A National Study of the Provision of Oncofertility Services to Female Patients in Canada

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Abstract

Objective: This study aimed to gain a better understanding of the fertility preservation services provided by Canadian fertility clinics to women with cancer.

Methods: We invited a total of 76 fertility clinics across Canada to complete a mailed questionnaire related to the availability, accessibility, affordability, and utilization of fertility preservation services for oncology patients.

Results: The total response rate was 59.2%: 72.4% for IVF clinics and 51.1% for fertility centres without on-site IVF. Not all the responding IVF centres accepted oncology referrals for women. Six clinics without on-site IVF accepted cancer patients for consultation. The medical consultation fees are covered by public health insurance in all provinces. The majority of respondents expedited the referrals to schedule an initial medical appointment within three days. Despite that, the referral volume reported by respondents was markedly low for all except two facilities. With over 4000 young women of reproductive age given a diagnosis of cancer each year in Canada, the findings suggest that cancer patients are severely under-served by fertility clinics.

Conclusion: There is a need to develop a stronger partnership between the fields of oncology and reproductive medicine to further improve access of patients with cancer to fertility preservation services. Development of evidence-based practice guidelines covering medical, clinical, psychosocial, ethical, and legal aspects geared to the Canadian health care system would help to avoid ambiguity relating to the roles and responsibilities in the provision of fertility preservation services. Such processes would ensure optimization of services so that all young cancer patients would receive the best care in protecting their fertility.

Résumé

Objectif : Cette étude visait à mieux comprendre les services de préservation de la fertilité offerts par les cliniques de fertilité canadiennes aux femmes atteintes d’un cancer.

Méthodes : Nous avons invité, au total, 76 cliniques de fertilité de partout au Canada à remplir un questionnaire postal traitant de la disponibilité, de l’accessibilité, de l’abordabilité et de l’utilisation des services de préservation de la fertilité destinés aux patientes en oncologie.

Résultats : Le taux de réponse total a été de 59,2% : 72,4% des cliniques de FIV et 51,1% des centres de fertilité n’offrant pas de services de FIV sur place. Ce ne sont pas tous les centres de FIV ayant répondu au questionnaire qui acceptaient de recevoir des femmes ayant été orientées vers eux par des services d’oncologie. Six cliniques n’offrant pas de services de FIV sur place acceptaient d’offrir des services de consultation aux patientes atteintes d’un cancer. Les frais de consultation médicale sont couverts par les régimes publics d’assurance-santé dans toutes les provinces. La majorité des répondants accéléraient le traitement des dossiers des patientes orientées vers leurs services, et ce, en vue de mettre à l’horaire la consultation médicale initiale dans un délai de trois jours. Malgré cela, le volume des orientations signalé par les répondants était sensiblement faible pour tous les établissements, sauf deux. Compte tenu que plus de 4 000 jeunes femmes en âge de procréer reçoivent un diagnostic de cancer chaque année au Canada, ces résultats semblent indiquer que les patientes atteintes d’un cancer sont gravement mal desservies pas les cliniques de fertilité.

Key Words: Fertility preservation, oncofertility, female cancer patients

Competing Interests: None declared.

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**Conclusion** : Nous nous devons de développer un partenariat plus serré entre les domaines de l’oncologie et de la médecine génésique pour améliorer davantage l’accès des patientes atteintes d’un cancer aux services de préservation de la fertilité. L’élaboration de directives cliniques factuelles traitant des aspects médicaux, cliniques, psychosociaux, éthiques et légaux, dans le contexte du système de santé canadien, contribuerait à éviter l’ambiguïté en ce qui concerne les rôles et les responsabilités dans le domaine de l’offre de services de préservation de la fertilité. De tels procédés permettraient d’assurer l’optimisation des services, de façon à ce que toutes les jeunes patientes atteintes d’un cancer puissent recevoir les meilleurs soins en vue de préserver leur fertilité.

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**INTRODUCTION**

Since 2009 it is estimated that over 80,000 Canadian women annually have been found to have cancer; among them, more than 4,000 are in the reproductive age group of 20 to 39. Advances in diagnostic techniques and cancer therapy have led to a growing number of women surviving cancer; the five-year survival rates for cancers of the breast and uterus are 88% and 85%, respectively. With the societal trend of more Canadian women delaying childbearing and parenthood until their thirties, many young women might not yet have achieved their family-building goals when receiving a diagnosis of cancer.

For young and nulliparous cancer patients, fertility is very important, second only to mortality, and having children is an important life goal for many of them once they have survived cancer. Oncologists have been focused traditionally on providing the most effective treatment for curing cancer and prolonging life. Much attention is now devoted to improving the quality of life, including fertility and reproductive health, of those who survive cancer.

Unfortunately, many intensive cancer therapies that are used to save lives (such as alkylating agents, bone marrow transplantation, and pelvic radiation) have serious adverse effects on ovarian and uterine function that may severely compromise future reproductive capacity. Although procedures such as ovarian transposition, ovarian cystectomy, or radical trachelectomy are available for specific cancers, these do not protect against the effects of systemic chemotherapy, bone marrow transplantation, or total body irradiation.

In the past, young female patients undergoing cancer therapy could not protect their fertility because of the lack of reproductive technologies. The parallel scientific and clinical advances in fertility preservation methods, such as improved slow freezing techniques and new vitrification protocols, allow young women to freeze not only embryos, but also mature oocytes and immature oocytes, using in vitro maturation. Retrospective studies on survivors of cancer have found favourable views about using cryopreservation procedures to preserve fertility. Having a medical consultation from a reproductive endocrinology and infertility specialist is the most preferred way for receiving information. Overall, there is strong support to make fertility services more widely available and accessible to cancer patients, especially female patients.

The pivotal role of oncology health care providers in initiating fertility discussions and facilitating referrals is irrefutable. Much advocacy work has been done in the past decade in raising the awareness of fertility issues in cancer care. Clinical practice guidelines published by oncology medical societies in Australia, the United Kingdom, and the United States have put the onus of responsibility on oncology health care providers for informing young cancer patients about the potential fertility risks and the options for preserving fertility prior to cancer therapy. The intersection of oncology and reproductive medicine is an emerging discipline called “oncofertility.” Despite that, infertility is an area that has not received sufficient attention in oncology practice. Previous studies have shown that oncology health care providers do not always inform young cancer patients about the potential fertility risks when making plans for cancer treatment. Canadian clinical guidelines have not yet been developed to address fertility issues in oncology practice.

While numerous studies have been conducted relating to the perspectives of fertility preservation among oncology health care providers and cancer survivors, there are limited data regarding the actual services received by patients with cancer prior to commencing cancer treatment. To date, no study has been conducted in Canada to explore the fertility preservation services provided by fertility centres to female oncology patients. The purpose of this study was to gain a better understanding of the current state of oncofertility service provision across Canada. We report here the findings concerning female cancer patients. The project was commissioned by the Canadian Task Force on Adolescents and Young Adults with Cancer, a task force funded by the Canadian...
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Partnership Against Cancer that works in collaboration with C17, the consortium of the directors of all pediatric oncology centres across Canada. The task force’s mission is to ensure that AYA cancer patients and AYA survivors have prompt and equitable access to the best care.25

METHODS

An Internet search was conducted in March 2011 using multiple websites to generate a list of Canadian fertility facilities (Appendix 1). A total of 76 fertility clinics were identified. Of these, 29 offered full in vitro fertilization services and 47 had no on-site IVF. The provincial distribution of new estimated female cases of cancer in 20111 and the location of 76 fertility facilities across Canada are summarized in Table 1.

Among the 29 IVF clinics, all except one had a website. Only seven IVF clinics had web-based fertility preservation information specific to cancer patients; two provided generic information for all cancer patients and five provided specific information for female patients. Among the 47 fertility centres, only 16 had a website and none provided cancer-related fertility information for female patients. The remaining 31 centres had only contact information on the Internet.

A self-administered questionnaire was developed by the task force with representation from clinical medicine, academia, and counselling in both cancer and reproductive endocrinology (Appendix 2). The questions were devised on the basis of clinical experience and a comprehensive literature review of the provision of fertility preservation services to patients with cancer. The questionnaire had 18 closed-ended and four open-ended questions on the availability, accessibility, affordability, and utilization of fertility preservation services. Questions related to perceived obstacles to providing optimal fertility preservation services and recommendations to improve patient access to services were also included. For face and content validity, the questionnaire was pilot tested by a physician and a nurse who had experience in providing fertility preservation services to female patients with cancer, and also an academic colleague who has expertise in survey design.

The first package was mailed in mid-August 2011 to the medical directors or clinic managers to invite their participation in the study. The package contained a cover letter, fertility preservation surveys covering both male and female patients with cancer, a “decline to participate” form, and a stamped return envelope. Checkboxes were provided for clinics to indicate whether their facility offered oncology fertility preservation services to males and females. A second mailing to non-respondents was sent six weeks later, followed by an email (where available) after a further six weeks. A final phone call to remaining non-respondents was made six weeks after the email reminder.

Quantitative data were analyzed by SPSS, version 19.0 (IBM Corp., Armonk NY). Descriptive comments in open-ended questions were analyzed to identify emerging themes. Extracts from the written comments, where applicable, were reported together with descriptive statistics to illustrate the themes.

Institutional ethics approval was obtained from the Research Ethics Board of McMaster University and Hamilton Health Sciences.

RESULTS

The total response rate was 59.2%: 72.4% for IVF clinics and 51.1% for fertility centres without on-site IVF services. The survey responses and the provision of oncology fertility preservation services to female patients indicated by respondents are summarized in Table 2. Seventeen facilities, all IVF clinics, provided both medical consultation and cryopreservation procedures; two IVF clinics provided medical consultation, but not cryopreservation procedures for female patients with cancer; six fertility centres without on-site IVF services accepted referrals for medical consultation. Clinics responding that they did not provide any fertility preservation services to patients with cancer were excluded. A total of 25 surveys were available for data analysis. The majority of respondents wrote comments in response to one or more open-ended questions.

Availability and Accessibility of Services

Among the 25 respondents, 12 (48%) indicated that they used satellite clinics for cycle monitoring to minimize travel for out-of-town patients during the cryopreservation process. For the 17 IVF clinics that provided full fertility preservation services, 14 (82.4%) provided oocyte freezing, five (29.4%) provided in vitro maturation, and only three (17.6%) provided ovarian tissue banking, in addition to the standard cryopreservation protocol of embryo freezing.

All 25 facilities gave priority to oncology referrals, although there was variation in how quickly medical consultation could be arranged. The time frame was within three days for 16 clinics (64%), one week for four clinics (16%), two weeks for two clinics (8%), and three weeks for the remaining three clinics (12%).
Affordability of Services

The medical consultation fees were covered by public health insurance in all provinces. All clinics except one waived the one-time administration fee, which was approximately $250. Two clinics charged a fee ($160, $200) for orientation/teaching regarding the medical procedures involved in IVF. Fertility medications and treatments, including cryopreservation procedures, are covered by provincial health insurance for the facilities located in Quebec. For IVF clinics located outside Quebec, all except three provided free compassionate fertility medications for ovarian stimulation. Six facilities were affiliated with a financial subsidy program through a non-profit organization called Fertile Future, and four provided other types of financial assistance through various charitable organizations. Thirteen clinics offered additional discounts and flat rate fee reductions to cancer patients with financial needs, such as waiving the first year’s storage fee for cryopreserved eggs or embryos. Many respondents commented that they felt the costs should be covered by provincial health insurance because cancer patients undergoing cryopreservation procedures had a medical indication to do so.

Utilization of Services

Notably, the referral volume of cancer patients seeking fertility preservation services was markedly low for most of the responding facilities, based on the survey data.

Table 1. Provincial distribution of estimated new female cancer cases in 2011 and the location of fertility facilities across Canada

<table>
<thead>
<tr>
<th>Females</th>
<th>Cancer distribution, %</th>
<th>IVF clinics*</th>
<th>Fertility centres*</th>
<th>Total facilities and distribution, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>84,800†</td>
<td>100%†</td>
<td>29</td>
<td>47</td>
</tr>
<tr>
<td>Ontario</td>
<td>32,400</td>
<td>38.2</td>
<td>13</td>
<td>27</td>
</tr>
<tr>
<td>Quebec</td>
<td>22,500</td>
<td>26.5</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>British Columbia</td>
<td>10,200</td>
<td>12.0</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Alberta</td>
<td>7,600</td>
<td>9.0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Manitoba</td>
<td>3,000</td>
<td>3.5</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Nova Scotia</td>
<td>2,800</td>
<td>3.3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Saskatchewan</td>
<td>2,400</td>
<td>2.8</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>New Brunswick</td>
<td>2,100</td>
<td>2.5</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Newfoundland and Labrador</td>
<td>1,250</td>
<td>1.5</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Prince Edward Island</td>
<td>410</td>
<td>0.5</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

*Number of clinics as of March 2011.
†May not sum to column because of rounding.

Table 2. Female fertility preservation survey responses

<table>
<thead>
<tr>
<th></th>
<th>IVF clinics</th>
<th>Fertility centres</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total participants</td>
<td>29</td>
<td>47</td>
<td>76</td>
</tr>
<tr>
<td>Undelivered mail</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Returned mail</td>
<td>21</td>
<td>24</td>
<td>45</td>
</tr>
<tr>
<td>Response rate</td>
<td>72.4% (21/29)</td>
<td>51.1% (24/47)</td>
<td>59.2% (45/76)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>21 respondents</th>
<th>24 respondents</th>
<th>45 respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decline participation</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Do not provide any fertility preservation services</td>
<td>1</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>Provide fertility preservation consultation only</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Provide both fertility preservation consultation and cryopreservation procedures</td>
<td>17</td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>Available for data analysis</td>
<td>19</td>
<td>6</td>
<td>25</td>
</tr>
</tbody>
</table>
Only two facilities had a high monthly referral volume of approximately 15 patients. Four facilities received five to seven referrals per month, and the remainder indicated that referrals were received very infrequently, ranging from zero to two per month. One clinic had just begun offering this new program and had not yet seen any cases. Most referrals came from cancer centres and teaching hospitals and most were referred by medical oncologists, followed by gynaecologic oncologists. The most common age range of referred women was 30 to 34, followed by 25 to 29. A few respondents indicated that they hardly ever received referral of cancer patients who were not in a partnered heterosexual relationship; respondents speculated that this may be because of the lack of awareness of the oocyte cryopreservation option for single women.

**Availability of Information and Patient Resources**

Facilities were asked to indicate if they provided any educational materials about female fertility preservation services to referring agencies and cancer patients. Only seven facilities (28%) indicated that they had clinic-designed fertility preservation information. Eleven clinics (44%) used the brochures published by Assisted Human Reproduction Canada and/or Fertile Future for patient education. Seven facilities (28%) did not use any educational materials at all. Despite that, the importance of providing fertility preservation information to oncology teams was well recognized among respondents. Some suggested having better communication with oncology centres and cancer societies about the types of cryopreservation options available, in order to help them disseminate the information through their networks.

**Recommendations to Improve Patient Access to Services**

Thirteen facilities (52%) indicated that they had provided training on oncology fertility preservation in female patients in various formats, including grand rounds, seminars, training workshops, and conferences. Two clinics reported an increase in referral volume after conducting the training. Participants were asked to rank 11 barriers to female cancer patients’ accessing fertility services. The three highest ranked barriers were time pressure of starting cancer treatment, cryopreservation fees, and inadequate patient awareness of the negative impact of cancer treatment on future fertility. Most clinics did not think the location of cryopreservation facilities and the availability of REI specialists were barriers to accessing fertility services.

The majority of respondents wrote comments in the open-ended questions to suggest how to improve patient access to fertility services. Illustrative comments are summarized in Table 3 under four main themes. Some facilities strongly believed that greater awareness of and attention to fertility matters by oncologists would increase the number and timeliness of referrals. A few respondents felt either that oncologists did not refer or that referrals were sent too late for fertility intervention.

**Table 3. Illustrative comments for open-ended questions**

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
</tr>
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</table>
| Raising the awareness of fertility risk in cancer care | • The subject of fertility preservation should be discussed with every patient who may be at risk; preferably patients should have the option to see an REI specialist to address fertility matters.  
• Educate surgeons and GPs, who may then be able to refer patients sooner, before the cancer clinic visit, at which time it is sometimes too late. |
| Availability of fertility preservation resources | • Canadian Cancer Society websites need a very obvious link to resources. They have some fertility preservation information on their site but this is not easy to find, certainly not prominent.  
• Pamphlets in oncology departments produced by fertility centres explaining possibilities for treatment on fertility preservation. |
| Accessibility of fertility preservation services | • Timely referrals are key, therefore oncologists need to be armed with information and resources so that their patients will be offered fertility preservation.  
• Alerting the media about this issue and available centres that offer treatment. |
| Collaboration between oncology and reproductive medicine | • The greatest challenge hinges on the fact that success requires a coordinated effort between two separate disciplines.  
• Greater communication between fertility clinics and oncology centres. Informing oncologists about what is available and possible. |
DISCUSSION

Based on the information provided by the respondents in this study, not all Canadian IVF centres accept oncology referrals. On the other hand, six fertility clinics without on-site IVF do accept cancer patients for fertility consultation, and then redirect those who are interested in cryopreservation to an IVF clinic. A desired outcome in successful fertility intervention in cancer care is that all patients of childbearing age are informed about the potential fertility risks associated with cancer treatment; those who are interested in exploring cryopreservation options should have expeditious access to consult an REI specialist for informed decision making. Canadian survey studies on the retrospective views of cancer survivors who had had consultation with a fertility clinic found that reproduction was a vital concern for many of them, and many valued the opportunity to have a fertility consultation about cryopreservation options prior to commencing cancer treatment. Other studies have also confirmed the benefits for patients with cancer to have a fertility consultation, regardless of the outcome of their decision.

As shown in Table 1, 38.2% of cases of female cancer and 52.6% of fertility facilities are located in Ontario, and less-populated provinces have a lower proportion of fertility facilities to cases of cancer. Poorer provision of facilities in remote areas will present a barrier to referral and possible treatment. Not all patients with cancer choose ultimately to proceed with cryopreservation, but medical consultation can be provided by physicians who are trained in REI or by clinics without on-site IVF.

Methods of preserving fertility for females are time sensitive. Cancer patients who have not yet started cancer treatment usually respond better to stimulation protocols and have more gametes cryopreserved than those who have just completed or are still undergoing cancer treatment. Patients who are referred late or hastily to complete fertility preservation yield fewer oocytes and embryos for cryopreservation than patients who are referred early. Although oncologists are willing to adjust the schedule of cancer treatment to accommodate the completion of cryopreservation, there is a high expectation that referred patients will have an expeditious fertility consultation (within a week), so that an IVF procedure can be started as soon as possible.

From the survey responses, the majority of fertility clinics expedited the referrals to schedule a medical consultation within three days. Overall, waiting time does not seem to be a barrier to accessing fertility services. However, with over 4000 young women of reproductive age developing cancer each year in Canada, the extremely low referral volume of cancer patients reported by responding fertility clinics is disconcerting.

Recent studies conducted in the United States and the United Kingdom have found strong support among oncology health care providers for addressing fertility issues in cancer care and referring patients for fertility services. However, a recent Canadian study found a significant disparity in knowledge of and attitudes towards fertility preservation among oncologists in different medical specialties and clinical settings. Variations in practice behaviours and referral patterns for female patients with cancer were reported. Approximately 45% of physicians did not know where to refer patients for fertility consultation and 70% rarely made a referral. In Canada many female cancer patients may not be aware of the fertility risks associated with their cancer treatment, and are therefore not referred to fertility clinics to discuss cryopreservation options. There is an urgent need to design training modules to raise the awareness and knowledge of fertility preservation options for female patients with cancer among Canadian oncology health care providers.

Two clinics reported a relatively high volume of monthly referrals, suggesting that the utilization of fertility services is correlated with established collaboration and referral protocols. Understandably, oncology health care providers who do not have an established referral relationship with REI physicians or fertility clinics are less likely to initiate fertility discussions with cancer patients if they do not know where to send them. Oncologists may also be reluctant to send referrals if they are uncertain about the availability of cryopreservation services, or if they assume that the waiting time to see an REI specialist is long and that preserving eggs and embryos prior to cancer treatment is not feasible. The development of collaborative relationships between fertility clinics and oncology teams through establishing robust referral protocols would help to remove structural barriers. A pilot study has demonstrated that simply establishing an efficient referral system between an oncology centre and an IVF clinic resulted in a nine-fold increase in fertility service inquiries within a 12-month period.

Our website search of Canadian fertility clinics found that many of them, including IVF centres that accept oncology referrals, do not have web-based information for patients with cancer. Being able to locate fertility clinics and REI specialists for consultation may pose a significant challenge for oncology health care providers.
who are not familiar with resources offered by the field of reproductive medicine. The accessibility and availability of fertility resources and services were cited as barriers for Canadian cancer patients to make fully informed decisions in preserving their reproductive options.14,24 As the Internet has become the most popular means of locating information, fertility clinics should consider updating their websites by providing more current information on their oncology fertility preservation program. Fertile Future, a Canadian non-profit patient organization, has taken the initiative of establishing a national directory of fertility resources.33 Future efforts to expand such a portal should build on the information made available to include up-to-date and locally relevant resources, as well as standardized information on the effect of cancer treatment on fertility. Such a directory should also include a list of specialized centres that have ethics board-approved cryopreservation protocols for procedures that are considered experimental, such as ovarian tissue banking; this is an emerging cryopreservation option for pubertal girls.

Cost is often cited as a prohibitive factor for referring female patients to fertility services.18,30,31 The ethical dilemmas encountered by oncology health care providers in initiating fertility discussions with cancer patients who presumably cannot afford the fees are reported in the research literature.18,31 The fees associated with cryopreservation procedures were also found to be a major barrier for Canadian cancer patients who wanted to preserve oocytes or embryos but did not have the financial means to do so.14 Our findings indicate that medical consultation with REI specialists was covered by public health insurance in all provinces. At present, Quebec is the only province that provides medical insurance coverage for fertility treatments and medications, including fees for cryopreservation procedure.34 Understandably, the assumption of out-of-pocket expenses for medical consultation may dissuade oncologists from referring cancer patients. Fertility clinics need to clearly communicate the fees, the payment options, and the availability of financial subsidy in their fertility preservation programs for oncology patients. Finally, the medical reason for cancer patients undergoing cryopreservation procedures because of the side effects of cancer treatment is not addressed in public health care. There is a strong argument to extend provincial health funding to cover the costs of oncology fertility services, given the medical setting.

This study has identified some important areas to consider for improving patient access to oncology fertility preservation services in Canada based on the data provided by participating fertility clinics. The six key recommendations arising from the study are listed in Table 4.

Overall, a high level of enthusiasm was found among responding IVF centres about providing training to oncology health care providers. Strategic planning in organizing training modules by professional bodies may help to target oncology health care providers with different medical backgrounds and from different practice settings. Finally, institutional endorsement by cancer societies and medical bodies of the importance of considering fertility preservation would help to increase patients’ awareness of taking precautions in protecting fertility. As the window of preserving fertility is time sensitive, more collaborative planning at the regional level between oncology teams and fertility clinics is needed. The development of evidence-based practice guidelines covering medical, psychosocial, ethical, and legal aspects geared to the Canadian health care system would help to avoid ambiguity relating to roles and responsibilities in the provision of fertility services.

Table 4. Recommendations to improve oncology fertility preservation services in Canada

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Establish an up-to-date national directory of fertility clinics that provide fertility preservation consultation and cryopreservation services to cancer patients to increase accessibility of services.</td>
</tr>
<tr>
<td>2.</td>
<td>Develop training programs to provide oncology health care providers with updated knowledge on the novelty and efficacy of fertility preservation options.</td>
</tr>
<tr>
<td>3.</td>
<td>Increase the accessibility of fertility preservation resources and patient educational materials by having the information posted on the websites of major cancer societies and organizations.</td>
</tr>
<tr>
<td>4.</td>
<td>Encourage collaboration between oncology and reproductive medicine to develop robust liaison systems and referral protocols so that cancer patients who are interested in exploring fertility preservation options would have expeditious access to see a reproductive endocrinologist and infertility specialist.</td>
</tr>
<tr>
<td>5.</td>
<td>Evolve a national strategy to address the barriers related to accessing fertility preservation services, including the awareness of fertility risks associated with cancer treatment, and the availability of fertility preservation services at convenient locations.</td>
</tr>
<tr>
<td>6.</td>
<td>Implement a provincial strategy to increase the affordability of fertility preservation services to cancer patients through public health funding.</td>
</tr>
</tbody>
</table>
This study has several limitations. The exact number of facilities providing female cryopreservation services is unknown, since not all clinics replied to the surveys. Clinics with no contact information available on the Internet were not included in the sampling frame. As with all such surveys, clinics with more favourable attitudes towards providing services to cancer patients and more resources allocated to program development may have been more willing to participate in the study. We are unable to compare the differences between respondents and non-respondents. Nonetheless, the findings contribute to the limited data pertaining to the provision of fertility preservation services for female oncology patients in Canada.

CONCLUSION

Although cancer patients seem to be infrequent users of fertility preservation services, growing awareness of the fertility risks associated with cancer treatment have led to a steady increase in patients with cancer seeking consultations about their future fertility. There is a need to develop a stronger partnership between the fields of oncology and reproductive medicine to improve access to fertility preservation services for oncology patients. Such processes would ensure optimization of services so that all cancer patients would receive the best care in protecting their fertility.

ACKNOWLEDGEMENTS

This study was funded by the Canadian Task Force on Adolescents and Young Adults with Cancer, supported by the Canadian Partnership Against Cancer.

REFERENCES


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**APPENDIX 1.**

**Canadian websites used to generate a participant list**

1. Infertility Awareness Association of Canada (http://www.iaac.ca)
2. Infertility Network (http://www.infertilitynetwork.org)
3. Family Helper (http://www.familyhelper.net)
5. Fertilityclinics.ca (http://www.fertilityclinics.ca)
6. IVF.ca (http://www.ivf.ca)
7. Fertile Future (http://fertilefuture.ca)
8. Yellow Pages (http://www.yellowpages.ca)
APPENDIX 2.

Female Oncology Fertility Preservation Service Provision Questionnaire

1. What types of female oncology fertility preservation services are provided by your facility?
2. Does your facility provide on-site IVF, including laboratory services (e.g. oocyte retrieval, and oocyte/embryo freezing)?
3. If your facility provides on-site IVF, do you use satellite clinics to do cycle monitoring for out-of-town patients to minimize their traveling during cycle monitoring?
4. In general, what is the estimated percentage of female cancer patient referrals in each of the following age groups? (i.e. <15 years old, between 15 and 19, between 20 and 24, between 25 and 29, between 30 and 34, and ≥ 35)
5. How does your facility provide cancer specific female fertility preservation information to referrers and cancer patients?
6. On average, how many new female cancer patient referrals does your facility receive per month?
7. In general, when embryo freezing rather than oocyte freezing is considered, what is the percentage of female cancer patients who do not have a male spouse/partner and may require the use of donor sperm when considering fertility preservation?
8. How often does your facility receive female cancer patient referrals from the following sources? (i.e. gynecologists, gynecologic oncologists, pediatric oncologists, medical oncologists, surgical oncologists, radiation oncologists, family doctors, and others)
9. How often does your facility receive referrals from oncology medical professionals who are affiliated with the following groups? (i.e. regional cancer centres, university affiliated teaching hospitals, non-teaching hospitals, community based/group practice, independent medical health care providers, and others)
10. Does your clinic give priority to new cancer patients? If yes, what is the estimated waiting time to book a medical appointment after receiving a referral?
11. What fees are applicable for female cancer patients seeking the following fertility preservation services?
12. Does your facility provide any subsidy for cancer patients seeking cryopreservation services?
13. How does your facility provide counselling to cancer patients who are considering using donor sperm to create embryos for cryopreservation purpose?
14. Has your facility ever been involved in providing training (e.g. seminar and grand rounds) to oncology medical professionals in female fertility preservation?
15. From your practice experience, what do you see as the barriers for female cancer patients to consider fertility preservation prior to cancer treatment? (ranking using a Likert scale)
   a. Lack of support from oncology health care providers for cancer patients to consider fertility preservation
   b. Inadequate support from major cancer societies/organizations to raise patient awareness on fertility preservation issues
   c. Poor collaboration between cancer societies, CFAS and SOGC in developing strategies to address oncology fertility preservation issues
   d. Inadequate patient awareness of the negative impact of cancer treatment on their future fertility
   e. Inadequate patient awareness of the importance of considering cryopreservation prior to cancer treatment to preserve future fertility
   f. Deficient access to accurate female fertility preservation information from reliable sources
   g. Non-availability of fertility specialists for consultation
   h. Location of IVF facilities
   i. Referrals not received in a timely manner
   j. Time pressure of starting cancer treatment
   k. IVF and cryopreservation fees
16. Do you have any recommendations of how to educate oncology health care providers about fertility preservation services and the latest assisted reproductive treatment options?
17. Do you have any recommendations of how to educate cancer patients about fertility issues related to cancer treatment and also fertility preservation services?
18. Do you have any recommendations of how to improve female cancer patients' access to fertility preservation services?