

# Symptom burden and information needs in prostate cancer survivors: a case for tailored long-term survivorship care

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## Objectives

To determine the relationship between long-term prostate cancer survivors' symptom burden and information needs.

## Patients and Methods

We used population-based data from the Michigan Prostate Cancer Survivor Study (2499 men). We examined unadjusted differences in long-term information needs according to symptom burden and performed multivariable logistic regression to examine symptom burden and information needs adjusting for patient characteristics.

## Results

High symptom burden was reported across all domains (sexual 44.4%, urinary 14.4%, vitality 12.7%, bowel 8.4%, emotional 7.6%) with over half of respondents (56%) reporting they needed more information. Top information needs involved recurrence, relationships, and long-term effects. Prostate cancer survivors with high symptom burden

more often searched for information regardless of domain ( $P < 0.05$ ). High sexual burden was associated with greater need for information about relationships [odds ratio (OR) 2.05, 95% confidence interval (CI) 1.54–2.72] and long-term effects (OR 1.60, 95% CI 1.23–2.07). High bowel burden was associated with greater information need for long-term effects (OR 2.28, 95% CI 1.43–3.63).

## Conclusions

Long-term prostate cancer survivors with high symptom burden need more supportive information. Tailoring information to these needs may be an efficient approach to support the growing population of long-term prostate cancer survivors.

## Keywords

survivorship, quality, information needs, tailoring, self-management

## Introduction

There are more than one million new prostate cancer diagnoses each year resulting in millions of prostate cancer survivors globally [1,2] with reduced quality of life due to treatment-related symptoms [3–5]. Treatment type and satisfaction with treatment have distinct impacts on quality-of-life domains (e.g., urinary, sexual, bowel, emotional, vitality) [4]. In addition, prostate cancer survivors may be 'lost in transition' between active treatment and survivorship care leaving them vulnerable to persistent, untreated symptoms [6]. While the number of survivors continues to increase, the lack of consensus as to who is responsible for follow-up care (primary care clinicians, urologists) increases the risk of persistent symptom burden [7–10].

Plans for improved survivorship care are being developed and implemented, including the recent American Cancer Society guidelines for prostate cancer survivorship care [11]. These guidelines can support primary care clinicians in providing long-term prostate cancer survivorship care. However, even when prostate cancer symptom burden is high, men may still not report urinary complaints and sexual dysfunction to their primary or specialty care clinicians. In some cases, clinicians may feel uncomfortable or ill equipped to handle these sensitive topics [12,13]. As such, prostate cancer survivors may engage in symptom self-management by seeking health information, and then, caring for themselves. For patients with cancer in general, having the appropriate amount of cancer-relevant information from various sources improves patient outcomes across the cancer control continuum

[14,15]. Information not only improves shared decision-making about treatment [16,17], but aids in coping and reducing stress [15,18,19] and may improve overall satisfaction with treatment outcomes [20].

There are differing information needs and seeking behaviours throughout the trajectory of treatment and survivorship for men with prostate cancer [21]. Most studies examine information needs immediately after treatment and during the initial years of survivorship rather than examining needs later in the survivorship experience, when many men may continue to struggle with symptoms. Due to the natural history of prostate cancer, survivors are likely to need ongoing supportive care and information when it comes to treatment side-effects and symptom management [12,22–26]. Moreover, evidence suggests that tailoring cancer-specific and self-management information to the stage of cancer control continuum (e.g., diagnosis, treatment, post-treatment) most appropriately meets survivors' needs [14]. The additional benefit of extending this tailored information paradigm to a prostate cancer survivor's long-term symptom burden is under studied, and better understanding of the relationship between symptom burden and information needs may help identify the most efficient ways to support the growing population of prostate cancer survivors (i.e., focusing on those with the highest symptom burdens).

The objective of the present study was to determine if survivors' domain-specific symptom burden was associated with increased long-term information needs. We also sought to determine additional patient characteristics (e.g., race, treatment type) that may be associated with increased information needs. This analysis focused on symptom burden and information needs for two reasons. First, long-term symptom burden is a documented problem in prostate cancer survivors, many of whom do not seek care for their symptoms [12]. Second, data suggest that prostate cancer survivors need more information about various topics, including symptom management and coping [12,22,23]. Individualised approaches are not typically feasible in healthcare systems due to resource constraints. As such, our analysis identified factors (e.g., high sexual burden) to consider for more efficient information tailoring (e.g., relationship advice).

## Patients and methods

We used data from the Michigan Prostate Cancer Survivor Study, a State-wide survey of long-term prostate cancer survivor outcomes (see original study for detailed methods) [12]. Men diagnosed with prostate cancer in Michigan between 1985 and 2004 and alive as of 31 December 2005 were identified from the Michigan Cancer Registry. Stratified random sampling was conducted to ensure adequate inclusion of prostate cancer survivors based on race/ethnicity, residence

(urban vs rural), and number of years since diagnosis. African-Americans were oversampled due to their increased prostate cancer risks. Exclusion criteria included: unconfirmed cancer, incarceration, inability to locate, non-resident of Michigan, unable to complete the survey, and physician recommendation against patient contact. Surveys were mailed to 6 531 eligible participants, and to maximise response rates, up to two follow-up surveys (every 6 weeks) were mailed to non-respondents. Our final response rate was 38.3% (2 499 surveys completed). Demographic and treatment factors (age, race, marital status, income, education level, years since diagnosis, treatment type, and disease status) were collected through self-reporting.

## Symptom Burden

To measure prostate cancer survivors' symptom burden, we focused on responses to a single domain-specific survey item that captured burden over the prior 4-week period. These domains and single-item questions were taken from the Expanded Prostate Cancer Index Composite 26-item (EPIC-26) for use in the survey. For each domain (urinary, sexual, bowel, vitality) and an additional emotional domain, respondents were asked, 'Overall, how much of a problem, if any, have urinary (sexual, bowel, vitality, emotional) symptoms been for you during the past 4 weeks?'. Participants indicated their level of burden on a 5-point scale (no problem, very small problem, small problem, moderate problem, big problem). For each domain, we split the participants into low- and high-symptom-burden groups by placing those participants with moderate or big problems into the high-symptom-burden group and the rest into the low-symptom-burden group. Additionally, we conducted a sensitivity analysis by splitting the participants into low- and high-symptom-burden groups using median splits within each domain. For some domains (bowel, vitality, emotional), the median score was 1, indicating 'no problem'. We determined that using the moderate to big problem thresholds (instead of median splits) resulted in a more conservative grouping method. The language used in the survey (face validity) captured those who were truly burdened; thus, this was the method used for subsequent analyses.

## Information Needs

We were interested in identifying the primary areas of information need to describe topics that could be addressed during clinical encounters with prostate cancer survivors, and the extent to which these needs were associated with symptom burden. We assessed information needs by asking: 'Which areas of prostate cancer-related information do you feel that you need more complete information on? Check all that apply'. Respondents selected topics from the following list of common survivorship-related information

needs: 'Information on prostate cancer in general; Causes of cancer/prevention of cancer; Diagnosis of cancer; Long-term effects/recovery from cancer; Symptoms of cancer; Where to get medical care; Effect of cancer on my spouse or partner; Recurrence of prostate cancer; Cancer organisations; Coping with cancer/dealing with cancer; Paying for medical care/insurance; Screening/testing/early detection; Treatment/cures for cancer; Alternative/home remedies; Effect of cancer on my marital relationship; Other (please specify); None'.

### Statistical Analysis

We used descriptive statistics to describe our study population and included the following variables: age, race, education level, marital status, income, time since diagnosis, treatment type, and low/high domain-specific symptom burden (urinary, sexual, bowel, vitality, emotional). We also examined the percentage of patients reporting specific cancer survivorship-related information needs to identify the most common topics that providers might need to address. Next, we assessed the adjusted differences in information need according to domain-specific symptom burden using chi-square tests with Bonferroni corrections. Last, we used multivariable logistic regression to examine the association between high symptom burden and the most common reported survivorship-related information need topics (recurrence, relationship effects, and long-term effects) adjusting for patient characteristics.

Research approval was granted by the Michigan Public Health Institute (MPHI) and the Michigan Department of Community Health (MDCH) Institutional Review Boards, the MPHI privacy officer, and the MDCH Scientific Advisory Panel. All analyses were conducted using SPSS™ software version 22 (IBM SPSS, Armonk, NY, USA).

### Results

There were 2 499 respondents (Table 1) who were at a median (interquartile range) of 9 (7) years from diagnosis, with a median age of 76 years. Nearly 20% identified themselves as non-White. Most were married (78.4%) and had some level of college education (59.8%), with the median income ranging from \$35 000 to 49 999 (American dollars). Of those who received treatment, most underwent prostatectomy alone (55.1%). A few respondents (12.3%) reported having a recurrence. We found differences in the degree of symptom burden across quality-of-life domains, with the sexual domain having largest group of highly burdened men (high sexual burden 44.4%), followed by urinary (14.4%), vitality (12.7%), bowel (8.4%), and emotional domains (7.6%).

We found that 56% of respondents reported needing more complete cancer survivorship information. The leading

**Table 1** Characteristics of the Michigan Prostate Cancer Survivor Study population (2499 men).

Characteristic	N (%)
Age <sup>a</sup> , years	
≤64	342 (13.8)
65–74	824 (33.3)
≥75	1309 (52.9)
Race <sup>b</sup>	
White	1870 (80.2)
Non-White	461 (19.8)
Education level attained <sup>c</sup>	
Less than high school education	345 (13.9)
High school graduate or General Education Development (GED)	651 (26.3)
Some college to college graduate	989 (40.0)
Some graduate school to graduate degree	489 (19.8)
Marital status <sup>d</sup>	
Not married	535 (21.6)
Married	1938 (78.4)
Income <sup>e</sup> , \$ (American dollars)	
≤20 000	316 (13.6)
20 000–34 999	637 (27.3)
35 000–49 999	461 (19.8)
50 000–74 999	418 (17.9)
≥75 000	498 (21.4)
Time since diagnosis <sup>f</sup> , years	
≤5	266 (11.1)
5–9	983 (40.9)
10–14	692 (28.8)
≥15	465 (19.3)
Treatment type <sup>g</sup>	
Prostatectomy	1207 (55.1)
Combination (including prostatectomy)	982 (44.9)
Disease status <sup>h</sup>	
No recurrence	2119 (87.7)
Recurrence	297 (12.3)
Urinary symptom burden <sup>i</sup>	
Low	2077 (85.6)
High	350 (14.4)
Bowel symptom burden <sup>j</sup>	
Low	2214 (91.6)
High	202 (8.4)
Sexual symptom burden <sup>k</sup>	
Low	1217 (55.6)
High	971 (44.4)
Vitality symptom burden <sup>l</sup>	
Low	1994 (87.3)
High	291 (12.7)
Emotional symptom burden <sup>m</sup>	
Low	2075 (92.4)
High	170 (7.6)

<sup>a</sup>Median age 76 years, 24 missing values; <sup>b</sup>169 missing values; <sup>c</sup>25 missing values; <sup>d</sup>26 missing values; <sup>e</sup>169 missing values; <sup>f</sup>Median time since diagnosis 9 years, 25 missing values; <sup>g</sup>310 missing values; <sup>h</sup>84 missing values; <sup>i</sup>72 missing values; <sup>j</sup>83 missing values; <sup>k</sup>311 missing values; <sup>l</sup>214 missing values; <sup>m</sup>254 missing values.

information needs related to recurrence of prostate cancer (55.5%), effects on spouse/relationship (50.2%), and long-term effects/recovery from cancer (44.5%) (Table 2). The least information was sought for 'other' (4.9%) and for cancer organisations (5.5%). When stratifying by symptom burden level and domain, individuals with high symptom burden compared with low symptom burden were more likely to need more information on at least one of the leading topics (i.e., recurrence of prostate cancer, effects on spouse/

**Table 2** Information need topics reported by prostate cancer survivors (1397 men).

Information need topic	N (%)
Recurrence of prostate cancer	776 (55.5)
Effects on spouse/relationship	701 (50.2)
Long-term effects/recovery from cancer	621 (44.5)
Causes of cancer/prevention of cancer	496 (35.5)
General information on prostate cancer	478 (34.2)
Treatment/cures for cancer	451 (32.2)
Symptoms of cancer	327 (23.4)
Screening/testing/early detection	270 (19.3)
Diagnosis of cancer	246 (17.6)
Coping with cancer/dealing with cancer	234 (16.8)
Alternative/home remedies	158 (11.3)
Paying for medical care/insurance	144 (10.3)
Where to get medical care	128 (9.1)
Cancer organisations	77 (5.5)
Other	68 (4.9)

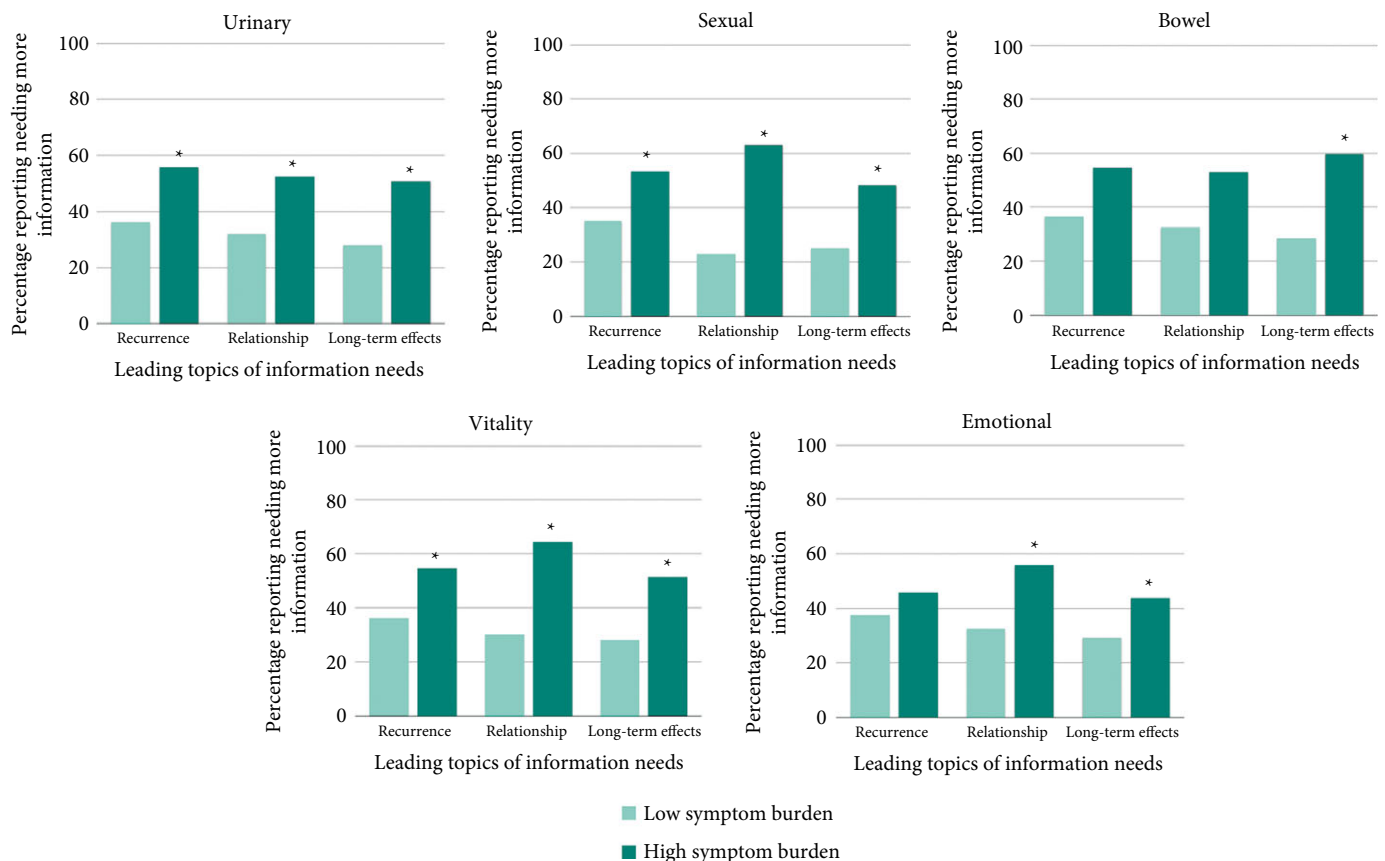
Multiple answers given; excludes those who said 'None' to needing more complete information on prostate cancer.

relationship, and long-term effects/recovery from cancer) regardless of the specific domain (Fig. 1). There was a strong association between a need for information regarding the

identified topics and the degree of symptom burden across all five domains: urinary, bowel, sexual, emotional, and vitality (all  $P < 0.05$ ). Needing more information about long-term effects/recovery from cancer was significantly associated with high symptom burden across all domains ( $P < 0.001$ ). Additionally, needing more information about recurrence of prostate cancer and effects on spouse/relationship varied across urinary ( $P = 0.007$ ,  $P = 0.03$ ), sexual ( $P = 0.004$ ,  $P < 0.001$ ), vitality ( $P = 0.01$ ,  $P < 0.001$ ), and emotional domains ( $P = 0.06$ ,  $P < 0.001$ ). The difference in information needs for prostate cancer recurrence and the impact on spouse/relationships was not significant for those with high vs low bowel symptoms ( $P = 0.15$ ,  $P = 0.20$ ).

We then examined the association between demographic and treatment factors, including symptom burden and information needs (Table 3). Factors associated with greater information needs about recurrence of prostate cancer included non-White race [odds ratio (OR) 1.36, 95% CI 1.00–1.85], having higher income (OR 1.72, 95% CI 1.03–2.87), and undergoing a combination of treatments for prostate cancer (OR 1.79, 95% CI 1.41–2.28). Factors associated with

**Fig. 1** Information needs differences between prostate cancer survivors with low- vs high-domain-specific symptom burden. When stratifying by symptom burden level and domain, individuals with high symptom burden compared with low symptom burden were more likely to need more information on at least one of the leading topics (i.e., recurrence of prostate cancer, effects on spouse/relationship, and long-term effects/recovery from cancer), regardless of the specific domain (\* $P < 0.05$ ).



**Table 3** Factors associated with information needs in long-term prostate cancer survivors (2499 men).

Information needs	Recurrence		Effects on spouse/ relationship		Long-term effects/recovery	
	OR <sup>a</sup> (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
Age, years						
≤64	Ref.		Ref.		Ref.	
65–74	1.22 (0.85–1.73)	0.28	0.91 (0.62–1.34)	0.64	0.92 (0.64–1.33)	0.67
≥75	1.05 (0.72–1.54)	0.80	<b>0.62 (0.40–0.96)</b>	<b>0.03</b>	0.72 (0.48–1.08)	0.11
Race						
White	Ref.		Ref.		Ref.	
Non-white	<b>1.36 (1.00–1.85)</b>	<b>0.05</b>	<b>2.46 (1.76–3.44)</b>	<b>0.00</b>	<b>1.43 (1.04–1.96)</b>	<b>0.03</b>
Marital status						
Not married	Ref.		Ref.		Ref.	
Married	0.97 (0.72–1.33)	0.87	<b>2.64 (1.74–4.02)</b>	<b>0.00</b>	1.01 (0.72–1.40)	0.97
Income, \$ (American dollars)						
≤20 000	Ref.		Ref.		Ref.	
20 000–34 999	1.31 (0.83–2.07)	0.25	1.48 (0.84–2.59)	0.17	0.94 (0.58–1.52)	0.80
35 000–49 999	1.44 (0.89–2.33)	0.14	1.52 (0.85–2.72)	0.16	1.08 (0.65–1.80)	0.76
50 000–74 999	1.40 (0.85–2.32)	0.19	1.15 (0.63–2.12)	0.65	0.99 (0.58–1.68)	0.96
≥75 000	<b>1.72 (1.03–2.87)</b>	<b>0.04</b>	1.38 (0.74–2.56)	0.32	1.26 (0.73–2.16)	0.41
Treatment type						
Prostatectomy	Ref.		Ref.		Ref.	
Combination <sup>b</sup>	<b>1.79 (1.41–2.28)</b>	<b>&lt;0.001</b>	1.09 (0.82–1.44)	0.56	<b>1.63 (1.26–2.12)</b>	<b>&lt;0.001</b>
Disease status						
No recurrence	Ref.		Ref.		Ref.	
Recurrence	1.17 (0.80–1.71)	0.42	1.23 (0.79–1.91)	0.36	<b>1.53 (1.03–2.28)</b>	<b>0.04</b>
Sexual symptom burden						
Low	Ref.		Ref.		Ref.	
High	1.13 (0.88–1.44)	0.33	<b>2.05 (1.54–2.72)</b>	<b>0.00</b>	<b>1.60 (1.23–2.07)</b>	<b>&lt;0.001</b>
Bowel symptom burden						
Low	Ref.		Ref.		Ref.	
High	0.88 (0.56–1.40)	0.60	1.15 (0.68–1.95)	0.61	<b>2.28 (1.43–3.63)</b>	<b>0.001</b>

<sup>a</sup>Adjusted ORs. We controlled for the following additional covariates: education, time since diagnosis, and urinary, vitality and emotional symptom burden levels. <sup>b</sup>Includes a combination of treatments (e.g., radical prostatectomy, external radiation, hormone replacement therapy). Bold values indicate significant OR.

needing more information about prostate cancer's effects on a spouse/relationship included being aged ≥75 years (OR 0.62, 95% CI 0.40–0.96), non-White (OR 2.46, 95% CI 1.76–3.44), married (OR 2.64, 95% CI 1.74–4.02), and having high sexual burden (OR 2.05; 95% CI 1.54–2.72). Last, we found that being non-White (OR 1.43, 95% CI 1.04–1.96), undergoing a combination of treatments for prostate cancer (OR 1.63, 95% CI 1.26–2.12), having a recurrence (OR 1.53; 95% CI 1.03–2.28), having high sexual burden (OR 1.60; 95% CI 1.23–2.07), and having high bowel burden (OR 2.28, 95% CI 1.43–3.63) were all factors associated with needing more information about the long-term effects/recovery from prostate cancer.

## Discussion

Using a State-wide cancer registry of long-term prostate cancer survivors, we found that unmet information needs are a lasting problem. The leading topics of unmet information needs related to recurrence of prostate cancer, effects on spouse/relationship, and long-term effects/recovery from prostate cancer. Not surprisingly, survivors with higher symptom burden compared with those with lower symptom burden, regardless of quality-of-life domain, continue to need

more supportive information many years after diagnosis, especially for managing the long-term or late effects of prostate cancer treatment. In addition, we identified subgroups of survivors who were particularly vulnerable to needing more information about their recovery and survivorship period including non-White prostate cancer survivors and those who have undergone a combination of treatments. Healthcare systems and providers should remain vigilant to these unmet information needs long after diagnosis and help survivors navigate towards resources to improve their quality of life. Based on our present findings, outreach efforts should be tailored to survivors at greatest risk of unmet information and treatment needs (e.g., those with the greatest symptom burden).

Prostate cancer survivors need more long-term information support. Men with greater symptom burden may have greater information needs for at least two reasons. First, men with greatest symptoms may have greater unmet clinical needs due to lack of access to information. Second, men with the greatest symptom burden may not be seeking care for all their concerns, perhaps, thinking that nothing could be done to alleviate particular symptoms due to lack of information. While providers may be in tune with the need for

information about prostate cancer recurrence, directing survivors to resources and/or help with search strategies for other concerns may be beneficial for these groups of men. For example, providers could refer survivors to sexual health counsellors or online resources.

The 2014 American Cancer Society prostate cancer survivorship care guidelines call for reducing such unmet needs. The present results identify critical unmet needs in addition to particular sub-groups for whom targeted, tailored interventions might be warranted rather than a 'one size fits all' supportive approach for the entire survivor population [11]. Our present findings also suggest that using a patient-centred approach and identifying individuals who may be at a greater risk for reduced quality of life due to their symptom burden could be one way to tailor appropriate survivorship care. Automated symptom assessment via interactive voice response (IVR) technology is one feasible, low cost, and efficient strategy to identify prostate cancer survivors with high symptom burden [27]. Using new technologies to monitor outcomes over time and then tailor appropriate follow-up care may further improve patient-centred prostate cancer survivorship care.

The present study has several limitations. First, this was a cross-sectional survey, so we cannot determine causal relationships over time. However, the large sample size and extended time since diagnosis both indicate that information needs and symptom burden persist long after a cancer diagnosis. Further exploration of how symptom burden evolves in long-term survivors and the subsequent impacts on changing information needs appears warranted, similar to how a changing disease state (i.e., cancer recurrence) influenced information needs as discovered in the present study. While the extent to which survivors in this study were already engaged in symptom management was also not known, we continued to find high long-term symptom burden and information needs among selected patients indicating further support appears warranted. Second, the sample is limited to prostate cancer survivors in the state of Michigan. Nonetheless, there is no reason to suspect that this State-based sample would diverge from national estimates given the stable and non-trivial rates of side-effects after prostate cancer treatment across all settings. While we do not have prostate cancer pathology for patients in the present study to help contextualise our findings, we did capture self-reported recurrence and over half of patients were treated with surgery indicating the generalizability of our findings to current long-term survivor population. Third, our present response rate was 38.3% among eligible participants; however, this is favourable compared with similar cancer survivorship studies [28]. Fourth, our present symptom burden measure is based on a dichotomised measure of overall domain-specific burden. We used a sensitivity analysis to examine different threshold values and the findings still support the conclusion

that survivorship information should be tailored to symptom burden. Last, we did not prospectively test whether information needs would be better met with tailored materials. As healthcare systems and providers continue to improve automated patient-reported assessments, understanding how to tailor information to individual patients will be critical to optimising the quality of survivorship care.

In conclusion, we found that unmet information needs are a lasting problem among long-term prostate cancer survivors. Our present findings suggest that non-White race, multimodality treatment, recurrence, and high symptom burden were all significant correlates of needing more long-term supportive information in specific topic areas. Provision of information may acknowledge patient concerns and facilitate primary care clinician and specialist efforts to achieve the highest possible long-term quality of life after cancer treatment. Future research should assess the effectiveness of tailored information support for survivors of prostate cancer to determine whether a personalised approach can help satisfy long-term information needs and improve overall quality of life by promoting self-management and appropriate healthcare utilisation.

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## Conflicts of interest

None declared.

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**Abbreviations:** EPIC-26, Expanded Prostate Cancer Index Composite 26-item; MDCH, Michigan Department of Community Health; MPHI, Michigan Public Health Institute, OR, odds ratio.