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Evaluating long-term patient-centered outcomes following prostate cancer treatment: findings from the Michigan Prostate Cancer Survivor study

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Abstract

Context Advances in screening and treatment of prostate cancer have dramatically increased the number of survivors in the US population. Yet the effect of screening is controversial, and in some instances may not be beneficial. Previous studies have typically only reported outcomes of treatment and symptoms within a short time frame following treatment. The persistence of such symptoms over time necessitates an improvement of survivor care so that the medical and support needs of these patients are met.

Objective This study aims to perform a patient-centered survey of prostate cancer survivors in the Michigan Cancer Registry to identify treatment side effect rates, evaluate survivors' access to preventive care services post-prostate cancer treatment, and assess the informational needs of these survivors regarding their prostate cancer.

Design, setting, and patients Linking case files of the Michigan Cancer Registry with records from the National Death Index, we identified prostate cancer patients diagnosed between 1985 and 2004 and alive on 31 December 2005. Participants were selected using a stratified cross-sectional sampling strategy to ensure adequate inclusion of survivors based upon race and ethnicity, urban versus rural location, and number of years since diagnosis of prostate cancer. A total of 2,499 surveys were completed and returned.

Main outcome measures (1) Physical symptoms—assessing bowel, sexual, urinary, and vitality symptoms by treatment modality. (2) Access to care—identifying whether diagnostic tests for prostate cancer (prostate-specific antigen (PSA) and digital rectal examination) were performed. Determining whether the survivors had knowledge of the "watchful waiting" paradigm for prostate cancer surveillance. (3) Informational

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Informed consent was obtained from the study subjects.

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needs—assessing whether the informational needs of patients were addressed by providers. Evaluating the significant predictors associated with seeking information about prostate cancer from any other source. Identifying what factors influenced a person to actively seek out information and what factors guide which primary information source a survivor would use.

Results Median duration between prostate cancer diagnosis and survey response was 9 years. Of the study population, 80 % was diagnosed at an early stage. Survivors had reported significant problems in the 4 weeks prior to survey. Of the survivors, 88.1 % reported having a PSA test since diagnosis of prostate cancer, with 93 % of them having it done at least once per year. Of the survivors, 82.6 % reported that a healthcare provider gave them information on prostate cancer. Of this 82.6 %, 86.4 % had this information provided by a urologist, 45.4 % by a primary care physician, and 29.2 % by an oncologist. The primary source of information for these survivors was "healthcare provider" (59.2 %).

Conclusion Persistent symptoms subsequent to prostate cancer treatment suggest a gap in symptom management. Future research should support long-term studies of active surveillance versus active treatment outcomes to understand the feasibility of minimizing the burden of long-term physical symptoms arising from prostate cancer treatment. Clinicians must assess post-treatment distress long after treatment has ended to identify when supportive care is needed. More informational resources should be allocated to prostate cancer survivors to ensure that they are well-educated about their prognosis.

Implications for Cancer Survivors This study is needed to ensure that the post-treatment symptoms of prostate cancer survivors are properly addressed and managed by healthcare providers over the long term.

Keywords Prostate · Cancer · Oncology · Treatment · Survivorship · Symptoms · Active surveillance · Symptom management · Care gaps · Primary care

Introduction

Over the last 30 years, advancements in the early diagnosis and treatment of cancer have led to an ever-increasing number of cancer survivors. Today, nearly 12 million cancer survivors are living in the USA; it is estimated that over the next two decades, this number will continue to rise to more than 22 million [1]. The American Cancer Society estimates that there are now more than two million prostate cancer survivors living in the USA [2]; one recent study estimated the number of prostate cancer survivors living in the USA in 2010 at 2.31 million [3]. In Michigan, as with the rest of the country, nearly 100 % of men diagnosed with local disease live at least 5 years after diagnosis, with more than 90 % of men living at least 10 years postdiagnosis [4]. While most population-based prostate cancer survivorship studies have focused on the first 2–5 years postdiagnosis, few have examined the health status and quality of life of this patient population long term. Prostate cancer survivors frequently face a constellation of problems, including physical side effects, psychological duress, and socioeconomic vulnerabilities, many of which can negatively influence their quality of life for many months or years after completion of treatment [5].

While various treatment modalities have been shown to be effective at curing prostate cancer, these same treatments can be associated with a wide range of lasting symptoms, which can persist for years [6]. Previous reports have shown that between 10 and 20 % of men treated with a radical prostatectomy report severe long-term urinary changes (i.e., incontinence, leakage, and frequent urination), while more than 50 % report erectile dysfunction, and between 4 and 23 % report bowel changes (i.e., diarrhea, painful bowel movements, urgency, rectal wetness, painful hemorrhoids, and rectal bleeding) [7, 8]. Similar studies looking at long-term effects following early treatment with radiotherapy (external radiation and brachytherapy) have described resultant urinary changes, erectile dysfunction, and bowel changes [7, 9–11]. Patients treated with androgen deprivation therapy (ADT) report many physical changes including loss of libido and erectile dysfunction (up to 80 %) and gynecomastia or mastodynia (between 20 and 50 %) [12, 13]. ADT also has been associated with increased body fat mass (ranging from 9 % to as high as 50 %) [14–16]. As a result of these initial treatments, prostate cancer survivors are more susceptible to developing long-term complications. One such complication is osteoporosis attributed to ADT, which results in a higher risk for developing fractures [17–19]. ADT also induces hypogonadism, which has been linked to the onset of metabolic syndrome ,coronary heart disease, peripheral vascular disease, stroke, and type 2 diabetes mellitus [20–26]. Treatment modalities are available for these postprostate cancer morbidities, including behavioral therapy, pharmacotherapy, medical device implantation, and corrective surgery [27–29]. The survivorship period is an expensive and highly variable phase of the cancer care cycle [30].

But whether these survivors have continued access to medical services, including preventive care, has not been fully elucidated. Moreover, following the diagnosis of prostate cancer, many patients are left to decipher complicated medical terminology in order to make informed decisions about their medical care. But little is known what types of information sources prostate cancer survivors seek, as well as the information-seeking styles of these individuals.

The objectives of the Michigan Prostate Cancer Survivors Study are to (1) quantify the long-term physical symptoms experienced by survivors post-treatment; (2) evaluate patterns of continuation care provided to prostate cancer survivors after completion of treatment; and (3) evaluate the demographic, diagnostic, treatment, and psychosocial factors associated with types of information sources sought by prostate cancer survivors.

Materials and methods

The study was conducted by the Michigan Public Health Institute (MPHI) in collaboration with the Michigan Department of Community Health (MDCH). Prostate cancer cases diagnosed in Michigan between 1985 and 2004 and not reported as deceased as of 31 December 2005 were identified by linking case files of the Michigan Cancer Registry (maintained by the MDCH Michigan Cancer Surveillance Program) with records of the National Death Index. Study participants were selected using a stratified random sampling strategy to ensure adequate inclusion of prostate cancer survivors based upon race and ethnicity, urban versus rural location, and number of years since diagnosis of prostate cancer. Racial/ethnicity groups sampled included white, black, and non-white/non-black. An oversampling of African American men was performed to allow better representation of this racial population for comprehensive analysis. Since the majority (80 %) of Michigan's African American adults reside in only five Michigan cities, and because the incidence of prostate cancer in men of African descent is generally higher, black prostate cancer survivors were oversampled upfront using race identification in the registry's case file to compensate for an anticipated lower proportion potentially identified by random sampling techniques and also to ensure an adequate number of black men consenting to the study. All prostate cases diagnosed during the years sampled were then extracted with nonresident and known deceased patients filtered out. A random number was assigned to each remaining patient eligible for recruitment. This random number was then used to sequentially select the patients needed to satisfy the target number for each stratum.

The healthcare facility reporting each case to the Michigan Cancer Registry was contacted and asked to confirm the survivor's diagnosis, as well as his vital status, current address, and physician of record. The survivor's physician of record was then contacted, provided with study information, and asked to provide confirmation of the survivor's diagnostic and vital status. Each physician on record also was asked if there was another physician that might be a more appropriate contact and whether patient contact for purposes of the survey would be medically appropriate. Both facility and physician contacts were passive in that a failure on either of their parts to respond to the study inquiry would not exclude a patient from participation.

Based upon these efforts, researchers determined the eligibility of the potential study participants that had been identified. The study population consisted of men who had been diagnosed with prostate cancer identified through the population-based Michigan Cancer Registry who had responded affirmatively to receiving a specified treatment for prostate cancer with the prime intention of curing the cancer. The survivors were also asked about whether they used watchful waiting but the proportion who reported choosing watchful waiting was so small (<2 %) it did not account for many cases. During this study, active surveillance had not yet emerged as an evidence-based treatment option. However, the persistence of incontinence and impotence revealed from this study provides additional evidence that active surveillance might be a very viable option for men without aggressive disease. Survivors were classified as being ineligible for the study if their cancer was unconfirmed; they were incarcerated, could not be located, or had moved out of state; they were unable to complete the survey; or their physician had recommended against patient contact. Of the 7,763 potential participants resulting from the initial stratified random sampling, 1,232 cases (15.9 %) were determined to be ineligible for one or more of these reasons, leaving 6,531 eligible participants.

Prior to survey implementation, research approval was obtained from the MPHI and MDCH Institutional Review Boards, the MPHI privacy officer, and the MDCH Scientific Advisory Panel. Potential study participants were contacted by mail, invited to participate, and offered a $10 gift card in exchange for return of their completed survey. Survivors who did not respond were mailed a new survey every 6 weeks until they had received a total of three surveys, the last of which was sent by certified mail.

The survey utilized selected items from the University of Michigan Expanded Prostate Cancer Index Composite short version to obtain information on the physical symptoms (urinary, bowel, sexual, and vitality related) currently experienced by survivors [31]. Urinary symptoms were defined as dripping or leaking urine, pain or burning with urination, bleeding with urination, weak urine stream or incomplete emptying, or a need to urinate frequently during the day at least once a week over a 4-week period. Bowel symptoms were defined as an urgency to have a bowel movement, an increased frequency of bowel movements, losing bowel control, bloody stools, or abdominal, pelvic, or rectal pain experienced at least once a week over a 4-week period. Sexual symptoms were defined as an inability or poor ability to have or maintain an adequate erection for sexual activity when desired or an inability or poor ability to reach orgasm at least once a week in a 4-week period. Vitality symptoms were defined as hot flashes, breast tenderness or enlargement, a change in body weight, a feeling of depression, or a lack of energy experienced at least once a week over a 4-week period.

The number of years since prostate cancer diagnosis was gathered from Michigan Cancer Registry records. Survey respondents were asked to provide supplemental information for age, race/ethnicity, marital status, educational level attained, and treatments received. Descriptive statistics were calculated for categorical variables using frequencies and proportions. Differences among age and racial groups were evaluated using the chi-square test.

Analysis for this study examined only prostatectomy, external beam radiation, hormone therapy, or a combination of these three modalities as distinct entities of treatment; internal radiation, chemotherapy, cryotherapy, and watchful waiting were excluded from the study analysis due to small number of applicable cases [1].

Factors associated with the receipt of preventive care once prostate cancer treatment had concluded were identified. Respondents were asked whether diagnostic tests for prostate cancer [prostate-specific antigen (PSA) and digital rectal examination (DRE)] had been performed primarily to assess post-prostate cancer treatment follow-up as opposed to identifying evidence in support of PSA or DRE in post-prostate cancer surveillance. Logistic regression analysis was conducted to ascertain the significant predictors associated with the watchful waiting paradigm for prostate cancer surveillance.

Informational sources used by prostate cancer survivors were delineated. Logistic and multivariate regression analyses were conducted using multiple covariates to (1) assess whether the informational needs of patients were addressed by providers, (2) ascertain the significant predictors associated with seeking information about prostate cancer from any other source, and (3) identify what factors influenced a person to actively seek out information and (4) determine what factors guide which primary information source a survivor would use.

Results

The median age of the respondents was 76 years, and the median number of years since prostate cancer diagnosis was 9 years (Table 1). Three quarters (75.5 %) of the respondents identified themselves as white, 18.6 % as black, and 5.9 % as “other,” multiracial, or unspecified race. The distribution of the study respondents among Michigan counties closely mirrored the geographical density of Michigan residents. A total of 2,499 surveys were completed and returned, yielding an overall response rate of 38.3 % among the 6,531 eligible cases.

Table 2 summarizes the type and number of physical symptoms experienced by respondents within the 4 weeks prior to their completion of the survey. Sexual symptoms were the most common and troublesome difficulty reported by participants. It is important to note that nearly 90 % of survivors in the study reported that they had experienced one or more sexual symptoms within the past 4 weeks, and seven out of 10 respondents reported that they had experienced at least one urinary-related side effect. In addition, nearly half of all respondents said they had experienced one or more vitality-

Table 1 Characteristics of the Michigan Prostate Cancer Survivor Study Population

Characteristic	*N* (%)
Age at time of survey[a]	
64 years or less	342 (13.8)
65–74 years	824 (33.3)
75 years or greater	1,309 (52.9)
Race[b]	
White	1,870 (75.5)
Black	461 (18.6)
Other/race unspecified/multiracial	145 (5.9)
Educational 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]	
Single (never married)	85 (3.4)
Divorced	173 (7.0)
Married	1,938 (78.4)
Widowed	277 (11.2)
Years since prostate cancer diagnosis[e]	
Less than 5 years	266 (11.1)
5–9 years	983 (40.9)
10–14 years	692 (28.8)
More than 15 years	465 (19.3)
Treatments received for prostate cancer[f]	
Prostatectomy	1,592 (67.5)
External beam radiation	779 (33.0)
Hormone therapy	466 (19.8)
Internal radiation	236 (10.0)
Chemotherapy	85 (3.6)
Cryotherapy	50 (2.1)
Active surveillance (watchful waiting)	37 (1.6)
All therapies received for prostate cancer[g]	
Prostatectomy monotherapy	1,207 (55.1)
External radiation monotherapy	320 (14.6)
Prostatectomy and external radiation	196 (9.0)
External radiation and hormone therapy	181 (8.3)
Prostatectomy and hormone therapy	107 (4.9)
Hormone therapy	96 (4.4)
Prostatectomy, external radiation, and hormone therapy	82 (3.7)

[a] Median age=76 years, N=2,499, missing values=24

[b] N=2,499, missing values=23

[c] N=2,499, missing values=25

[d] N=2,499, missing values=26

[e] Median=9 years, N=2,499, missing values=93

[f] Multiple responses given and treatment categories are not exclusive; N=2,499, missing values=140

[g] Internal radiation, chemotherapy, cryotherapy, and watchful waiting are excluded from analysis, N=2,189

Table 2 Number of symptoms experienced in past 4 weeks by prostate cancer survivors

	Urinary[a] (n=2,215)		Bowel[a] (n=2,086)		Sexual[a] (n=2,083)		Vitality[a] (n=2,117)	
Number of symptoms reported	*N*	%	*N*	%	*N*	%	*N*	%
0	666	30.1	1,151	55.2	217	10.4	1,164	55.0
1	678	30.6	524	25.1	157	7.5	489	23.1
2	493	22.2	265	12.7	160	7.7	301	14.2
3	317	14.3	118	5.7	502	24.1	122	5.8
4	20	0.9	21	1.0	1,047	50.3	35	1.6
5	41	1.9	7	0.3	–	–	6	0.3

Urinary symptoms include respondents who reported experiencing leaked urine, pain, or burning on urination, bleeding with urination, weak urine stream or incomplete emptying, or a need to urinate frequently during the day more than once a day to once a week in the past 4 weeks

Bowel symptoms include respondents who reported an urgency to have a bowel movement, an increased frequency of bowel movements, losing bowel control, bloody stools, or abdominal, pelvic, or rectal pain more than once a day to once a week in the past 4 weeks

Sexual symptoms include respondents who reported experiencing erections that were "not firm enough for intercourse," erections occurring "about half the time when desired to never occurring when desired," rated erections as "poor to none," or rated orgasms as "poor to none" in the past 4 weeks

Vitality symptoms include respondents who reported experiencing hot flashes, breast tenderness or enlargement, feeling depressed, a lack of energy, or a change in body weight more than once a day to about once a week in the past 4 weeks

[a] Respondents who reported any of these problems existed prior to prostate cancer were excluded from this analysis

related and/or bowel-related symptoms (45.0 and 44.8 %, respectively) during the previous month.

Table 3 presents the physical symptoms that were most frequently experienced by respondents during the previous 4 weeks by age and treatment (prostatectomy and external beam radiation monotherapy only). In general, participants in the oldest age group reported the greatest degree of symptoms. Sexual symptoms were the most commonly reported problems across age and treatment groups, and sexual symptoms reported by men who had received either type of treatment tended to increase by age, with the greatest percentage of men experiencing such symptoms being 75 years of age or older. Among respondents 75 years of age or older who had received prostatectomy monotherapy, the most commonly reported sexual side effect (89.3 %) was an erection that was not firm enough for intercourse. Among respondents of the same age group who had received external beam radiation monotherapy, the most commonly reported sexual side effect (89.7 %) was erections that either never occurred when desired or occurred about half the time when desired.

Urinary symptoms were the second most commonly reported problems across age and treatment groups; as was the case with sexual symptoms, urinary symptoms reported by men who had received either type of treatment also tended to increase by age, with the greatest percentage of men experiencing such symptoms being 75 years of age or older. Among respondents 75 years of age or older who had received prostatectomy monotherapy, the most commonly reported urinary side effect (59.6 %) was leaked urine. Among respondents of the same age group who had received external beam radiation monotherapy, the most commonly reported urinary side effect (57.5 %) was a need to urinate frequently.

The third most commonly reported symptoms across age and treatment groups were related to bowel function. Among respondents who had received prostatectomy monotherapy, feelings of urgency were the most commonly reported bowel-related side effect, with the greatest percentage of men (37.3 %) experiencing such symptoms being 75 years of age or older. Although urgency was also the most commonly reported bowel side effect among those who had received external beam radiation monotherapy, the greatest percentage of men reporting urgency problems were those 65–74 years of age (46.3 %), followed closely by men age 75 years or older (44.6 %).

Figure 1 illustrates the patient's perception of the extent to which physical symptoms in these four categories are considered a problem. Urinary, sexual, and vitality symptoms were reported as a problem by approximately two thirds of survey respondents (69.0, 68.0, and 67.0 %, respectively), while more than half of respondents (54.4 %) reported that bowel symptoms were a problem in their lives. Slightly more than half (51.6 %) of all respondents said they considered sexual symptoms to be a "moderate" or "big" problem in their lives. Nearly one fourth (24.1 %) of the respondents reported that vitality symptoms were a "moderate" or "big" problem in their lives, while 19.7 % of respondents reported that urinary symptoms were a "moderate" or "big" problem and 14.0 % or respondents reported that bowel symptoms were a "moderate" or "big" problem for them.

When asked to identify the types of providers from whom they had sought treatment for their symptoms, 33 % of study respondents with self-reported urinary symptoms and 57 % of study respondents with self-reported sexual symptoms answered "no one." Survey results indicated that utilization of support services, such as a sexual therapist, was almost nonexistent among the study population. Yet, these men were still engaged in the healthcare system on a routine basis: 88 % of survivors in the study indicated they were currently seeing a primary care provider and nearly 20 % indicated they were seeing an urologist for their general care.

Regarding access to preventive care services, 88.1 % of the survivors reported having a PSA test since diagnosis of prostate cancer, with 93 % of them having it done at least once per

Table 3 Symptoms experienced in past 4 weeks by men who had prostatectomy monotherapy and external beam radiation monotherapy, by age

	Prostatectomy monotherapy						External beam radiation monotherapy					
	64 Years or less (*n*=205)		65–74 Years (*n*=476)		75 Years or older (*n*=516)		64 Years or less (*n*=25)		65–74 years (*n*=66)		75 Years or older (*n*=225)	
	N	% (95 % CI)	*N*	% (95 % CI)	*N*	% (95 % CI)	*N*	% (95 % CI)	*N*	% (95 % CI)	*N*	% (95 % CI)
Urinary[a]												
Leaked urine[b]	110	55.8 (62.8–48.8)	234	52.3 (56.9–47.7)	274	59.6 (64.1–55.1)	9	36.0 (55.3–16.8)	18	31.6 (43.8–19.4)	83	45.4 (52.6–38.2)
Weak urine stream[b]	34	18.3 (23.9–12.7)	72	18.3 (22.1–14.5)	109	28.7 (33.3–24.1)	–	–	22	44.9 (59.0–30.8)	76	46.3 (54.0–38.6)
Need to urinate frequently[b]	75	39.3 (46.2–32.4)	150	36.9 (41.6–32.2)	197	49.6 (54.5–44.7)	14	56.0 (75.9–36.1)	30	53.6 (66.8–40.4)	103	57.5 (64.8–50.2)
No symptoms experienced[c]	69	33.7 (40.2–27.2)	148	31.1 (35.3–26.9)	116	22.5 (26.1–18.9)	10	40.0 (59.6–20.4)	19	28.8 (39.8–17.8)	52	23.1 (28.6–17.6)
Bowel[a]												
Urgency	47	24.9 (31.1–18.7)	109	25.6 (29.7–21.5)	168	37.3 (41.8–32.8)	–	–	25	46.3 (59.7–32.9)	79	44.6 (51.9–37.3)
Increased frequency	23	12.4 (17.1–7.7)	51	12.8 (16.1–9.5)	76	19.3 (23.2–15.4)	–	–	16	31.4 (44.3–19.5)	44	28.9 (36.1–21.7)
Pelvic/abdominal/rectal pain	–	–	–	–	15	3.8 (1.9–5.7)	–	–	–	–	8	5.5 (1.8–9.2)
No symptoms experienced[c]	133	67.9 (74.5–61.3)	286	62.4 (66.8–58.0)	237	47.6 (52.0–43.2)	13	56.5 (77.2–35.8)	25	40.3 (52.6–28.0)	71	33.8 (40.2–27.4)
Sexual[a]												
Poor erection to none	102	54.8 (62.0–47.6)	314	76.6 (80.7–72.5)	365	84.9 (88.3–81.5)	10	55.6 (79.2–32.0)	34	64.2 (77.2–51.2)	157	87.2 (92.1–82.3)
Erection not reliable[d]	98	54.4 (61.7–47.1)	319	78.8 (82.8–74.8)	347	87.0 (90.3–83.7)	13	72.2 (93.5–50.9)	35	66.0 (78.9–53.1)	139	89.7 (94.5–84.9)
Erection not firm[e]	112	60.5 (67.6–53.4)	324	79.2 (83.1–75.3)	374	89.3 (92.3–86.3)	10	58.8 (82.9–34.7)	33	61.1 (14.2–48.0)	152	86.4 (91.5–81.3)
No symptoms experienced	59	30.6 (37.1–23.5)	50	11.3 (14.2–8.4)	20	4.2 (6.0–2.4)	–	–	10	17.2 (27.0–7.4)	–	–
Vitality[a]												
Hot flashes	10	5.3 (8.5–2.1)	24	5.8 (8.0–3.6)	25	6.0 (8.3–3.7)	–	–	–	–	16	9.5 (14.0–5.0)
Felt depressed	43	22.8 (28.8–16.8)	60	14.3 (17.7–10.9)	51	12.3 (15.5–9.1)	–	–	8	15.1 (24.8–5.4)	29	17.3 (23.0–11.6)
Lack of energy	58	30.9 (37.5–24.3)	106	25.5 (29.7–21.3)	140	33.0 (37.5–28.5)	8	34.8 (54.7–14.9)	14	25.9 (37.7–14.1)	72	39.8 (47.0–32.6)
No symptoms experienced[c]	115	56.1 (62.9–49.2)	284	59.7 (64.1–55.3)	256	49.6 (53.9–45.3)	14	56.0 (75.9–36.1)	37	56.1 (68.2–44.0)	91	40.4 (46.8–24.0)

[a] Respondents who were diagnosed with these symptoms before prostate cancer were excluded

[b] Respondents reported experiencing symptoms about once a week to more than once per day

[c] Respondent answered “rarely” or “never” to all side effect questions

[d] Respondent reported erections occurred about half the time when desired to never occur when desired

[e] Respondent reported erections not firm enough for intercourse

– Number of cases in cell is too small to report a reliable rate

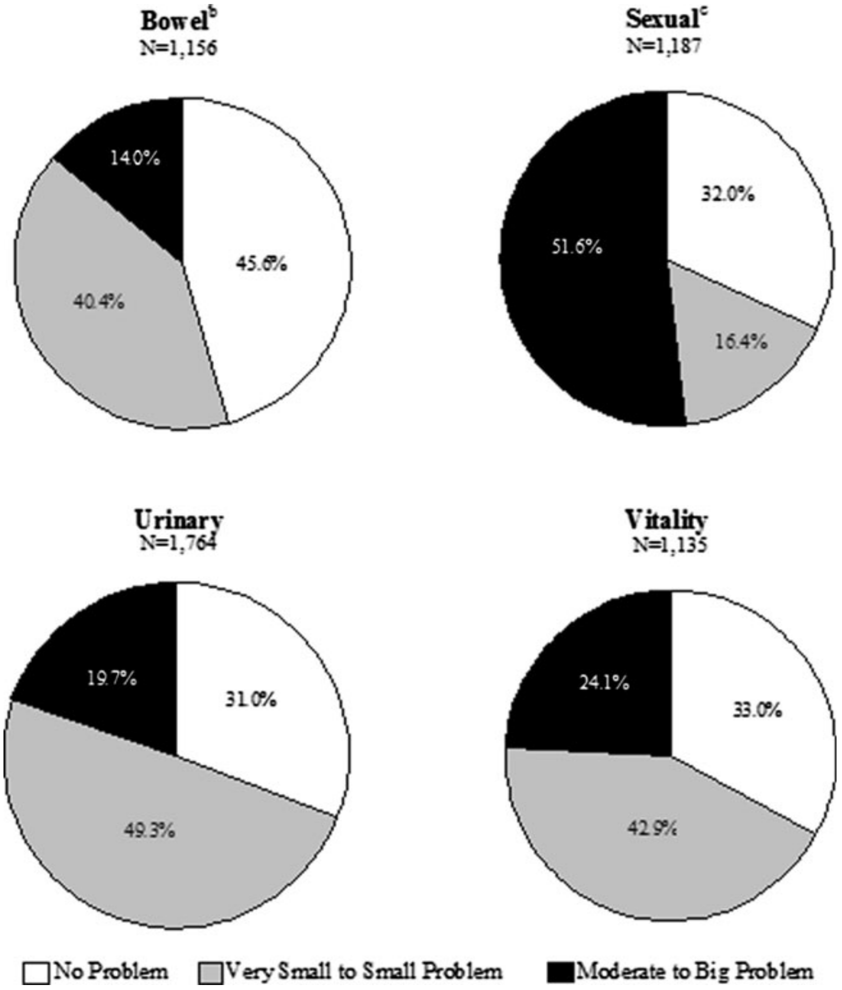

Fig. 1 Extent to which physical symptoms were a problem in past 4 weeks as reported by prostate cancer survivors. **a** Respondents who "rarely or never" experienced urinary (30.1 %), bowel (55.2 %), and vitality symptoms (55.0 %) were excluded. For sexual symptoms, men who said their ability to have an erection or to reach orgasm was "good to very good," men who reported having erections "whenever they wanted one," and men who reported erections "firm enough for intercourse" were excluded from this analysis (10.4 %). **b** Respondents who reported bowel problems were present prior to prostate cancer were excluded from this analysis (5.0 %). **c** Respondents who reported erectile dysfunction was present prior to prostate cancer were excluded from this analysis (8.1 %)

year. 98 % of survivors described that their primary care physician had ordered the test. Of the survivors, 60.6 % recalled having a DRE examination performed since diagnosis of prostate cancer with 73.3 % of them having the evaluation done at least once per year. Of the survivors, 71 % reported that their primary care physician had performed this evaluation, compared to 75 % of urologists and 83 % of oncologists. Between 83 and 95 % of survivors reported that their healthcare provider did not refer them to general supportive services (which included dietician or nutritionist, physical therapist, occupational therapist, mental health professional, social worker, pain management specialist, spiritual or pastoral counselor, sexual therapist, support group, or other service) and hence did not seek them out. Of the survivors, 43.7 % knew what watchful waiting was, but only 1.1 % chose to follow the paradigm. Age and race were significant predictors of whether PSA test was performed, as serum PSA provided the most predictive information about the results of biopsy of the prostate at the time and also because it naturally correlated with age and race as previously described in the literature [32]. Age and race were also significant predictors on whether the watchful waiting paradigm was approached with survivors, albeit the absolute numbers counseled on this strategy were small.

When evaluating informational needs, 82.6 % reported that a healthcare provider gave them information on prostate cancer. Of this 82.6 %, 86.4 % had this information provided by a urologist, 45.4 % by a primary care physician, and 29.2 % by an oncologist. 37.9 % responded that they had looked for such information on their own. 29.4 % of the survivors reported that someone else had looked for information for them. The top five sources of information included "healthcare provider" (59.2 %), "someone with prostate cancer" (39.4 %), "brochures or pamphlets" (37.5 %), "National Cancer Institute/American Cancer Society" (36.1 %), and "internet" (31.0 %). 51.2 % of the survivors would go to their healthcare provider first for information, with 18.8 % resorting to the internet. Age and race were significant factors in assessing whether informational needs of survivors were addressed by healthcare providers: older survivors and white survivors reported that a healthcare provider had spoken to them about providing information on prostate cancer. Age was a significant predictor in both survivors' seeking information about prostate cancer and whether someone else had ever looked for information on their behalf. Education was the only significant factor predicting which primary source of information a survivor would seek first; those with a college education or higher tended to go to the internet for initial information as compared to those with high school or less education who more often sought initial information directly from the healthcare provider.

Discussion

The lifelong physical effects associated with prostate cancer treatment quantified in our study warrant earnest attention by providers and health systems. Our study clearly documents a high frequency of symptoms at 5 years and even 10 years following cancer treatment. Moreover, the fact that many men reported that these symptoms were at least a “moderate,” if not “big,” problem for them within the last 4 weeks underscores the importance of these findings to prostate cancer survivors. While some of the reported symptoms could be attributed to aging, all these men have undergone definitive localized prostate cancer treatments with which such symptoms occur frequently.

These findings suggest a strong, but often unmet, need for symptom management even many years post-treatment. Primary care providers and urologists need to address long-term, post-treatment symptoms with survivors and provide the necessary care for these symptoms.

This study is a uniquely large population-based survey of prostate cancer survivors drawing cases from the statewide cancer registry and providing a level of detail on cancer treatment outcomes not available in the literature. Other follow-up studies, mostly clinic-based, have reported prostate cancer treatment sequelae and post-treatment symptoms, but have been limited by short follow-up selection bias.

The findings of the Michigan Prostate Cancer Survivors Study are important, not only because they identify unmet needs of a large population of survivors, but also because they identify potential policy-relevant triggers for improvement of post-treatment follow-up and care. According to the American Cancer Society, patients and their primary care providers should be provided with a cancer treatment synopsis, also known as a survivorship care plan, when the patients are discharged from cancer care [33]. One purpose of this recommendation is to ensure that both the patient and the provider are informed about the imminent risk for possible symptoms and how to manage such symptoms if they do occur.

It is unclear how widespread this practice of providing post-treatment care plans is, but data suggest that many primary care providers are uncomfortable treating the symptoms that may occur after prostate cancer treatment. In one recent study, more than 45 % of internists reported feeling they were not adequately prepared to assess or manage the long-term effects of cancer survivors in general [34]. Additionally, in a survey of all primary care providers in Michigan, many providers reported they believed they would benefit from guidance on how to identify and manage the possible symptoms[1] associated with prostate cancer treatment [35].

Of course, in contrast to the notion of unmet need, it must be noted that some men may choose not to have their symptoms treated, particularly if they are only minimally bothered, have limited access to specialty care, or are unaware that treatment is available. It is plausible that the survivors did not seek care for their complaints perhaps believing that nothing could be done about their particular symptoms. Indeed, although most of the respondents in our study had routine care with a primary care provider and 20 % were still seeing a urologic specialist, a third of respondents said that they had not sought care for their urinary complaints, and almost 60 % said that they had not sought care for sexual dysfunction symptoms. The survey attempted to address these side effects with a series of follow-up questions such as “Who do you go to for care regarding this problem?”, “What do you use to help alleviate the symptom?”, “Are you satisfied with the treatment for your symptom?”, and “Do you wish you had more help for symptom?” These questions were asked for urinary, bowel, sexual, and emotional side effects. It should also be mentioned that between 83 and 95 % of survivors reported that their healthcare provider did not refer them to general supportive services as reason for why they did not seek them out. Developing a survivorship care plan that the survivor can share with his primary care provider upon his discharge from specialty care has the potential to address awareness and communication gaps that can exist in today's fragmented health care.

In addition to highlighting the magnitude of the problem, our study also highlights the need to determine which type of provider is best able to assume responsibility for patient care and the after-effects of prostate cancer treatment many years post-treatment. This study found that men sought care after treatment from both primary care providers and urologists. Regardless, men still had ongoing questions related to recurrence, and to overcoming side effects many years after treatment had ended (i.e., ongoing survivorship care). The results of this study indicated that not all care needs were met by either type of provider. While this study did not identify which type of provider should provide care,

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[1] In response to the needs of prostate cancer survivors and providers alike, MDCH, in collaboration with MPHI and the Michigan Cancer Consortium Prostate Cancer Action Committee, developed and disseminated a series of 12 fact sheets with guidelines for use by primary care providers who are managing prostate cancer survivors’ ongoing symptoms. The same collaborative partners developed a companion set of 14 symptom management fact sheets in English, Spanish, and Arabic versions for survivors and their families [31].

subjects reported troubling side effects many years after treatment ended. The fact that many men reported ongoing symptoms 10 or more years after treatment might indicate that primary care providers must address the needs of prostate cancer survivors since most men 10 years post-treatment are no longer receiving specialty care. Primary care providers seem to be in the best place to provide survivorship care. With the findings indicating the presence of unmet needs, and results of a companion study of primary care providers indicating 50 % were only somewhat comfortable managing ongoing side effects, our expert advisory committee recommended we develop guidelines to assist providers to manage these ongoing post-treatment problems.

Because the number of prostate cancer survivors has grown rapidly over the last decade and is, in fact, still growing, it must be recognized that it is unlikely that the relatively small number of practicing urologists and even oncologists will be able to handle this need. More realistically, the management of the post-treatment symptoms of prostate cancer survivors will need to be the responsibility of primary care providers who have documented survivorship care plans for their patients and other types of support from specialists.

It is worth noting that the findings of this study should be considered in the context of several limitations. Causal attribution of these findings directly to prostate cancer treatment or aging is not possible with this cross-sectional design. Prior work in which age-matched controls were compared to localized prostate cancer patients treated with surgery/radiation therapy have found that men without prostate cancer generally had better disease-specific quality-of-life indicators [36]. However, the inability to attribute causality neither diminishes the impact nor lessens the unmet need for care. Moreover, excluding internal radiation, chemotherapy, cryotherapy and active surveillance may have also lead to bias. Biases associated with survey studies should be acknowledged, including nonresponse bias, voluntary response bias, and survey bias.

Although the 38.3 % overall response rate among eligible participants also should be recognized, it does compare favorably to similar studies of cancer survivors recruited from a shorter survival period, and the respondents of our study were similarly distributed compared to all sampled cases with regard to cancer therapy method [37].

On a final note, we should add that the demographic profile of our study population included a relatively high educational level. (Approximately 60 % of our survey respondents said they had attended at least some college or had earned one or more postsecondary degrees.) Yet, the need for better follow-up and symptom management was evident even among members of this more highly educated group, which indicates that these needs are real and immediate, independent of a cancer survivor's personal level of educational attainment.

Conclusion

Prostate cancer survivors continue to endure long-term physical symptoms, even years after the completion of cancer treatment. These findings support the need for the health care community to focus on, and provide the resources for, delivery of urologic care to prostate cancer survivors years post-treatment to ensure that they continue to enjoy a high quality of life years out [38].

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References

1. Surveillance, Epidemiology, and End Results (SEER) Program. limited-use data (1973–2006), National Cancer Institute, Division of Cancer Control and Population Sciences, Surveillance Research Program, Cancer Statistics Branch; released April 2009, based on the November 2007 submission. www.seer.cancer.gov. Accessed 23 Nov 2009.
2. American Cancer Society. Prostate cancer overview: what is prostate cancer? www.cancer.org/Cancer/ProstateCancer/OverviewGuide/prostate-cancer-overview-key-statistics. Accessed 11 July 2011.
3. Mariotto AB, Yabroff KR, Shao Y, Feuer EJ, Brown ML. Projections of the cost of cancer care in the United States: 2010–2020. J Natl Cancer Inst. 2011;103(2):117–28.
4. Surveillance, Epidemiology, and End Results (SEER) Program. Research data (1973–2008), Division of Cancer Control and Population Sciences, Surveillance Research Program, Cancer Statistics Branch; released April 2011, based on the November 2010 submission. www.seer.cancer.gov. Accessed 7 June 2011.
5. Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahana B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. Psychooncology. 2006;15(4):306–20.
6. Aziz NM, Rowland JH. Trends and advances in cancer survivorship research: challenge and opportunity. Semin Radiat Oncol. 2003;13(3):248–66.
7. Potosky AL, Davis WW, Hoffman RM, Stanford JL, Stephenson RA, Penson DF, et al. Five-year outcomes after prostatectomy or radiotherapy for prostate cancer: the prostate cancer outcomes study. J Natl Cancer Inst. 2004;96(18):1358–67.
8. Shrader-Bogen CL, Kjellberg JL, McPherson CP, Murray CL. Quality of life and treatment outcomes: prostate carcinoma patients' perspectives after prostatectomy or radiation therapy. Cancer. 1997;79(10):1977–86.
9. Litwin MS. Health-related quality of life after treatment for localized prostate cancer. Cancer. 1995;75 Suppl 7:2000–3.

10. Litwin MS, Hays RD, Fink A, et al. Quality-of-life outcomes in men treated for localized prostate cancer. JAMA. 1995;273(2):129–35.
11. Miller DC, Sanda MG, Dunn RL, Montie JE, Pimentel H, Sandler HM, et al. Long-term outcomes among localized prostate cancer survivors: health-related quality-of-life changes after radical prostatectomy, external radiation, and brachytherapy. J Clin Oncol. 2005;23(12):2772–80.
12. Dobs A, Darkes MJM. Incidence and management of gynecomastia in men treated for prostate cancer. J Urol. 2005;174(5):1737–42.
13. Potosky AL, Knopf K, Clegg LX, Albertsen PC, Stanford JL, Hamilton AS, et al. Quality-of-life outcomes after primary androgen deprivation therapy: results from the prostate cancer outcomes study. J Clin Oncol. 2001;19(17):3750–7.
14. Berruti A, Dogliotti L, Terrone C, Cerutti S, Isaia G, Tarabuzzi R, et al. Changes in bone mineral density, lean body mass and fat content as measured by dual energy X-ray absorptiometry in patients with prostate cancer without apparent bone metastases given androgen deprivation therapy. J Urol. 2002;167(6):2361–7.
15. Boxer RS, Kenny AM, Dowsett R, Taxel P. The effect of 6 months of androgen deprivation therapy on muscle and fat mass in older men with localized prostate cancer. The Aging Male. 2005;8(3–4):207–12.
16. Smith JC, Bennett S, Evans LM, Kynaston HG, Parmar M, Mason MD, et al. The effects of induced hypogonadism on arterial stiffness, body composition, and metabolic parameters in males with prostate cancer. J Clin Endocrinol Metab. 2001;86(9):4261–7.
17. Daniell HW, Dunn SR, Ferguson DW, Lomas G, Niazi Z, Stratte PT. Progressive osteoporosis during androgen deprivation therapy or prostate cancer. J Urol. 2000;163(1):181–6.
18. Higano C, Shields A, Wood N, Brown J, Tangen C. Bone mineral density in patients with prostate cancer without bone metastases treated with intermittent androgen suppression. Urology. 2004;64(6):1182–6.
19. Shahinian VB, Kuo Y-F, Freeman JL, Goodwin JS. Risk of fracture after androgen deprivation for prostate cancer. N Engl J Med. 2005;352(2):154–64.
20. Braga-Basaria M, Dobs AS, Muller DC, Carducci MA, John M, Egan J, et al. Metabolic syndrome in men with prostate cancer undergoing long-term androgen-deprivation therapy. J Clin Oncol. 2006;24(24):3979–83.
21. Muller M, Grobbee DE, den Tonkelaar I, Lamberts SW, van der Schouw YT. Endogenous sex hormones and metabolic syndrome in aging men. J Clin Endocrinol Metab. 2005;90(5):2618–23.
22. Dockey F, Bulpitt CJ, Agarwal S, Donaldson M, Rajkumar C. Testosterone suppression in men with prostate cancer leads to an increase in arterial stiffness and hyperinsulinaemia. Clin Sci (Lond). 2003;104(2):195–201.
23. Keating NL, O'Malley AJ, Smith MR. Diabetes and cardiovascular disease during androgen deprivation therapy for prostate cancer. J Clin Oncol. 2006;24(27):4448–56.
24. Leaksonen DE, Niskanen L, Punnonen K, Nyyssönen K, Tuomainen TP, Valkonen VP, et al. Testosterone and sex hormone-binding globulin predict the metabolic syndrome and diabetes in middle-aged men. Diabetes Care. 2004;27(5):1036–41.
25. Satariano WA, Ragland KE, Van Den Eeden SK. Cause of death in men diagnosed with prostate carcinoma. Cancer. 1998;83(6):1180–8.
26. Smith MR, McGovern FJ, Fallon MA, Schoenfeld D, Kantoff PW, Finkelstein JS. Low bone mineral density in hormone-naïve men with prostate carcinoma. Cancer. 2001;91(12):2238–45.
27. Poon SA, Silberstein JL, Savage C, Maschino AC, Lowrance WT, Sandhu JS. Surgical practice patterns for male urinary incontinence: analysis of case logs from certifying American urologists. J Urol. 2012;188(1):205–10.
28. Faucheron JL, Chodez M, Boillot B. Neuromodulation for fecal and urinary incontinence: functional results in 57 consecutive patients from a single institution. Dis Colon Rectum. 2012;55(12):1278–83.
29. Chung E, Brock G. Sexual rehabilitation and cancer survivorship: a state of art review of current literature and management strategies in male sexual dysfunction among prostate cancer survivors. J Sex Med. 2013;10 Suppl 1:102–11.
30. Skolarus TA, Zhang Y, Miller DC, Wei JT, Hollenbeck BK. The economic burden of prostate cancer survivorship. J Urol. 2010;184(2):532–8.
31. Wei JT, Dunn RL, Litwin MS, Sandler HM, Sanda MG. Development and validation of the expanded prostate cancer index composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. Urology. 2000;56(6):899–905.
32. Grunkemeier MN, Vollmer RT. Predicting prostate biopsy results: the importance of PSA, age, and race. Am J Clin Pathol. 2006;126(1):110–2.
33. American Cancer Society. Survivorship: during and after treatment: survivorship care plans. www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/SurvivorshipCarePlans/index. Accessed 7 Jun 2011.
34. Bober SL, Recklitis CJ, Campbell EG, Park ER, Kutner JS, Najita JS, et al. Caring for cancer survivors: a survey of primary care physicians. Cancer. 2009;115 Suppl 18:4409–18.
35. Skolarus TA, Holmes-Rovner M, Northouse LL, Fagerlin A, Garlinghouse C, Demers RY, et al. Primary care perspectives on prostate cancer survivorship: implications for improving quality of care. Urol Oncol. 2013;31(6):727–32.
36. Wei JT, Dunn RL, Sandler HM, McLaughlin PW, Montie JE, Litwin MS, et al. Comprehensive comparison of health-related quality of life after contemporary therapies for localized prostate cancer. J Clin Oncol. 2002;20(2):557–66.
37. Smith T, Stein KD, Mehta CC, Kaw C, Kepner JL, Buskirk T, et al. The rationale, design, and implementation of the American Cancer Society's studies of cancer survivors. Cancer. 2007;109(1):1–12.
38. Michigan Cancer Consortium. MCC prostate cancer resources. www.michigancancer.org/CancerPlan/ProstateCancer_Resources.cfm. Accessed 7 Jun 2011.