# An environmental scan of sexual health services for cancer survivors among Canadian institutions

Ryan Flannigan[1,2*], Andrew Matthew[3*], Sydney Sparanese[1,2*], Eugenia Wu[2], Steven Guirguis[3], Monita Sundar[2], Fred Saad[4], Andrew Loblaw[5], Jessica Nargi[6], Luke Witherspoon[1,2], Christina Canil[7], Ricardo A. Rendon[8], Laura Labelle[9,10], Jill Turner[11,12], Celestia Higano[1,2]

[1]Department of Urologic Sciences, University of British Columbia, Vancouver, BC, Canada; [2]Prostate Cancer Supportive Care Program, Vancouver Prostate Centre, Vancouver, BC, Canada; [3]Department of Surgical Oncology, Princess Margaret Cancer Centre, Toronto, ON, Canada; [4]Department of Surgery, Division of Urology, Centre Hospitalier de l'Université de Montréal, Université de Montréal, Montreal, QC, Canada; [5]Odette Cancer Centre, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, ON, Canada; [6]Department of Physical Therapy, University of Toronto, Toronto, ON, Canada; [7]Department of Medicine, Division of Medical Oncology, The Ottawa Hospital and the University of Ottawa, Ottawa, ON, Canada; [8]Department of Urology, Queen Elizabeth II Health Sciences Centre and Dalhousie University, Halifax, NS, Canada; [9]Supportive Care Lead, South Cancer Care Alberta, Alberta Health Services, AB, Canada; [10]Division of Psychosocial Oncology, Department of Oncology, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada; [11]Supportive Care Lead, North Cancer Care Alberta, Alberta Health Services, AB, Canada; [12]Division of Palliative Medicine, Department of Oncology, University of Alberta, Edmonton, AB, Canada

*Equal contributor*

Cite as: Flannigan R, Matthew A, Sparanese S, et al. An environmental scan of sexual health services for cancer survivors among Canadian institutions. *Can Urol Assoc J* 2023;17(2):61-3. http://dx.doi.org/10.5489/cuaj.8093

Published online September 30, 2022

## NEED FOR SEXUAL HEALTH SERVICES

Following treatment, cancer survivors face many lasting side effects that can negatively impact their quality of life. Sexual dysfunction, in particular, is cited as one of the most common and challenging side effects in gynecological and urological malignancies.

Among Canadian men, prostate cancer is the most common malignancy. The side effects of treating prostate cancer pose significant obstacles, including sexual dysfunction (i.e., erectile dysfunction, loss of libido), urinary incontinence, complex pain, and fatigue. Erectile dysfunction is reported to be as high as 60–70% in patients treated with nerve-sparing radical prostatectomy and between 20–50% in patients treated with radiation therapy. Upwards of 60% of men report "moderate" to "big" bother with their sexual symptoms two years post-surgery, further underscoring the deleterious and lasting effects on their quality of life. Systemic therapies, such as androgen deprivation therapy, are associated with detrimental effects on sexual function, including five- to six-fold increased risk of reduced libido, impaired penile contractility, and reduced response to phosphodiesterase type 5 inhibitors.

Adjustment after cancer treatment requires individualized, patient-centered approaches to navigate changes in sexual function. There is increasing evidence supporting a biopsychosocial approach to holistically address the medical, psychological, and interpersonal aspects of sexual health (SH). In Canada, there is ongoing work to adapt this framework in establishing cancer survivorship resources and clinics to address the sexual dysfunction among survivors and their partners.

## DEVELOPMENT OF THE CANADIAN ONCOLOGY SEXUAL HEALTH INITIATIVE

Despite the demand, SH needs in the oncology patient population are currently underaddressed and underfunded. Multidisciplinary SH clinics in oncology settings are uniquely positioned to address the complexities of cancer-related SH concerns. The Canadian Oncology Sexual Health Initiative (COSHI) was conceived to facilitate and improve the delivery of SH resources across Canadian cancer care settings. COSHI proposes a national, multidisciplinary coalition of SH experts working towards the following objectives: 1) develop SH virtual resources for cancer centers; 2) develop standardized treatment protocols for SH; 3) develop cancer-type-specific guidelines for SH treatment; 4) leverage a nationwide team approach to research SH in oncology settings, and develop novel treatment strategies and resources. COSHI will begin with a focus on prostate cancer and then expand to include other cancer subtypes across biological sex and gender.

KEY MESSAGES

- This is the first prospective, survey-based study comparing patient and physician thresholds for NOA treatment successes and associated costs.
- Urologists underestimate the minimum acceptable increase in outcomes of pregnancy and live birth patients would tolerate for additional NOA treatment.
- Urologists' estimates of financial thresholds for additional NOA treatment were concurrent with patients' reported values.

Clinical programs that provide sexual medicine for cancer survivors were contacted to participate in the development of COSHI, with purposeful effort to ensure regional and multidisciplinary representation. In June 2021, a meeting was held to define the scope, mission, and governance of COSHI. It was agreed that an essential first undertaking was to characterize the current state of programmatic sexual healthcare in oncology in Canada. Accordingly, the COSHI team developed and distributed a survey querying the nature or characteristics of the sexual healthcare offered at 13 healthcare institutions. The participating institutions were purposefully sampled to ensure regional and multidisciplinary representation of sexual medicine provision in oncology in Canada.

## SURVEY RESULTS

Of the 13 institutions participating, 12 cancer centers, representing a broad regional and multidisciplinary scope, reported on the delivery of SH care in oncology in Canada. All sites reported at least some form of SH care: seven have clinics for cancer-specific care, three have SH clinics for all cancers, regardless of organ site, and five have sexual education classes. These are offered mainly in person, with fewer sites offering virtual care or web-based educational materials. MDs (urologists) provide patient care at most locations, with 50% or fewer programs having dedicated psychologists, counsellors, physiotherapists, or social workers. While nearly all institutions that were reached with our survey identified that the partners of patients are actively involved in the treatment, there was a noticeable gap in the provision of care that is inclusive of gender and sexual diversity. The collection of patient-reported outcomes was inconsistently reported. All centres polled agree that SH should be an integral part of cancer care for Canadians, but many additionally identified that, at present, this was a gap in patient care.

## CALL TO ACTION

Sexual dysfunction in cancer survivors is complex and requires a treatment plan addressing the physiological and psychosocial factors that contribute to sexual identity, mental health, and overall quality of life. While most centers reached with this survey do have some form of SH educational materials to offer cancer survivors, all responding institutions agreed that their programs would benefit from more resources to address this perceived gap in patient care. We identified the following potential areas for improvement:

1. Given advancements in digital healthcare, web-based interventions can provide an innovative and accessible model of oncological sexual healthcare. Compounded by the current COVID-19 pandemic, existing literature has demonstrated a desire for virtual health interventions in cancer survivorship and SH.
2. Survivorship programming is shifting to include a biopsychosocial perspective to focus on the interpersonal and psychological factors contributing to sexual function. SH clinics would benefit from a multidisciplinary team, including psychosocial practitioners (e.g., social workers and psychologists), sex therapists, and nurses trained to examine the psychosocial factors affecting sexual dysfunction: arousal, desire, masculinity, grief, and anxiety.
3. To quantify where patients experience gaps in care, it is critical to establish baseline and ongoing assessments of patient and partner experience in biopsychosocial domains of wellness using validated questionnaires and clinical interviews. This would provide enormous potential for creating a national database that will enable quantification of the efficacy of ongoing sexual rehabilitation interventions, identification of areas for improvement and development, and development of research strategies.
4. Accounting for diversity in sexual identity and relationships is critical during sexual rehabilitation, and personalized programming to account for differences in SH goals is essential for equitable care. The side effects of prostate cancer treatment create different challenges

for men who have sex with men: this population may experience disproportionate changes in self-esteem and psychological distress, which contribute to a more significant decline in quality-of-life metrics and less satisfaction with their medical care when compared to heterosexual men.

## CONCLUSIONS

There is a need for improved access to interdisciplinary, culturally safe treatment approaches and educational materials with collection of standardized outcomes to evaluate their efficacy. These results underpin the importance of the establishment of this initiative. COSHI proposes a national, multidisciplinary coalition of SH experts working to develop globally accessible resources for cancer survivors, standardized sexual health treatment protocols and cancer-specific guidelines for healthcare providers, and the development of a national database that is inclusive of clinical and patient-reported outcomes of SH in a stepwise approach.

COMPETING INTERESTS: Dr. Flannigan has been an advisory board member for Acerus Labs (Natesto); received speaker honoraria from Boston Scientific and Paladin Labs; received a fellowship grant from Boston Scientific; and has been the principal investigator on scrotal pain phase 1 clinical trial supported by Sustained Therapeutics. Dr. Saad has been an advisory board member for and has received payment/honoraria from Amgen, Astellas, AstraZeneca, Bayer, Janssen, Knight, Myovant, Novartis, Pfizer, Sanofi, and Tolmar; and has participated in clinical trials supported by Amgen, Astellas, AstraZeneca, Bayer, Janssen, Novartis, Pfizer, and Sanofi. Dr. Canil has been an advisory board member for Bayer, BMS, Eisai, Ipsen, Janssen, Merck, Pfizer, and Seattle Genetics; is a member of the Genitourinary Research Committee (sponsored by Janssen); has been a speaker for Janssen; has participated in clinical trials supported by Eisai and Pfizer; and is on the Medical Advisory Board of Kidney Cancer Canada. Dr. Rendon has been an advisory board and speakers' bureau member for and has received honoraria from AbbVie, Amgen, Astellas, Astra Zeneca, Bayer, Ferring, Jansen, Pfizer, Roche, Sanofi, and Tolmar; has received honoraria/grants from AbbVie, Astellas, Bayer, Ferring, Janssen, Sanofi, TerSera, and Tolmar; holds investments in Myovant; and has participated in clinical trials supported by AbbVie, Astellas, Bavarian Nordic, Bayer, Ferring, Janssen, Myovant, and Sanofi. Dr. Higano has participated in one-time advisory boards for Astellas, AstraZeneca, Genetech, Menarini, Merck, Myovant, Sharp & Dohme, Tolmar, Vaccitech, and Verity; has received payment from: Alliance Foundation, AstraZeneca, Candel, Exelixis for trials conducted by these companies in prostate and/or bladder cancer; has serve as a consultant to the Prostate Cancer Clinical Trials Consortium as a medical monitor and member of the operations team; is the consulting Medical Director of the Prostate Cancer Supportive CAre Program; hold investments in CTI Biopharma; and was a member of the Steering Committee and one of the principal investigators for the PRONOUNCE trial supported by Ferring. The remaining authors do not report any competing personal or financial interests related to this work.

This paper has been peer-reviewed.

CORRESPONDENCE: Dr. Sydney Sparanese, Department of Urologic Sciences, University of British Columbia, Vancouver, BC, Canada; sydney.sparanese@alumni.ubc.ca