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ORIGINAL ARTICLE

Comparing fertility preservation resources and policies between NCCN member and non-member institutions

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Abstract

Purpose The National Comprehensive Cancer Network (NCCN) created guidelines to facilitate implementation of fertility preservation (FP) discussions and referrals for adolescent and young adult patients. We assessed if availability of workplace FP resources and referral policies differed among learners in the Educating Nurses about Reproductive Health in Cancer Healthcare (ENRICH) training program based on NCCN membership.

Methods Learners completed a baseline application, including demographic information and the availability of FP resources and referral policies. Learners were categorized as either NCCN members or non-members and chi-square tests compared resources between the two groups.

Results Learners from NCCN institutions reported the highest rates of established FP referral guidelines ($p < .01$), reproductive endocrinologist and infertility specialist (REI) on staff ($p < .01$), partnerships with REI, educational materials for staff ($p < .05$), and patients ($p < .01$).

Conclusion FP resources and referral policies were highest among learners from NCCN member institutions, but areas for development with fertility issues still exist and learners from non-member institutions may assist their workplaces in improving rates of discussions and referrals based on their ENRICH training.

Practice implications The variation of available resources and referral policies between groups suggests more FP education and training; focusing on implementation programs is needed to make steps towards impactful institutional level resources and policies.

Keywords Fertility · Communication skills · Quality of life · Resources · Education

Introduction

An estimated 70,000 adolescents and young adults (AYA), ages 15–39 [1, 2], are diagnosed with cancer annually in the USA [3]. Infertility can often be a late effect of cancer treatments that varies based on cancer type, site, stage, treatment type, and dose as well as the age and pre-treatment fertility status of the patient [4]. In females, infertility (as well as premature ovarian insufficiency) can occur [5], similarly, males may be temporarily or permanently azoospermic [4]. Fortunately, there are established methods to preserve fertility through assisted reproductive technologies such as oocyte and

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embryo cryopreservation and ovarian transposition for females and sperm banking for males [4]. Receiving information regarding risk of infertility and fertility preservation (FP) options has been shown to improve quality of life and decrease anxiety in AYA oncology patients and survivors [6].

In 2013, the American Society of Clinical Oncology (ASCO) published updated clinical practice guidelines on patients of reproductive age [4]. These guidelines not only highlighted the need for discussions about fertility risk, preservation options, and referrals to specialists, but also extended the responsibility beyond the medical oncologist to include other physician specialties, nurses, and allied health care professionals in the oncology care setting [4]. Despite ASCO guidelines, both provider-reported and medical chart-documented rates of these discussions are low due to barriers such as knowledge, suggesting a need for professional education and training [7–9]. Professional and advocacy organizations such as the National Comprehensive Cancer Network (NCCN) have created AYA guidelines that include fertility considerations to facilitate fertility discussions and FP referrals [10].

The NCCN Member Institutions, which are all National Cancer Institute (NCI) Designated Cancer Centers, contribute to and provide clinical care based on guidelines that are either site or population specific; and care spans the cancer continuum from screening and diagnosis to survivorship and palliative care [11]. NCCN guidelines are developed by expert panels with members from each of the 27 member institutions and NCCN promulgates the clinical care guidelines that are used by 95% of oncology clinicians [10–12]. The AYA Fertility and Endocrine Considerations states "discuss risks for infertility due to cancer and its therapy, the use of fertility preservation, and contraception prior to the start of therapy," "fertility preservation should be an essential part in management of AYA's with cancer," and "initiate referral for fertility preservation clinics within 24 hours for interested patients" as specific guidelines for oncology healthcare providers [10].

Oncology nurses are well positioned to initiate conversations about fertility with AYA patients [4, 13, 14]. ENRICH (Educating Nurses about Reproductive Issues in Cancer Healthcare), a web-based curriculum for building communication skills, was developed to provide oncology nurses with the necessary training to have reproductive health discussions with AYA patients, raise awareness of FP resources, and impact institutional resources and FP policies. Previous reports have detailed the development, training, and outcomes from the ENRICH training program [15, 16]. This study describes the reported availability of FP resources and referral guidelines at the time of entry into the ENRICH training program. Further, we assessed if these resources and guidelines differed based on whether the participating nurse's institution was a NCCN member or non-member institution.

Methods

In brief, the ENRICH web-based curriculum includes eight psychosocial, biological, clinical, and skill-building modules to help oncology nurses communicate timely and relevant fertility information to their AYA patients [15]. While there are many definitions from various organization on the definition of AYA, for the purposes of the training, we used the National Cancer Institute's definition of AYA (ages 15–39) as many are still in reproductive years well into their 30s [1, 2]. Nurses were recruited through nominations by program co-investigators and consultants, conference promotions, emails through nursing professional organizations and nurse education alumni associations, and the Children's Oncology Group newsletter. Eligible nurses included those who were at minimum: a registered nurse (RN), see $\geq$ 5 AYA patients/year, and work in an oncology care setting.

In brief, over the course of 8 weeks, nurses completed a series of six content modules and two skill-building modules comprised of narrated PowerPoint presentations delivered by national experts, readings from the course textbook, case studies, and learning assignments. Training topics included (1) male reproductive health and cancer; (2) female reproductive health and cancer; (3) pediatrics and reproductive health; (4) FP options; (5) sexuality; and (6) alternative family building options. The last two focused on skill building specific to discussion of infertility and FP options, including (7) communication skills training in which a fertility nurse specialist modeled discussions; and (8) practical applications in which a fertility navigator discussed strategies to overcome institutional, system, and financial barriers to FP. Ethical, legal, and psychosocial considerations were infused throughout all modules. Participants completed the course at their own pace within the 8 weeks allotted for the training program; however, they were required to complete the course in sequence and could only move from one module to the next after completing all previous module components. The time commitment was ~ 60–90 min per module. Nurses completing all course requirements received 11 continuing education units.

As part of the ENRICH application and enrollment process, learners completed a baseline application, which included demographic information (ethnicity, race, and sex), education/training, and general practice setting (workplace name, type of practice setting). Additionally, learners provided information about the availability (yes/no) of institutional resources including established FP referral guidelines/procedures, reproductive endocrinologist and infertility specialist (REI) on staff, institutional partnership with an REI, and educational material for staff and for patients. This information was compared to NCCN guidelines (Table 1). Learners' workplace and the NCCN member institution membership directory [17] were used to assign learners to either NCCN member or non-member categories.

Table 1 Comparison of NCCN guidelines to ENRICH application questions

NCCN guideline	ENRICH application question
Fertility preservation should be an essential part in management of AYA's with cancer	Please indicate whether or not the following are available in your workplace about fertility preservation: • Educational material for personnel • Established fertility preservation referral guidelines/procedures • Partnership/contract with reproductive endocrinologist(s) in the area • Reproductive endocrinologist on staff
Discuss risks for infertility due to cancer and its therapy, fertility preservation prior to the start of therapy	Please indicate whether or not the following are available in your workplace about fertility preservation: • Patient education material • Established fertility preservation referral guidelines/procedures

Table 2 Participant demographics by NCCN member and non-member institutions

	Total ($n = 277$)	NCCN membership institutions ($n = 93$)	Non-member institutions ($n = 184$)
Ethnicity			
Hispanic/Latino	16 (6%)	3 (5%)	13 (7%)
Not Hispanic/Latino	255 (92%)	53 (93%)	167 (91%)
Prefer not to respond	6 (2%)	1 (2%)	4 (2%)
Race**			
White	243 (88%)	47 (83%)	32 (89%)
Black/African-American	7 (3%)	3 (5%)	4(2%)
Asian	7 (3%)	0 (0%)	5 (3%)
Other	28 (11%)	8 (15%)	17 (10%)
Gender			
Male	5 (2%)	1 (2%)	4 (2%)
Female	272 (98%)	56 (98%)	180 (98%)
Region			
Northeast	56 (20%)	9 (16%)	37 (20%)
South	90 (33%)	26 (46%)	58 (31%)
Midwest	59 (21%)	17 (30%)	27 (14%)
West	72 (26%)	5 (9%)	62 (34%)
Highest degree			
Associate's	24 (9%)	3 (5%)	17 (9%)
Bachelor's	131 (47%)	26 (46%)	95 (52%)
Graduate	122 (44%)	28 (49%)	72 (39%)
Years in nursing			
1–10	104 (38%)	23 (40%)	82 (45%)
11–20	78 (28%)	13 (23%)	47 (26%)
21–30	42 (15%)	10 (18%)	29 (16%)
31+	53 (19%)	11 (19%)	26 (14%)
Workplace setting			
Academic cancer center	134 (55%)	33 (61%)	81 (51%)
Community cancer center	42 (17%)	9 (17%)	26 (17%)
University hospital	14 (6%)	3 (6%)	10 (6%)
Community hospital	26 (11%)	3 (6%)	21 (13%)
Private practice	10 (4%)	2 (4%)	8 (5%)
Other	18 (7%)	4 (7%)	12 (7%)

**Participants could choose more than one

Chi-square tests compared the availability of FP resources and referral policies, guidelines, or procedures between NCCN membership and non-member institutions.

Results

A total of 277 learners completed the ENRICH course over a 4-year period (2012–2016). The majority were non-Hispanic (92%), White (89%), and female (98%) (Table 2). One third of learners (34%; $n = 93$) were identified as employees of an NCCN member institution. The remaining 66% ($n = 184$) were from non-member institutions (Table 2). One third (38%; $n = 104$) of learners had between 1 and 10 years of experience in nursing and nearly half (47%; $n = 131$) had at least a bachelor's degree. Learners were distributed across US regions: Northeast (20%; $n = 56$), South (33%; $n = 90$), Midwest (21%; $n = 59$), and West (26%; $n = 72$). More than half (55%; $n = 134$), were from academic cancer centers, 17% ($n = 42$) community cancer centers, 6% ($n = 14$) university hospitals, 10% ($n = 27$) community hospitals, 4% ($n = 10$) private practice, and 7% ($n = 18$) other (Table 2).

Compared to non-member institutions, learners from NCCN institutions reported higher rates of established FP referral guidelines/procedures (63% vs 32%; $p < 0.01$), REI on staff (41% vs 25%; $p < 0.01$), educational materials for staff (55% vs 44%; $p = 05$), and patient education materials (68% vs 65%; $p = 01$) (Table 3). Although in the same direction, the effect for partnership with REI was not statistically significant (43% vs 34%; $p = .24$).

Table 3 Comparison of established FP referral policies and resources at NCCN member and non-member institutions

Application item	% (*n*)	*p* value
Established FP referral policies*		.000
NCCN member institutions	63% ($n = 59$)	
Non-member institutions	32% ($n = 59$)	
REI on staff**		.001
NCCN member institutions	41% ($n = 38$)	
Non-member institutions	25% ($n = 45$)	
Partnership with REI		.242
NCCN member institutions	43% ($n = 40$)	
Non-member institutions	34% ($n = 63$)	
Educational materials for staff**		.046
NCCN member institutions	55% ($n = 51$)	
Non-member institutions	44% ($n = 80$)	
Patient education materials		.011
NCCN member institutions	68% ($n = 63$)	
Non-member institutions	65% ($n = 119$)	

*Significant at $p < .01$

**Significant at $p < .05$

Discussion and conclusion

Discussion

Results indicated learners from NCCN institutions had higher rates of FP policies and REIs on staff, which suggests NCCN guidelines may serve to motivate member institutions to adopt policies and provide resources relevant to this important issue. Although NCCN institutions are academic centers and likely have more resources than their non-member counterparts, areas for continued development in regard to addressing fertility issues for AYA patients still exist. One option to increase fertility discussions, FP-related resources, and appropriate referrals for AYA patients as a continuing designation that promotes the pertinent FP institutional level policies and resources that enable the oncology care team to adhere to guidelines proposed by ASCO and NCCN [4, 10]. The Fertile Hope Centers of Excellence program (FHCOE), which awarded cancer centers this designation in recognition of having established policies and resources to address cancer and fertility-related issues, is an example of such distinction, but this program is no longer active; there is a need for future programs to establish and monitor FP programs [18].

While providing important information about existing FP resources and policies in a broad-based sample of oncology care institutions across the US, findings should be considered in light of certain limitations. Unlike meeting specific criterion to attain formal designations, such as FHCOE, specific NCCN guidelines do not necessarily have to be followed by member institutions. Additionally, because the presence or absence of FP resources were self-reported by learners, it is possible they were reported incorrectly.

Conclusion

Not surprisingly, rates of FP resources and referral policies were higher among NCCN membership institutions. These academic facilities have heightened resources and are committed to a standard of care that includes the discussion of risk of future infertility and referral to appropriate reproductive specialist for all AYA cancer patients. These findings support the possible impact of both practice-based guidelines and healthcare provider training as an important approach to ensuring that fertility needs of AYA patients are met, which is a quality of life issue that extends into survivorship.

Practice implications

The variation of available resources and referral policies between NCCN and non-member institutions suggests more

education and training, focusing on implementation of FP programs, is needed to make steps towards impacting institutional level resources and policies [10]. While training and education are important mechanisms to ensuring AYA patients receive important and timely information regarding infertility and FP, this alone is not likely to make long-term changes in an institution. One of components of the ENRICH curriculum includes strategies for implementing FP programs, aiming to empower learners to make improvements and changes within their workplace. A follow-up survey was administered 6 months, 1 year, and every year thereafter following program completion to assess institutional resources and policies as well as individual practice behaviors. Future directions include dissemination of follow-up surveys to evaluate workplace level changes, including FP policies and resources, and individual practice behaviors across all cohorts of ENRICH to compare resources between the two groups pre- and post-course completion.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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