

"Just what the doctor ordered": Factors associated with oncology patients' decision to bank sperm

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Abstract

Introduction: The purpose of this cross-sectional study was to explore factors associated with oncology patients' decision to bank sperm prior to cancer treatment.

Materials and Methods: Patients who were referred to the oncology sperm banking program between January 2009 and March 2010 were invited to complete an 18-item questionnaire during one of their sperm banking visits.

Results: Of the 157 cancer patients referred to the Mount Sinai Oncology Sperm and Tissue Bank for sperm banking during the 15-month period, 79 questionnaires were returned (50% response rate). Of the respondents, 89% were informed about sperm banking by their physician. Future family planning was cited as the main reason to bank. Cost was not a barrier for the vast majority of respondents. Forty percent of respondents banked sperm within 4 days prior to initiating cancer treatment. Most respondents relied on their physician for verbal information on sperm banking. Eighty-one percent were unaware of any patient organizations that have educational materials on oncology fertility preservation.

Conclusion: Sperm banking prior to cancer treatment is the only proven method of preserving fertility for cancer patients. The two main determinants associated with deciding whether to bank sperm were: the physician's recommendation and the patient's desire for future fatherhood. Physicians play a key role in influencing patients' decisions. The recommendation to bank sperm is a persuasive message if patients are clearly informed about their potential risk of infertility post-cancer treatment, and that sperm banking is an effective way of preserving fertility. Providing patients with education materials might enhance compliance in sperm banking.

Résumé

Introduction : Le but de cette étude transversale était d'explorer les facteurs influant sur la décision des patients atteints de cancer de mettre du sperme en banque avant un traitement anticancéreux.

Matériel et méthodologie : Les patients qui ont été orientés vers le programme de conservation de sperme pour patients cancéreux entre janvier 2009 et mars 2010 ont été invités à remplir un questionnaire à 18 questions au cours d'une de leurs visites à la banque de sperme.

Résultats : Sur les 157 patients cancéreux orientés vers la banque de sperme et de tissus du Mount Sinai Hospital pour la mise en banque de sperme durant la période de 15 mois, 79 ont retourné un questionnaire (taux de réponse de 50 %). De ces répondants, 89 % avaient reçu des informations sur la banque de sperme de la part de leur médecin. La planification familiale était mentionnée comme la principale raison d'utiliser la banque. Le coût n'était pas un obstacle pour la grande majorité des répondants. Quarante pour cent des répondants ont mis du sperme en banque dans les quatre jours précédant le début du traitement anticancéreux. La plupart des répondants avaient reçu des informations verbales de leur médecin sur la mise en banque de sperme. Quatre-vingt-un pour cent n'étaient pas au courant s'il existait des organisations de patients offrant du matériel éducatif sur la préservation de la fertilité chez les patients cancéreux.

Conclusion : La mise en banque de sperme avant un traitement contre le cancer est la seule méthode éprouvée de préservation de la fertilité chez les patients atteints de cancer. Les deux principaux facteurs déterminants dans la décision de procéder à la mise en banque de sperme étaient les suivants : recommandation du médecin et volonté du patient de devenir père plus tard. Les médecins ont une grande influence sur la décision des patients. La recommandation de mettre du sperme en banque est un message persuasif si les patients sont bien informés au sujet du risque potentiel d'infertilité après le traitement anticancéreux, et s'ils savent que la mise de sperme en banque est un moyen efficace de préserver sa fertilité. Fournir du matériel éducatif aux patients pourrait accroître leur observance quant aux programmes de mise en banque de sperme.

Introduction

According to the latest cancer data released by the Canadian Cancer Statistics, an estimated 90 000 men will be newly diagnosed with cancer in 2010.¹ Among these men, it is projected that 6960 men will be between the age range of 20 and 49. Medical advances in diagnostic techniques and cancer treatment have greatly improved the survival chances of cancer patients, which means more cancer patients are able to survive cancer and live a productive life after treatment.

For many cancer survivors, quality of life also includes potential reproductive capacity.^{2,3} Unfortunately, both surgical and medical treatments for malignancies may result in

sterility. Although advances in chemotherapy have resulted in fewer side effects, including gonadotoxicity, some cancer patients never resume spermatogenesis after treatment.⁴⁻⁷ Cancer survivors who did not bank sperm before cancer treatment and subsequently became infertile reported having substantial psychosocial distress.^{2,3,14} Some were upset about not being warned about the possibility that they may never be able to have biological children post-cancer treatment.^{8,9}

Oncology and reproductive medicine professional organizations support the idea that sperm banking prior to cancer treatment should be recommended routinely to all patients who wish to preserve fertility.^{10,11} Despite this backing, oncology sperm banking services continue to be underutilized.^{6,12,13} Existing evidence suggests that less than a quarter of childless cancer survivors banked sperm before cancer treatment. At least half did not recall receiving information on cancer-related infertility.^{2,9,14} Common reasons for not banking include lack of information about sperm banking, lack of time to complete the banking process and not knowing where to bank sperm.^{3,8,9,14} Some of those who did not bank sperm said they had never been warned by their health care providers about the negative impact of cancer treatment on fertility.^{3,9,14}

Most of the existing data were collected retrospectively years after cancer treatment.^{2,3,8,9,14,15} Retrospective design studies have limitations of recall bias. At present, very limited data are available on patients' perspectives at the time of sperm banking.¹⁶ The purpose of this cross-sectional survey study was to explore factors associated with cancer patients' decision to bank sperm.

Methods

Approval was obtained from the hospital research ethics board prior to data collection. Males who were referred to the Mount Sinai Oncology Sperm and Tissue Bank between January 2009 and March 2010 were given an 18-item questionnaire with 4 open-ended questions by a medical secretary during one of their sperm banking visits. Participation was voluntary and anonymous. A drop-off box was available to collect the returned surveys. Respondents' written comments in the open-ended questions are reported in quotation marks.

Results

Of the 157 cancer patients referred to the hospital for sperm banking during the 15-month period, 79 questionnaires were returned, with a 50% response rate. Patient demographic data, including age grouping, marital status and employment status and paternity, were recorded (Table 1). The mean age of respondents was 28.4 (standard deviation [SD] = 8.2), with age ranging from 14 to 52. A total of 83.5% respon-

Table 1. Demographic data of respondents

Age grouping	
≥ 19 years old*	12 (15.2%)
Between 20 and 29 years old	36 (45.6%)
Between 30 and 39 years old	25 (31.6%)
Between 40 and 49 years old	5 (6.3%)
≥50 years old	1 (1.3%)
Total	79 (100%)
Marital status	
Single	42 (53.2%)
Married or partnered	36 (45.6%)
Separated or divorced	1 (1.3%)
Total	79 (100%)
Children status	
No biological children	66 (83.5%)
Have biological children	11 (13.9%)
Did not specify	2 (2.5%)
Total	79 (100%)
Employment status	
Student	21 (26.6%)
Part-time employment	5 (6.3%)
Full-time employment	43 (54.5%)
Unemployed	10 (12.7%)
Total	79 (100%)

*5 were either 14 or 15 years old; 6 were either 17 or 18 years old; 1 was 19 years old.

dents did not have children at the time of banking. The 3 top ranking cancer types were testicular (35.4%), Hodgkin lymphoma (13.9%), and non-Hodgkin lymphoma (12.7%) (Table 2).

Although only 60.8% of respondents were employed, the sperm banking cost was irrelevant (34.9%) or not important (27.3%) to most respondents. They ranked religion (90.9%) and culture (83.8%) as either irrelevant or not important in influencing their sperm banking decision (Table 3).

The time lapse between the sperm banking date and the planned cancer treatment date was recorded (Table 4). Overall, there was a sense of urgency to bank sperm because of the short time window for some respondents to begin can-

Table 2. Cancer types of respondents

Testicular	28 (35.4%)
Hodgkin lymphoma	11 (13.9%)
Non-Hodgkin lymphoma	10 (12.7%)
Colorectal	7 (8.9%)
Sarcomas	5 (6.3%)
Brain tumor	3 (3.8%)
Leukemia	2 (2.5%)
Cancer type not specified	6 (7.6%)
Miscellaneous cancer types	7 (8.9%)
Total	79 (100%)

Table 3. Factors influencing decision to bank sperm

Factors	Irrelevant	Not important	Somewhat important	Very important	Extremely important
Sperm sample collection method	28.7%	17.1%	27.1%	15.7%	11.4%
Future family planning	0	0	3.9%	15.8%	80.3%
Finance	34.9%	27.3%	30.3%	4.5%	3%
Culture	58.8%	25%	11.8%	1.5%	2.9%
Religion	63.6%	27.3%	7.6%	0	1.5%

cer treatment. In an open-ended question that asked about ways to improve sperm banking services, one cancer patient wrote: "I would like to know about this a few weeks earlier. We could have gotten more samples. I only had time to bank two samples before chemotherapy."

A total of 94% of respondents were informed about sperm banking by their health care providers (Table 5). Among them, 89.2% were informed by their physicians. Only 6% knew about it through their family and friends. When asked about factors influencing their sperm banking decision in an open-ended question, some respondents wrote: "doctor told me to bank," and "oncologist told me to come here." Others commented on the therapeutic values of cryopreservation that preserving their fertility potential gave them "a sense of hope," and "a peace of mind going into surgery." One male cancer patient who was diagnosed with testicular cancer wrote: "I want to be sure in case I'm left sterile."

When asked if their referring physician discussed the potential side effects of cancer treatment on fertility, 93.6% indicated that it was discussed, but 6.4% said "no." Overall, 87.7% were satisfied with the amount of information provided by their physicians, and 89% were satisfied with the quality. Those who were not satisfied with the information from physicians wrote: "it was too brief," "hoping for more explanation," "information was not detailed," and "not enough knowledge on the effect of my treatment." The vast majority of respondents (81%) were unaware of any patient organizations that have educational materials and information on oncology fertility preservation. For example, very few had heard about Lance Armstrong and Fertile Hope in the United States, and almost no one knew about Fertile Future in Canada.

Future family planning was cited as the main reason for sperm banking, with 80.3% indicating that this option was "extremely important" and 15.8% ranking it "very impor-

tant." The wish to have genetic children and be a father in the future was also salient for younger respondents. For example, a 17-year-old respondent who was diagnosed with Hodgkin lymphoma wrote: "all I want is to have children one day."

The respondents also indicated that follow-up by the sperm banking facility to provide information about the sperm sample quality was very important. In this open-ended question, a few respondents stated: "I just need the nurses to inform me about whether the sample is fertile before my treatment has started," "provide in depth analysis of samples after it has been analyzed," and "give the patient a better understanding of the results produced and if there is a possibility for improvement."

Discussion

In our study, 83.5% of respondents who chose to bank sperm had not yet had children. But the remaining 13.9% who already had children were still interested in preserving their fertility. Also, 7.6% of them were over 40 years old. Although the percentage is small, it supports the existing research data that older male cancer patients are also interested in having children in late adulthood, and would like to consider the oncology sperm banking option.^{9,17} Our data also show that the demographics of those who banked sperm were quite diverse with regard to relationship status, paternity, employment status and age. Our data suggest that socio-demographics are not reliable parameters to determine whether patients would be interested in fertility preservation through sperm banking.

Banking sufficient samples to preserve one's fertility is particularly important if the proposed cancer treatment has a high chance of causing future infertility. One of the disconcerting findings is that 40.6% of respondents banked sperm in less than 4 days before their cancer treatment. This would pose a significant challenge for patients who wish to bank multiple samples prior to initiating cancer treatment. Ideally, a 2-day abstinence in between banking visits to optimize sperm quantity is recommended, but a 1-day time lapse is still acceptable in urgent circumstances. Some respondents in our study lamented not being informed of the cryopreservation option earlier as they did not have the opportunity to bank sufficient samples for future use. This gap could

Table 4. Days between the sperm banking date and the planned cancer treatment date

Less than 4 days	28 (40.6%)
Between 5 and 8 days	20 (29%)
Between 9 and 12 days	6 (8.7%)
Over 13 days	15 (21.7%)
Total	69* (100%)

*10 respondents did not specify the cancer treatment date and were excluded

Table 5. Who informed the respondents about oncology sperm banking*

Suggested by doctors	n (%)
Oncologist	58 (69%)
Urologist	11 (13%)
Family doctor	3 (3.6%)
Other medical doctors	3 (3.6%)
Total	89.2%
Suggested by other health care professionals	
Nurses	4 (4.8%)
Total	4.8%
Suggested by others	
Family members	3 (3.6%)
Friends	2 (2.4%)
Total	6%

*Several respondents entered more than one selection, total responses = 84

easily be rectified if patients were informed earlier. Knowing where a convenient banking facility is located, and sending referrals in a timely fashion are also vital to avoid delay in cancer treatment. Most fertility clinics have sperm banking services. Some facilities are open on the weekends and statutory holidays to accommodate urgent banking needs of oncology patients (Appendix 1).

Our findings indicate that physicians play a key role in influencing cancer patients' decision to bank sperm. Existing research literature has also consistently shown that most cancer patients banked sperm because it was strongly recommended by their physicians.^{18,25,26} Physicians have more persuasive power when delivering health-related information to their patients because of their medical expertise, credibility and trustworthiness.¹⁹ The recommendation to bank sperm is a convincing message if cancer patients are clearly informed about their potential risk of infertility post-cancer treatment, and that sperm banking is an effective way of preserving fertility for future family building.^{10,11}

Most respondents in our study relied on their physicians for information. However, physicians are usually pressed for time when other medical issues take priority during the appointment.²⁰ Fertility issues may also be overlooked if patients do not initiate the discussion or do not ask for information. Even when it is discussed, some patients may feel so overwhelmed and preoccupied with immediate survival issues that they may not be fully able to comprehend all the information. The ability for health care providers to effectively counsel cancer patients can be hampered if no resources are available. Providing patients and their families with education materials from reliable sources such as the web-based resources would enhance information retention (Appendix 2). A multidisciplinary team approach,²¹⁻²³ such as involving nurses and social workers to facilitate the sperm banking referrals and provide emotional support to patients,

Appendix 1. Directory of fertility clinics across Canada

Canadian Fertility and Andrology Society (www.cfas.ca)
 Fertile Future (www.fertilefuture.ca)
 Infertility Awareness Association of Canada (www.iaac.ca)
 Infertility Network (www.infertilitynetwork.org)

might help minimize their stress and ensure compliance.

In our program, a designated nurse provides a follow-up phone call to all patients after the banking to inform them about the pre-freeze and post-thaw sperm quality, and to answer any questions they might have about their future fertility options through the use of assisted reproductive treatment. This gives patients a sense of assurance and a realistic appraisal of their future treatment plan. Recent reports from two hospital-based in-vitro fertilization (IVF) clinics in Ontario also showed encouraging statistics in treatment outcomes using cryopreserved sperm from cancer patients. The pregnancy rates for intrauterine insemination were between 21% and 36.4%, and 50% for IVF with or without intracytoplasmic injection (ICSI).^{13,24} At present, there is no evidence to our knowledge to suggest an increased risk of chromosomal abnormalities or birth defects in children born through the use of cryopreserved sperm from cancer patients based on neonatal outcomes.^{10,11}

Appendix 2. Cancer and fertility preservation materials

Organization	Booklet, brochure or leaflet
Assisted Human Reproduction Canada	<i>Cancer and Preserving your Fertility: A Guide for Patients</i> ^{a,b} www.ahrc-pac.gc.ca (search under 'Report and Publication')
American Society of Clinical Oncology	<i>ASCO's Guideline on Fertility Preservation</i> ^a <i>Fertility and Cancer Treatment</i> ^a <i>Having a Child After Cancer Treatment, Part I and II</i> ^a <i>What if I've Already Had Cancer Treatment and Didn't Take Measures to Preserve My Fertility?</i> ^a www.cancer.net (search under 'Publication and Resources')
American Society of Reproductive Medicine	<i>Cancer and Fertility Preservation</i> ^a www.asrm.org (search under 'Patient Resource')
Fertile Future (Canada)	<i>Cancer and Fertility Guide for Young Adults</i> ^{a,b} www.fertilefuture.ca (search under 'Information Pamphlets')
Fertile Hope (US)	<i>Cancer and Fertility: Patient Education Booklet</i> ^{a,b} <i>Cancer and Fertility: Fact Sheets for Oncology Professionals</i> ^{a,b} www.fertilehope.org (search under 'Order Print Materials')

^aAvailable in PDF format for downloading;

^bAvailable by mail order for free.

The sperm processing, freezing cost and first year storage fee in our program is \$300 for the initial sample, and then \$150 for repeated samples. Despite the perception of medical professionals that cost is a major barrier to sperm banking,^{18,25,26} the banking fee was not cited as an important consideration factor in our findings. Although the sperm banking fee may not be an immediate concern for most respondents, some assisted reproductive treatment (ART), such as IVF and ICSI, are expensive and could be out of reach for some cancer survivors when they are ready to consider ART. The province of Quebec is now providing full health coverage for IVF cycles and fertility drugs through Medicare.^{27,29} The Manitoba government has also approved a refundable personal income tax credit of up to \$8000 per year to cover 40% of eligible expenses for fertility treatment and drugs.^{28,29} Other provinces may eventually follow to provide coverage. A few clinics have set up charitable funds to provide subsidy for patients who are unable to afford the costs of IVF.²⁹ A national patient organization, Fertile Future, has recently launched a financial assistance program called the 'Power Of Hope' to provide financial subsidy to Canadian cancer patients who wish to pursue fertility preservation.³⁰

Conclusion

We found that the two key determinants associated with the sperm banking decision were the physician's recommendation and the patient's desire for future fatherhood. Sperm banking is simple, safe and non-invasive. It is, at present, the only proven method of preserving fertility in male cancer patients. All patients should be asked routinely about their desire to have children and if they would like to consider sperm banking as an option prior to starting cancer treatment. We hope our findings can sensitize urologists involved in cancer care to adopt a proactive approach when counselling their cancer patients about fertility preservation through oncology sperm banking.

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