

Practice patterns and perceptions of survivorship care in Canadian genitourinary oncology: A multidisciplinary perspective

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Abstract

Introduction: There is little knowledge of survivorship care specific to genitourinary (GU) cancers. To improve care delivery to this patient population, we need to clearly define physician perceptions of survivorship care. We therefore conducted a study to determine the challenges to GU cancer survivorship care in Canada.

Methods: A web-based questionnaire was e-mailed to physicians treating GU cancers in Canada, including urologists, radiation oncologists, and medical oncologists. Five domains were assessed: demography, current post-cancer treatment care, perspectives on barriers to survivorship care, accessibility to survivorship resources, and perspectives about advocacy groups.

Results: There were 306 responses, with 260 eligible for study. A total of 82% of physicians involve primary care practitioners (PCPs) at some point in survivorship care. Most physicians provide some form of written follow-up plan to PCPs. However, only 25% provided lifestyle recommendations and 53% included persistent and late effects of therapy. Lack of time or resources dedicated to survivorship care was the most commonly reported barrier. There was variation in accessibility to survivorship support programs among different subspecialties and regions. Advocacy groups generally were underutilized, particularly in testis cancer. Low response rate and the potential response bias are the main limitations of this survey.

Conclusion: To our knowledge this is the first study to address the challenges of GU cancer survivorship care in Canada. The barriers and accessibility of survivorship care quoted in this survey may be used to improve care for this group of patients. Underutilization of advocacy groups may stimulate the advocacy groups and institutions to address its causes and solutions.

Introduction

With improvements in healthcare systems, earlier cancer detection, and effective cancer treatments, the number of cancer survivors is rapidly increasing in Canada and may double by 2020.¹⁻³ Cancer survivorship is generally felt to begin when primary treatment ends and survivorship continues until disease recurrence, second malignancy or death.² Survivors face a range of complex medical and psychosocial issues.²

Genitourinary (GU) cancer patients constitute the largest single disease group of Canadian cancer survivors, accounting for over 50% of male cancer survivors and nearly 25% of all cancer survivors.⁴ However, according to a Canadian report, the proportional investment in prostate and bladder cancer survivorship research is well below what would be expected given the disease burden and there was notably no investment in kidney cancer survivorship.³ A Canadian GU survivorship meeting held in 2011 highlighted the urgent need for improved GU survivorship care. Meeting participants identified the value in (1) the collaboration between clinicians, researchers and cancer survivors/advocacy groups and (2) enhanced access to GU cancer survivorship resources and services.⁵

To date there is limited information regarding GU cancer survivorship care in Canada and worldwide. There have been many surveys assessing physician attitudes towards cancer survivorship for breast and colorectal cancer, but none for GU cancer. There have also been national studies in the United States and Canada to assess the attitudes of oncologists and primary care physicians (PCP) on the delivery of cancer survivorship care, but mainly for non-GU cancers.^{6,7} Finally, a 2008 Canadian report raised the issue that follow-up practice and services for cancer survivors are inconsistent across the country.⁸ To address these gaps,

we examined current GU cancer physicians' attitude and perception toward cancer survivorship care in Canada. We hypothesized that there is heterogeneity in the attitudes and perceptions of GU cancer physicians toward cancer survivorship care and between different subspecialties involved in the primary treatment of GU cancers. Furthermore, there may be geographic variability as health care is a provincial responsibility. Finally, facilities at university-affiliated hospitals may differ from community hospitals – this may also contribute to the heterogeneity.

Finally, participants at the 2011 Canadian GU survivorship meeting highlighted that clinicians and researchers lacked awareness of the capabilities of cancer patient advocacy groups – we have also addressed this issue.⁵

Methods

Survey instrument development

Our survey instrument was based on questionnaires developed at the Roswell Park Institute in Buffalo⁹ and the Electronic Living Laboratory for Interdisciplinary Cancer Survivorship Research (ELLICSR), a health, wellness and cancer survivorship centre at Princess Margaret Hospital.

In total, 27 questions were developed and categorized in 5 domains (1) participant demographic characteristics (8 questions); (2) current post-treatment care practice (3 questions); (3) perspectives on barriers to practicing survivorship care (4 questions); (4); accessibility to survivorship resources (7 questions); and (5) their perspectives regarding GU advocacy groups (5 questions). Questions were either multiple choice or 5-point unipolar Likert scale type questions (<http://journals.sfu.ca/cuaj/index.php/journal/article/view/2279/1949>). A French language translation was piloted to assess comprehension and accuracy. The survey was approved by the University Health Network Research Ethics Board.

Survey administration

The web-based survey was distributed by e-mail using a secure, Canadian-based survey platform¹⁰ to all urologists, radiation oncologists and medical oncologists using distribution lists maintained and provided by the Canadian Urological Association (CUA), the Canadian Association of Medical Oncologists (CAMO) and the Canadian Association of Radiation Oncologists (CARO). We used a non-targeted recruitment strategy to capture both university- and community-affiliated physicians. Only physicians treating GU cancer were invited to access the web-based survey. An informed consent statement appeared in the e-mail script and completion of the survey indicated implied consent. The links to both English and French versions were pro-

vided for participants to choose their preferred language. To enhance the response rate, potential participants were given the opportunity upon survey completion to enter their names and contact information for a draw for 1 of 3 prizes worth \$400 to \$600. An email reminder of the survey was sent 2 weeks following the initial e-mail invitation.

Statistical analysis

Descriptive statistics using SAS software version 9.2 were performed. The chi-square test was used to assess association between question responses and demographic criteria: (1) subspecialty; (2) geographical region of practice; and (3) practice base (university vs. community hospital). A $p \leq 0.05$ was considered significant for all tests. Surveys with demographic responses only were censored from analysis. For clarity, the 5-point Likert scale questions have been grouped into 3 in the analysis of the survey. Responses never and rarely were grouped as rarely; often and always grouped as often. This produced 3 groups; often, sometimes and rarely. The 5-Likert point question for the accessibility of survivorship care recourses were also grouped for analysis: very accessible and accessible to easily accessible; difficult to access and very difficult to access grouped to difficult to access producing (easily, moderately and difficult to access).

Results

The survey was distributed to 1775 physicians: 632 urologists, 800 radiation oncologists and 343 medical oncologists. Nearly all urologists, 25% of CAMO members and 10% of CARO members treat GU cancers. These latter numbers were extrapolated from the membership of the academic GU oncology societies. A total of 306 physicians completed the survey of the 800 estimated to be eligible, for a response rate of 38% (Fig. 1). We tallied the demographic characteristics of participating physicians (Table 1).

Practice patterns of GU physicians

In post-treatment survivorship care practices, about half of the respondents reported discharging patients to the PCP at some point during follow-up (Fig. 2). There was a significant association between follow-up care practice patterns and subspecialty, geographical location of practice, and practice base (university affiliated vs. community hospitals) ($p \leq 0.05$). Among the radiation oncologists ($n = 90$), 75% of respondents discharged survivors at some point to the PCP compared to medical oncologists at 53% ($n = 45$) or urologists at 42% ($n = 125$). Conversely, urologists were most likely to share follow-up care with the PCP indefinitely (37%) compared to medical oncologists (22%) and radiation oncologists (13%). Urologists were more likely to exclude the PCP

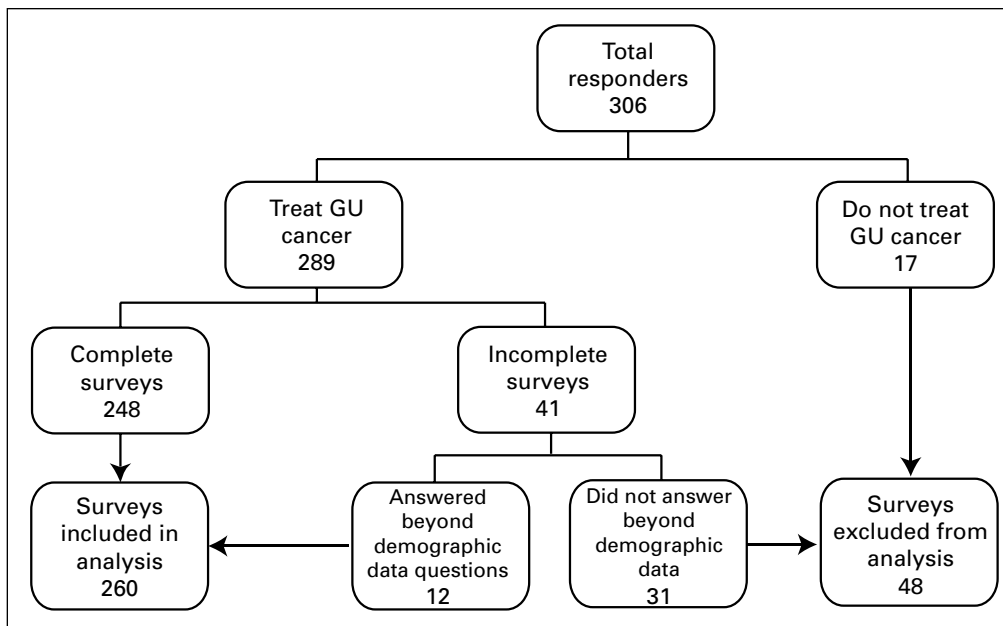


Fig. 1. Pattern of responses from the various physician groups.

from cancer-related follow-up (18%) compared to radiation oncologists (7%) and medical oncologists (4%). There was wide geographic variation in post-treatment follow-up care (Fig. 3). Physicians working in university-affiliated hospitals were most likely to discharge survivors at some point to the

PCP (63%) compared to physicians in the community (41%), who often excluded the PCP from follow-up care.

Physicians who reported PCP involvement ($n = 230$) were asked if a written care plan was provided to the PCP to guide follow-up practices. About 47% answered always, 33% often, 12% sometimes, 6% rarely and 3% answered never. To further evaluate written survivorship management practices, physicians who reported providing a written plan were also asked about the content of the written plan (Fig. 4). Most respondents included the diagnosis, stage, and summary of treatment, including toxicities experienced and surveillance guideline for identifying recurrent disease; only 53% included expected persistent and late effects of therapy and only 25% included lifestyle recommendations. The only association was found between providing lifestyle recommendations and the subspecialty groups ($p < 0.05$). While 36% ($n = 102$) of urologists and 24% ($n = 41$) of medical oncologist provided lifestyle recommendations in their written care plans, radiation oncologists provided these recommendations in their written plans only 10% ($n = 79$) of the time. There was no association between providing lifestyle recommendations and the geographical location or practice base.

Barriers to meeting the post-treatment survivorship needs of GU patients

Most respondents (50%) identified a lack of time or resources to support patients through this phase of their cancer experience as the most frequent barrier (Fig. 5). Survey responses for this domain were not associated with the subspecialty, geographical area of practice or practice base ($p > 0.05$).

Table 1. Demographics of the responders

	Frequency ($n = 260$)	Percentage (%)
Subspecialty		
Urology	125	48
Medical Oncology	45	17
Radiation Oncology	90	35
Region of practice		
British Columbia	32	12
Prairie provinces	46	18
Ontario	121	47
Quebec	41	16
Atlantic Canada	19	7
Duration of practice teaching GU cancers		
<10 years	108	42
10 to <25 years	102	39
≥25 years	50	19
No. with additional training in GU cancer	99	38
Practice type		
Community	80	31
University-affiliated	152	58
Both	26	10
No. affiliated with provincial cancer centres	200	77
No. who attended a course or workshop in survivorship care	82	32

GU: genitourinary.

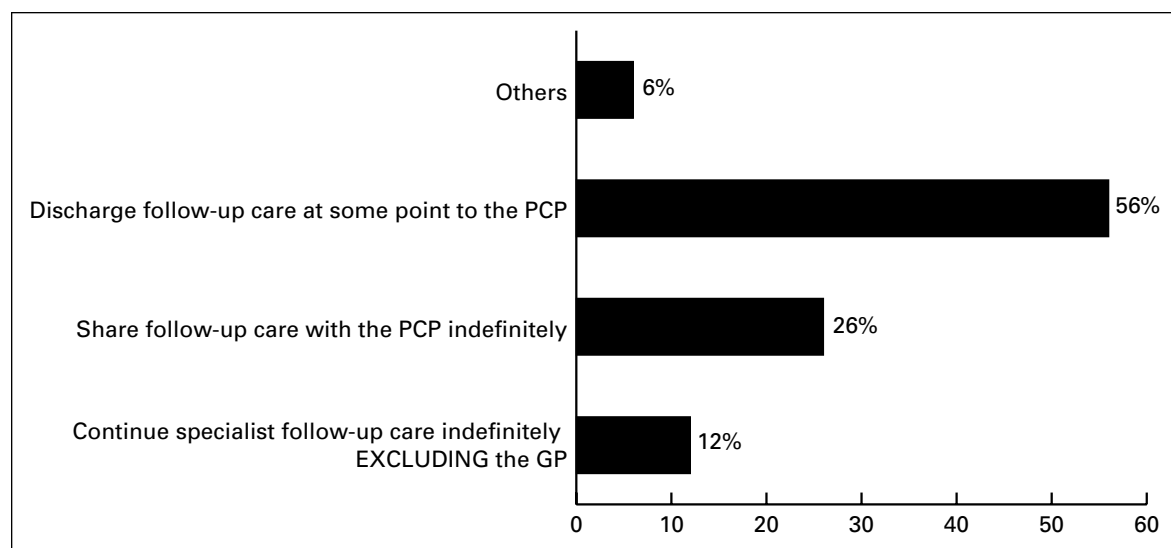


Fig. 2. Frequency of follow-up care patterns. GP: general practitioner; PCP: primary care practitioner.

Physician's perspective of accessibility of services to patients

Of the respondents, 44% ($n = 254$) reported that cancer rehabilitation programs were most difficult to access. The other services were less frequently difficult to access: genetic counselling (38%), fertility counselling (30%), and psychosocial support (30%) (Fig. 6). We observed an association between difficulty in accessibility and the use of psychosocial support and genetic counselling programs within the subspecialty groups ($p < 0.05$). While 45% ($n = 123$) of urologists reported difficulty accessing psychosocial support programs, only 23% ($n = 43$) of medical oncologists and 10% ($n = 88$) of radiation oncologists reported similar experiences. Similarly, 48% of urologists and 35% of radiation oncologists reported difficulty accessing genetic counselling, compared to only 14% of medical oncologists.

There was an association between geographical location of practice and reported difficulties in accessing rehabilitation programs ($p < 0.05$). While 91% ($n = 32$) of physicians in British Columbia reported difficulty, participants from other areas reported lower rates of difficulty (44% [$n = 18$] for the Atlantic provinces, 42% [$n = 41$] for Quebec, 37% [$n = 117$] for Ontario and 31% [$n = 45$] for the Prairies).

Physicians practicing in community hospitals reported greater difficulty in accessing survivorship care services compared to physicians at academic centres: psychosocial support (48% vs. 18%), pain management (20% vs. 12%), fertility (46% vs. 20%) and genetic counselling programs (48% vs. 29%), respectively ($p < 0.05$).

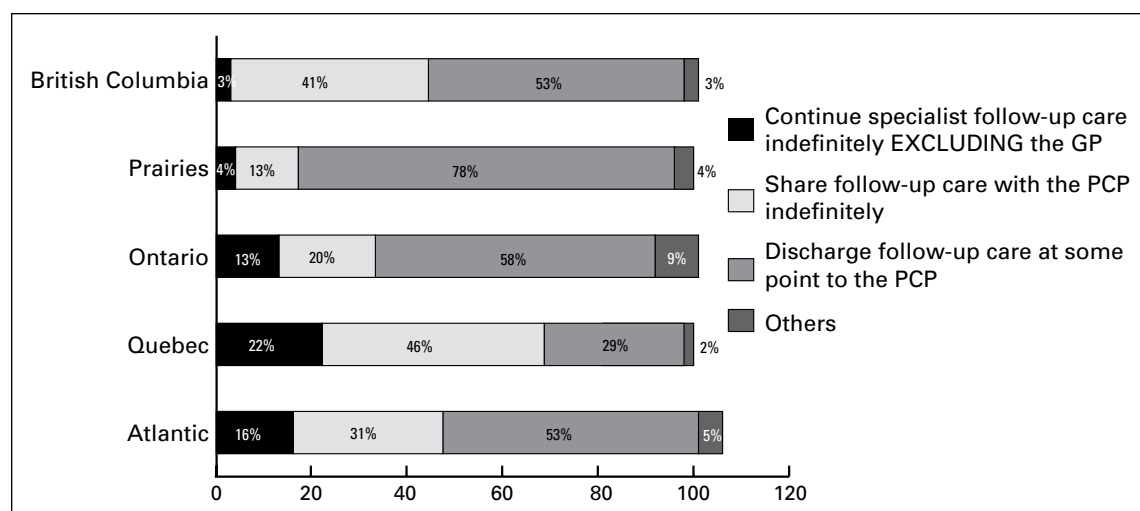


Fig. 3. Post-treatment follow-up care in different regions.

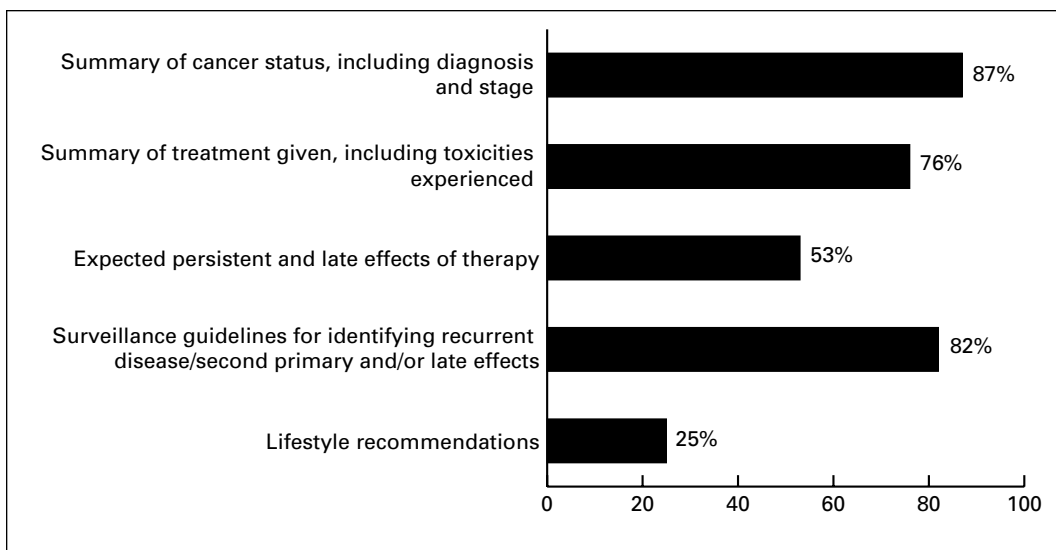


Fig. 4. When a written care plan was provided, what components were included? (n = 230).

Referrals to patient advocacy groups

Overall, referral to patient advocacy groups is low for all physicians caring for GU cancer survivors (Fig. 7). While there was no association between referral rates to Testicular Cancer Canada and the different subspecialties, differences were observed for bladder, prostate and kidney cancer advocacy groups ($p < 0.05$). Urologists were the most likely to refer to bladder advocacy groups 26% (n = 121) compared to 21% (n = 43) and 2% (n = 84) for medical oncologists and radiation oncologists, respectively. Medical oncologists refer patients to kidney cancer advocacy groups more frequently than urologists (51% vs. 27%). Urologists were most

likely to refer patients to prostate cancer advocacy groups (62%) compared to radiation oncologists (42%) and medical oncologists (32%).

There was an association between the frequency of referral to Prostate Cancer Canada and the geographical location of practice ($p < 0.05$). Physicians from Quebec were the least likely to refer patients to prostate cancer advocacy groups 30% (n = 40).

In total, 248 respondents selected 3 initiatives to collaboratively enhance survivorship care with the advocacy groups (in order of preference): (1) create a website to describe all relevant cancer advocacy groups, community supports and their services (81%); (2) create a pamphlet to describe

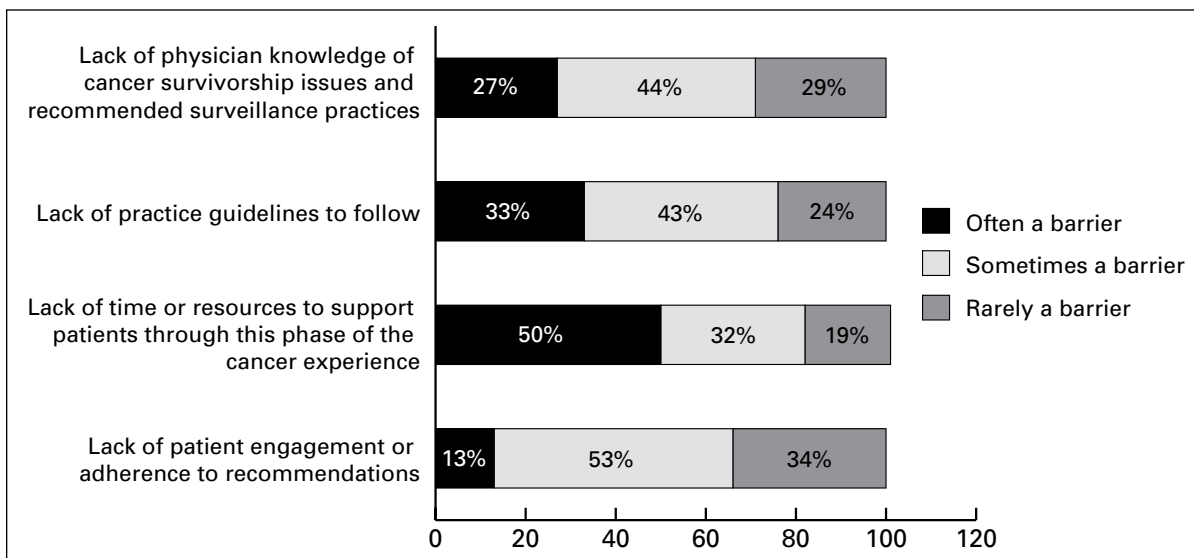


Fig. 5. Barriers to meeting the post-treatment care needs of survivors? (n = 254).

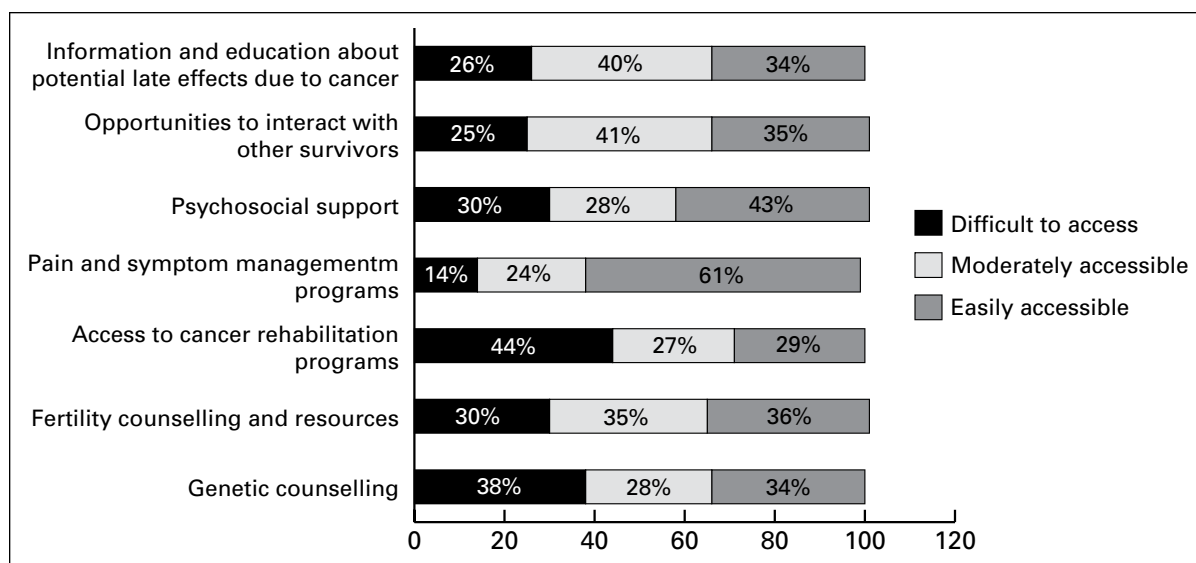


Fig. 6. Accessibility of services to individual physician's patients (n = 254).

all relevant cancer groups and community support services (56%); and (3) to create learning opportunities to educate healthcare professionals on the function and credibility of patient advocacy groups (38%).

Discussion

This study evaluated Canadian GU cancer physician survivorship care attitudes, perceptions and practices. To our knowledge, this is the first study of its kind from Canada.

Several models for survivorship care delivery have been proposed.^{2,11-13} One ideal care model is that of shared care of follow-up between the cancer specialist and the PCP.² In our survey, only one-quarter of GU cancer specialists share survivorship care with PCPs indefinitely, while more than

half of them discharge patients at some point to PCP. With the increased number of cancer survivors that require follow-up care, this may result in a decreased capacity for cancer specialists to attend to new cancer patients. A reasonable solution would be to involve PCPs in follow-up. Regardless of which approach is employed, it should fulfil the major components of cancer survivorship care as outlined by the Institute of Medicine, including prevention of recurrence and new cancers, surveillance for recurrence and late side effects; intervention for treatment related consequences, and the coordination between the specialist and PCP to ensure all the survivors needs are met.

It is critical to patient care that this transfer from specialist care to PCP care be smooth. For this to occur (1) PCPs need to be willing to assume care of survivors, (2) patients need

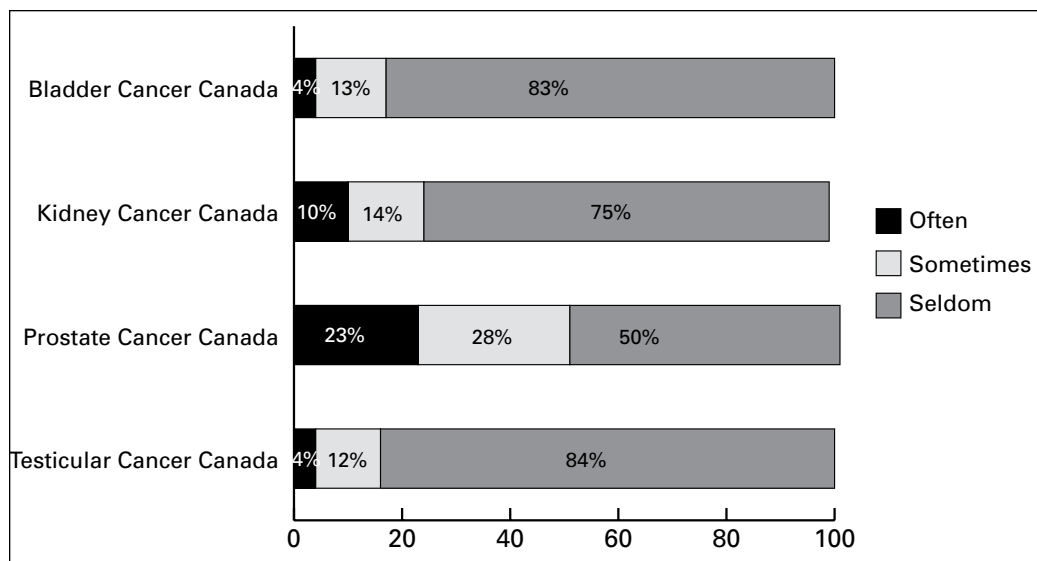


Fig. 7. Rates of patient referral to Canadian Genitourinary patient advocacy groups (n = 248).

to be satisfied with PCP follow-up, and most importantly (3) there should be communication between the cancer specialist and the PCP. Canadian PCPs are willing to take part in the management of cancer survivors and even take full responsibility after completion of active treatment if they are provided with the appropriate information and guidelines for follow up.¹⁴⁻¹⁷ A survey of breast cancer survivors by Grunfeld and colleagues in 2006 noted that most patients accept their PCP taking responsibility of their cancer follow-up, although 45% were unwilling to be transferred.¹⁸ To overcome this issue it has been suggested that PCPs become involved early in the survivor's experience using a shared care model that encourages continued communication and coordination between the PCP and cancer specialist.¹⁹ This may encourage the patient to develop trust in the care provided by their PCP so that when the transition happens they are comfortable. The American Society of Clinical Oncology strongly recommends effective communication between the specialist and the PCP to ensure a continuum of care into primary practice.²⁰ Most of the GU physicians who participated in this survey would provide written plans to PCPs, although these plans tend to lack important details, such as recommendations for the management of persistent and late effects of treatment and lifestyle recommendations.^{21,22} To enhance communication, implementation of a standardized template for dictation to the PCP was shown to improve PCP satisfaction regarding the information provided²³ – this may improve patient confidence in the PCP provision of follow-up care.

Cancer survivors are at an increased risk of developing a second cancer, cardiovascular disease, diabetes mellitus, osteoporosis and other chronic illnesses. These can be caused by their cancer treatment or lifestyle factors or predispositions. Lifestyle factors are modifiable, and recommendations are supported by the Institute of Medicine report and the American Cancer Society (ACS).^{2,24,25} Most respondents provided a written plan; however, lifestyle recommendations were often not included. This may be due to the specialist's expectation that the PCP will explore this with the patient or that the specialist provides this information verbally. We did not specifically ask if the specialist's provide lifestyle recommendations, but in a survey conducted by Kidney Cancer Canada (KCC) to assess the types of information provided to patients before and after surgery, only 50% of patients received lifestyle recommendations from their urologist.²⁶ It is not clear what percentage receive this recommendation either from the specialists or PCP, thus we recommend better communication with the PCP.

Interestingly only half of GU physicians who participated in the survey provided information and guidelines for the management of persistent and late effects of treatment in their written plan to the PCP. The literature suggests that PCPs are less confident in managing late side effects.²⁷

Providing PCPs with guidelines and more information on the management of treatment side effects may improve their confidence in caring for GU cancer survivors.

Many barriers to cancer survivorship care have been reported and these were clearly summarized in the report by the Institute of Medicine.² From a Canadian report in 2008, a lack of financial resources was the most common barrier in cancer survivorship care, followed by a lack of models for follow-up care and evidence-based guidelines.⁸ In our survey, physicians universally reported a lack of time and resources regardless of subspecialty, practice location or practice base. These are important barriers that should be studied further. To improve care, it appears that the physician needs to devote time to understand the patient's supportive care needs (such as psychosocial and other issues related to survivorship care) which would require additional reimbursement to physicians.²⁸

A lack of practice guidelines was the second most commonly cited barrier to the provision of survivorship care. Current guidelines for GU cancer care focus on the detection of new or recurrent cancers. These guidelines lack information on other important aspects of survivorship care, such as lifestyle recommendations and psychosocial dysfunction. Most guidelines also lack information on how to assess and manage persistent and late effects of cancer treatment. The development and dissemination of standardized survivorship care guidelines and assessment tools for GU cancer is an important goal. To further advance survivorship care, innovative models that reduce cost and improve efficiency of care are needed. Their development will depend on research funding, scientific rigor, knowledge translation opportunities at early stages of training and focus on patient-centered quality of care. The differences in practice patterns between academic and community oncologists also indicate that models and guidelines must also be relevant to the setting in which the patient is being treated.

Although rehabilitation is important for cancer survivors,^{2,29-33} about one half of GU physicians in our study reported difficulty in accessing rehabilitation programs. Little variation was found between regions, except for British Columbia where more (91%) GU physicians reported difficulty. It is not known, however, whether these low levels of accessibility reflect a lack of available programs or merely a lack of knowledge of their existence and, consequentially, underuse.

Urologists are the least likely to refer patients for psychosocial support and genetic counselling, with about 50% of urologists reporting difficulty with access. Since these services appeared to be easily accessible by other subspecialties, the observed underutilization may be due to low levels of awareness of these services or of specific patient needs.

We also found that GU cancer advocacy groups were underutilized. The most commonly used advocacy group

was for prostate cancer. This may be because it is the most established in Canada and prostate cancer is the most common GU cancer. To explore means to enhance collaboration between advocacy groups and GU cancer physicians, we asked respondents to rank initiatives proposed by the GU cancer survivorship conference consensus.⁵ Respondents felt that written information, electronic information and learning opportunities provided by the advocacy groups were most likely to improve collaboration.

Limitations of this study include our inability to verify that respondents in fact treated GU cancer and which respondents were trainees. The survey was directed to GU cancer physicians and may not be applicable to other cancer site groups. Close-ended questions may have limited the strength of the responses. Answers assessing the accessibility of services may be biased toward the awareness of the physician, rather than represent a true lack of services. We acknowledge that the practice patterns may differ according to the stage of the disease, which is not covered in this survey. We did not include it for the sake of brevity – a long survey may have affected our response rate. This issue may need to be covered in a future survey. The response rate appears low, but it is comparable to other web-based surveys of health providers. We chose a web-based survey to appeal to the busy physician responders, while recognizing the potential lower response rate. Other survey methods by mail or telephone would have enhanced the rate. The results may also be subject to bias because respondents may have been more interested in cancer survivorship. This is an exploratory study, and stratification was done to better understand the associations among the variables. Proportions and *p* values may be specific to the study population, but may not be generalizable. Future studies would be helpful in further validating our results.

Conclusion and practice implications

Canada has well-developed patient advocacy groups and other organizations that provide survivorship support. Most GU cancer physicians discharge survivors to PCPs at some point after treatment. There is variability in practice between different GU subspecialties, geographical areas of practice and practice bases (university affiliated vs. community hospitals). GU specialists do not appear to provide sufficient information to the PCP. Lack of physician time and the limited availability of other resources are key barriers to providing survivorship care and may limit physician cooperation. GU physicians lack knowledge about available cancer survivorship care facilities. Advocacy groups are underutilized with variation between subspecialties and geographical location of practice. The findings from our survey highlight several areas that require further investigation.

We recommend that a standardized dictation template. This template would include information on diagnosis, treatment received, record of side effects experienced during and after treatment, expected short- and long-term side effects with management options, guidelines for follow-up, including screening for recurrence of disease, proposed caregiver responsibilities, and a list of available services and programs including relevant advocacy groups. Lack of physician knowledge about survivorship care appears to be an important barrier. The inclusion of cancer survivorship issues in the curricula of Canadian medical schools and in rotations for PCP residency programs would improve physician awareness. Developing and supporting standardized programs and services for patients, as well as informing physicians about survivorship care programs and facilities, may increase awareness and positively affect access. We recommend involving advocacy groups to help educate physicians about their services to increase the utilization of these groups.

Competing interests: Dr. Almatar, Dr. Richter, Dr. Lalani, Dr. Bender, Dr. Wiljer, Dr. Alkazaz, Dr. Legere, Dr. Maganti, Dr. Sridhar and Dr. Catton have no competing financial or personal interests. Dr. Jewett is a member of the Advisory Board for Pfizer. He has also received grants from Novartis, GSK and Pfizer. Lastly, he has participated in clinical trials with Novartis, GSK and Pfizer.

This paper has been peer-reviewed.

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