

Contraception: the Need for Expansion of Counsel in Adolescent and Young Adult (AYA) Cancer Care

Olivia Fridgen¹ · Ivana Sehovic² · Meghan L Bowman² · Damon Reed³ · Christina Tamargo² · Susan Vadapampil^{3,4} · Gwendolyn P Quinn^{3,4}

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Abstract Little is known about oncology provider recommendations regarding best practices in contraception use during cancer treatment and through survivorship for adolescent and young adult (AYA) cancer patients. This review examined the literature to identify related studies on contraception recommendations, counseling discussions, and methods of contraception in the AYA oncology population. A literature review was conducted using PubMed, including all peer-reviewed journals with no publication date exclusions. A systematic review of the literature was conducted using combinations of the following phrases or keywords: “oncology OR cancer” AND “contraception, family planning, contraceptive devices, contraceptive agents, intrauterine devices OR IUD, vaccines, spermicidal agents, postcoital, immunologic, family planning, vasectomy, tubal ligation, sterilization” AND “young adult OR adolescent” AND “young adult

AND adolescent”. Reviewers assessed articles using the “Quality Assessment Tool for Quantitative Studies” which considers: (1) selection bias; (2) study design; (3) confounders; (4) blinding; (5) data collection methods; and (6) withdrawals and dropouts. A total of five articles were included and all studies were quantitative. Results showed no consistent recommendations among providers, references to guidelines, or methods of contraceptive types. Provider guidelines for discussions with AYA patients should be expanded to provide comprehensive, consistent, and quality cancer care in the AYA population.

Keywords Adolescent and young adult · Contraception · Cancer · Oncology · Quality of life · Quality of care

Introduction

The National Cancer Institute and the LIVESTRONG Foundation define adolescents and young adults (AYAs) with cancer as those aged 15–39 years [1, 2]. However, other researchers and organizations examine contraception within the context of reproductive age, thus contraception studies may include patients up to the age of 45. AYAs with cancer experience many unique challenges and quality of life (QoL) issues throughout their cancer diagnosis, treatment, and into survivorship including issues with infertility [3, 4], body image dissatisfaction [5], difficulty establishing relationships [5, 6], and other aspects of physical and social functioning [7–9].

Cancer treatments can impact fertility in the AYA population by causing temporary or permanent damage to reproductive organs, sperm, or egg functioning. The likelihood of damage depends on cancer site, treatment, and age of the patient,

✉ Gwendolyn P Quinn
gwen.quinn@moffitt.org

¹ Adolescent and Young Adult Oncology Program, H Lee Moffitt Cancer Center and Research Institute, 12902 Magnolia Dr, FOB1, Tampa, FL 33612, USA

² Health Outcomes and Behavior Program, H Lee Moffitt Cancer Center and Research Institute, 12902 Magnolia Dr, MRC CANCONT, Tampa, FL 33612, USA

³ Adolescent and Young Adult Oncology Program, Sarcoma Oncology Program, H Lee Moffitt Cancer Center and Research Institute, 12902 Magnolia Dr, FOB1, Tampa, FL 33612, USA

⁴ University of South Florida, Morsani College of Medicine University of South Florida, 12901 Bruce B Downs Blvd, Tampa, FL 33612, USA

with younger patients less likely to have permanent damage. Leading US health and professional organizations such as the National Comprehensive Cancer Network [10] (NCCN) and the American Society for Clinical Oncology [11, 12] (ASCO) have established guidelines on fertility and preservation for the AYA population. These recommendations include: discussing the potential impact of treatment on fertility, fertility preservation options, and referrals to reproductive endocrinologists. It is recommended that patients receive this information as early as possible upon diagnosis to allow optimal time for decision-making. These guidelines, as well as education and training on discussing fertility and reproductive health and cancer for AYA, are available for health care professionals. However, there is little information or guidance specific to contraception during active cancer treatment and through survivorship. The World Health Organization's definition of reproductive health includes "the right of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice [13]." With this definition in mind, there is a clear need for provider recommendations and guidelines regarding contraception for AYA cancer patients and survivors.

There are several barriers to the discussion of contraception with AYAs. First, the message of infertility due to cancer treatment may be oversold and patients may assume they are infertile. Second, there is a misperception among providers that cancer patients are too ill to engage in or be interested in sex. AYAs are not asexual simply because of their diagnosis, nor are they unanimously infertile during or after treatment. AYAs with cancer are found to engage in sexual behaviors at similar rates as their cancer-free peers [14]. Further, the AYA population may engage in sexual risk-taking behavior more often than their older, cancer-free peers and may be at a greater risk to use unreliable methods of contraception such as withdrawal, or may not use any form of contraception [15].

Pregnancy risks are substantial for female patients on active treatment, and patients with compromised immune systems are at a higher risk for sexually transmitted infections (STI) and other diseases [14, 16]. Several studies suggest AYA survivors are at a higher risk for unintended pregnancy than the general population since they are often unaware of their fertility status or assume they are infertile [17–21]. AYA patients need counseling not only on the proper and consistent use of contraceptives, but also on the risks and benefits associated with each contraceptive method to make personal and informed decisions [22]. Many cancer treatments pose teratogenic risks to a fetus, and females who conceive during active treatment may be faced with the decision of pregnancy termination. QoL is impacted by a cancer diagnosis but can be exacerbated by unplanned pregnancies, pregnancy termination, or a child born with special needs. One way to prevent these unnecessary stressors is to provide directed contraceptive counseling to AYAs with cancer.

A few studies have identified that sexual health and sexuality were desired discussion and education topics by AYA cancer patients and survivors, yet limited information exists on best practices for these discussions [14, 15, 23]. A recent study identified that women who received directed counseling on reproductive issues had a higher QoL and less regret than those who did not receive counseling prior to initiating cancer treatment [24].

Contraception conversations may be unlikely to happen in a clinic room as providers are focused on cancer treatment plans and outcomes and patients may be uncomfortable initiating questions or unaware of the need to discuss concerns with providers [25, 26]. The discomfort surrounding contraception is exacerbated if family members are present, the provider is of the opposite gender, or the patient is sexually inactive [27, 28].

The objectives of this review were to examine the available literature on contraception in the AYA oncology population and to identify studies related to contraceptive methods and contraception counseling.

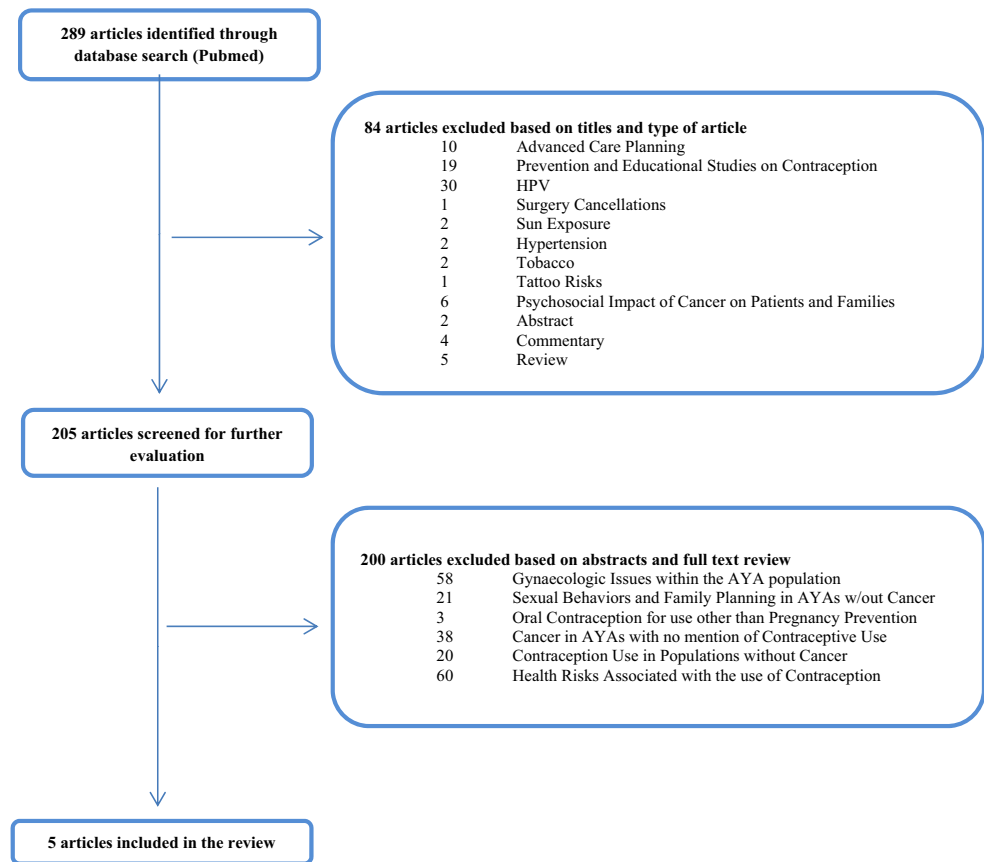
Methods

Search Strategy and Study Selection

A review of available literature was conducted through the PubMed database using PRISMA guidelines. The search included all peer-reviewed journals and publications dates. The MeSH terms used included: "oncology OR cancer" AND "contraception, family planning, contraceptive devices, contraceptive agents, intrauterine devices OR IUD, vaccines, spermocidal agents, postcoital, immunologic, family planning, vasectomy, tubal ligation, sterilization" AND "young adult OR adolescent" AND "young adult AND adolescent." Selection criteria then excluded: oral contraceptive use for reasons other than disease and pregnancy prevention, contraception with any populations other than AYA cancer patients or survivors, studies in any language other than English, and unoriginal research (reviews, commentaries, and abstracts).

A total of 289 articles were identified in PubMed (Fig. 1). Articles were originally filtered by title and type of article, which removed articles exclusively focused on advance care planning ($n=10$), prevention and educational studies on contraception ($n=19$), HPV ($n=30$), surgery cancellations ($n=1$), sun exposure ($n=2$), hypertension ($n=2$), tobacco ($n=2$), tattoo risks ($n=1$) and the psychosocial impact of cancer on patients and families ($n=6$) as well as unoriginal research including abstracts ($n=2$), commentaries ($n=4$), and reviews ($n=5$). Remaining articles were then filtered by abstract and full text to determine subsequent elimination, including articles that spoke only to gynecologic issues within the AYA population ($n=58$), sexual behaviors and family

Fig. 1 Flow diagram illustrating the search strategy for articles included in the review



planning in young people without cancer ($n=21$), oral contraception for use other than pregnancy prevention ($n=3$), cancer in AYAs with no mention of contraception use ($n=35$), contraception usage in populations without cancer ($n=20$), and health risks associated with the use of contraception ($n=60$).

The search was made complete by adding any relevant articles from reference lists included in the original query. A total of 5 articles were included in this review.

Three reviewers assessed each article using the “Quality Assessment Tool for Quantitative Studies” which considers: (1) selection bias; (2) study design; (3) confounders; (4) blinding; (5) data collection methods; and (6) withdrawals and dropouts. Articles were ranked as strong (no weak ratings in any of the six categories), moderate (one allowable weak rating in one of the six categories) or weak (two or more weak ratings in one of the six categories) [29]. Differences or incongruities in scoring between reviewers were discussed until a conclusion was reached. The included articles were all rated in the strong or moderate categories.

Data Synthesis

Table 1 details the extracted data from each article included in the review. Data extracted included authors, evidence criteria, contraception methods, AYA population

definition, study population, cancer type, sample size, study aims, methods, outcomes and measures, and key findings. All authors appraised the articles and confirmed the inclusion of articles in this review. The information included for each article was reviewed by all authors until consensus was reached.

Results

Study Information

The majority of articles included in the review defined AYA as between the ages of 15–45 ($n=4$) while one article defined its population as reproductive age only. The study participants were AYA cancer patients and survivors ($n=4$) and teenage/pediatric oncology providers ($n=1$). All cancer types were included in four articles, while one article focused on non-gynecologic cancers only. Cancer stages included in this review ranged from a cancer diagnosis within the past 5 years ($n=2$) to cancer survivorship without any limitations ($n=2$). Sample sizes for these studies range from 15–1041. All methods of contraception were included in the reviewed articles and all five studies were quantitative.

Table 1 Reviewed Articles

Authors (country)	Evidence criteria	Contraception methods	AYA Definition	Study population	Cancer type	Sample size (M/F, %)	Study aim(s)	Methods	Outcomes	Key findings
Quinn MM, Letourneau JM, Rosen MP (USA)	Quantitative, survey	Barrier, hormonal, tubal ligation, vasectomy, intrauterine device and other	18–40 years of age	AYA cancer survivors	Non-gynecologic cancers	AYA cancer survivors (N = 1,041, 100 % female)	(1) To describe contraceptive methods utilized by young female cancer survivors and (2) determine whether pretreatment fertility counseling decreases unintended pregnancy risk	1041 non-gynecologic cancer survivors, who had resumed menstrual bleeding following treatment and had not undergone surgical sterilization, responded to a survey on their contraceptive methods utilized and history of fertility counseling before treatment began. Subjects were defined at risk of unintended pregnancy if they reported unprotected vaginal intercourse within the last month and did not desire conception	918 women (88 %) received treatment with potential to affect fertility (chemotherapy, radiation or sterilizing surgery). Of 476 women younger than 40 years old who still had menses, 58 % did not want to conceive; of these 275 women, 21 % reported unprotected intercourse in the prior month and were defined at risk of unintended pregnancy. This compared to the 7.3 % risk of unintended pregnancy reported by the National Center for Health Statistics. Increasing age was associated with greater risk of unintended pregnancy (odds ratio 1.07, P = 0.006). The following contraceptive methods were reported: barrier (25.5 %), hormonal (24.5 %), tubal ligation (21.3 %), vasectomy (17.5 %), intrauterine devices (7.2 %), and other (4.0 %). 67 % of women received pretreatment fertility counseling. Counseling prior to treatment did not decrease risk of unintended pregnancy (P = 0.93).	Sexually active cancer survivors are at a threefold increased risk of unintended pregnancy compared to the US population. Contraceptive counseling in this high-risk population is recommended post-treatment
Canada AL, Schover LR, Li Y (USA)	Quantitative, intervention	Cancer-specific concerns related to STDs and contraception	15–25 years of age	AYA cancer patients treated within the past 5 years	All	AYA cancer patients and survivors (N = 2,124, 57.25 % Female)	(1) Develop and test an intervention designed to enhance psychosocial development in adolescents and young adults with cancer	A total of 21 patients, aged 15–25 years, and treated for cancer within the past 5 years, completed the counseling intervention. Patients were adaptively randomized to begin the intervention immediately, or to be placed on a 3-month wait list, after which time, they were reassessed and began the intervention. Questionnaires were completed at baseline, post-treatment, and at 3-month follow-up.	21/24 participants who entered the study, completed the pre-intervention questionnaire(s), both counseling sessions, and at least one follow-up questionnaire. Participant stress levels increased while on the waiting list to begin intervention (P = 0.046). Data gathered from the waitlisted group compared to the intervention group showed improvements including: more knowledge about the effects of cancer on sexuality and fertility (P = 0.040), greater confidence in dating situations (P = 0.004) and less emotional distress (P < 0.001). Gains were maintained through the 3-month follow-up.	Addressing issues of reproductive health in the adolescent/young adult with cancer can and should be offered as a part of comprehensive pediatric cancer care.
Laurence V, Gbolade BA, Morgan SJ, Glaser A (UK)	Quantitative, Survey	Natural methods (none, withdrawal, periodic abstinence), oral contraceptives (oral combined pill, progestin-only pill, emergency contraception), injectable	None specified	Teenage cancer units or pediatric oncology units within the UK	All	Pediatric providers (N = 15, not available)	(1) To determine whether UK cancer units had predetermined contraception policies for their AYA patients	21 respondents were asked to fill out a questionnaire asking whether they had a policy regarding contraception issues for their potentially sexually active teenage patients. 15 responses were collected.	All (100 %) of the 15 respondents stated that they did not have any policies regarding contraception issues for their potentially sexually active teenage patients.	Contraceptive issues need to be highlighted with teenage and young adult patients with cancer as this demands the awareness and education of the oncology teams and collaboration with family planning units.

Table 1 (continued)

Authors (country)	Evidence criteria	Contraception methods	AYA Definition	Study population	Cancer type	Sample size (M/F, %)	Study aim(s)	Methods	Outcomes	Key findings
Patel A, Sreedevi M, Malanati R, Sutaria R, Schoenhage MB, Patel AR, Radeke EK, Zaren HA (USA)	Quantitative, cross-sectional survey	Contraceptives, implant contraceptives, IUDs, barrier methods (diaphragm, cervical cap, vaginal sponge, female condom, male condom, vaginal spermicides) Abstinence, barrier methods (foam, condoms), other	15–44 years of age	AYA patients	All (90 % breast, 10 % other)	AYA patients (N = 20, 100 % female)	The purpose of this study was to pilot a survey instrument and to develop descriptive data about the reproductive goals of reproductive-aged women with cancer	Cross-sectional pilot survey study of 20 women who were diagnosed with various types of cancers at the oncology clinic of Stroger Hospital of Cook County, Chicago, from January–July 2006.	Of the 20 patients whose cases were surveyed, the mean age was 36.6 years and 90 % of the women had breast cancer. 10 % of patients would continue pregnancy, if they became pregnant while receiving treatment. Contraception was used by 55 % of patients (n = 11), of whom 55 % of the women (n = 6) were using abstinence.	The results of this pilot study demonstrate the need for reproductive health counseling in women with cancer; the range of discussion must include fertility interest, contraception, and fertility preservation.
Maslow BL, Morse CB, Schame A, Loren A, Domchek SM, Gracia CR (USA)	Quantitative, cross-sectional survey	All forms of contraception	18–45	AYA patients and survivors within 5 years of a diagnosis	All	AYA patients and survivors (N = 107, 100 % female)	(1) To characterize contraceptive choices in a group of young women recently diagnosed with cancer and identify factors associated with use of effective methods and (2) evaluate the impact of contraceptive counseling by health care professional on contraceptive use	Cross-sectional, survey study of reproductive-aged women at a large tertiary health care system with a recent cancer diagnosis (less than 5 years).	107 women completed the survey. 82 women reported 101 different contraceptive choices. 27 % of all methods used were Tier I/II and 35 % were Tier II/IV. Among women reporting sexual activity after diagnosis (n = 71): 27 % reported using Tier I/II 30 % reported using Tier III/IV 23 % reported abstinence 14 % reported using no-method Factors significantly associated with using Tier I/II included no college degree, intercourse during treatment, and non-breast cancer. Report of contraceptive counseling was positively associated with Tier I/II contraceptive use during cancer treatment.	Reproductive-aged women diagnosed with cancer underutilized Tier I/II contraceptive agents, especially IUDs. Contraceptive counseling by physicians increases contraceptive use, particularly methods most effective at preventing pregnancy.

Study Aims

Two articles described the contraceptive choices of AYA women and determined whether contraception counseling had an impact on overall use and specific higher efficacy contraception use [15, 17]. One study piloted an intervention to increase knowledge surrounding sexual health, contraception, and fertility desires of AYA patients and to promote psychosexual development [30]. Another study determined whether pediatric cancer units in the United Kingdom had developed contraception policies for use with AYA patients [16]. The final article piloted a survey to assess the reproductive goals of AYA women and whether use of contraception aligned with their goals [31].

Contraception Methods

Contraception methods used by AYA cancer patients were varied. Higher education, cancer type, and desire for sex during treatment correlated with usage of more reliable contraception methods, (e.g., long acting reversible contraception [LARC] and oral contraception pill [OCP]). Breast cancer patients were especially unique, as OCP is not recommended for this population. While breast cancer patients used contraception as often as patients with other disease sites, they were more likely to use barrier protection and other Tier III contraceptive methods (considered less reliable than OCP [15]). Several cancer patients in this study believed their treatment had permanently affected their fertility and that contraception was not necessary [15, 31]. Patel et al. reported that 70 % of women were considered fertile post-treatment based on present menses, yet 55 % believed they would never become pregnant due to their treatment [14].

Contraception Counseling

Maslow et al. surveyed 15 pediatric oncology units in the UK about contraception recommendations and knowledge during cancer treatment and identified that 80 % of respondents thought contraception was “very important” during treatment; yet, none had pre-established contraception guidelines for physicians to follow with potentially sexually active AYA patients [15]. Laurence et al. identified that contraceptive counseling by a physician made patients six times more likely to use contraception than patients who received no counseling [16]. Maslow et al. found counseling recommendations for contraception use during treatment, as well as discussing abstinence and safer sex practices, allowed patients to be more confident in relationships, strengthened their communication of sexual desires and preferences, and provided them with a greater knowledge about risks related to unprotected sex. Conversely, Quinn, Letourneau and Rosen identified that 67 % of women who received pre-treatment contraception

counseling stated it had no effect on their contraception decisions made post-treatment [17]. Patel et al. found that 40 % of women made contraceptive selections individually while 60 % include their partner in the decision-making process [31].

Discussion

This review sought to identify available research on contraception methods and counseling for the AYA oncology population. AYA men and women with cancer may wish to defer pregnancy either temporarily or permanently at cancer diagnosis, during therapy or after treatment. There are limited guidelines for providers to manage the contraceptive needs of AYA. The Society for Family Planning (SFP) reviewed available evidence on safety and efficacy of methods of contraception for women diagnosed with cancer, and recommended that “women of childbearing age who are being treated for cancer avoid combined hormonal contraceptive methods (containing estrogen and progestin) when possible because they may further increase the risk of venous thromboembolism.” The SFP further suggested that the copper T380A intrauterine device be considered “the first-line contraceptive option for women with a history of breast cancer.” The SFP also recommended the levonorgestrel-containing intrauterine system (IUS) was preferable for women being treated with tamoxifen for breast cancer. Women who develop anemia may benefit from use of a progestin-containing contraceptive. Additionally, women who develop osteopenia or osteoporosis following chemotherapy should avoid the progestin-only contraceptive injection. The SFP concluded their recommendations with the caveat that additional information was needed on IUS effects and the risk of breast cancer recurrence. Also, it was unknown whether hormonal contraceptives affect the risk of breast cancer among women who have received chest wall, or mantle field radiation. The SFP suggests further research on the safety and effectiveness of IUS for use by immunosuppressed women and whether progestin-only contraceptives affect the risk of fracture among cancer survivors with osteopenia [25].

The NCCN states the following in their guidelines for oncology providers in the care of AYA cancer patients: “Discuss risks of infertility due to cancer and its therapy, the use of fertility preservation, and contraception prior to the start of therapy [32]” yet the types of discussion or acceptable type of contraceptive methods are not included.

The Clinical Oncology Society of Australia Guidelines for AYA with cancer state: “As part of ongoing monitoring of survivors’ reproductive and sexual health, health professionals should provide information about fertility options, sexuality, contraception, breast feeding, relationships and inheritable cancers and refer patients to counseling or support as required [33]”.

While National and International organizations have begun to address this important issue, further consideration is needed for integrating guidelines into clinical care. As demonstrated by the Laurence study in the United Kingdom, no institutions appear to have adapted National guidelines, or developed their own guidelines or recommendations for providers regarding AYA contraception [16].

Contraception efficacy and the adverse effects of each method should be discussed in relation to cancer diagnosis and treatment as some drug interactions may lower contraceptive efficacy. Other factors such as previous health history, including ectopic pregnancies and neutropenia, alter risks and benefits for certain contraceptive methods [22]. The contraceptive choices of AYA patients, specifically the efficacy of the contraception, depend largely on their reproductive goals [15]. For example, LARC and OCP show the most reliability, which is desirable during active treatment, but should be coupled with barrier protection if disease/infection prevention is also necessary [34]. Permanent contraception, such as tubal ligation, would be appropriate to suggest to a patient who does not wish to have any more children [35].

Decisions about contraception in AYA cancer patients and survivors should be made in consultations with their health care provider and also with input from a partner. In Patel et al.'s study, the majority (60 %) of patients jointly made decisions relating to contraception with their partner and suggested that if a partner was present during the medical appointment, they should be included in the discussion. However, if an AYA patient attends a visit with a parent or friend, he or she may be less inclined to initiate the conversation or ask or answer questions concerning contraception. Sexual identity, sexual activity, and overall sexual health are often uncomfortable topics for AYA in particular [36]. Expanded provider guidelines may need to address how to excuse family members and guests at an appointment to discuss contraception with a patient one-on-one. If the patient is a minor, this may present barriers.

As comfort levels rise with fertility preservation and informing patients of risks and benefits, similar mindsets must be achieved with contraception. An important misconception on which to educate patients would be the notion that all cancer treatments render a patient infertile and that contraception is not needed during or after treatment [23]. As fertility and infertility may wane post-treatment, contraception should be used whenever a pregnancy is not desired.

Current provider practices may vary depending on the provider's sensitivity to fertility and reproductive issues. However, it has been well documented that oncology providers do not discuss reproductive issues with patients on a regular basis. Barriers to these discussions include knowledge, attitude, and behaviors about reproductive health and cancer [37–39]. Similar barriers may arise in contraception discussions, since several studies with oncology nurses highlighted

that sexual topics were among the hardest to initiate with patients [40]. Nurses in an oncology setting are in a strategic position to have contraception discussions with AYA patients as they understand the treatment plan set by the physician and have multiple points of patient interaction throughout treatment to address reproductive goals and offer contraception education [23]. Nursing staff may have the finesse required in order to respect confidentiality of the adolescent while delivering appropriate counseling throughout the treatment continuum.

Physician and nurse recommendations may influence a patient's choice of contraception; however, it is imperative the provider understand the patient's short- and long-term reproductive goals to deliver appropriate contraceptive counseling [15, 41]. Contraception discussions should occur not only at initial diagnosis but also post-treatment as needs and desires change throughout a patient's cancer continuum [31]. Patients' reproductive goals during active treatment may differ from goals in survivorship, yet contraception will still play a role. Even if the prevention of pregnancy is not the primary goal, contraception discussions are needed to protect against infection and disease [14, 16, 42, 43]. Due to the variety of available contraceptive methods, reproductive goals, and personal preferences of patients, guidelines must be expanded with the flexibility to address individual needs and preferences for each patient. Providers will likely need support and training on how to discuss these issues.

Recommendations for oncology providers who treat AYA patients should include the following: (1) identify future child-bearing goals; (2) discuss types of contraception and the efficacy of each; (3) include all decision-makers in the contraception conversation, i.e., the partner or spouse; (4) exclude family and friends who are not decision-makers; and (5) dispel the myth that a patient will not be fertile during or after treatment.

Limitations

This study is not without limitations. Only one search engine, PubMed, was used to locate relevant studies. Studies included in this review, although strong and verified through evidence criteria, had small sample sizes and focused mainly on female patients. The research questions in each of the five included studies were not consistent with one another which made trends and comparisons difficult. These studies identified contraceptive uses and preferences of AYA patients and survivors but little, if any, data were collected about preferred methods of contraceptive counseling. Contraception discussions will need to be tailored to patients' specific needs, so guidelines may not be detailed or rigid, posing difficulties in standardizing recommendations. Lastly, all studies focused on contraception for prevention of undesired pregnancies, and disease and infection prevention was not a major focus of any of the studies.

Conclusion

Expanded provider guidelines for discussions about contraception with AYA patients are critical to comprehensive and quality cancer care in this population. While NCCN and ASCO guidelines require that risk of infertility be discussed with all patients at the time of diagnosis, the neighboring topic of contraception lacks equally clear provider practice guidelines. National organizations are urged to expand upon existing guidelines for oncology providers. Additionally, discussions regarding contraceptive methods should occur at multiple points along the cancer care continuum, including during active treatment and through survivorship.

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