Predictors of prostate cancer survivors' engagement in self-management behaviors

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ABSTRACT

Introduction: Prostate cancer survivors experience a multitude of late treatment effects, resulting in greater unmet needs, elevated symptom burden, and reduced quality of life. Survivors can engage in appropriate self-management strategies post-treatment to help reduce the symptom burden. The objectives of this study were to: 1) explore the unmet needs of prostate cancer survivors using the validated Cancer Survivor Unmet Needs

KEY MESSAGES

- Erectile dysfunction and nocturia were the most frequently experienced symptoms by prostate cancer survivors, with the highest symptom severity.
- Prostate cancer survivors' unmet needs were predicted by symptom severity.
- Prostate cancer survivors' readiness to engage in self-management was predicted by an income of less than $49 000.

instrument; 2) explore predictors of high unmet needs; and 3) explore prostate cancer survivors' willingness to engage in self-management behaviors.

Methods: Survivors were recruited from a prostate clinic and a cross-sectional survey design was employed. Inclusion criteria was having completed treatment two years prior. Descriptive statistics were used to summarize participant characteristics. Univariate and multivariate analyses were done to determine predictors of unmet needs and readiness to engage.

Results: A total of 206 survivors participated in the study, with a mean age of 71 years. Most participants were university/college-educated (n=123, 61%) and had an annual household income of ≥$99 999 (n=74, 38%). Participants reported erectile dysfunction (81%) and nocturia (81%) as the most frequently experienced symptoms with the greatest symptom severity ($\bar{x}$=5.8 and $\bar{x}$=4.5, respectively). More accessible parking was the greatest unmet need in the quality-of-life domain (n=34/57, 60%). Overall, supportive care unmet needs were predicted by symptom severity on both univariate (p<0.001) and multivariate analyses (odds ratio [OR] 1.81, 95% confidence interval [CI] 0.92–1.00, p<0.001). Readiness to engage in self-management was predicted by an income of less than $49 000 (OR 3.99, 95% CI 1.71–9.35, p=0.0014).

Conclusions: Income was the most significant predictor of readiness to engage in self-management. Consideration should be made to establishing no-cost and no-barrier education programs to educate survivors about how to engage in symptom self-management.

INTRODUCTION

Prostate cancer is one of the most commonly diagnosed cancers and approximately one in eight Canadian males is expected to develop the disease in their lifetime.[1] In Canada, most prostate cancers are diagnosed at an early stage and the net five-year survival is approximately 93%.[2] Recent diagnostic and therapeutic advancements in prostate cancer have enabled patients diagnosed with the disease to transition into post-treatment survivorship, resulting in a greater number of survivors. However, late post-treatment effects may lead to greater symptom burden,[3,4] which translates to impacts on patients' overall well-being,[5] quality of life,[6] and greater costs to the healthcare system.[7] As such, it is imperative that appropriate follow-up care and continued long-term support are provided as part of post-treatment prostate cancer management. Having limited long-term support may result in greater supportive care unmet needs, including informational and quality of life-related needs, which can lead to elevated symptom burden and a greater need for supportive care interventions.

With limited capacity for survivorship care and a dearth of expertise in primary care, the opportunity to equip survivors in self-management warrants exploration. Cancer self-management is defined as "what a person does, in collaboration with their healthcare team, to

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manage the symptoms, medical regimens, treatment side-effects, physical changes, psychosocial consequences, and lifestyle changes following a cancer diagnosis and/or treatment".[12] Enabling prostate cancer survivors to become more involved in self-managing their symptoms can provide several benefits since patients are best able to identify and monitor their experience with symptom burden[13, 14] if appropriate training/preparation was available to them.[15] Currently, few self-management strategies are routinely incorporated into the delivery of cancer care, including the survivorship phase of care.[16] In addition, even when self-management supports are available, personal efforts to engage in survivorship care can be impeded by socio-economic factors incongruent with health including the costs associated with accessing support programs in terms of parking and time off work, location including rural areas that are geographically distant from supports,[17] and lower socioeconomic status.[18] If an appropriate and accessible level of support was provided, survivors may effectively reduce symptom burden on their own.[13]

While several guidelines have been developed to help healthcare providers learn how to better care for prostate cancer survivors, less guidance exists to equip prostate cancer survivors to self-manage. Many clinical studies have demonstrated the value of patient engagement with healthcare providers in terms of safer care and better health outcomes.[10] Engaging patients and repositioning their role from passive recipients to active contributors can equip them to have clear expectations of needed care and to know who to approach for help.[11, 12] The objectives of this study were to: (1) explore the unmet needs of prostate cancer survivors; (2) to explore the predictors of high unmet needs and to; (3) and to explore predictors of prostate cancer survivors' self-management behaviours.

METHODS

This study employed a mixed-methods cross sectional design, and study approval was granted by the University Health Network Research Ethics Board (UHN REB# 16-5831). Prostate cancer survivors receiving follow-up care at Princess Margaret Cancer Centre between May and November of 2017 were invited to complete a 20–30-minute, one-time, self-administered questionnaire. Inclusion criteria were: 18 years of age or older, able to read and write in English, and completed prostate cancer treatment two years prior. Depending on their preference, participants were given the option of completing a paper survey in clinic, or an electronic survey. Completion of the questionnaire implied consent and participation was voluntary. Participant identification numbers were used to protect respondent identity.

Questionnaire

A survey package was developed to identify factors that could promote self-management among prostate cancer survivors. The survey also collected information on survivor supportive care needs, level of interest and ability in self-managing their survivorship care, and potential strategies to improve survivorship care. The survey package included a combination of validated measures and in-house developed measures. The in-house developed measures included a multi-

item survey to ascertain survivor readiness to engage in survivorship care and a measure of survivor information needs and preferences. The surveys were developed using an iterative process with several subject matter experts engaged and were tested for face validity with survivors. Both in-house developed surveys underwent several rounds of revision before being finalized. The survey package consisted of five main sections:

Participant characteristics

Demographic and clinical characteristics
This section collected demographic variables including age, education level, work-related activity, annual household income, marital status, and race. Additionally, participants were asked about the type of treatment they received and years since completing their treatment. To determine the types of symptoms experienced, participants were asked: (1) if they experienced the symptom; (2) to indicate the level of severity of the symptom using a 10-point scale with 0 being none and 10 being very severe; and (3) if they would be able to learn how to manage the symptom on their own.

Health literacy and self-efficacy measures
The validated Cancer Health Literacy Test 6-item measure (CHLT-6) was used to measure participants' levels of health literacy by asking a number of questions related to cancer topics such as treatment and side effect management. This tool was adapted from the CHLT 30-item instrument (CHLT-30) but was designed to rapidly identify patients with low cancer-related health literacy.[19] Participants with adequate health literacy received a CHLT-6 score >4, while participants with inadequate health literacy received a CHLT-6 score of ≤4. To measure participants' self-efficacy, the validated Stanford Self-Efficacy for Managing Chronic Disease 6-item scale[20, 21] was used. The scale encompasses several chronic disease domains, which include questions about role function, emotional functioning, symptom control and communication with healthcare providers. Included self-efficacy measures assessed participants' confidence in managing a number of symptoms using a 10-point scale.

Cancer survivors' unmet needs
A modified version of the validated Cancer Survivors' Unmet Needs (CaSUN) instrument was used to evaluate prostate cancer survivors' unmet needs. The CaSUN consists of 36 items separated into four major domains: (1) 9 items within the Information Needs & Medical Care Issues domain; (2) 9 items within the Quality of Life domain; (3) 10 items within the Emotional & Relationship Issues domain and (4) 7 items within the Life Perspective Issues domain. Respondents were asked to select whether the 'need was fully met', 'need was not fully met' or 'not applicable' (see Appendix). An overall CaSUN score is calculated by summing mean scores from all four domains, with a larger score indicating greater needs.

Managing survivorship care

The readiness to engage in survivorship care measure (see Appendix) included eight items. All items were measured using a 5-point Likert scale, from 'strongly disagree' to 'strongly agree'. A total score was calculated by summing all items, with a maximum score of 40, and a mean score of 24. A score above 24 indicates greater readiness to engage, and a score equal to, or below 24 indicates less readiness to engage in self-management. Participants were also asked how helpful it would be to play a bigger role in their survivorship care using a 5-point Likert scale from 'not at all helpful' to 'very helpful'.

Information needs and preferences

Participants were asked how they would prefer to receive information about four topics: (1) cancer-related drugs and side effects; (2) lifestyle changes; (3) how to manage symptoms from cancer treatment and (4) on-going surveillance for cancer recurrence. Participants were asked if they wanted information on the topic, did not want information on the topic, or if the topic was not applicable, and were given a list of modalities to select from to indicate their preferred learning mode (e.g., consultation with the doctor, video, pamphlets, telephone, websites, podcasts, and e-Learning).

Statistical analysis

Continuous variables were described using means, standard deviations, medians, and ranges. Categorical variables were described using frequencies and percentages. Cronbach Alpha was done to measure reliability of the Readiness to Engage measure and had a value of 0.868. A Cronbach Alpha value above 0.8 is considered to have good internal consistency. Univariate analyses were done to identify the factors associated with prostate cancer survivors' unmet needs and readiness to engage in survivorship care. Marital status (coupled and uncoupled) and employment (not working and working) were categorized for univariate analyses. Multivariate logistic regression analyses were used to estimate adjusted odds, based on variables that were found to be statistically significant from univariate analyses ($p<0.05$). For readiness to engage, data was only available on 186 participants and those were used throughout the univariate analyses. For multivariable logistic regression, 14 responses were missing and analyses were done for 172 cases. For CaSUN, data was available for all 206 patients, and those were used in univariate analysis. For multivariable regression analyses, 20 responses were missing and analyses were done for 186 cases. R Studio statistical software was used for analyses.

RESULTS

Participant demographic and clinical characteristics
Two hundred six (206) patients completed the survey. Demographic information is reported in Table 1. The mean reported age was 71, most respondents were Caucasian (N= 152, 78%), and married (N= 162, 82%). Greater than half of the respondents were retired (N= 130, 64%) and were college or university-educated (N=123, 61%) and most had an annual household income of greater than $99,000 (N= 74, 38%). Most received radiation treatment for their prostate cancer (N= 126, 61%), followed by surgery (N= 113, 55%) and were last treated 4 to 10 years prior (N= 96, 60%). The majority of respondents had adequate health literacy scores (N= 160, 77%) and the mean reported self-efficacy score was 8.3 (SD = 2.0). Further details are shown in Table 1. Mean symptom severity was 1.8 (SD = 1.3) and symptoms most frequently reported were erectile dysfunction (81%) and nocturia (81%). Highest reported symptom severity was erectile dysfunction (mean = 5.8) and anejaculation (mean = 4.5). Further details are shown in Table 2

Met and unmet supportive care needs
The overall CaSUN unmet needs score was 11.2 (SD = 10.6) of a possible 36. Overall, the proportion of participants reporting unmet needs was low, however top reported unmet needs included more accessible hospital parking (N=34/57, 60%) and an ongoing case manager to whom I can go to find out about services whenever they are needed (N=21/38, 55%). The majority of met needs were from the Information Needs & Medical Care Issues domain, with the top reported item being to know that concerns about care were addressed well (N=133/142, 94%). Further details provided in Table 3.

Univariate analysis was conducted to explore whether unmet needs were associated with employment, education, income, marital status, years since treatment, treatment modality, age, and symptom severity. Univariate analysis revealed that greater unmet needs were associated with patients who were younger (p = 0.046) and those who had greater symptom severity (p < 0.001). See Table 4. Multivariate analysis revealed symptom severity (OR: 1.81, 95% CI 0.92-1.00, p<0.001) to be the strongest predictor of unmet needs; with an 81% increase in the odds of having unmet needs per increase in symptom severity score, when adjusted for age.
Table 4. Factors associated with prostate cancer survivors' unmet needs

Managing survivorship care

Readiness to engage in survivorship care
The vast majority of respondents agreed to strongly agreed that they were satisfied with their prostate cancer survivorship care (N=166/191, 87%) and half agreed to strongly agreed that they would like to know more about symptoms and what they can do about them (N=89/178, 50%) (Figure 1). Just under half of respondents said it would be helpful to very helpful to have a bigger role in managing their survivorship care (84/173, 49%). The mean readiness to engage

score was 24.0 (SD = 6.8, Range = 6-39). The majority of respondents felt that prostate cancer survivors could play a bigger role in managing their cancer-related health needs (N=111/147, 76%).

Univariate analysis revealed that greater readiness to engage in survivorship care was higher in survivors with an income of less than $49,000 (p<0.001), uncoupled survivors (p =0.034), and survivors with greater symptom severity (p = 0.018) (Table 5).

Table 5. Factors associated with prostate cancer survivors' readiness to engage in their survivorship care.

On multivariate analysis, higher readiness to engage in survivorship care was predicted by an income of less than $49,000 (OR: 3.99, 95% CI 1.71-9.35, p = 0.0014) and greater symptom severity (OR: 1.38, 95% CI 1.07-1.78, p = 0.013).

Information needs & communication preferences

The vast majority of prostate cancer survivors indicated that they wanted information about all four topics: drug side effects (N=139, 82%), lifestyle changes (N=138, 81%), treatment side effects (N=153, 89%) and ongoing cancer surveillance (N=163, 95%).

When asked to indicate the preferred modality for receiving this information, most participants indicated that one-on-one consultation with their doctor/nurse was preferred across all topics, followed by websites and pamphlets (Table 6).

DISCUSSION

This study contributes to the literature as it furthers our understanding of issues faced by prostate cancer survivors several years after treatment. Unmet needs of participants were low overall, likely due to low symptom burden.[22, 23] The most common unmet need identified by participants was accessible hospital parking, which is reinforced in the literature,[24] and has been endorsed by patients as a top health service need.[25] We found that the strongest predictor of unmet needs in prostate cancer survivors was symptom severity. Erectile dysfunction was the most commonly reported symptom, with the highest symptom severity score. This aligns with results by Watson et al., demonstrating that enduring symptoms are associated with greater unmet needs in prostate cancer survivors[23] and that >80% of prostate cancer survivors continue to report poor sexual function (e.g. erectile dysfunction) as a severe and persistent issue, several months to years after treatment.[24, 26] Without appropriate education, there may be greater use of services to help address concerns about sexual function[3] and greater out-of-pocket costs for survivors with treatment-related dysfunctions.[27] Studies have shown that erectile dysfunction[28] results in reduced quality of life, body image concerns, such as reduced masculinity,[29] and elevated distress about partner satisfaction.[30, 31]

Our finding regarding high symptom severity, unmet needs relating to supportive care and willingness to engage in symptom self-management, suggests that current self-management preparation/education of survivors may not be sufficient, and traditional biomedical interventions

that have been developed to help address these issues thus far have been inadequate on their own.[32] Recent research demonstrating the efficacy and utility of biopsychosocial interventions has shown promise, as they incorporate a "holistic" approach to therapy.[32] In one study examining the effectiveness of a sexual rehabilitation intervention, prostate cancer survivors and partners received sexual health education virtually over a twelve-week period, through trained health professionals, a series of e-Learning modules and various resources, in order to build the skills and knowledge confidence required to manage their symptoms and concerns on their own.[32] The intervention was found to be feasible, with the majority of participants completing the entire program and reporting high levels of satisfaction.[33] These findings suggest that with appropriate education and support, survivors can be equipped to engage in self-management strategies.

Self-management support largely depends on appropriate tailoring of survivorship care. Some survivors may require pharmacological management through prescription of oral medications to treat erectile dysfunction (for example, phosphodiesterase type 5 inhibitors), while some may need to engage in specific exercises – such as pelvic floor exercises or bladder retraining - to help alleviate nocturia, or require a combination of both strategies.[23] Further, beginning these discussions closest to treatment is considered a "teachable moment", as survivors are most receptive and willing to learn how to self-manage symptoms early on,[34, 35] and find an approach that works best for them. Some evidence indicates that survivors may be more likely to discuss symptoms such as bowel and urinary issues at follow-up, as opposed to sexual changes, suggesting that there also may be a lack of awareness or comfort discussing what some may perceive to be a sensitive topic.[36] This may in turn lead to survivors neglecting their symptoms, leading to elevated symptom burden and lower quality of life. Initiating the conversation about symptom self-management early with survivors and offering appropriate training and ad-hoc discussions with providers, may be a feasible approach that enables survivors to determine the best strategy for their survivorship self-care.

The finding that household income predicted survivors' readiness to engage in care was notable. To our knowledge, this is the first study to report that prostate cancer survivors in low-income groups are more ready to engage in their care than their higher income counterparts. However, while this population of cancer survivors may be more willing to engage in self-management, prostate cancer survivors may not do so due to a lack of conversations with their healthcare provider, and an inability to access these interventions due to temporal or geographical constraints. The literature reports that survivors in low-income groups are at heightened risk for not discussing follow-up care with their provider and often do not receive follow-up care as needed.[37] Possible reasons for the lack of discussion about follow-up care may include fatalistic beliefs, being told that symptoms are normal or perceiving their concerns to not be severe enough (e.g. emergency symptoms) to warrant professional help.[38] Survivors in low-income groups have also been reported to be less likely to attend survivorship care programs that are offered in person[36] due to scheduling difficulties and temporal and financial restrictions, such

as inability to take time off work, distance from the cancer centre,[39] transportation and having limited childcare options.[40]

Taken together, our results suggest that while survivors in lower-income groups may be willing to engage in self-management, lack of knowledge, awareness and access to survivorship programs may prevent them from seeking appropriate follow-up care.[41-43] The use of virtual self-management education programs may be a feasible solution, and training healthcare experts to offer online support and targeted resources may help improve access for this population of prostate cancer survivors.[18, 44] This also highlights a need to train healthcare providers to be able to identify at-risk groups, as well as be equipped and proactive in discussing potential concerns with survivors such that referrals are made to appropriate tailored programs.

Our findings have important implications for the development of comprehensive self-management programs addressing acute and long-term treatment effects of prostate cancer survivors. The use of virtual interventions may be an ideal approach for delivering survivorship care due to their ability to standardize the delivery of information and promote greater reach[36, 44] The literature indicates that survivors feel more comfortable discussing their symptoms over the phone or via a virtual platform[45] and have been shown to be more likely to continue to utilize survivorship programs if there is an improvement in their symptoms.[36] Further research is warranted to elucidate the specific role of survivors in engaging in their own survivorship care, such as access, cost, and format, as well as receptivity to virtual survivorship care plans.

This study has some limitations, including the nature of the cross sectional survey design and use of non-probability sampling, thus it may not be possible to generalize the study results. The participant population was better educated and less diverse than the local population. As discussed, most of the participants in this study had high levels of education. This could be a result of an English-language only survey, and a nonresponse sample bias where the method of data collection unintentionally biased individuals with lower education attainment to decline participation in the study. Although we made efforts to mitigate this possibility by writing the study questions in plain language and using short measures where possible, participants were still required to complete a long survey package. It is also possible that voluntary surveys such as this will recruit those most well adapted to managing life after cancer treatment in comparison with the general patient population, and future studies may need to use purposive sampling to better reach patients of different social strata.

CONCLUSIONS

Prostate cancer survivors continue to experience symptoms years after treatment, and symptom severity is the strongest predictor of unmet needs in this population. Survivors in low-income groups reported being more ready to engage in their survivorship care. Further research is needed to explore barriers and facilitators to survivors' self-management and use of virtual survivorship self-management support.

References

1. Canadian Cancer Society Prostate cancer statistics. https://cancer.ca/en/cancer-information/cancer-types/prostate/statistics (accessed December 14, 2021).
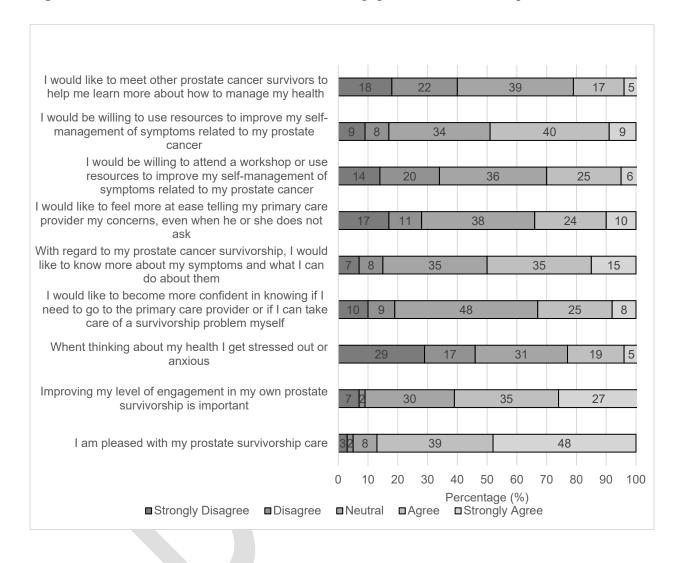2. Canadian Cancer Society Survival statistics for prostate cancer. https://cancer.ca/en/cancer-information/cancer-types/prostate/prognosis-and-survival/survival-statistics (accessed December 14, 2021).
3. Skolarus, T. A.; Wittmann, D.; Hawley, S. T. Enhancing prostate cancer survivorship care through self-management. *Urol Oncol* 2017; *35* (9), 564-568.
4. Zhou, E. S.; Bober, S. L.; Nekhlyudov, L., et al. Physical and emotional health information needs and preferences of long-term prostate cancer survivors. *Patient Education and Counseling* 2016; *99* (12), 2049-2054.
5. Cheung, W. Y.; Aziz, N.; Noone, A. M., et al. Physician preferences and attitudes regarding different models of cancer survivorship care: a comparison of primary care providers and oncologists. *J Cancer Surviv* 2013; *7* (3), 343-54.
6. Penson, D. F.; Litwin, M. S. Quality of life after treatment for prostate cancer. *Curr Urol Rep* 2003; *4* (3), 185-95.
7. Goonewardene, S. S.; Persad, R., Unmet Needs and Problems Faced by Prostate Cancer Survivors. In *Prostate Cancer Survivorship*, Goonewardene, S. S.; Persad, R., Eds. Springer International Publishing: Cham, 2018; pp 177-178.
8. Miller, K. D.; Nogueira, L.; Mariotto, A. B., et al. Cancer treatment and survivorship statistics, 2019. *CA: A Cancer Journal for Clinicians* 2019; *69* (5), 363-385.
9. Warren, J. L.; Mariotto, A. B.; Meekins, A., et al. Current and Future Utilization of Services From Medical Oncologists. *Journal of Clinical Oncology* 2008; *26* (19), 3242-3247.
10. Wilkinson, A. N.; Brundage, M. D.; Siemens, R. Approach to primary care follow-up of patients with prostate cancer. *Can Fam Physician* 2008; *54* (2), 204-210.
11. O'Brien, R.; Rose, P.; Campbell, C., et al. "I wish I'd told them": a qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Educ Couns* 2011; *84* (2), 200-7.
12. Cancer Care Ontario *Self-Management in Cancer: Quality Standards*; Toronto, Canada, 2018.
13. Paterson, C.; Jones, M.; Rattray, J., et al. Identifying the self-management behaviours performed by prostate cancer survivors: a systematic review of the evidence. *Journal of Research in Nursing* 2014; *20* (2), 96-111.
14. Bernat, J. K.; Wittman, D. A.; Hawley, S. T., et al. Symptom burden and information needs in prostate cancer survivors: a case for tailored long-term survivorship care. *BJU International* 2016; *118* (3), 372-378.
15. Ryan, P.; Sawin, K. J. The Individual and Family Self-Management Theory: background and perspectives on context, process, and outcomes. *Nurs Outlook* 2009; *57* (4), 217-225 e6.
16. Ose, D.; Winkler, E. C.; Berger, S., et al. Complexity of care and strategies of self-management in patients with colorectal cancer. *Patient Prefer Adherence* 2017; *11*, 731-742.

17. Blusi, M.; Kristiansen, L.; Jong, M. Exploring the influence of Internet-based caregiver support on experiences of isolation for older spouse caregivers in rural areas: a qualitative interview study. *Int J Older People Nurs* 2015; *10* (3), 211-20.

18. Chauvin, J.; Rispel, L. Digital technology, population health, and health equity. *J Public Health Policy* 2016; *37* (Suppl 2), 145-153.

19. Dumenci, L.; Matsuyama, R.; Riddle, D. L., et al. Measurement of cancer health literacy and identification of patients with limited cancer health literacy. *J Health Commun* 2014; *19 Suppl 2* (0 2), 205-224.

20. Lorig, K. R.; Sobel, D. S.; Ritter, P. L., et al. Effect of a self-management program on patients with chronic disease. *Eff Clin Pract* 2001; *4* (6), 256-62.

21. Self-Management Resource Center, Self-Efficacy for Managing Chronic Disease 6-Item Scale.

22. Gilbert, S. M.; Dunn, R. L.; Wittmann, D., et al. Quality of life and satisfaction among prostate cancer patients followed in a dedicated survivorship clinic. *Cancer* 2015; *121* (9), 1484-1491.

23. Watson, E.; Shinkins, B.; Frith, E., et al. Symptoms, unmet needs, psychological well-being and health status in survivors of prostate cancer: implications for redesigning follow-up. *BJU International* 2016; *117* (6B), E10-E19.

24. Mazariego, C. G.; Juraskova, I.; Campbell, R., et al. Long-term unmet supportive care needs of prostate cancer survivors: 15-year follow-up from the NSW Prostate Cancer Care and Outcomes Study. *Supportive Care in Cancer* 2020; *28* (11), 5511-5520.

25. Hall, A.; Bryant, J.; Sanson-Fisher, R., et al. Top Priorities for Health Service Improvements Among Australian Oncology Patients. *Patient Relat Outcome Meas* 2021; *12*, 83-95.

26. Watson, E.; Shinkins, B.; Frith, E., et al. Symptoms, unmet needs, psychological well-being and health status in survivors of prostate cancer: implications for redesigning follow-up. *BJU Int* 2016; *117* (6B), E10-9.

27. de Oliveira, C.; Bremner, K. E.; Ni, A., et al. Patient time and out-of-pocket costs for long-term prostate cancer survivors in Ontario, Canada. *Journal of Cancer Survivorship* 2014; *8* (1), 9-20.

28. Messaoudi, R.; Menard, J.; Ripert, T., et al. Erectile dysfunction and sexual health after radical prostatectomy: impact of sexual motivation. *International Journal of Impotence Research* 2011; *23* (2), 81-86.

29. Hyde, M. K.; Zajdlewicz, L.; Wootten, A. C., et al. Medical Help-Seeking for Sexual Concerns in Prostate Cancer Survivors. *Sex Med* 2016; *4* (1), e7-e17.

30. Crowley, S. A.; Foley, S. M.; Wittmann, D., et al. Sexual Health Concerns Among Cancer Survivors: Testing a Novel Information-Need Measure Among Breast and Prostate Cancer Patients. *Journal of Cancer Education* 2016; *31* (3), 588-594.

31. Sanda, M. G.; Dunn, R. L.; Michalski, J., et al. Quality of Life and Satisfaction with Outcome among Prostate-Cancer Survivors. *New England Journal of Medicine* 2008; *358* (12), 1250-1261.

32. Yuen, W.; Witherspoon, L.; Wu, E., et al. Sexual rehabilitation recommendations for prostate cancer survivors and their partners from a biopsychosocial Prostate Cancer Supportive Care Program. *Support Care Cancer* 2022; *30* (2), 1853-1861.

33. Matthew, A. G.; Trachtenberg, L. J.; Yang, Z. G., et al. An online Sexual Health and Rehabilitation eClinic (TrueNTH SHAReClinic) for prostate cancer patients: a feasibility study. *Support Care Cancer* 2022; *30* (2), 1253-1260.

34. Wibowo, E.; Wassersug, R. J.; Robinson, J. W., et al. An Educational Program to Help Patients Manage Androgen Deprivation Therapy Side Effects: Feasibility, Acceptability, and Preliminary Outcomes. *Am J Mens Health* 2020; *14* (1), 1557988319898991-1557988319898991.

35. Santa Mina, D.; Matthew, A. G.; Hilton, W. J., et al. Prehabilitation for men undergoing radical prostatectomy: a multi-centre, pilot randomized controlled trial. *BMC Surg* 2014; *14*, 89-89.

36. Agochukwu, N. Q.; Skolarus, T. A.; Wittmann, D. Telemedicine and prostate cancer survivorship: a narrative review. *Mhealth* 2018; *4*, 45.

37. DiMartino, L. D.; Birken, S. A.; Mayer, D. K. The Relationship Between Cancer Survivors' Socioeconomic Status and Reports of Follow-up Care Discussions with Providers. *J Cancer Educ* 2017; *32* (4), 749-755.

38. Fitch, M.; Nicoll, I.; Lockwood, G. Exploring the reasons cancer survivors do not seek help for their concerns: a descriptive content analysis. *BMJ supportive & palliative care* 2020.

39. Syed, S. T.; Gerber, B. S.; Sharp, L. K. Traveling towards disease: transportation barriers to health care access. *J Community Health* 2013; *38* (5), 976-993.

40. Longo, C. J.; Fitch, M. I.; Loree, J. M., et al. Patient and family financial burden associated with cancer treatment in Canada: a national study. *Support Care Cancer* 2021; *29* (6), 3377-3386.

41. Hedden, L.; Pollock, P.; Stirling, B., et al. Patterns and predictors of registration and participation at a supportive care program for prostate cancer survivors. *Supportive Care in Cancer* 2019; *27* (11), 4363-4373.

42. Maddison, A. R.; Asada, Y.; Urquhart, R. Inequity in access to cancer care: a review of the Canadian literature. *Cancer Causes & Control* 2011; *22* (3), 359-366.

43. Asada, Y.; Kephart, G. Equity in health services use and intensity of use in Canada. *BMC Health Services Research* 2007; *7* (1), 41.

44. Lopez, C. J.; Edwards, B.; Langelier, D. M., et al. Delivering Virtual Cancer Rehabilitation Programming During the First 90 Days of the COVID-19 Pandemic: A Multimethod Study. *Arch Phys Med Rehabil* 2021; *102* (7), 1283-1293.

45. Head, B. A.; Keeney, C.; Studts, J. L., et al. Feasibility and Acceptance of a Telehealth Intervention to Promote Symptom Management during Treatment for Head and Neck Cancer. *J Support Oncol* 2011; *9* (1), e1-e11.

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Figures and Tables

Figure 1. Prostate cancer survivors' readiness to engage in their survivorship care.

Table 1. Prostate cancer survivors' demographic & clinical characteristics			
Variable		**n**	**%**
Age (years) (n=203)	Mean (SD)	70.6 (7.5)	–
	Median (range)	72 (47, 89)	–
Employment status (n=206)	Retired	131	
	Working	68	
	Unemployed	3	
	Receiving disability payment	2	
	Other	2	
Education (n=201)	College/university to graduate school	123	61.2
	High school to some college/university	48	23.9
	Grade school to some high school	30	14.9
Marital status (n=198)	Married	162	81.8
	Single	11	5.6
	Divorced	11	5.6
	Separated	7	3.5
	Widowed	6	3.0
	Other	1	0.5
Income (n=193)	More than $99 999	74	38.3
	$50 000–74 999	38	19.7
	$25 000–49 000	33	17.1
	$75 000–99 999	33	17.1
	Less than $25 000	15	7.8
Race (n=195)	Caucasian/European	152	77.9
	Black/African	13	6.7
	East Asian	7	3.6
	South Asian	7	3.6
	Other	5	2.6
	Arab/West Asian	4	2.1
	Latin American	4	2.1
	I prefer not to answer	3	1.5
Previous cancer treatment[*] (n=206)	Radiation	125	60.7
	Surgery	113	54.9
	Hormone	34	16.5
	Chemotherapy	4	1.9
	Other	5	2.4
Years since treatment (n=160)	4 to 10 years	96	60.0
	<4 years	43	26.9
	>10 years	21	13.1
Health literacy (0–6) (n=206)	Inadequate health literacy (CHLT-6 ≤4)	47	22.7
	Adequate health literacy (CHLT-6 >4)	160	77.3

Self-efficacy (n=190)	Mean (SD)	8.3 (1.95)	
	Median (min, max)	8.8 (1.6-10.0)	
Symptom severity score (n=188)	Mean (SD)	1.8 (1.3)	–
	Median (min, max)	1.6 (0-6.5)	–

*Respondents selected >1 response. CHLT: Cancer Health Literacy Test; SD: standard deviation.

Table 2. Prostate cancer survivors' symptom experience & severity					
Symptom	**Survey responses, n**	**Yes n (%)**	**No n (%)**	**Not sure n (%)**	**Mean symptom severity (0–10)**
Erectile dysfunction	176	142 (80.7)	25 (14.2)	9 (5.1)	5.8
Nocturia	180	145 (80.6)	31 (17.2)	4 (2.2)	4.0
Anejaculation	171	114 (66.7)	47 (27.5)	10 (5.8)	4.5
Decreased libido	180	118 (65.6)	51 (28.3)	11 (6.1)	3.8
Urinary urgency	176	111 (63.1)	57 (32.4)	8 (4.5)	3.5
Metabolic syndrome	184	95 (51.6)	79 (42.9)	10 (5.4)	1.9
Dribbling/persistent leakage of urine	179	90 (50.3)	81 (45.3)	8 (4.5)	2.2
Fear of cancer recurrence	186	89 (47.8)	74 (39.8)	23 (12.4)	2.5
Fatigue/decreased activity	183	82 (44.8)	74 (40.4)	27 (14.8)	2.0
Rectal/fecal urgency	185	74 (40.0)	97 (52.4)	14 (7.6)	2.1
Hot flushes	181	37 (20.4)	129 (71.3)	15 (8.3)	0.9
Diarrhea	182	65 (35.7)	101 (55.5)	16 (8.8)	1.4
Excessive gas	182	63 (34.6)	95 (52.2)	24 (13.2)	1.7
Distress	182	62 (34.1)	96 (52.7)	24 (13.2)	1.5
Irregular bowels	185	53 (28.6)	119 (64.3)	13 (7.0)	1.3
Climacturia	171	40 (23.4)	107 (62.6)	24 (14.0)	1.2
Cramps	187	40 (21.4)	126 (67.4)	21 (11.2)	1.0
Decline in muscle mass	185	38 (20.5)	101 (54.6)	46 (24.9)	0.8
Painful urination	177	19 (10.7)	152 (85.9)	6 (3.4)	0.6
Urinary retention	182	31 (17.0)	140 (76.9)	11 (6.0)	0.8
Anal sphincter dysfunction	184	29 (15.8)	143 (77.7)	12 (6.5)	0.6
Financial problems	175	26 (14.9)	144 (82.3)	5 (2.9)	0.7
Relationship problems	179	20 (11.2)	147 (82.1)	12 (6.7)	0.7
Osteoporosis	182	16 (8.8)	119 (65.4)	47 (25.8)	0.4
Challenges with body image	177	12 (6.8)	152 (85.9)	13 (7.3)	0.4
Return to work problems	169	11 (6.5)	154 (91.1)	4 (2.4)	0.4
Bone fracture	180	8 (4.4)	106 (58.9)	29 (16.1)	0.1

Table 3. Prostate cancer survivors' top-reported met and unmet needs, per domains					
Domain*	Mean (SD), range, median (IQR)	CaSUN item	"Need was fully met" n (%)	"Need was not fully met" n (%)	Not applicable n (%)
Information needs and medical care issues	5.1 (3.7), 0–18	To know that concerns about my care are addressed well.(n=187)	133 (71%)	9 (5%)	45 (24%)
		To feel like I am able to manage my health together with the medical team (n=188)	133 (71%)	6 (3%)	49 (26%)
		The very best medical care (n=187)	119 (64%)	7 (4%)	61 (33%)
		Information provided in a way that I can understand (n=186)	114 (61%)	4 (2%)	68 (37%)
Quality of life	2.2 (2.9), 0–13	Help to manage ongoing symptoms and side effects (n=182)	55 (30%)	16 (9%)	111 (61%)
		Help to adjust to changes in my quality of life as a result of cancer (n=187)	56 (30%)	14 (8%)	117 (63%)
		Help to reduce stress in my life (n=189)	40 (21%)	17 (9%)	132 (70%)
		More accessible hospital parking (n=184)	23 (13%)	34 (19%)	127 (69%)
		Help to manage my concerns about the cancer coming back (n=184)	82 (45%)	16 (9%)	86 (47%)

Emotional & relationship issues	2.8 (3.7), 0–18	To talk to others who have had cancer (n=183)	39 (21%)	4 (2%)	140 (77%)
		Help to address problems with my/our sex life (n=179)	36 (20%)	28 (16%)	115 (64%)
		An ongoing case manager to whom I can go to find out about services whenever they are needed (n=181)	17 (9%)	21 (12%)	143 (79%)
Life perspective	1.2 (2.4), 0–12	Help to try to make decisions about my life in the context of uncertainty (n=179)	26 (15%)	7 (4%)	146 (82%)
		How to deal with my own and/or others expectations of me as a "cancer survivor" (n=180)	26 (14%)	9 (5%)	145 (81%)
		Help to move on with my life (n=180)	26 (14%)	5 (3%)	149 (83%)
		Help to make my life count (n=169)	22 (13%)	3 (2%)	144 (85%)

Table 4. Factors associated with prostate cancer survivors' unmet needs					
	Survey responses	**Total sample (n=206)**	**Need met (n=102)**	**Unmet need (n=104)**	**p**
Employment	204				0.66
Unemployed		136 (67%)	69 (68%)	67 (65%)	
Employed		68 (33%)	32 (32%)	36 (35%)	
Education	201				0.56
College/university to graduate school		123 (61%)	57 (58%)	66 (65%)	
Grade school to some high school		30 (15%)	17 (17%)	13 (13%)	
High school to some college/ university		48 (24%)	25 (25%)	23 (23%)	
Income	193				0.16
<$49 999		48 (25%)	23 (24%)	25 (26%)	
$50 000–74 999		38 (20%)	24 (25%)	14 (14%)	
$75 000 –99 999		33 (17%)	12 (13%)	21 (21%)	
>$99 999		74 (38%)	36 (38%)	38 (39%)	
Marital status	198				0.27
Coupled		162 (82%)	82 (85%)	80 (78%)	
Uncoupled		36 (18%)	14 (15%)	22 (22%)	
Years since treatment	160				0.1
<4		43 (27%)	13 (19%)	30 (33%)	
>10		21 (13%)	11 (16%)	10 (11%)	
4–10		96 (60%)	46 (66%)	50 (56%)	
Previous cancer treatment	206				
Radiation					0.2
No		81 (39%)	45 (44%)	36 (35%)	
Yes		125 (61%)	57 (56%)	68 (65%)	
Surgery					0.78
No		93 (45%)	45 (44%)	48 (46%)	
Yes		113 (55%)	57 (56%)	56 (54%)	
Hormone therapy					0.85
No		172 (83%)	86 (84%)	86 (83%)	
Yes		34 (17%)	16 (16%)	18 (17%)	
Chemotherapy					0.62
No		202 (98%)	101 (99%)	101 (97%)	

Yes		4 (2%)	1 (1%)	3 (3%)	
Other					1
No		201 (98%)	100 (98%)	101 (97%)	
Yes		5 (2%)	2 (2%)	3 (3%)	
Age					**0.046**
Mean (SD)	203	70.6 (7.5)	71.7 (7.6)	69.6 (7.3)	
Median (min, max)		72 (47, 89)	73 (47, 89)	71 (53, 83)	
Symptom severity	188				**<0.001**
Mean (SD)		1.8 (1.3)	1.3 (1)	2.2 (1.4)	
Median (min, max)		1.6 (0, 6.5)	1.2 (0, 4.5)	2 (0, 6.5)	

SD: standard deviation.

Table 5. Factors associated with prostate cancer survivors' readiness to engage in their survivorship care					
	Survey responses	Full sample (n=186)	Lack of readiness to engage (n=96)	Readiness to engage (n=90)	p
Employment	185				0.54
Not working		121 (65%)	60 (63%)	61 (68%)	
Working		64 (35%)	35 (37%)	29 (32%)	
Education	182				0.84
College/university to graduate school		116 (64%)	61 (66%)	55 (62%)	
Grade school to some high school		26 (14%)	13 (14%)	13 (15%)	
High school to some college/ university		40 (22%)	19 (20%)	21 (24%)	
Income	177				**0.0038**
>$99 999		68 (38%)	44 (49%)	24 (28%)	
$50 000–74 999		34 (19%)	17 (19%)	17 (20%)	
$75 000–99 999		31 (18%)	16 (18%)	15 (17%)	
<$49 999		44 (25%)	13 (14%)	31 (36%)	
Marital status	181				**0.037**
Coupled		147 (81%)	82 (87%)	65 (75%)	
Uncoupled		34 (19%)	12 (13%)	22 (25%)	
Years since treatment	161				0.44
<4		44 (27%)	19 (23%)	25 (32%)	
>10		21 (13%)	12 (14%)	9 (12%)	
4–10		96 (60%)	52 (63%)	44 (56%)	
Radiation					0.45

No		72 (39%)	40 (42%)	32 (36%)	
Yes		114 (61%)	56 (58%)	58 (64%)	
Surgery					1
No		82 (44%)	42 (44%)	40 (44%)	
Yes		104 (56%)	54 (56%)	50 (56%)	
Hormone therapy					0.7
No		154 (83%)	78 (81%)	76 (84%)	
Yes		32 (17%)	18 (19%)	14 (16%)	
Chemotherapy					0.62
No		182 (98%)	93 (97%)	89 (99%)	
Yes		4 (2%)	3 (3%)	1 (1%)	
Other					1
No		181 (97%)	93 (97%)	88 (98%)	
Yes		5 (3%)	3 (3%)	2 (2%)	
Age	184				0.98
Mean (SD)		70.2 (7.4)	70.2 (8)	70.2 (6.7)	
Median (min, max)		72 (47,85)	72 (47,85)	71.5 (52,83)	
Symptom severity	185				**0.016**
Mean (SD)		1.8 (1.3)	1.6 (1.3)	2 (1.2)	
Median (min, max)		1.7 (0,6.5)	1.2 (0,6.5)	1.9 (0,5.5)	

SD: standard deviation.

Table 6. Preferred modality for receiving information about survivorship topics				
Preference and modality	**Cancer drug-related side effects**	**Lifestyle changes**	**Managing treatment side effects**	**Ongoing surveillance**
Total responses	171	171	172	172
Yes (n, %)	139, 82%	138, 81%	153, 89%	163, 95%
One-on-one with doctor/nurse	112, 54%	96, 47%	129, 63%	146, 71%
Websites	56, 27%	63, 31%	54, 26%	43, 21%
Pamphlets	40, 19%	39, 19%	32, 16%	16, 8%
eLearning	27, 13%	30, 15%	26, 13%	16, 8%
Video	18, 9%	20, 10%	20, 10%	9, 4%
Telephone	12, 6%	11, 5%	12, 6%	12, 6%
Podcasts	6, 3%	9, 4%	4, 2%	1, 1%
Other	6, 3%	6, 3%	2, 1%	4, 2%
No	6	10	7	2
Not applicable	26	23	12	7