-ENRICH training: formed new policies (30%), provided in-service education (37%), provided educational materials (26%), initiated a fertility patient navigator role (28%), and developed workplace collaboration with reproductive specialists (46%)	ENRICH improves nursing knowledge and involvement in activities addressing fertility needs of AYA patients with cancer. RNs will be better prepared to discuss fertility and reproductive health, which will lead to improvements in quality of life for AYA patients with cancer.	RNs are capable of implementing change in their clinical practice after being properly educated.
Wright et al., 2018	To explore RNs' experiences and associated meanings attached to undertaking fertility-related discussions with teenagers and YAs with cancer and to understand factors that facilitate or hinder FP discussions; 11 oncology RNs were recruited at a Teenage Cancer Trust Unit in a U.K. hospital.	Qualitative study; 11 semistructured interviews were conducted in 2016.	Lack of knowledge was considered a significant barrier, which resulted in avoidance of FP discussion. The limited time frame for female patients was felt to inhibit FP discussions and FP.	Implementation of CE efforts and support for RNs will likely improve patient outcomes. RNs need to consider ways to ensure that female patients benefit from improved information regarding risks to fertility and FP options.	Reiterates the lack of knowledge and need for nursing education

ASCO—American Society of Clinical Oncology; AYA—adolescent and young adult; CE—continuing education; CNS—clinical nurse specialist; DM—decision-making; ENRICH—Educating RNs About Reproductive Issues in Cancer Healthcare; FP—fertility preservation; GnRH—gonadotropin-releasing hormone; HCP—healthcare provider; NP—nurse practitioner

Literature Search

In the authors' initial search, 85 articles were retrieved from the electronic search. Inclusion criteria were as follows: published in English; peer reviewed and published through April 14, 2020; contained key terms including AYA, cancer, and fertility preservation; and related to nursing practice. Exclusion criteria were as follows: systematic reviews or meta-analyses, gray literature, descriptive papers, abstract-only publications, and publicly available theses and dissertations (see Figure 1).

C.C. and L.A. reviewed all titles and abstracts, removing duplicates; thereafter, 59 articles were sent

to D.R.A. and T.F.G. to review for inclusion. They identified 11 articles to be included in or excluded from the review. T.F.G. and D.R.A. then switched their article pool to ensure consistency of article inclusion or exclusion. In total, 11 articles met the inclusion criteria, including empirical (e.g., case studies, cross-sectional analyses) and theoretical reports. Most were excluded because they were descriptive in nature, were not specific to AYA FP, or had no review of nursing involvement. Data analysis was completed using the constant comparison method that recommends extracting data into systematic categories to facilitate distinct themes and

relationships (Patton, 2002; Whittemore & Knaf, 2005).

Data extraction: To analyze and synthesize the evidence, data from the 11 primary sources were first ordered alphabetically (first author) and then categorized by research type (empirical or theoretical), study sample characteristics (e.g., nurses, physicians), and setting for data collection (e.g., single site, multiple sites) in a preliminary chart.

Data analysis: Data from sources were then indexed to include the study's primary and secondary findings, recommendations, and key findings relevant to nursing involvement by C.C. and L.A., allowing the entire study team (C.C., L.A., T.F.G., and D.R.A.) to review extracted data thereafter. Through consensus, C.C. and L.A. further stratified the data by categories and themes. All authors reviewed the stratified data, compared findings, and synthesized data into subgroups of barriers and recommendations. Each identified theme was then coded per article, creating a total frequency for each theme (C.C. with team review). The team then compared frequencies and reduced data from this larger matrix to identify primary themes and abstracted findings. Methodologic quality was evaluated during each stage, specifically when coding relevance and frequency of the noted themes. As a final step, the study team synthesized conclusions and summarized interpretations, referencing the synthesized data chart and the larger thematic matrix concurrently. This integrative review did not require an institutional ethics review but was completed in compliance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist. All articles were critically appraised and met standards for methodologic quality.

Results

Synthesis of Literature Search

For initial analysis of research design type, a total of four articles used quantitative methods, four used qualitative methods, and three employed a mixed-methods design. Nine studies used cross-sectional surveys and interviews to evaluate perceptions of FP using quantitative ($n = 4$), qualitative ($n = 4$), or mixed-methods approaches ($n = 1$). Regarding sample characteristics, nine studies evaluated RNs only, and the remaining two studies included other types of healthcare providers in addition to RNs (Graham et al., 2017; Panagiotopoulou et al., 2017). Two studies included either an intervention or program implementation approach to evaluate

nursing education for FP and evaluate nurse attitudes, perceptions, and levels of engagement with FP. All studies were published within the past 12 years. See Table 1 for study characteristics.

Data Evaluation

The studies relevant to this analysis were limited in quantity and consist of a diverse sample of cross-sectional self-report measures and qualitative analyses and one randomized trial; therefore, a direct comparison of study quality was not suited for this integrative review (Whittemore & Knaf, 2005). Current data are limited by largely observational, cross-sectional studies. Study samples were largely recruited from annual conference attendance and academic hospitals where research was conducted. Although both types of recruitment mechanisms show benefits related to examining nurses' views about FP in large academic settings, such recruitment methods exclude the perceptions and experiences of RNs in community-based and rural settings. For instance, community nursing perspectives about FP, access to FP centers, and cultural factors for patients and RNs may vary significantly for these community-based and rural cohorts. The majority of the studies used survey-based research methods to assess clinician perspectives, which is highly subject to recall bias. The research could be significantly improved by evaluating electronic health records (EHRs) for evidence of nursing involvement in the FP trajectory of care. Longitudinal research is also needed to capture the effectiveness and optimal timing of FP interventions over time, to monitor changes in fertility concerns throughout the illness trajectory, and to evaluate intervention success throughout survivorship. Although a variety of providers are included in the studies to date, few integrate fertility specialists in their evaluations, which is a necessary disciplinary perspective to address FP needs of AYAs with cancer. With only one intervention study identified, further intervention research that leverages the role of nursing is needed in future work.

Data Synthesis

Extracted data were reviewed and indexed by barriers and success for FP nursing and non-nursing involvement, and by recommendations specific to increasing nursing involvement in FP. Relevant themes were categorized by clinician, patient, and systemwide barriers. The frequency of themes per study is noted in Figure 2. All themes were compared and analyzed to identify final barriers and recommendations.

FIGURE 2. Barriers and Recommendations Identified in Eligible Studies**Clinician-Related Barriers**

Combined (nursing and non-nursing)

- Lack of knowledge (n = 7)
- Low comfort (n = 4)

Nursing (RN and nurse practitioner)

- Lack of knowledge (n = 7)
- Role confusion (n = 4)
- Ethical concerns (n = 2)

Non-nursing (e.g., physician, allied healthcare professionals, physician assistants)

- Lack of knowledge (n = 1)

Clinician-Related Recommendations

Addressing knowledge gaps: educational interventions

- Increase awareness about FP guidelines; this could be a major source of change in clinical practice and the subsequent delivery of care.
- Teach nursing students about late effects of cancer, including impacts on fertility.
- Incorporate more advanced concepts (FP options) within chemotherapy certification standards and ongoing continuing education.
- Stay abreast of advancements in FP technology.
- Create tools and educational materials that RNs can use to increase their knowledge and confidence while satisfying the needs of patients and families.
- Develop web-based training programs to promote continuing nursing education (can reach more people at a lower cost).
- Develop targeted educational initiatives, which may improve nurses' knowledge and confidence and increase their willingness to undertake such discussions.

Forging interprofessional collaborations

- Interprofessional (particularly physician, nurse practitioner, and RN) communication is paramount to delineating desired roles and developing interventions specific to practice contexts.
- Integrate care team members (physicians, RNs, clinical health psychologists, and social workers) so that they also feel competent and comfortable discussing these interventions with AYA patients and families and/or are aware of where to refer patients for more information.
- Effective communication among providers and ongoing education in the rapidly advancing area of FP in cancer care appear to be important areas for future study to enhance quality of care and the quality of life and future fertility of AYAs with cancer.

Future research

- Future studies would benefit from including a qualitative component to examine additional factors that affect decision-making and better capture the dynamic process.
- Case studies and role-play can be used as needed to promote comfort in content delivery.
- More research is needed to understand system, educational, and institutional culture considerations, which may affect perceptions of the oncology RN scope of practice.

- Larger prospective studies are needed to determine the impact of an oncofertility nurse navigator and concerted educational efforts on access to and uptake of FP among patients with cancer of reproductive age.
- Assess and manage treatment risks and availability of FP options.
- Implementation strategies should focus on matching identified barriers to interventions shown to create a receptive environment while taking into account the local context because this approach has been shown to be more effective in bridging evidence and clinical practice gaps.
- Research should focus on evaluating the effectiveness of training initiatives in raising nurses' confidence to discuss fertility issues and teenagers' and young adults' views on fertility information provision.

Patient-Related Barriers

- Poor prognosis/severity of disease (n = 5)
- Time (related to urgency of treatment) (n = 4)
- Age (n = 5)
- Patient/family distress level (n = 4)
- Gender (female) (n = 2)
- Lesbian, gay, bisexual, transgender, and queer (n = 2)
- HIV-positive status (n = 1)

Patient-Related Recommendations

Interventions

- As FP technology improves, understanding the issues surrounding the clinical adoption of the discussion is critical in ensuring that patients receive FP information.
- Barriers, such as lack of comfort in finding resources for patients, could be overcome through educational materials, and training could be offered as part of continuing education for RNs.

Future research

- Trends in the behaviors and attitudes of pediatric oncology RNs toward FP discussions should be revisited in subsequent years to determine whether the additional time helped to facilitate FP guidelines.
- Future researchers should examine differences in FP conversations by patient's age and differences between pediatric and adult oncologists.
- Additional research and resources should also be targeted to providers in adult cancer care settings. Because of the perception that there are fewer encounters with patients of reproductive age in the adult setting, it may be that additional education and practice interventions could be tailored for the adult care provider that are synergistic to emerging practices in pediatric care settings.
- Barriers, such as lack of comfort in finding resources for patients, could be overcome through educational materials, and training could be offered as part of continuing education for RNs.
- More research is needed with multicultural and international patients, families, and oncology providers to assess generalizability of feelings (feelings regarding increasing hope for patients and families whereas oncologists feel it is a burden to bear).

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FIGURE 2. Barriers and Recommendations Identified in Eligible Studies (Continued)

Institutional Barriers

- Time (n = 6)
 - RN meets patient after treatment has begun (n = 2)
 - Not enough time for physician in oncology consultation (n = 2)
 - Not enough time within RN shift (n = 2)
- Difficulty finding FP centers or lack of access to FP providers (n = 5)
- Lack of patient education materials (n = 5)
- Availability of FP guidelines in the facility (n = 2)
- Cost (related to lack of insurance coverage) (n = 2)

Institutional Recommendations

Interventions

- There is a need for institutional support in incorporating the guidelines into practice.
- Active knowledge translation strategies, such as interprofessional collaborations and communications, identification of local opinion leaders or champions, society endorsements, continuing medical education opportunities, dedicated FP programs, referral networks, and decision support systems, are needed.
- Creation of resource tools (posters, decision aids) for clinicians and patients also has the potential to improve levels of fertility-related discussions.
- Efforts are needed to mitigate barriers to timely initiation of FP treatment.

- Increased collaboration between pediatric cancer providers and fertility specialists, as well as better FP education, will improve the FP care and outcomes of AYA female patients with cancer.
 - Providing RNs with more knowledge and information would increase RNs' comfort in discussing FP.
 - Discussions need to be stimulated among RNs about the role of the RN in the FP discussion and to develop educational interventions and practice guidelines aimed at oncology RNs to help facilitate discussions with patients.
 - Provide discussion topics for integrated care teams related to the responsibility of discussing fertility risk and FP options with patients.
 - A liaison system between oncologic and reproductive specialties may be useful in providing nurses with clarity about their fertility discussion responsibilities and promote a sense of ownership.
- #### **Future research**
- Future research should examine how institutional administration and culture should change to better facilitate FP guidelines.
 - An area of future research involves national surveys of academic and community-based cancer centers to determine the implementation of American Society of Clinical Oncology guidelines specific to FP education and counseling.
 - Further research is needed to generate testable hypotheses among the representative sample of RNs regarding the discussion.

AYA—adolescent and young adult; FP—fertility preservation

Note. The n values indicate the number of studies identifying a specific barrier.

Note. Based on information from Clayton et al., 2008; Covelli et al., 2019; Graham et al., 2017; Keim-Malpass et al., 2018; King et al., 2008; Murray et al., 2016; Norton & Wright, 2020; Panagiotopoulou et al., 2017; Vadaparampil et al., 2007, 2016; Wright et al., 2018.

Barriers

Each study revealed several barriers that RNs face in addressing FP with AYAs with cancer. Primary themes included lack of knowledge, low comfort, role confusion, and ethical concerns. Patient-level barriers included patients' poor prognosis, time limitations, age variability, distress level, gender, and lesbian, gay, bisexual, transgender, and queer (LGBTQ)/HIV factors. Institutional barriers included difficulty accessing FP center, lack of educational materials, and cost. The authors will discuss the role and involvement of each theme related to nursing involvement in FP stratified by clinician, systemwide, and patient factors.

Clinician-Related Barriers

Lack of knowledge regarding national guidelines and institutional policies among RNs and clinicians emerged as the most prominent barrier to FP (Clayton et al., 2008; Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Murray et al., 2016; Panagiotopoulou et al., 2017; Wright et al., 2018). Lack of knowledge largely correlated with the comfort level of RNs and

was noted in studies by Keim-Malpass et al. (2018), King et al. (2008), Panagiotopoulou et al. (2017), and Wright et al. (2018). RNs emphasized that they would feel more comfortable engaging in FP discussions if they possessed more knowledge (King et al., 2008; Wright et al., 2018) and had clearer roles regarding FP (Keim-Malpass et al., 2018; King et al., 2008; Murray et al., 2016; Wright et al., 2018). In general, RNs reported that oncologists were primarily responsible for initiating FP discussions, but RNs expressed the desire to be involved in the FP process. RNs also endorsed feeling that they should follow up with patients after FP is introduced by the oncologist to ensure patients' understanding, answer any follow-up questions, and provide access to resources and support (role confusion) (King et al., 2008). This role was exemplified by RNs in Norton and Wright's (2020) study; however, RNs were not informed whether the patient/family received FP education at the initial physician consultation, causing further role confusion. The final provider barrier was related to ethical concerns of FP for adolescent patients. RNs identified ethical conflicts as a

barrier to FP and reported unique concerns when parents of a child of reproductive age ask RNs to withhold FP information (Murray et al., 2016; Norton & Wright, 2020). RNs in Norton and Wright's (2020) study noted that adolescents' parents/family often occupy the role of self-appointed gatekeepers to the patient and, thereby, hinder FP conversations. RNs also expressed concerns regarding provision of pornographic material to male adolescent patients aged younger than 18 years (Vadaparampil et al., 2007). In addition, RNs reported concerns and barriers specific to the patient's age, religiosity, cultural background, and sexual orientation. These findings highlight the unique challenges experienced by pediatric oncology RNs, more so than adult oncology RNs. In addition, four studies in the authors' review did not specify whether the RNs worked in pediatric or adult settings.

Institutional Barriers

Institutional factors may also serve as barriers to RNs discussing FP with AYA patients with cancer. Time was noted as the most frequently reported institutional barrier (Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Panagiotopoulou et al., 2017). Specifically, limited time during busy RN shifts and lengthy clinician oncology consultations were identified as other time-related barriers. Timing, in the context of diagnosis and treatment, for nursing involvement in FP was also stressed as a barrier. For instance, RNs often care for patients with cancer after treatment has begun, which nullifies the opportunity to engage in FP discussions at critical moments of care prior to surgery, chemotherapy, or radiation therapy (Keim-Malpass et al., 2018; King et al., 2008). Their lack of access to patient educational materials also emerged as a significant barrier to providing FP care (Clayton et al., 2008; Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Vadaparampil et al., 2007). Lack of access to local fertility centers and knowledge of their location were highlighted as systemic barriers to connecting patients in four U.S. studies and one Canadian study (Clayton et al., 2008; Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Vadaparampil et al., 2007). Lastly, high costs associated with FP procedures were noted as an institutional barrier, which is evidence of potential disparities in care. A lack of insurance coverage was noted as a specific barrier in two studies (Covelli et al., 2019; King et al., 2008).

Patient-Related Barriers

Patient-related barriers also constrain RNs from engaging in FP conversations. A patient's poor

prognosis and severity of disease was the most common patient barrier to FP discussions and appeared in five studies (Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Panagiotopoulou et al., 2017; Vadaparampil et al., 2007). Timing within their diagnosis and treatment plan was also a factor, where the urgency of a patient's treatment preceded FP dialogue and intervention (Covelli et al., 2019; Graham et al., 2017; Vadaparampil et al., 2007; Wright et al., 2018). For example, an RN interviewed in Keim-Malpass et al.'s (2018) study described a typical patient scenario with a diagnosis of acute myeloblastic leukemia, which requires immediate initiation of treatment, leaving no time for egg retrieval. Female gender appeared as a barrier in two studies. Nurses in Clayton et al.'s (2008) study reported that guidelines were more available for male patients, and respondents in Covelli et al.'s (2019) study noted that females face different challenges because FP costs associated with necessary female FP procedures are more expensive. Patient age or maturity level was underscored in four studies (Graham et al., 2017; King et al., 2008; Murray et al., 2016; Panagiotopoulou et al., 2017); however, the concept of age was vaguely introduced and younger or older age was not specified. Nurses described challenges in honoring patient autonomy in the presence of parental involvement. For example, in Murray et al. (2016) and Norton and Wright (2020), RNs described encounters where parents specifically requested that fertility not be discussed with the patient. RNs also expressed hesitancy in providing pornographic materials to males aged younger than 18 years (Vadaparampil et al., 2007). Patients' distress levels were clarified (Covelli et al., 2019; Murray et al., 2016; Vadaparampil et al., 2007) where RNs expressed reluctance to discuss fertility risks because of fear of exacerbating negative emotions and heightening information overload. Of note, a patient's sexual orientation—LGBTQ status and HIV-positive history—dissuaded RNs from FP discussions (Murray et al., 2016; Vadaparampil et al., 2007).

Facilitators

Despite a multitude of barriers, facilitators were also highlighted. RNs were more likely to engage in FP discussions with adequate access to resources and patient education materials (Vadaparampil et al., 2007). RN FP discussions were also more likely with patients who were married or engaged (Vadaparampil et al., 2007) or who had at least one child (Clayton et al., 2008). Two studies noted that RNs were more likely to discuss FP if the

patient initiated the conversation (King et al., 2008; Vadaparampil et al., 2007).

Recommendations

Study recommendations focused on solutions to addressing knowledge gaps, forging interprofessional collaboration, and optimizing the full scope and breadth of the RN role in FP.

Addressing Knowledge Gaps

Recommendations to address RNs' limited or lack of knowledge were discussed in eight studies (Clayton et al., 2008; Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Panagiotopoulou et al., 2017; Vadaparampil et al., 2007, 2016; Wright et al., 2018), with two studies testing interventions to improve RN knowledge gaps (Murray et al., 2016; Vadaparampil et al., 2016). Clayton et al. (2008) stressed the importance of improving RNs' knowledge gaps regarding national guidelines, and, surprisingly, 96% of the participants were unaware of ASCO FP guidelines. However, Clayton et al. (2008) emphasized that the mere knowledge of guidelines is insufficient to ensure knowledge translation and FP engagement. As a result, Clayton et al. (2008) called upon cancer facilities to provide institutional support that may facilitate the integration of guidelines into clinical practice. Examples of institutional support include advocacy for interprofessional collaboration, identification of institutional and local leaders/champions, society endorsements, continuing education, dedicated FP programs, referral networks, and decision support systems (Clayton et al., 2008). To evaluate the efficacy of institutional education and implementation of FP guidelines, Keim-Malpass et al. (2018) recommended conducting national surveys among academic and community cancer centers to ensure FP engagement. However, national guidelines recommend standardized documentation of FP education, which is presently lacking in the majority of cancer care institutions.

Recommendations related to the use of continuing nursing education programs emerged in five studies (Clayton et al., 2008; Keim-Malpass et al., 2018; Vadaparampil et al., 2007, 2016; Wright et al., 2018). Wright et al. (2018) advised future researchers to evaluate the effectiveness of FP RN training initiatives to confirm their utility. These recommendations set the stage for Vadaparampil et al.'s (2016) ENRICH (Educating RNs About Reproductive Issues in Cancer Healthcare) study, which emphasized RNs' ability to successfully incorporate FP into clinical practice after undergoing sufficient education.

Forging Interprofessional Collaborations

Improving interprofessional collaboration was highlighted in four studies (Graham et al., 2017; Keim-Malpass et al., 2018; Murray et al., 2016; Wright et al., 2018). For example, Keim-Malpass et al. (2018) and Murray et al. (2016) emphasized the need for targeted collaborations within the interprofessional oncology team, comprised of clinicians, RNs, and nurse practitioners. The studies by Graham et al. (2017) and Wright et al. (2018) emphasized the need for collaboration between FP specialists and the oncology team, such as a liaison system between the two teams that may help clarify RN responsibilities and promote ownership, which is an identified barrier to FP conversations.

Optimizing the Full Scope and Breadth of the RN Role

Although four studies concluded that RNs are ideally suited to discuss FP given their training, expertise, and the unique relationship with the patient (King et al., 2008; Murray et al., 2016; Norton & Wright, 2020; Vadaparampil et al., 2007), further research regarding the nursing role is warranted. King et al. (2008) emphasized the need to explore and clarify RNs' role, stating that discussions need to take place within nursing groups to develop educational interventions and guidelines specifically for RNs. In addition, Keim-Malpass et al. (2018) encouraged the pursuit of further research to better understand the system, educational, and institutional cultural considerations that affect RN perceptions, as well as the need for larger prospective studies to determine the impact of an oncofertility nurse navigator.

Review of Findings

The majority of the studies in the current review found FP to be an essential aspect of oncologic care in AYAs and reported that patients of all reproductive ages should be offered information about FP prior to treatment. However, evidence suggests that nursing knowledge of FP clinical guidelines remains limited (Clayton et al., 2008; King et al., 2008; Wright et al., 2018). Clayton et al.'s (2008) study revealed that 96% of nurses were unaware of the ASCO guidelines. In addition, RNs are not engaging in FP discussions with their patients (Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008; Vadaparampil et al., 2007), with Keim-Malpass et al. (2018) noting that 77% of RNs rarely or never discuss FP with their patients. Although RNs recognize the importance of FP discussions, they also report a general lack of knowledge, resulting in decreased comfort levels and limited

discussions. Of note, patients endorse feeling more comfortable discussing fertility concerns with RNs as opposed to clinicians (King et al., 2008). Therefore, efforts are needed to expand the role and scope of nursing with regard to FP by equipping RNs with the knowledge, confidence, and competence to initiate FP discussions with AYAs with cancer and their families.

Discussion

This integrative review summarized and evaluated the existing quality of evidence on oncology nurses' role in FP for AYAs and provides recommendations to improve AYA FP outcomes. Study findings indicate that RNs have a minimal role in FP because of numerous provider, institutional, and patient-related barriers, even though they are well positioned to improve FP care in AYAs with cancer. Despite long-standing ASCO guidelines, research suggests that many providers do not disclose the risks or do so inadequately (Lee et al., 2006). Less than 60% of oncologists discuss fertility risk, and less than 40% of oncologists refer patients with fertility risk to reproductive specialists (Quinn et al., 2015). Although oncologists are incredibly skilled in treating disease and are capable of FP, they are often burdened by institutional barriers and may benefit from delegating FP tasks through a collaborative approach.

Implications for Practice

Oncology nurses must be integrated into AYA FP management as a way for healthcare systems to properly adhere to practice guidelines. This review underscores the importance of using interprofessional approaches to meet FP needs of AYA populations. Interventions to enhance nurses' knowledge about FP, improve EHR documentation, and facilitate institutional support are needed to address barriers and support the nursing role in FP for AYAs with cancer.

Recommendations to Address

Clinician-Related Barriers

Lack of knowledge, low comfort, ethical concerns, and role confusion were consistently identified as primary barriers to RN involvement in FP discussions with AYAs with cancer. Although lack of knowledge was the most prominent barrier, evidence shows that RNs are successful in knowledge translation through FP educational interventions. As an example, Vadaparampil et al.'s (2016) program implementation study found that after completing the ENRICH program, more than 70% of RNs met with providers to discuss reproductive health issues, nearly half reviewed practice

guidelines, and many formed FP committees, created patient education materials, contributed to in-service education, and assisted in creating collaborative relationships with FP specialists. Educational interventions, such as ENRICH, can improve FP implementation and increase RN comfort level in engaging in FP discussions. Recognizing that no single group of healthcare professionals possesses all the knowledge and skills necessary to adequately address all FP issues (Barbour et al., 2013), there is an urgency for interprofessional approaches. Collaborations with fertility specialists, social work, psychology, palliative care, and chaplaincy are essential to mitigate ethical concerns and clinician barriers. In addition, oncology nursing organizations should be called upon to incorporate FP into certification courses and continuing education courses. FP education should also address parental preferences and patients' age and maturity to ensure that RN interventions are patient-centered and age-appropriate.

Role confusion for RNs persists despite the inclusion of RNs in the 2013 ASCO FP guidelines. RNs state that clinicians and nurse practitioners are ultimately responsible (Keim-Malpass et al., 2018); however, the majority consider themselves to be capable of involvement in FP. RNs may benefit from specific guidelines from cancer institutions, oncology nursing organizations, and other professional healthcare organizations. RNs and advanced practice RNs (APRNs) occupy a variety of roles within the oncology setting, such as bedside RNs, RN navigators, clinical nurse specialists, and nurse practitioners, each of whom can address important barriers to FP for AYAs with cancer. An example of fully leveraging nursing in FP has been demonstrated at Princess Margaret Cancer Centre in Toronto, Ontario, Canada, which launched a successful AYA program where APRNs conduct consultations, identify FP needs and resources, and educate staff RNs to eliminate knowledge-related barriers (Hendershot et al., 2016). Although role confusion exists for RNs, increased role transparency, collegial support, and appropriate training could scaffold their role in FP.

Recommendations to Address

Patient-Related Barriers

Patient-level barriers, including poor prognosis and severity of disease, time related to urgency of treatment, age, distress level, gender, sexuality, and HIV-positive history, continue to play a role in FP access and engagement. In exploring ways to improve FP for AYAs with cancer, evidence suggests that

patients are more comfortable discussing challenging aspects of FP with RNs than physicians (King et al., 2008); therefore, RNs are in an ideal position to address patient barriers as they relate to FP. Meanwhile, patient factors, such as being married or engaged (Vadaparampil et al., 2007), having at least one child (Clayton et al., 2008), and initiating the FP conversation (King et al., 2008; Vadaparampil et al., 2007), seem to facilitate RN involvement in FP. In addition, lack of standardized documentation remains problematic in being able to assess whether FP education is actually occurring in patient encounters. Although documentation of FP education before treatment is often required, Quinn et al. (2015) noted that only 26% of providers documented discussions pertaining to infertility risk and 24% documented FP options, leaving a large population of individuals who are likely not receiving such discussions. King et al. (2008) suggested the development of an electronic notification to automatically remind healthcare professionals to discuss FP or generate referrals—a place RNs could scaffold FP-concordant care. EHR reviews provide an opportunity to assess ongoing documentation rates. Patient-related barriers to FP care should also be addressed when ideating solutions. Patient distress, a noted barrier to engaging in FP discussions (Covelli et al., 2019; Murray et al., 2016; Vadaparampil et al., 2007), can be addressed through psychological support that has been shown to reduce fertility-related distress (Skaczkowski et al., 2018) and, therefore, should be incorporated into patients' plans of care.

Recommendations to Address Institutional Barriers

With regards to institutional barriers, time, access to FP centers/referrals and patient educational materials, availability of facility-based FP guidelines, and cost of FP emerged as the most common factors. Time remains a notable barrier to FP (Covelli et al., 2019; Keim-Malpass et al., 2018; King et al., 2008). New institutional and reimbursement structures are needed to allow discussions about fertility risks and options to be deemed billable and reimbursable. Insurance companies also need to improve coverage for cancer-induced FP to remove cost-related barriers for AYAs with cancer. Nurses should ideally be included in pretreatment discussions about FP, as well as be informed about and have the ability to initiate referral processes (Clayton et al., 2008; Covelli et al., 2019; Keim-Malpass et al., 2018). Collaborations with neighboring FP centers are particularly needed to streamline referrals.

KNOWLEDGE TRANSLATION

- Fertility preservation (FP) among adolescents and young adults (AYAs) is not part of routine cancer care, but nurses are well positioned to address this gap by providing support, referrals, and education.
 - Addressing clinician-related, institutional, and patient-related barriers will optimize the nurse's role in meeting FP guidelines among AYAs with cancer, as well as promote patient-centered care.
 - Enhancing the nursing role in FP among AYAs with cancer may improve quality of life for patients and their families.
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Institutional support is needed to create facility-based guidelines and increase access to educational materials and financial resources for RNs who care for AYAs with cancer. Numerous national oncology organizations (e.g., Oncofertility Consortium, Livestrong Foundation) provide accessible national guideline-based decision support tools for providers and educational and financial resources for AYA patients. Examples of successful defined care models that address age, development, and gender-based considerations are outlined by Anazado, Ataman-Millhouse, et al. (2018), and those that address the interprofessional involvement in documentation and psychosocial support are outlined by Anazado, Laws, et al. (2018). Through institutional support, oncology RNs and APRNs can apply their dynamic roles to educate and refer patients to necessary resources.

Conclusion

Although FP is an integral aspect of AYAs' experience with cancer, to date, adherence to practice guidelines is low. The authors' findings show that RNs pose a strong solution to providing guideline-concordant FP care; however, RNs have minimal involvement in FP because of numerous provider-, institutional-, and patient-specific barriers. Addressing these barriers will optimize nurses' role in meeting FP guidelines among AYAs with cancer, as well as promote patient-centered care.

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Journal clubs can help to increase and translate findings to clinical practice, education, administration, and research. Use the following questions to start discussion at your next journal club meeting. Then, take time to recap the discussion and make plans to proceed with suggested strategies.

1. Discuss the current state of fertility preservation for men and premenopausal women with cancer.
2. What are some of the perspectives that inform fertility preservation in men and women?
3. How can oncology nursing improve the implementation of fertility preservation in men and women with cancer?
4. As an oncology nurse, how comfortable are you in having conversations related to fertility preservation with patients and family members?

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