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

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Abstract

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

Subjects/patients and methods: We used population-based data from the Michigan Prostate Cancer Survivor Study (n=2,499). 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 (OR=2.05; 95% 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.

Introduction

There are more than one million new prostate cancer diagnoses each year resulting in millions of prostate cancer survivors around the globe (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 cancer patients in general, having the appropriate amount of cancer-relevant information from a variety of 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 behaviors 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, 23) (24-26) 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 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 this 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 a variety of topics, including symptom management and coping. (12, 22, 23) Individualized approaches are not typically feasible in health care 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).

Subjects/patients and methods

Study population

We used data from the Michigan Prostate Cancer Survivor Study, a statewide survey of long-term prostate cancer survivor outcomes (see original study for detailed methods). (12) Individuals diagnosed with prostate cancer in Michigan between 1985 and 2004 and alive as of December 31, 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 versus 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 eligible participants (n=6,531), and to maximize response rates, up to two follow-up surveys (every six 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 four-week period. These domains and single-item questions were taken from the Expanded Prostate Cancer Index Composite-26 (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 cutoffs (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 organizations; 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.

Results

There were 2,499 respondents (Table 1) who were a median of 9 years from diagnosis (IQR=7) with a median age of 76 years. Nearly 20% identified themselves as non-white. The majority was married (78.4%) and had some level of college education (59.8%), with median income ranging from $35,000 - $49,999. Of those who received treatment, the majority 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 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 organizations (5.5%). When stratifying by symptom burden level and domain, individuals with high symptom burden compared to 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 (Figure 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 with regard to prostate cancer recurrence and the impact on spouse/relationships was not significant for those with high versus 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% Confidence Interval (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 needing more information about prostate cancer's effects on a spouse/relationship included being 75 years or older (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 long term effects/recovery from prostate cancer.

Discussion

Using a statewide 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 to those with lower symptom burden, regardless of quality of life domain, continue to need more supportive information many years after diagnosis, especially with respect to managing the long-term or late effects of prostate cancer treatment. In addition, we identified sub-groups of survivors who were particularly vulnerable to needing more information regarding their recovery and survivorship period including non-white prostate cancer survivors and those who have undergone a combination of treatments. Health care 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 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 regarding 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 counselors or online resources.

The 2014 American Cancer Society prostate cancer survivorship care guidelines call for reducing such unmet needs. Results reported here 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 findings also suggest that using a patient-centered 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-centered prostate cancer survivorship care.

This 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 this 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 this study to help contextualize 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 response rate was 38.3% among eligible participants; however, this is favorable compared to similar cancer survivorship studies. (28) Fourth, our symptom burden measure is based on a dichotomized measure of overall domain-specific burden. We used a sensitivity analysis to examine different cutoff 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 health care systems and providers continue to

improve automated patient-reported assessments, understanding how to tailor information to individual patients will be critical to optimizing the quality of survivorship care.

In conclusion, we found that unmet information needs are a lasting problem among long-term prostate cancer survivors. Our 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 prostate cancer survivors to determine whether a personalized approach can help satisfy long-term information needs and improve overall quality of life by promoting self-management and appropriate health care utilization.

Acknowledgments

Abbreviation key

Interactive voice response (IVR)

Expanded Prostate Cancer Index Composite-26 (EPIC-26)

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Figure legend

Figure 1. Information need differences between prostate cancer survivors with low versus high domain-specific symptom burden. When stratifying by symptom burden level and domain, individuals with high symptom burden compared to 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 < .05).

Table 1. Characteristics of the Michigan Prostate Cancer Survivor Study population (n=2,499)

Characteristic	N (%)
Age[a]	
≤64 years	342 (13.8)
65 – 74 years	824 (33.3)
≥75 years	1309 (52.9)
Race[b]	
White	1870 (80.2)
Non-white	461 (19.8)
Education level attained[c]	
Less than high school education	345 (13.9)
High school graduate or GED	651 (26.3)
Some college to college graduate	989 (40.0)
Some graduate school to graduate degree	489 (19.8)
Marital status[d]	
Not married	535 (21.6)
Married	1938 (78.4)
Income[e]	
≤ $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[f]	
≤ 5 years	266 (11.1)
5 – 9 years	983 (40.9)
10 – 14 years	692 (28.8)
≥ 15 years	465 (19.3)
Treatment type[g]	
Prostatectomy	1207 (55.1)
Combination (including prostatectomy)	982 (44.9)
Disease status[h]	
No recurrence	**2119 (87.7)**
Recurrence	**297 (12.3)**
Urinary symptom burden[i]	
Low	2077 (85.6)
High	350 (14.4)
Bowel symptom burden[j]	

Low	2214 (91.6)
High	202 (8.4)
Sexual symptom burden[k]	
Low	1217 (55.6)
High	971 (44.4)
Vitality symptom burden[l]	
Low	1994 (87.3)
High	291 (12.7)
Emotional symptom burden[m]	
Low	2075 (92.4)
High	170 (7.6)

Note: a Median age = 76 years, missing values=24; b missing values=169; c missing values=25; d missing values=26; e missing values=169; f Median times since diagnosis = 9 years, missing values=25; g missing values=310; **h missing values = 84;** i missing values=72; j missing values = 83; k missing values=311; l missing values=214; m missing values=254

Table 2. Information need topics reported by prostate cancer survivors (n=1,397)

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 Organizations	77	5.5
Other	68	4.9

Note: Multiple answers given; Excludes those who said 'None' to needing more complete information on prostate cancer

Table 3. Factors associated with information needs in long-term prostate cancer survivors (n=2,499)

Information Needs	Recurrence			Effects on spouse/relationship			Long-term effects/Recovery		
Factors	OR[1]	95% CI	p	OR	95% CI	p	OR	95% CI	p
Age									
≤64 years	ref			ref			ref		
65 – 74 years	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 years	1.05	0.72 – 1.54	0.80	**0.62**	**0.40 – 0.96**	**0.03**	0.72	0.48 – 1.08	0.11
Race									
White	ref			ref			ref		
Non-white	**1.36**	**1.00 – 1.85**	**0.05**	**2.46**	**1.76 – 3.44**	**0.00**	**1.43**	**1.04 – 1.96**	**0.03**
Marital Status									
Not married	ref			ref			ref		
Married	0.97	0.72 – 1.33	0.87	**2.64**	**1.74 – 4.02**	**0.00**	1.01	0.72 – 1.40	0.97
Income									
≤ $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	**1.72**	**1.03 – 2.87**	**0.04**	1.38	0.74 – 2.56	0.32	1.26	0.73 – 2.16	0.41
Treatment type									
Prostatectomy	ref			ref			ref		
Combination[2]	**1.79**	**1.41 – 2.28**	**0.00**	1.09	0.82 – 1.44	0.56	**1.63**	**1.26 – 2.12**	**0.00**
Disease status									
No recurrence	ref			ref			ref		

	OR[1]	95% CI	p	OR[1]	95% CI	p	OR[1]	95% CI	p
Recurrence	1.17	0.80 – 1.71	0.42	1.23	0.79 – 1.91	0.36	**1.53**	**1.03 – 2.28**	**0.04**
Sexual symptom burden									
Low	*ref*			*ref*			*ref*		
High	1.13	0.88 – 1.44	0.33	**2.05**	**1.54 – 2.72**	**0.00**	**1.60**	**1.23 – 2.07**	**0.00**
Bowel symptom burden									
Low	*ref*			*ref*			***ref***		
High	0.88	0.56 – 1.40	0.60	1.15	0.68 – 1.95	0.61	**2.28**	**1.43 – 3.63**	**0.001**

Note: [1]Adjusted odds ratios. We controlled for the following additional covariates: education, time since diagnosis, and urinary, vitality and emotional symptom burden levels. [2]Includes a combination of treatments (e.g., radical prostatectomy, external radiation, hormone replacement therapy).

Figure 1. Information need differences between prostate cancer survivors with low versus high domain-specific symptom burden.