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Documentation of fertility preservation discussions for young adults with cancer: Examining compliance with treatment guidelines

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Abstract

Background—Professional guidelines have been developed to promote discussion between providers and newly diagnosed young adults with cancer about the possibility of cancer treatment-related infertility, but previous research suggests many young adults fail to receive this information. The aim of this study was to examine rates of and factors predictive of oncologists' compliance with national guidelines for discussing potential treatment-related infertility with newly diagnosed young adults seen at an NCI-designated comprehensive cancer center.

Methods—We reviewed data from the electronic medical record for new clinic encounters between medical oncologists and young adults with cancer (ages 18–39) from 2010 to 2012. Data from oncologist discussions of fertility preservation were abstracted, as were patient (age, gender, race, ethnicity, cancer type) and oncologist (gender, graduation year from fellowship) characteristics.

Results—1018 cases were reviewed with 454 patients (M=31.5 years old, 67.8% women) meeting inclusion criteria. Overall, 83% of patients were informed about potential treatment-

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related infertility with patients with breast cancer (85% informed), Hodgkin lymphoma (95% informed), Non-Hodgkin lymphoma (94% informed), leukemia (88% informed) or testicular cancer (100% informed) more likely to be informed than other cancer types (60%–74% informed). There was a significant effect for patient gender (OR=3.57, CI: 1.33, 9.60, $p=0.012$) with females being more likely to be informed than males.

Conclusions—Reported compliance with fertility preservation guidelines was greater than published rates. Higher compliance rates in female patients and in patients with cancers more common among young adults may reflect greater awareness of fertility-related concerns among these patients and their providers.

INTRODUCTION

Every year, approximately 70,000 young adults (ages 18–39) are diagnosed with cancer. These young adults immediately face multiple challenges that will affect their health-related quality of life, including the potential for their disease and/or treatment to affect their fertility. Yet research has demonstrated that few of these individuals are provided with information about the fertility-impairing potential of their treatment(s)^{1, 2} and this can be a common source of regret among young adult survivors of cancer.³

Providing information at the time of diagnosis about risk of infertility and the availability of existing interventions to maintain biological reproductive potential is critical to assist patients in making decisions about fertility preservation⁴. The American Society for Reproductive Medicine (ASRM),⁵ American Society of Clinical Oncology (ASCO),^{6, 7} and the National Comprehensive Cancer Network (NCCN),⁸ have each established national guidelines to enhance provider adherence and facilitate patient and provider discussions about fertility preservation options. Guidelines recommend oncologists should inform all patients about the potential effects of their disease and/or treatment on their fertility. Patients who ask for information about fertility preservation should receive it, as well as a referral to a reproductive specialist when appropriate.

Previous studies suggest oncologists face many communication challenges when discussing fertility preservation with patients. Challenges are related to physician attributes (e.g., knowledge barriers), patient attributes (e.g., cultural or religious prohibitions for assisted reproduction), and healthcare factors (e.g., time demands).⁹ Findings from these studies suggest oncologists do not often refer their patients to fertility preservation specialists with <50% of providers following recommended ASRP/ASCO/NCCN guidelines.⁹ Oncologist characteristics have also been related to referrals such that male and older oncologists are less likely to provide referrals.^{9, 10} Educational materials exist yet are rarely used (<25% of US oncologists were either aware of or distributed educational materials to their patients).¹⁰ Furthermore, research suggests some providers are uncomfortable engaging in these discussions, which may be due to the belief that fertility preservation adds more stress to the situation or is inappropriate for patients with a poor prognosis.¹¹ Other providers may lack sufficient knowledge to address questions about fertility preservation options.⁹

This study examines provider adherence to guidelines for discussing fertility preservation as documented in the medical record within a single institution for both men and women across

multiple years. Although the ASCO guidelines to foster greater patient and provider communication about potential treatment-related infertility were published in 2006, very little has been published on clinician or patient level data from the medical record in the subsequent years.¹² To address this scientific gap, we sought to examine compliance with treatment guidelines at an NCI-designated comprehensive cancer center, the Robert H. Lurie Comprehensive Cancer Center (RHLCCC) of Northwestern University. Based on the published self-report data of providers' attitudes and practices regarding fertility preservation discussions: 1) It is hypothesized that the RHLCCC's medical oncologists will be more adherent to fertility preservation guidelines (>50%); and 2) It is hypothesized that a higher rate of fertility preservation discussions will be initiated by the RHLCCC's female oncologists or when patients are diagnosed at a younger age.

METHODS

Patients and Procedures

This work was conducted in compliance with the Scientific Review Committee of the RHLCCC and the Northwestern University Institutional Review Board. Data were abstracted from the electronic medical record (EMR) using a query of the Northwestern Clinical Enterprise Data Warehouse (EDW). The EDW is a joint initiative across the Northwestern University Feinberg School of Medicine, Northwestern Medical Group and Northwestern Memorial HealthCare Corporation and serves as a single, comprehensive, and integrated repository of all clinical and research data sources on the campus. We reviewed all new clinic encounters between medical oncologists and young adult cancer patients from January 1, 2010 to December 31, 2012. Beginning in March of 2010, a full-time fertility preservation patient navigator was employed. In 2006, the EMR was programmed to include a "stop gap" screen to log fertility preservation discussions between medical oncologists and cancer patients aged 45 and younger during new office visits, with the exception of neuro-oncology. Medical oncologists were required to indicate if the patient was informed about the impact their treatment may have on fertility (yes, no, or not applicable), inquire if the patient was interested in fertility preservation (yes or no), and provide a fertility preservation consult referral if the patient was interested. For encounters where oncologists used a "not applicable" response, we conducted a chart review to identify the most probable reasons for oncologist determination of non-applicability, including a review of social and medical histories, cancer stage, treatment plan, and documented discussions between the patient and oncologist.

Patient encounters were eligible if they were from patients between the ages of 18 and 39^{13, 14} who had a histologically confirmed new diagnosis of a primary cancer and had not yet begun chemotherapy. Any cancer stage was eligible. Patient encounters were not eligible if they were from patients being seen for a second opinion only; with a diagnosis of benign neoplasms, neoplasms of uncertain behavior or neoplasms of an unspecified nature; who had a cancer diagnosis and/or treatments prior to 2010; with a history of recurrent cancer or a second primary cancer; with prior fertility-threatening surgery or radiation; or with an infertility diagnosis or fertility treatments prior to cancer diagnosis.

Measures

We obtained patient characteristics from the EMR including gender, age at first medical oncology visit, partner status, race, ethnicity, cancer type, cancer stage, and ECOG performance status.¹⁵ Medical oncologists' specialty (gynecologic oncology, hematology/oncology) was obtained from the EMR, but additional demographic characteristics (gender and year oncology fellowship was completed) were obtained from a review of the physician biographical section of the Northwestern University Feinberg School of Medicine faculty profiles website.

Statistical Analysis

A patient encounter was classified as "adherent to guidelines" if the medical record reported the patient had been informed about the impact treatment may have on fertility. We estimated the rate of adherence with 95% confidence intervals. Among patients who were informed about the effect treatment may have on their fertility, the proportion interested in fertility preservation and the proportion referred for fertility preservation consultations were also estimated.

We used bivariate logistic models to compare patient and oncologist characteristics between encounters in which guidelines were met versus not met. Since patients were clustered within oncologists (n=36), mixed effects models with a random effect for oncologist were used for more robust statistical comparisons. The mixed model included all fixed effects of interest: encounter year, patient age, patient gender, cancer type, cancer stage, patient race/ethnicity, oncologist gender, oncologist's subspecialty, and year oncology fellowship was completed.

RESULTS

Data retrieved from the EDW included 1018 new encounters with young adults seen during the three year period from 2010 to 2012. Individual chart review to confirm eligibility resulted in 527 cases being excluded. These cases were excluded for the following reasons: 205 patients had a cancer diagnosis and/or cancer treatments prior to 2010, 106 patients were being seen for a second opinion only, 123 patients had initiated treatment at an outside institution and were transferring their care to the RHLCCC, 26 patients had multiple primaries, 33 patients had experienced a recurrence, 30 patients had a history of infertility or fertility treatment prior to their cancer diagnosis, and 4 patients did not have an eligible cancer diagnosis. In addition, since neuro-oncology and surgical oncology encounters did not generate the automated fertility preservation questions, encounters for 36 patients seen in neuro-oncology and 1 seen in surgical oncology were also excluded, leaving 454 analyzable encounters.

Patient and oncologist characteristics for the 454 included encounters are presented in Table 1. The most common cancers affecting young adults in this patient population were breast, Hodgkin lymphoma, non-Hodgkin lymphoma, testicular, and leukemia. Cancer types represented by this sample were generally consistent with SEER data.¹⁶ Based on oncologists' responses to the EMR questions about potential treatment-related infertility,

over half of the patients were informed of the effect treatment may have on their fertility (275/431 = 63.8%, 95% CI: 59.1% – 68.4%). When examined by year, the rate was highest in 2012: 2010 = 62.2%, 2011 = 58.6%, 2012 = 70.6%; however this finding was not significant ($p=0.136$). Of those who were informed, 56% were interested in fertility preservation and 77% of those interested were referred to a specialist (Table 2).

Of the 114 encounters (26.4% of all encounters in the final sample) where oncologists documented a “not applicable” response for informing their patients about the potential impact of treatment on their fertility, the probable “not applicable” reasons are listed in Table 2. Patients for whom chemotherapy was not indicated were coded as “probably adherent” as were those who had already received fertility preservation recommendations, were currently pregnant, or not interested in fertility preservation. Patients with HIV or metastatic disease and those with missing or unclear justification of the “not applicable” response were coded as “probably not adherent.” Patients who declined treatment and those for whom treatment was not indicated or plan was undecided were excluded from the remaining analyses. After this recoding, the adherence rate improves (336/404 = 83.2%, 95% CI: 79.2% – 86.7%), with some of the more common cancers among young adults demonstrating the highest adherence rates (breast cancer, 85%; leukemia, 88%; Non-Hodgkin’s lymphoma, 94%; Hodgkin’s lymphoma, 95%; and testicular cancer, 100%).

When adherence was examined at the bivariate level (Table 3) and after accounting for clustering within oncologist, several characteristics were associated with a greater likelihood of being informed of the potential effect treatment would have on fertility. For patients, being of a younger age at the first medical oncology visit ($P=.019$), being White ($P=.042$), being female ($P=.005$), and having an earlier stage of cancer ($P=.022$) were associated with being informed by their oncologist of the impact treatment might have on their fertility. Female oncologists were equally likely as their male counterparts to communicate with patients about the impact their treatment might have on their fertility ($P=0.418$).

Finally, in a mixed effects model including all variables and adjusting for clustering within oncologists, only patient gender remained significant (Table 4). Female patients were more likely to be informed by their physician of the potential impact of treatment on their fertility compared to male patients (OR=3.6; CI: 1.3, 9.6; $P=0.012$). Significant bivariate relationships between adherence and patient age at first medical oncology visit or between adherence and being a White patient were no longer significant in the mixed effects model but revealed trends ($P=.069$ and $P=.052$, respectively).

DISCUSSION

This study describes the degree of compliance with national clinical guidelines for discussing treatment-related infertility with newly diagnosed young adults seen at an NCI-designated Comprehensive Cancer Center over multiple years. As previously noted, some of the most common barriers to fertility preservation discussions are time demands and lack of information. In an environment with targeted resources such as a full-time fertility preservation patient navigator, these barriers should be less likely to affect patient care. The navigator is able to easily schedule patients at a moment’s notice within either the

reproductive endocrinology office for female patients or the reproductive urology office for male patients to discuss and participate in fertility preservation options like sperm banking, TESE, testicular tissue banking, egg or embryo banking, ovarian tissue banking, surgical placement of ovaries and hormonal management. Despite these strengths, our data yielded mixed findings.

We found support for our hypothesis that compliance with national fertility preservation guidelines at the RHLCCC would exceed 50%. That said, initial compliance rates from our sample were suboptimal at 63.8% (i.e., oncologists indicated “yes” they had informed patients of the potential impact of treatment on their fertility). When the probable “not applicable” encounters were recoded, compliance rates were substantially higher (83.2%). This represents a wide discrepancy in compliance rates and probably suggests a “best case” and “worst case” scenario. Although oncologists rarely provided justification for using “not applicable” within the stop gap question, our chart abstraction approach allowed our research team to identify probable reasons for the “not applicable” responses. This revealed a number of cases where oncologists had indeed informed patients about the potential impact of treatment on their fertility and initiated a discussion about options to preserve their fertility. It also highlighted cases when the treatment plan had not yet been determined or did not involve gonadotoxic chemotherapy treatment. However, there were a minority of cases (4%) where there were no clear clinical or patient-driven reasons why the “not applicable” response was used. Altogether, variability in potential reasons for oncologists’ use of the “not applicable” response underscored the complex nature of this decision process for young adults with cancer.

Our hypothesis that female oncologists would have a higher rate of compliance was not supported. After accounting for the influence of patient and provider characteristics, our mixed effects model demonstrated that female oncologists were as likely as male oncologists to inform patients about the potential of treatment-related infertility. In contrast, there was support for our hypothesis regarding patient age as this variable demonstrated a trend in our mixed effects model. Younger patients were slightly more likely to have been informed of the effect of treatment on their fertility than older patients ($p=.069$). Although this finding was independent of gender, oncologists may have perceived that older women were more likely to have greater parity or be content with their family size.

Although no specific hypotheses were advanced, there was a significant finding for patient gender and a trend for race. Female patients were more than three times as likely as their male counterparts to be informed about a potential loss of fertility. Given the varied options for fertility preservation for women and the potential impact any fertility preservation procedures might have on treatment initiation, it is encouraging that these discussions are prioritized for female patients during the initial medical oncology encounter. Although the relative frequency of communication about potential infertility is less among young males, all patients with testicular cancer in this sample were informed of the potential impact of treatment on their fertility. Similarly, the baseline rate of adherence to discussions of potential treatment related infertility was high among several of the most common cancers affecting young adults. For example, patients with breast cancer, leukemia, or Hodgkin or non-Hodgkin lymphoma were also more likely to be informed about a potential loss of

fertility. Given the increased awareness of potential infertility among patients with breast or testicular cancer, as well as for patients with lymphoma,^{1, 17–20} this is not surprising and may reflect clinic-specific practices among medical oncologists. Oncology providers at RHLCCC specialize in specific cancer diseases and those providers specializing in aforementioned cancer types see more young adult patients and theoretically are more comfortable discussing and referring patients for fertility preservation consults. In addition, White patients were twice as likely as non-White patients to be informed of the potential effect of treatment on their fertility. It is not clear why this finding emerged, but it is possible race may be assumed to be associated with socio-economic status and oncologists may be disinclined to refer patients of lower socio-economic status for fertility preservation discussions.²¹ Fertility preservation options are often costly and cost-prohibitive for patients with limited financial resources.²²

This study has limitations. First, as already noted, the data abstracted from the EMR were an underestimate of true compliance rates and the “not applicable” responses were apparently used to indicate a range of responses that suggested both adherence and non-adherence. This has obvious implications for conclusions about the “upper bound” of adherence rates by oncologists in our sample. A related concern is that data were abstracted from the EMR for only the patients’ first medical oncology visit since this was when the medical oncologists would have responded to the stop gap question about fertility preservation options. For a subset of patients, their disease stage and treatment plan were unknown at that time, making it difficult for our study team to determine if those not applicable responses were suggestive of adherence or non-adherence. Second, not all oncologists use these questions to document their discussions with young adults about potential treatment-related infertility. For example, despite the fact that central nervous system tumors are one of the more prevalent cancer types among young adults, neuro-oncology does not currently have these questions programmed into the EMR for their new patient encounters. Third, the study was conducted at a comprehensive cancer center with dedicated resources to support decision-making about fertility preservation and so results may not generalize to other institutions. However, most institutions do not even collect these data or know what their baseline compliance rate is or should be.² This underscores the unique and important aspect of this research despite these limitations.

Given the potential for a cancer diagnosis and subsequent treatments to affect fertility, it is important for newly diagnosed young adults with cancer to receive appropriate information from their oncologists early enough in their care to maximize their options to preserve their fertility, if they choose to do so. Comprehensive Cancer Centers and Fertile Hope Centers of Excellence often have institutional resources to help foster these discussions, but additional work is needed to ensure these discussions occur and patients clearly understand their options. This work could be advanced through a few different strategies. For example, qualitative research approaches would be useful to better understand patient and provider barriers and facilitators of fertility preservation decision-making.^{23, 24} In turn, this could guide more effective use of the EMR to increase guideline adherence and improve health services delivery. Variability in institutional resources and policies and the evolving information about fertility preservation options pose challenges to implementing best practices.^{4, 25} Eighty-five percent of young adult patients are not treated in large academic

institutions or cancer centers but in a variety of community-based settings and small oncology group practices,²⁶ and these practices often have few resources to support patients who are confronted with treatment that might impair their fertility. As such, it is possible the rate of adherence to fertility preservation guidelines at non-academic institutions or smaller cancer centers is much lower than reported in the current study. The development and testing of fertility preservation decision-making tools through randomized controlled trials may be a beneficial future direction. Improving provider adherence to fertility preservation guidelines is a meaningful first step to provision of family building information and fertility preservation options.

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Table 1

Patient (N=454) and Provider (N=36) Characteristics from Eligible Encounters

Patient Characteristics		
	Mean (SD)	Median (Range)
Age at first Medical Oncology visit	31.5 (5.3)	32 (18 – 39)
	N	%
Marital status at time of data extraction (n=5 missing)		
Divorced	9	2.0
Partnered	13	2.9
Separated	1	0.2
Married	193	43.0
Single	255	50.1
Other	6	1.3
Unknown	2	0.4
Gender		
Female	308	67.8
Male	146	32.2
Race (n=14 missing)		
American Indian or Alaska Native	4	0.9
Asian	22	5.0
Black or African American	52	11.8
Native Hawaiian or Other Pacific Islander	1	0.2
White	264	60.0
Other	26	5.9
Declined	66	15.0
Unknown	5	1.1
Ethnicity (n=20 missing)		
Declined	68	15.7
Hispanic or Latino	41	9.4
Not Hispanic or Latino	325	74.9
Cancer type (top 10 are listed)		
Breast cancer	125	27.5
Hodgkin lymphoma	47	10.4
Non-Hodgkin lymphoma	38	8.4
Testicular cancer	29	6.4
Leukemia	26	5.7
Colorectal cancer	22	4.8
Cervical cancer	18	4.0
Cervical cancer <i>in situ</i>	16	3.5
Soft tissue sarcoma	16	3.5
Ovarian cancer	14	3.1
Cancer Stage		

Patient Characteristics		
	Mean (SD)	Median (Range)
0	29	6.4
1	47	10.4
2	72	15.9
3	32	7.0
4	24	5.3
Unknown/not applicable/missing	250	55.1
Performance status (n=255 missing)		
0=Fully active, able to carry on all pre-disease performance without restriction	162	81.4
1=Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work	33	16.6
2=Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours	3	1.5
3=Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours	1	0.5
Provider Characteristics – by provider (n=36)		
	Mean (SD)	Median (Range)
Provider Oncology Fellowship Year Completed (n=10 missing)	1997 (12)	2001 (1979 – 2012)
Number of study patients per provider	12.6 (11.9)	10 (1 – 52)
Provider Gender	N	%
Female	21	58.3
Male	15	41.7
Oncologic Specialty		
Gynecologic Oncology	7	19.4
Hematology/Oncology	29	80.6

Table 2

Frequency Responses to Fertility Preservation Information Questions

Has patient been informed of impact on fertility? (n=23 missing)	N	%
Yes	275	63.8
No	42	9.7
Not applicable	114	26.4
<i>treatment not indicated or treatment plan undecided¹</i>	25	5.8
<i>patient declined treatment¹</i>	2	0.5
<i>chemotherapy not indicated²</i>	23	5.3
<i>patient interested in fertility preservation, already met with fertility preservation specialist, informed of potential treatment impact on fertility, or had provider recommend a fertility-sparing treatment²</i>	28	6.5
<i>patient currently pregnant or not interested in fertility preservation²</i>	10	2.3
<i>patient with metastatic disease or HIV positive³</i>	8	1.9
<i>missing or unclear justification³</i>	18	4.2
If yes, is patient interested in fertility preservation? (n=22 missing)		
Yes	142	56.1
No	111	43.9
If yes, patient referred for fertility preservation consult?		
Yes	110	77.5
No [*]	32	22.1

* Of the 32 patients who did not have a referral listed in the fertility preservation stop gap question field, 23 of them had a documented visit with a fertility preservation navigator and/or a fertility preservation specialist.

¹ Exclude from analysis

² Code as adherent

³ Code as non-adherent

Table 3

Bivariate Associations between Clinical or Demographic Variables and Adherence *

	No (n=68)	Yes (n=336)	% adherent	p-value [#]
Age at first visit	33.3 (4.7)	31.2 (5.5)		0.019
Female	38 (56%)	235 (70%)	F: 86% M: 77%	0.005
White	30 (44%)	201 (60%)	87%	0.042
Black	10 (15%)	40 (12%)	80%	0.432
Hispanic	8 (12%)	29 (9%)	78%	0.253
Breast cancer	16 (24%)	92 (27%)	85%	0.132
Hodgkin's	2 (3%)	42 (12%)	95%	0.410
Non-Hodgkin's	2 (3%)	33 (10%)	94%	0.323
Testicular cancer	0	28 (8%)	100%	NA
Leukemia	3 (4%)	21 (6%)	88%	0.800
Colorectal	8 (12%)	12 (4%)	60%	0.801
All other cancers	37 (54%)	108 (32%)	74%	0.002
Stage (n=213 missing or NA)				0.022
0	2 (8%)	26 (16%)	93%	
1	1 (4%)	45 (27%)	98%	
2	6 (24%)	57 (34%)	90%	
3	7 (28%)	23 (14%)	77%	
4	9 (36%)	15 (9%)	62%	
Female provider	26 (38%)	129 (38%)	F: 83% M: 83%	0.418
Provider fellowship year	1995.7 (8.8)	1994.7 (11.3)		0.912

[#] P-value from mixed model accounting for clustering within physician

* adherence outcome after recoding Not Applicable responses

Table 4Mixed Effects Model Associations among Clinical or Demographic Variables and Adherence^{*}

	Odds Ratio	95% CI	p-value
Year of visit, 2010 vs 2012	0.71	0.30, 1.68	0.433
Year of visit, 2011 vs 2012	0.61	0.26, 1.44	0.256
Age at first visit, per year	0.94	0.87, 1.00	0.069
Female versus Male	3.57	1.33, 9.60	0.012
White vs non-White	2.06	0.99, 4.26	0.052
Black vs non-Black	0.98	0.36, 2.68	0.966
Hispanic vs non-Hispanic	0.69	0.24, 1.98	0.484
Breast cancer vs all other [#]	2.84	0.64, 12.60	0.168
Hodgkin's vs all other [#]	3.30	0.40, 27.46	0.266
Non-Hodgkin's vs all other [#]	5.43	0.57, 51.39	0.139
Leukemia vs all other [#]	2.84	0.27, 29.64	0.377
Colorectal vs all other [#]	1.03	0.23, 4.68	0.967
Female provider vs Male	0.96	0.16, 5.88	0.967
Provider fellowship year, per year	1.02	0.94, 1.11	0.596

^{*} adherence outcome = adherence after recoding Not Applicable responses

[#] all other includes testicular cancer here because 100% adherence rate interferes with model convergence