A multidisciplinary evaluation of fertility preservation for oncology patients in Canada

The British Columbia perspective

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ABSTRACT

INTRODUCTION: Infertility represents a devastating side effect of antineoplastic agents, particularly in adolescents and young adults (AYA). A paucity of practitioner-initiated fertility preservation (FP) counseling has resulted in low uptake of assisted reproductive technologies. There is no dedicated FP program in British Columbia (BC) and few across Canada, leaving patients without adequate support. This study aimed to identify, analyze, and prioritize the FP needs of BC oncology patients, predominantly AYAs, according to healthcare providers.

METHODS: An online survey developed by a multidisciplinary team was distributed to practitioners across the British Columbia Cancer Network from March to September 2023. Survey data were analyzed descriptively.

RESULTS: Overall, our survey response rate was 74.2%. Of 120 responses recorded in total, 89 — from 27 oncologists, 58 nurses/nurse practitioners, two family physicians, one fertility specialist, and one care aide — were included in the analysis. While 43.6% of respondents indicated that their patients were likely to be impacted by treatment-related infertility, only 26.8% reported that their patients are usually referred to FP services, and 45.7% reported that their patients receive fertility counseling. Barriers to FP counseling included competing priorities, appointment length, lack of clinical knowledge, urgency to start treatment, perceived futility of FP, and perceived lack of financial resources. Facilitators of FP discussions were awareness, education, financial assistance, provider-initiated discussions, knowledgeable providers, and locally dedicated FP programs.

CONCLUSIONS: This study represents the first characterization of interdisciplinary provider practices and beliefs surrounding FP among oncology patients in BC, highlighting the need for an FP program to improve patient care and quality of life. This data can be leveraged nationwide to inform the development and evolution of FP programs for this critically underserved patient population.

INTRODUCTION

Fertility preservation (FP) has emerged as a critical concern for oncology patients, particularly with the advancement of patient-centered oncologic care.[1] Limited access to specialized pretreatment FP counseling has been associated with feelings of regret and decreased quality of life.[2,3] The populations at the highest risk of being impacted by treatment-related infertility are adolescents and young adults (AYA), defined as individuals aged 15–39 years.[3]

There are several FP options for individuals diagnosed with cancer. The most evidence-based methods in post-pubertal females include mature-oocyte cryopreservation and embryo cryopreservation.[2,4] In post-pubertal males, sperm cryopreservation is effective in FP, while in pre-pubertal boys, testicular tissue cryopreservation is being explored as an experimental procedure.[3,4] Counseling cancer patients on FP can be challenging for healthcare providers because of a lack of knowledge of available options, practical, cultural, and financial obstacles, and time restrictions before treatment onset.[4-10] Further barriers include patient unsuitability, a lack of knowledge concerning available services, and little awareness of increased success rates with FP techniques.[9,10]

The field of oncofertility aims to address these barriers, representing a cross-disciplinary, global collaboration between reproductive medicine and oncology.[11] Accordingly, the implementation of formal oncofer-

KEY MESSAGES

- We surveyed interdisciplinary oncologic healthcare providers in BC on current practices and gaps in fertility preservation (FP) patient care.
- Barriers to FP counseling included time constraints, limited knowledge, treatment urgency, financial concerns, and a sense of futility.
- Increased awareness, provider education, financial support, and dedicated FP programs were identified as factors that promote FP discussions.
- These findings highlight a key gap in patient care and can be used to develop improved FP practices across Canada.

tility programs has significantly increased access to education of FP options for cancer patients, as well as for healthcare providers.[12-14] Currently, the only dedicated AYA oncofertility preservation program in Canada is based at the Princess Margaret Cancer Center in Ontario, for patients aged 39 and younger. Following program implementation, infertility risk documentation increased from 56% to 85%, and FP discussions increased from 54% to 86%;[15] however, widespread implementation of FP programs requires an understanding of practitioner barriers to oncofertility care.

The present study serves as a baseline needs assessment that explores factors influencing oncology patients' access to FP and counseling in British Columbia (BC), Canada, through survey responses elicited from healthcare providers involved in the provision of oncologic care in BC.

METHODS

Survey development and distribution

A comprehensive background literature review of oncofertility programs across North America was conducted to inform the development of relevant themes related to oncofertility preservation. A multidisciplinary working group was established, composed of individuals involved in the provision of care to patients with cancer. The group consisted of medical students and residents, nurse practitioners (NP), oncologists, radiation oncologists, and urologists involved in caring for patients with cancer. The working group refined a final 31-question survey based on identified themes (practitioner and patient barriers/facilitators to FP).

The anonymous survey included multiple-choice, Likert-scale, and open-ended questions. Questions addressed various aspects of FP, including knowledge, attitudes, current practices, and perceived barriers. Comfort level and familiarity with FP were assessed using sliding-scale questions, where 1 corresponded to not comfortable, 5 to neutral, and 10 to very comfortable. Further, participants' attitudes and experiences towards FP were assessed using a sliding scale from 1–0, where 1 corresponded to strongly disagree, 5 to neutral, and 10 to strongly agree. Next, FP counseling practices were assessed via sliding-scale questions, where participants indicated percentages from 0–100 to represent their patient population. The survey distribution period was from March 1 to September 30, 2023. Surveys were distributed via email to cancer care practitioners identified within the BC Cancer organization and BC Children's Hospital Division of Oncology.

Statistical analysis

Descriptive and statistical analysis was performed in Excel. The statistical analysis was done using a two-tailed T-test, whereby the p-value was considered significant if it was <0.05 and highly significant <0.001. Excel was used to create all graphs and visual representations of the data.

RESULTS

Demographics

A total of 120 responses were recorded on the Checkbox software (77 complete; 12 incomplete; 28 left blank). Blank responses were excluded. Therefore, 89 responses were included in the analysis, representing a survey response rate of 74.2%. The majority of respondents (81.1%) identified as women, followed by men (17.8%), and trans women (1.11%). Further, most survey respondents were mid-career, with 83% at least five years into practice. Survey respondents were oncologists (n=27), nurses or NPs (n=58), family physicians (n=2), fertility specialists (n=1), and care aides (n=1).

Attitudes towards fertility preservation

A total of 37% of respondents strongly agreed with the statement, "FP is an expressed concern for my

patients," and 46% strongly agreed with the statement, "FP is a major concern for me when treating my patients" (Figure 1). Most respondents strongly disagreed with the statements, "I am aware of research on FP for oncologic adolescent and young adult patients" and "My training has helped me discuss FP with my patients" (62% and 57% of respondents, respectively) (Figure 1). A total of 43.6% of respondents indicated that their patient population is likely to be impacted by infertility due to treatment, 26.8% of their patient population is referred to FP services, and 45.7% of their patient population receives counseling on the risk of infertility with treatment.

Familiarity with fertility preservation and need for a formalized program

When asked, "In general, what is your comfort level in providing FP counseling for oncology patients?", the mean response was 3.6/10 (95% confidence interval [CI] 2.9, 4.2] for nurses/NP as compared to 6.8/10 (95% CI 5.9, 7.7) for oncologists ($p \leq 0.01$). When asked, "How familiar are you with the referral protocol for FP specialists?", the mean response was 2.9/10 (95% CI 2.2, 3.6) for nurses/NP, as compared to 6.2/10 (95% CI 5.2, 7.3) for oncologists ($p \leq 0.01$). Survey respondents were asked about having an FP referral protocol at their place of work (Figure 2). Most respondents (67.5%) indicated, "I don't know," followed by 18.1% indicating "No," and 14.5% indicating "Yes."

Survey respondents were asked about having ever counseled patients on FP, with 44% indicating "Yes," 33% indicating "No," and 22% indicating that a colleague had performed FP counseling. Survey participants identified oncologists as the primary responsible party for FP counseling (54% of respondents), followed by nurses or NP (12%). When asked when FP discussions should be initiated, 30% of respondents indicated "At diagnosis," 32% indicated "Prior to treatment," and 38% indicated "All of the above." Respondents were asked, "Do you agree with introducing a FP question prior to initiating cancer treatment?" and "Do you agree with introducing a FP checklist prior to initiating cancer treatment?". Most participants supported a pretreatment screening prompt at this visit (84%).

Fertility preservation education and enablers

When asked about the education received on the topic of FP for oncology patients, 61% of survey respondents indicated they had never received focused FP education. The remainder endorsed receiving education in the form of grand rounds (11%), lecture series (8%), fellowship (1%), education days (1%), and other (16%). Survey respondents identified several additional training resources that would help bolster their FP knowledge, including clinical practice guidelines and care pathways (Table 1).

Survey respondents selected face-to-face discussions (25%), a dedicated FP program (19%), and pamphlets (16%) as the preferred means of communication about FP to patients. Patient populations selected to be most at-risk included two-spirited or non-binary, perceived to be older than typical child-bearing age, those with a poor prognosis, patients clinically too unwell to delay treatment potentially, and patients with language barriers. The most selected facilitators of FP discussion were increasing awareness and education on FP (11%), financial assistance (11%), providers initiating the discussion on FP (10%), knowledgeable providers (10%), and a dedicated FP program (10%) (Table 2).

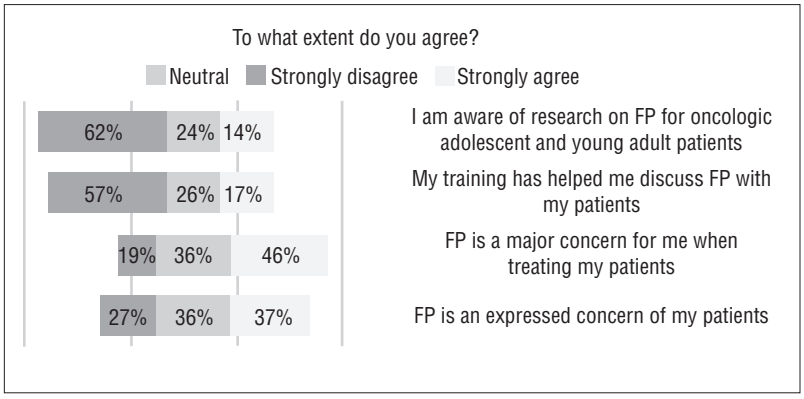

Figure 1. Responses to the question, "To what extent do you agree?" to the four statements listed. Results are expressed as a percentage of total responses, with n=81 respondents. The response rate was 67.5% for this question.

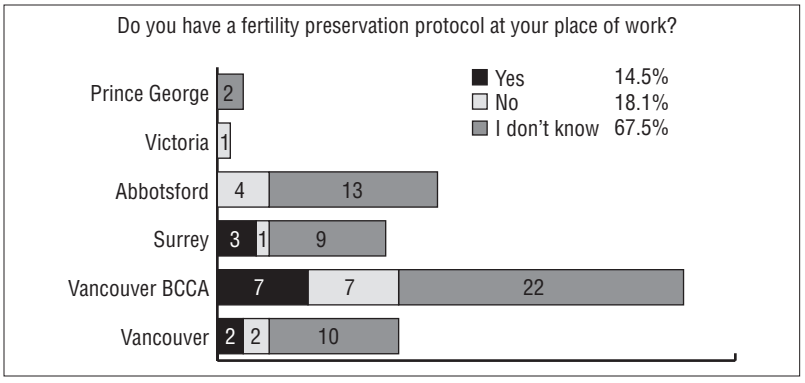

Figure 2. Responses to the question, "Do you have a fertility preservation protocol at your place of work?" stratified by location, n=83 respondents. The response rate was 69.2% for this question. BCCA: British Columbia Cancer Agency.

Table 1. Responses to the question, "What type of additional training would be helpful to equip you with information and logistical knowledge surrounding fertility preservation?"

Additional training	Count
Clinical practice guidelines or care pathway	43
Online modules	35
Training specific to adults and young adults (15–39)	35
Website resource	34
Grand rounds	33
Virtual lecture series	28
Pamphlets	16
All of the above	34
None of the above	1

Survey respondents were asked to select all statements that applied. Multiple responses could be recorded, n=259 (response rate 75 participants, 62.5%).

Table 2. Responses to the question, "Which of the following can facilitate patient access to fertility preservation services?"

Demographic characteristics, n		Health status & prognosis, n		Socioeconomic factors, n	
Two-spirited or non-binary	74	Patient with poor prognosis	63	Patient/family with language barriers	56
Patient who is perceived to be older than typical child-bearing age	63	Patient clinically too unwell to potentially delay treatment	62	Perceived cultural preferences of patient or family	36
Pediatric patient lacking emotional maturity	49	Prioritizing fertility preservation may compromise cancer outcome	50	Patient/family experiencing financial difficulties	34
Pediatric patient (non-child-bearing age)	45	Patient with high-risk cancer	38		
Biological female who identifies as a man or biological male who identifies as a woman	37	Perceived lack of therapeutic options	30		
Patient with non-heterosexual orientation	35				
Patient not in a relationship	32				

Survey respondents were asked to select all statements that applied. Multiple responses could be recorded, where n=705 selections (response rate 76 participants, 63.3%).

Barriers to fertility preservation

Respondents were asked to identify issues that limit FP conversations. Respondents cited competing priorities or lack of time in the clinical encounter (33% of respondents), followed by lack of clinical knowledge (24%), urgency to start treatment (17%), perceived futility for FP (10%), perceived lack of financial resources (9%), and other (7%). Survey respondents were asked, "Which of the following prevents patients from accessing fertility preservation services?". Respondents cited treatment cost (68% of respondents), patient's clinical status (62%), timeliness of access to fertility center services (60%), emotional preparedness (48%), patient age (47%), patient's distance from fertility center (37%), patient/family cultural or religious beliefs (33%), availability of psychosocial support (31%), invasiveness of procedure (29%), and limited or unproven/unestablished options (1%).

DISCUSSION

This survey-based provincial needs assessment reveals the attitudes and practices of healthcare professionals across BC involved in oncologic care. Overall, attitudes towards FP among healthcare providers varied, with just under half of participants indicating that FP is a major concern for them when treating patients. Of concern, over half of respondents strongly disagreed that their training had prepared them to discuss FP with patients. This was reflected in the FP counseling practices, with respondents indicating that, on average, 43.6% of their patient population is likely to be impacted by infertility due to treatment, yet only 26% of their patient population is referred to FP.

A gap in integrating FP into clinical practice is also possibly influenced by factors such as reduced comfort level and familiarity with FP among healthcare providers. Oncologists demonstrated significantly higher levels of comfort and familiarity with FP compared to nurses and NPs, highlighting the importance of targeted training and support, particularly in areas of Canada without readily available access to specialists. The absence of standardized FP referral protocols may further complicate the delivery of FP services, with a lack of written information and consensus on clinician-driven FP counseling known to delay access to FP.[5,6,16]

Our findings are broadly consistent with existing literature. A large, cross-sectional study using data from the American Society for Reproductive Medicine and the American Society of Clinical Oncology Quality Oncology Practice Initiative looked at FP counseling prior to chemotherapy (n=6976 patients). It found that 44% of patients obtained FP counseling, with women being more likely to receive counseling, and the frequency of counseling decreasing with patient age.[17] Similarly, in a Japanese study of 167 AYA cancer survivors who had received chemotherapy, only 42.3%

had received pretreatment information on FP methods. Oncologists from this survey cited lack of time for the discussion, perceived high cost, and lack of convenient facilities.[18]

In a pediatric study, referrals to fertility specialists were initiated >50% of the time by 46% of pediatric oncologists for pubertal oncologic male patients and 12% for pubertal oncologic female patients.[19] The most likely reasons not to recommend sperm banking included poor survival prognosis, aggressive disease, and lack of parental consent, with clinician discomfort representing the least likely reason.[5,6,15,16]

A lack of written information and unclear roles surrounding the most responsible clinician for driving FP counseling has contributed to challenges in establishing a dedicated FP team, a framework for patient-centered fertility counseling, and limited awareness of advocacy organizations.[6,9,20-22] Unfortunately, many patients are unable to access FP counseling as part of their care due to a complex interplay of patient and healthcare system factors.[23,24]

Organizations focused on FP include the Oncofertility Consortium and the International Society for Fertility Preservation.[25] The Oncofertility Consortium, a NIH-funded cooperative with over 140 oncofertility centers in the U.S., has played a significant role in advancing oncofertility services.[26] On a global scale, the International Society for Fertility Preservation is a non-profit organization that holds biennial congresses to share FP research, advancements in FP practice, and educate providers on FP.

Another example is the University of Miami Miller School of Medicine's FP program, initiated in 2016, consisting of FP counseling, an andrology laboratory, surgical equipment, specialized staff to perform invasive sperm retrieval, and an interdisciplinary research network. The rates of sperm banking among newly diagnosed oncologic patients increased from 3.3% in 2016 to 19.3% following the program's implementation.[12]

From a pediatric standpoint, the Pediatric Initiative Network of the Oncofertility Consortium has provided guidance for healthcare providers in establishing pediatric FP programs. Their aim is to create resources for FP counseling in children and adolescents, disseminating knowledge in biannual meetings and regular webinars. They also have developed a Best Practices subcommittee that has taken on projects such as stratifying future infertility risk in the pediatric population after gonadotoxic treatment.[27]

In our study, the main limitations to initiating FP discussions included competing priorities or lack of time in the clinical encounter, lack of clinical knowledge, urgency to start treatment, perceived futility for FP, and perceived lack of financial resources. One proposed explanation for decreased FP discussion initiation has been that clinicians may be unaware of the latest FP technologies and have been reported to lack confidence in discussions with patients, particularly when asked questions by patients;[28] however, in our study, only 1% of survey respondents indicated limited or unproven/unestablished options. Nonetheless, 61% of respondents indicated they had not received any education on FP.

Patient populations selected to be most at-risk included two-spirited or non-binary patients, reflecting the need for expanding FP to gender and sex-diverse individuals, in particular, given the limited research available on fertility in transgender and diverse sex development patient populations.[29] At the same time, some factors influence decision-making for patients and providers alike that were not captured in this survey. For instance, parity and marital status have been shown to impact patients' and providers' willingness to discuss FP.[30]

Overall, this study highlights the complexities and challenges inherent in integrating FP into oncology care and underscores the importance of addressing these issues to optimize patient outcomes and quality of life. A key strength of this study is the integration of allied health perspectives across an entire provincial network, providing well-rounded insight into this neglected area of patient care. Continued efforts to enhance FP awareness, education, and accessibility are essential to ensure that all patients have equitable access to FP options and support throughout their cancer journey.

CONCLUSIONS

The barriers experienced by cancer care providers underscore the importance of creating dedicated FP programs nationwide to address gaps in oncologic care and the underuse of oncofertility services. The results of this study can inform implementation strategies for a potentially organized future FP program in the Canadian healthcare context and help address gaps in education and awareness among healthcare providers. Additionally, identified barriers emphasize the need for improved structures, resources, and financial support to enhance accessibility to FP services across the province. Future research should focus on eliciting patient perspectives to address these barriers and enhancing the integration of oncofertility services into standard cancer care protocols to ensure equitable access for all patients.

COMPETING INTERESTS: Dr. Smrke has been and advisory board member and received consultant fees from BI, Dynamed, Eisai, GSK, Medison, and Merck. Dr. Peacock holds a leadership role with Inspire Health. Dr. Flannigan has received consulting fees, speaker honorarium, and fellowship educational grants from Boston Scientific, Coloplast, and Ferring; is co-founder, executive, and shareholder of Teumo Health Technologies inc., a digital health company for sexual medicine; and is principal investigator for a phase 1 and phase 2 clinical trial of slow-release lidocaine and an upcoming trial of intraurethral prostaglandin gel for erectile dysfunction supported by Sustained Therapeutics. The remaining authors do not report any competing personal or financial interests related to this work.

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