

Cancer and Fertility Program Improves Patient Satisfaction With Information Received

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A B S T R A C T

Purpose

A cancer and fertility program was established at a large cancer center to support clinicians in discussing treatment-related fertility risks and fertility preservation (FP) options with patients and in referring patients to reproductive specialists. The program provides resources, clinician education, and fertility clinical nurse specialist consultation. This study evaluated the program's impact on patient satisfaction with information received.

Patients and Methods

Retrospective cross-sectional surveys assessed satisfaction before (cohort 1 [C1]) and after (cohort 2 [C2]) program initiation. Questionnaires were investigator-designed, gender-specific, and anonymous.

Results

Most C1 (150 males, 271 females) and C2 (120 males, 320 females) respondents were 2 years postdiagnosis; the most frequently reported cancers were testicular, breast, and lymphoma. A significant difference in satisfaction with the amount of information received was seen between C1 and C2. For males, satisfaction with information on fertility risks was high in both cohorts but significantly greater in C2 for information on sperm banking ($\chi^2 = 9.3$, $P = .01$) and finding a sperm bank ($\chi^2 = 13.3$, $P = .001$). For females, satisfaction with information was significantly greater in C2 for information on fertility risks ($\chi^2 = 62.1$, $P < .001$), FP options ($\chi^2 = 71.9$, $P < .001$), help with decision making ($\chi^2 = 80.2$, $P < .001$), and finding a reproductive endocrinologist ($\chi^2 = 60.5$, $P < .001$). Among patients who received and read information materials, 96% of males and 99% of females found them helpful. Among C2 females, fertility clinical nurse specialist consultation was associated with significantly greater satisfaction with information on FP options ($\chi^2 = 11.2$, $P = .004$), help with decision making ($\chi^2 = 10.4$, $P = .006$), and finding a reproductive endocrinologist ($\chi^2 = 22.6$, $P < .001$), with 10% reporting lack of knowledge as a reason for not pursuing FP.

Conclusion

Improvements in patient satisfaction with information received demonstrate the potential for fertility programs in cancer care settings to improve the quality of clinician-patient discussions about fertility.

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INTRODUCTION

Each year, > 131,000 young people (aged 20-44 years) in the United States are diagnosed with cancer,¹ and many receive treatment that puts them at risk for infertility. Reproductive concerns can be considerable^{2,3} and may negatively affect quality of life⁴ and contribute to depression.⁵

Advances in reproductive medicine enable patients with cancer to preserve fertility before treatment, most commonly through sperm banking and egg or embryo cryopreservation. Professional guidelines from organizations such as

ASCO delineate the responsibility of health care providers to inform patients of potential risks to fertility as a result of treatment, discuss fertility preservation (FP) options, and refer interested patients to appropriate reproductive specialists.⁶⁻¹⁰ Nevertheless, oncology clinicians face a number of barriers to having these discussions, including a lack of knowledge, inadequate time in busy clinics, insufficient resources, and concerns about delaying treatment.¹¹ Although literature has emerged describing services and resources to help oncology clinicians better address fertility issues with patients and adhere to guidelines,¹²⁻¹⁸

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measurement of their success in integrating this into practice is challenging.

About 9,000 new patients begin treatment annually at Memorial Sloan Kettering Cancer Center (MSK), a large urban National Cancer Institute–designated comprehensive cancer center. Almost 1,300 patients are 18 to 45 years of age, and one half receive treatment that may put them at risk for infertility. In recognition of the lack of fertility-related services or resources available for these patients, MSK established the Cancer and Fertility Program in 2009 to support clinicians in providing information to patients about FP before treatment and about family building after treatment. The program is led by a fertility clinical nurse specialist (FCNS) and is built around five elements (Table 1). These include resources for patients (eg, written educational material, access to financial assistance), resources for clinicians (eg, intranet site with need-to-know information, a network of reproductive specialists for patient referrals, a clearly defined referral process), and ongoing clinician education. In addition, MSK clinicians can offer any interested patient (regardless of

age, diagnosis, treatment, or stage of disease) an FCNS consultation for education and counseling, help with decision making, and facilitation of referrals and care coordination as needed. Information about the program was disseminated to clinicians throughout the organization to help them to incorporate fertility discussions into their practice. Although some clinicians have long discussed fertility with patients (eg, urology and gynecology services), for others, this was a change in practice.

One metric used to evaluate the effectiveness of the Cancer and Fertility Program is monitoring the number of patients who receive an FCNS consultation (referral to an FCNS is initiated by a clinician). Increasing numbers of patients have been referred each year (from 79 in 2009 to 429 in 2015); since the inception of the program > 2,000 patients received an FCNS consultation. This data suggests that clinicians are increasingly discussing fertility with patients and referring those who request more information.

Patient satisfaction with information received was identified as another metric of the program’s effectiveness on the basis of the concept of patient centeredness, which is defined by the Institute of Medicine and the National Quality Forum as the delivery of care that is respectful of patient and family preferences, values, and cultures and that engages patients and families in making decisions about their care.¹⁹ This has particular relevance for young patients who must make decisions about FP before cancer treatment.

To evaluate patient satisfaction with fertility discussions we compared satisfaction with the amount of fertility-related information received between patients who started cancer treatment before and patients who started after the Cancer and Fertility Program was established. We also compared satisfaction with the amount of fertility-related information received between female patients who had FCNS counseling and those who did not. Finally, we described patient-perceived helpfulness of the written educational information about cancer and fertility developed by the Cancer and Fertility Program.

Table 1. Description of the Memorial Sloan Kettering Cancer Center Cancer and Fertility Program

Core Element	Implementation
Resources for patients	Written educational material for male and female patients on fertility risks, FP options, and family-building options; provided to interested patients Internet site with written and videotaped information and links to additional resources Access to financial assistance programs
Resources for clinicians	Network of local reproductive specialists for referral Clearly defined referral process with electronic resources Referral to outside reproductive specialist Males: provided with a list of local sperm banks and instructed to select one and call to schedule an appointment Females: provided with a list of fertility centers and instructed to select one and call to schedule an appointment; referral may be initiated by the oncology clinician Referral to the MSK FCNS for more detailed information and to coordinate referrals Intranet site with information and links to additional resources accessible at all MSK locations as needed
Education of clinicians	Annual didactic presentations incorporated into orientation for all incoming medical oncology, breast surgical, neuro-oncology, and pediatric oncology fellows Ongoing presentations to nurses and other health care providers throughout the year
Consult service	FCNS available for patient consultations before, during, or after treatment to provide education and counseling and to facilitate referrals and coordinate care as needed
Clinical research and quality improvement	Multiple collaborative research studies among clinicians of various disciplines Service-specific initiatives to improve practice

Abbreviations: FCNS, fertility clinical nurse specialist; FP, fertility preservation; MSK, Memorial Sloan Kettering Cancer Center.

PATIENTS AND METHODS

Study Design

Anonymous retrospective cross-sectional surveys were administered at two time points: in 2009 to patients who started cancer treatment in the year before program initiation (cohort 1 [C1]) and in 2013 to patients who started cancer treatment between 2010 and 2012 (cohort 2 [C2]). The study was approved as exempt research by the MSK institutional review board.

Eligibility Criteria

Patients were eligible to participate if they were 18 to 45 years of age at the start of treatment, had a cancer diagnosis, and received treatment associated with a risk of infertility, which was defined for this study as treatment with any systemic chemotherapy, endocrine therapy for female patients with breast cancer, pelvic radiotherapy, and/or pelvic surgery with a potential impact on reproduction. Patients had to be English-speaking US residents with a current postal or e-mail address.

Instrument

The instrument was an investigator-designed, gender-specific, self-report questionnaire, with items based on relevant literature^{3,20} and

multidisciplinary clinical expertise. Table 2 lists questions and response options about satisfaction with the amount of information received on various fertility-related topics and perceived helpfulness of written educational information about fertility. Items addressing satisfaction with information demonstrated adequate internal consistency (Cronbach α , .92 [females] and .87 [males]). To evaluate the impact of FCNS consultation for females in whom FP is a more-complicated process than for males, C2 female participants were asked whether they received an FCNS referral. Questionnaires were pilot tested with approximately 10 patients of each gender who met eligibility criteria and then refined on the basis of their comments. Questionnaires were available in paper-and-pencil format and on SurveyMonkey, a Web-based survey tool with secure sockets layer encryption. No patient identifiers were included to ensure anonymity.

Procedure

Eligible patients were identified by reviewing a hospital database of new patients within the specified years (C1: 7/1/2007-6/30/2008; C2: 1/1/2010-12/31/2012). All eligible patients were invited to participate. Invitations were sent to C1 through postal mail. To ensure representation of common young adult diagnoses (eg, testicular, breast, lymphoma, colorectal, sarcoma), eligible patients who started treatment within 3 years before the initiation of the MSK Cancer and Fertility Program and were not mailed a survey were approached in the clinic if they had a scheduled visit during a defined 1-month period of data collection. Invitations were sent to C2 through e-mail or postal mail. Participant’s submission of the questionnaire implied consent.

Statistical Analysis

Descriptive statistics were used to characterize the data. We used χ^2 and *t* tests to compare cohort characteristics for males and females and to compare satisfaction responses between cohorts, and between female C2 respondents who met with the FCNS and those who did not.

Among C2 respondents, descriptive statistics evaluated perceived helpfulness of patient education material. Patients who reported that they were not interested in receiving information about a specific topic were excluded from the satisfaction analysis for that topic. Data were analyzed with SPSS software (version 22, IBM, SPSS, Chicago, IL).

RESULTS

Response Rate

C1 comprised 150 males and 271 females; C2 comprised 120 males and 320 females. Response rates varied by data collection method, with a higher rate in C1 if distributed in clinic rather than by postal mail (97% *v* 36% for males; 88% *v* 38% for females) and a higher rate in C2 if sent by e-mail rather than by postal mail (25% *v* 15% for males; 32% *v* 24% for females). The overall response rate was 46% for C1 and 27% for C2. Because surveys were anonymous, statistical differences between responders and nonresponders could not be calculated. Review of the data indicated that among

Table 2. Select Survey Questions

Questions related to patient satisfaction with information received		
Topic	Were You Satisfied With the Amount of Information You Received	
	Males	Females
Treatment-related fertility risks	...about the effect of cancer treatment on your fertility (the ability to have a child from your own sperm)?	...about the effect of cancer treatment on your fertility (the ability to get pregnant naturally and/or carry a pregnancy)?
Fertility preservation options	...about the option to bank sperm before treatment?	...about the option to potentially preserve fertility by freezing eggs or embryos before treatment? ...to help you decide whether you wanted to freeze eggs or embryos before treatment?
Assistance with referrals	...about how to find a sperm bank?	...to help you to find a reproductive endocrinologist (fertility specialist)?
Alternative family-building options	...about other options to build a family if you were not able to bank sperm (eg, donor sperm, adoption)?	...about other options to build a family if you could not or did not want to preserve fertility before treatment (eg, donor eggs, surrogacy, adoption)?
Response options related to patient satisfaction questions		
<input type="checkbox"/> I was satisfied with the amount of information		
<input type="checkbox"/> I was not satisfied—I did not receive enough information		
<input type="checkbox"/> I was not satisfied—it was not discussed at all		
<input type="checkbox"/> I was not interested in receiving this information, or it was not applicable to me		
Questions related to helpfulness of written patient education information provided*		
Did your MSK physician or nurse give you written information about fertility?		
<input type="checkbox"/> Yes		
<input type="checkbox"/> No—I would have liked this information but did not receive it		
<input type="checkbox"/> No—I was not interested in receiving this information		
<input type="checkbox"/> I do not remember		
Did you read this information about fertility?		
<input type="checkbox"/> Yes—it was helpful		
<input type="checkbox"/> Yes—it was not helpful		
<input type="checkbox"/> No—I did not read it		
<input type="checkbox"/> I do not remember		
<input type="checkbox"/> I did not receive written information		

Abbreviation: MSK, Memorial Sloan Kettering Cancer Center.

*Only cohort 2 participants were queried because materials were not available before the program was established. In quantifying helpfulness, only patients who received and read the information were included in the denominator.

males, C1 included a greater proportion of patients with testicular cancer than observed in the overall cohort of male patients invited to participate (42% v 27%).

Cohort Characteristics

Table 3 describes respondent characteristics. Among males, the mean age at diagnosis was 34.6 years (standard deviation [SD], 7.7 years) in C1 and 35.6 years (SD, 8.1 years) in C2. The most frequently reported diagnoses were testicular cancer and lymphoma. Among females, the mean age at diagnosis was 37.9 years (SD, 5.9 years) in C1 and 37.3 years (SD, 6.5 years) in C2. The most frequently reported diagnoses were breast cancer and lymphoma.

Most respondents were white, had a college degree or higher, and were married or in a committed relationship before their diagnosis, which was approximately 2 years prior to completing the survey. One half of the respondents already had children, and more than one half wanted children in the future or were unsure. Group comparisons indicated no significant differences in cohort characteristics between C1 and C2, with the exception that differences

in race, ethnicity, and desire for future children could not be tested due to survey differences.

Satisfaction With Amount of Information Received

C1 versus C2. A significant difference in the proportion of male and female respondents who reported satisfaction with the amount of information received was seen between C1 and C2 (Table 4). For male patients, satisfaction with information on the effect of treatment on fertility was high in both cohorts but was significantly greater in C2 on the other topics queried (eg, sperm banking, finding a sperm bank, other family-building options). For female patients, satisfaction with the amount of information received was significantly greater in C2 on all topics queried (effect of treatment on fertility, options for FP, help with decision making, finding a reproductive endocrinologist, other family-building options).

FCNS consultation versus no FCNS consultation. Fifty-seven women in C2 received education and counseling by an FCNS. These women were younger at diagnosis ($t[193] = 2.26, P = .03$) and at time of survey completion ($t[185] = 2.27, P = .02$), less

Table 3. Cohort Characteristics*

	Male		Cohort 2		Female		Cohort 2	
	Cohort 1		Cohort 2		Cohort 1		Cohort 2	
	No.	%	No.	%	No.	%	No.	%
Age at time of diagnosis, mean years (SD)	34.6 (7.7)		35.6 (8.1)		37.9 (5.9)		37.3 (6.5)	
Range, years	18-45		18-45		18-45		20-45	
Time between diagnosis and survey, mean years (SD)	2.2 (0.9)		2.0 (0.8)		2.1 (0.8)		1.9 (0.8)	
Diagnosis†								
Breast					163	60	201	60
Colorectal	15	10	17	14	30	11	18	6
Gynecologic					24	9	34	11
Lymphoma	27	18	33	28	35	13	41	13
Sarcoma	17	11	12	10	7	3	4	1
Testicular	63	42	32	27				
Other	40	27	33	19	13	57	31	10
Race‡								
White	122	81	107	89	209	77	234	73
Asian	9	6	4	3	16	6	22	7
Black or African American	7	5	0	0	16	6	24	8
More than one race, other, unknown, preferred not to answer	8	5	5	4	2	1	24	8
Ethnicity‡								
Hispanic or Latino	11	7	6	5	25	9	11	3
Educational background								
College degree or higher	114	76	87	73	219	81	259	81
Some college or less	35	23	31	26	49	18	48	15
Additional demographics								
Considered cancer to be curable	128	85	108	90	239	88	272	85
Married/committed relationship	115	77	92	77	221	82	259	81
Had children before diagnosis	70	47	65	54	166	61	179	56
Wanted (more) children (or unsure)	95	63	79	66	142	52	198	62

NOTE. Data are missing for some items (male responses, 0.8%-6% missing; female responses, 0.6%-6% missing), so percentages may add to < 100.

Abbreviation: SD, standard deviation.

*Independent samples *t* and χ^2 tests were used to compare cohort characteristics for males and females and indicated no significant differences between cohorts 1 and 2. Differences in race, ethnicity, and wanted (more) children (or unsure) could not be tested because the questions were worded differently across cohort 1 and 2 surveys.

†Respondents could select more than one option, so percentages may add to > 100.

‡For cohort 1, ethnicity was asked as part of race, and for cohort 2, ethnicity and race were asked separately, which made it difficult to compare responses on this item between cohorts.

Table 4. Satisfaction With the Amount of Information Received

Topic	Cohort 1		Cohort 2		χ^2	P*
	No.	%	No.	%		
Males	150		120			
Effect of treatment on fertility	94 of 126	75	83 of 99	84	3.4	.18
Sperm banking	79 of 117	68	75 of 88	85	9.3	.01
Finding a sperm bank	58 of 107	54	61 of 76	80	13.3	.001
Other family-building options	29 of 98	30	34 of 52	65	18.7	< .001
Females	271		320			
Effect of treatment on fertility	99 of 216	46	186 of 249	75	62.1	< .001
Fertility preservation options	46 of 196	24	117 of 188	62	71.9	< .001
Help with decision making	30 of 190	16	100 of 177	57	80.2	< .001
Finding a reproductive endocrinologist	29 of 183	16	81 of 148	55	60.5	< .001
Other family-building options	18 of 186	10	55 of 135	41	44.7	< .001

NOTE. Patients who reported that they were not interested in receiving information were excluded from the denominator of each item.

*Degrees of freedom = 2.

likely to already have children ($\chi^2 = 35.37$, $P < .001$), and more likely to want children in the future ($\chi^2 = 28.12$, $P < .001$). No differences were observed based on time since treatment or marital/partnership status. In all but one of the topics queried females who had an FCNS consultation were more likely to report satisfaction than those who did not (Table 5).

Perceived Helpfulness of Fertility-Related Patient Education Information

Among C2 participants, 69% of interested males and 41% of interested females reported that they received written fertility-related patient education material from their clinicians. Among males, of the 77% (51 of 66) who reported having read the material, 96% found it helpful. Among females, of the 78% (71 of 91) who reported having read the material, 99% found it helpful.

FP Decisions

Patients in C2 were asked additional questions about their FP decisions. Among the 67 males who did not undergo sperm banking, 10% reported not knowing about sperm banking as the reason. Among the 255 females who did not undergo FP, 10% reported not knowing about FP as the reason. Females who received FCNS counseling were 6.1 times more likely (95% CI, 3.2 to 11.5) to undergo FP than those who did not.

DISCUSSION

A major goal of the MSK Cancer and Fertility Program is to support clinicians in providing education and support to patients about FP before treatment and family building after treatment. The program includes initiatives to educate clinicians about treatment-related fertility risks and FP options and has made resources readily available to assist them in having fertility discussions with patients and in making appropriate referrals.

This study compared cohorts of patients treated at MSK before and after program initiation (C1 and C2, respectively). Satisfaction with the amount of information received on almost all topics queried significantly increased after initiation of the Cancer and Fertility Program. To our knowledge, this study is the first to report changes in patient satisfaction with information received over time within a single institution. Two systematic reviews that focused on the fertility-related information needs of patients with cancer reported wide ranges of satisfaction with information (11% to 90%¹¹ and 36% to 65%²¹). Given variations in methodology, it is difficult to compare our findings to those of other researchers.

Satisfaction with information about other family-building options also increased after the program was initiated; however, 35% of males and 59% of females within C2 were not satisfied. This finding suggests a need to better inform patients about alternative family-building options not only before beginning cancer

Table 5. Satisfaction Among Cohort 2 Female Patients With the Amount of Information Received

Topic	No FCNS Consultation		FCNS Consultation		χ^2	P*
	No.	%	No.	%		
Effect of treatment on fertility	143 of 193	74	43 of 56	77	0.9	.62
Fertility preservation options	73 of 133	55	44 of 55	80	11.2	.004
Help with decision making	61 of 124	49	39 of 53	74	10.4	.006
Finding a reproductive endocrinologist	42 of 101	42	39 of 47	83	22.6	< .001
Other family-building options	31 of 95	33	24 of 40	60	8.9	.01

NOTE. Patients who reported that they were not interested in receiving information were excluded from the denominator of each item.

Abbreviation: FCNS, fertility clinical nurse specialist.

*Degrees of freedom = 2.

treatment as they consider FP options but also after treatment is completed.

A key service of the MSK program is the availability of an FCNS to provide in-depth education and counseling to patients, to help with decision making, and to facilitate referrals and coordinate care as needed. Referral to the FCNS was associated with younger age, no prior children, and desire for future children, which may reflect differences in patient interest or biases in provider referral practice. Females in C2 who had an FCNS consultation reported significantly higher rates of satisfaction than those who did not on all topics queried (information on FP options, 80% *v* 55%; help with decision making, 74% *v* 49%; help with finding a reproductive endocrinologist, 83% *v* 42%; information on other family-building options, 60% *v* 33%). These findings highlight the value patients find in speaking with specialists focused on fertility concerns. As reported by Letourneau et al,²² fertility consultations may lead to improvements in quality of life, with less decisional regret after treatment is completed.

The MSK Cancer and Fertility Program has developed gender-specific fertility-related education material for clinicians to provide to patients to reinforce information shared during discussion. Almost all patients who read this material reported it as helpful. However, a significant proportion of interested patients reported that they did not receive materials. Strategies to prompt clinicians to provide these materials to their patients should be considered, such as adding questions to patient intake forms to identify patients interested in receiving fertility-related information and providing fertility-related information packets before patients start cancer treatment that may affect their reproductive function.¹⁷ About one fourth of the sample who received the material did not read it; therefore, further work is needed to determine patient preferences for learning about fertility risks and FP options.

Compared with national figures, a high percentage of patients in C2 pursued FP (44% of males and 18% of females). Other US patient groups have reported lower rates (24% for sperm banking²³ and 5% to 10% for female FP^{2,22}). More than 75% of respondents in this sample reported having a college degree or higher and thus may have more financial resources than the general US population. In addition, these high FP rates may reflect a bias in that those who pursued FP may have been more likely to respond to the survey. However, a recent study of adolescent and young adult patients with cancer identified lack of knowledge as the reason for not pursuing FP (18% of males and 38% of females).²⁴ Only 10% of the current respondents reported lack of knowledge as a reason for not pursuing FP, which suggests that these differences may reflect the effectiveness of the Cancer and Fertility Program in providing patients with adequate information to make FP decisions.

A number of limitations should be considered in the interpretation of the study results, some of which introduce the potential for bias. Only English-speaking patients were eligible, and most respondents were white, non-Hispanic, and college educated; thus, responses may not be representative of the broader population of young patients with cancer. Surveys were anonymous, which made it impossible to validate responses or

compare characteristics of respondents with nonrespondents. Response rates varied based on methodology used to recruit participants and collect data, and C2 respondents who engaged with the program may have been more likely to respond. The study design was retrospective, and patients were on average 2 years postdiagnosis when surveyed, so responses may have been influenced by recall bias. There has been an increase in awareness among clinicians and the public about the availability of FP in the years between the time C1 and C2 participants started treatment, which may have contributed to the improvement in satisfaction with information between C1 and C2 respondents. C2 male participants were not asked whether they had an FCNS consultation, so comparisons between males based on FCNS consultation or between males and females could not be evaluated. Measures of patient satisfaction were investigator developed and need additional psychometric testing. Finally, although multiple comparisons were performed, *P* = .05 was preserved as the threshold for significance, which potentially resulted in a greater chance of false-positive results.

In conclusion, after initiation of a hospital-wide cancer and fertility program, significant improvements were observed in patient satisfaction with and perceived helpfulness of information about cancer treatment-related fertility risks and FP options. Among those who did not pursue FP, only a minority reported lack of information as the reason. These findings suggest that the establishment of a formal program within a cancer care setting to address fertility can improve the quality of clinician-patient discussions about fertility risks and options.

Refinement and validation of the instrument used to measure patient satisfaction with fertility-related information they received could provide a tool for other organizations that want to evaluate fertility services. In addition, the contribution of each program element in improving patient satisfaction should be evaluated to ensure optimal use of resources (eg, best approach to educating clinicians, most effective resources for clinicians and patients, type of clinician to provide patient education and counseling). Finally, further study is needed to determine the best way to introduce and implement cancer and fertility programs in cancer centers of varying sizes, patient populations, and resource constraints.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Disclosures provided by the authors are available with this article at www.jco.org.

AUTHOR CONTRIBUTIONS

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Cancer and Fertility Program Improves Patient Satisfaction With Information Received

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