Supportive Care in Cancer (2019) 27:4363–4373
https://doi.org/10.1007/s00520-019-04927-6

ORIGINAL ARTICLE

Patterns and predictors of registration and participation at a supportive care program for prostate cancer survivors

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Received: 7 August 2018 / Accepted: 6 June 2019 / Published online: 25 June 2019

Abstract

Purpose To examine registration rates, and the timing/intensity of follow-up with a prostate cancer supportive care (PCSC) program, and to explore clinical and sociodemographic factors associated with participation and non-participation.

Methods We used electronic medical records for a cohort of men diagnosed with prostate cancer (PC) who attended a PC-related appointment at the Vancouver Prostate Centre, January 2013–December 2016. We used multivariate logistic regression to quantify the effect of diagnostic treatment and sociodemographic characteristic PCSC program registration and subsequent attendance. We produced Kaplan-Meier estimators to assess the probability of program attendance over the disease trajectory for those who registered.

Results Almost 15% of the men who registered for the program did not end up using any services. An additional 23% attended only one session/clinical appointment. Surgical and radiation treatments increased the odds and intensity of participation. Long travel distance decreased the odds of registering and participating. Low income decreased the odds of registration but not subsequent participation.

Conclusions While the use of supportive care services can help address the detrimental effects of prostate cancer diagnosis and treatment, one in six men who register for supportive care do not end up using any. Offering these services at no cost and alongside treatment appears to be insufficient to ensuring access for all patients. Additional research is needed to understand barriers and facilitators of accessing supportive care in this population.

Keywords Prostate cancer · Survivor · Supportive care · Survivorship care

Introduction

Prostate cancer (PC) is the most common malignancy diagnosed in men, representing 21% of new cases [1]. In 2017, approximately 161,000 American and 21,000 Canadian men were diagnosed with the disease [1, 2]. Deaths from PC are declining, and 5-year survival currently stands at 98.6% [2]; therefore, while incidence has been declining steadily in recent years, the number of men currently living with PC and with the ongoing effects of its treatment has ballooned to well over three million in North America [1, 2].

The most common treatment approaches for PC are surgery (radical prostatectomy (RP)) and radiotherapy (either brachytherapy (BT) or external beam radiotherapy (EBRT)) [3]; however, for men diagnosed with less aggressive tumours, or who are very elderly or have significant comorbidities, active surveillance is increasingly recommended [4, 5]. For men with advanced disease androgen deprivation therapy (ADT), chemotherapy, radiation, or a combination of these is used [6].

All treatments for PC can be associated with both acute and long-term side effects including urinary incontinence, erectile dysfunction, and bowel problems [7–10]. The use of ADT in addition to or instead of definitive therapy may result in loss of libido, hot flashes and night sweats, irritability, and increases

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in long-term risk of sarcopenia, osteoporosis, obesity, and metabolic syndromes [11–14]. Diagnosis, treatment, and the resulting symptoms may have an adverse effect on PC patients' psychological well-being and overall quality of life, and that of their partners [15–17].

With the complex and chronic nature of PC treatment-related sequelae, supportive care needs for PC survivors are diverse [18, 19], and the majority of men who have been diagnosed report that they have supportive care needs that are unmet [20–23]. The highest level of need is related to sexuality and psychological issues [20–22]. In light of this, there are increasing calls for the development of comprehensive supportive care programs to improve the quality survivorship care for cancer patients. The American Society of Clinical Oncology and the American Cancer Society suggest that survivorship care for men with PC should include PC surveillance and screening for new cancers, the assessment and management of late effects of treatment, and support for addressing psychological and psychosocial issues [19, 24]. A reasonable body of evidence suggests that the physiological and psychosocial interventions included in supportive care enhance patient well-being [25, 26]. Furthermore, specific elements of our program have been shown to reduce pre-treatment and anxiety in both patients and partners [27] and program participants have expressed a high degree of satisfaction with the program [28]. While many large cancer centres have started to incorporate supportive care programs for cancer survivors into their clinics, most are not specific to men with PC and their unique unmet care needs (e.g. 10). There are few comprehensive supportive care programs specific to PC survivors, and there is a dearth of evidence on whether and how PC survivors access and participate in these programs when they are made available. Thus, we sought to understand the current patterns of the use of supportive care offered in our own PC supportive care program, and whether specific clinical or sociodemographic characteristics can predict whether and how patients will access and use services. In this study, following the methodology previously employed by Zheng et al. [29] in their paper on survivorship care for survivors of childhood cancers, we examine registration rates, and the timing and intensity of follow-up, diagnostic, treatment, and demographic factors associated with registration, participation, and non-participation.

Methods

Program description

The Prostate Cancer Supportive Care (PCSC) program at the Vancouver Prostate Centre (VPC) at Vancouver General Hospital aims to address the physical and psychological supportive needs of men and their partners from the time of PC diagnosis onwards. It is comprised of six complementary modules that are administered by medical professionals in urology, radiation and medical oncology, psychology, sexual medicine, couples' counselling, nutrition, and physical therapy/exercise. Modules currently include (1) deciding on treatment for prostate cancer, (2) managing the sexual impact of PC treatments, (3) forming healthy dietary and exercise habits, (4) thriving on androgen deprivation therapy, (5) strengthening pelvic floor muscles, and (6) coping with prostate cancer. The program includes group educational sessions and individual clinical appointments with health care providers, all administered in a centralized location. A complete description of the program elements can be found in a previously published article [28].

Most men with PC are referred to the program by their urologist either prior to or following treatment. Others are referred by an oncologist, general practitioner, or other health care provider. They may also self-refer through the program's website, a variety of print materials, or through word of mouth. The materials and services provided through the program are offered to all patients and families free of charge.

Study sample

We included all men diagnosed with PC between January 1, 2013, and December 31, 2016, who attended at least one PC-related visit at the VPC (over the same period). Within this cohort, we distinguished between men who registered for the PCSC programs ("registrants") from men who sought PC-related care at the VPC but who did not register for the program ("non-registrants"). We further stratified PCSC program registrants according to their subsequent interaction or non-interaction with the program. We defined "registrant participants" as those registrants who attended at least one PCSC education session or clinic visit, and "non-participants" as men who initially registered but who did not subsequently use any PCSC services during the study period.

Data sources and variables

We used data abstracted from patient electronic medical records at the VPC for this analysis. The datasets analysed during the current study are available from the corresponding author on reasonable request. Sociodemographic characteristics included age, travel distance to the clinic, and income quintile. Travel distance and income were derived from patient postal codes. For the latter, the postal codes were used to assign census enumeration areas, from which neighbourhood income quintiles were derived using a program and protocol developed and validated by Statistics Canada [30]. From the same data source, we also abstracted clinical variables including age of diagnosis, treatment history, Gleason Grade (< 7, $3 + 4$, $4 + 3$, 8, or 9–10 at biopsy), and clinical T stage at diagnosis. Treatment was assessed as a series of dummy variables for each of the following options: RP (yes/no), BT or EBRT or BT adjuvant to RP (yes/no), continuous/intermittent androgen deprivation therapy (yes/no), and active surveillance (yes/no).

We used a database of PCSC program records to assess the timing and intensity of program participation, and to determine how registrants were referred (urologist, oncologist, family physician, program media, other health care provider, and word of mouth). We calculated the intervals between diagnosis and program registration, program registration and program participation, and diagnosis and program participation for each participant. We conceptualized the intensity of program participation as the number of education sessions and clinical visits attended, categorized as none, 1 to 2, 3 to 4, or 5 or more.

Statistical analyses

We produced descriptive statistics for PCSC program non-registrants, and registrants (split into participants and non-participants). We conducted chi-square tests for all categorical variables, and one-way ANOVAs for age, age at diagnosis, and distance to clinic to assess unadjusted differences between the three groups. We used the same tests to examine unadjusted effects of clinical and sociodemographic characteristics on the intensity of program participation. We used a Kaplan-Meier estimator to assess the probability of participating in the PCSC program over the survivorship trajectory.

To examine the adjusted effect of specific independent variables on program registration and participation respectively, we constructed two multivariate binary logistic regression models. Lastly, we constructed an ordinal logistic regression model to assess whether the odds of more intense program participation (larger number of education sessions or clinic visits attended) differs across treatment, diagnosis, and demographic groups. We considered using both Poisson and negative binomial regression; however, in both cases the model fit was very poor due to over-dispersion in the count data.

Results

Patient characteristics

We identified 1341 PC survivors who were diagnosed between January 2013 and December 2016 and had at least one PC-related medical visit at the VPC. Among them, 638 (47.6%) registered for the PCSC program and 703 (52.4%) elected not to register. Among registrants, 526 (85.6%) participated in the program within the study period, and 92 (14.4%) did not. Mean age for the study sample was 67.8 (standard deviation (SD) 8.2), while mean age at diagnosis was 65.5 (SD 8.1). Three hundred twenty-six (24.5%) men had a Gleason Grade < 7, 389 (29.1%) had 3 + 4, 196 (14.6%) had 4 + 3, and 418 (32.0%) had a grade of 8 or higher. Seven hundred forty-nine (59.5%) had undergone an RP, while 154 (11.5%) had either BT or EBRT. One hundred sixty-six (13.0%) had undergone intermittent or continuous ADT.

The travel distance to the VPC varied dramatically and was highly left-skewed. The median distance was 18.5 km (11.5 miles) (SD 598.4 km (371.8 miles)). Individuals in the highest income quintile accounted for 28.0% ($N = 354$) of the sample. We observed (unadjusted) significant differences between non-registrants, non-participants, and participants for all demographic and clinical characteristics measured (Table 1).

Predictors of registration

Adjusting for other sociodemographic and clinical factors, men treated with RP had more than twice the odds of registering for the PCSC program compared to men who had not (OR 2.19, 95% CI 1.52–31.6) (Table 2, model 1). Men treated with continuous or intermittent ADT had significantly lower odds of registering compared to those not on ADT (OR 0.11, 95% CI 0.05–0.22). Travel distance and income also both affected odds of registration. Men who lived furthest from the clinic had lower odds of registration compared with those who lived closest (OR 0.30, 95% CI 0.22–0.41), while those in the highest two income quintiles had significantly higher odds of registering compared to those in the lowest quintile (4th quintile OR 1.76, 95% CI 1.15–2.69; highest quintile OR 1.65 (95% CI 1.09–2.47).

Predictors of participation

Factors associated with the odds of participation in the program were relatively consistent with those that predicted initial registration. Men treated with RP had more than four times the odds of participating compared to those who did not receive that treatment (OR 4.85, 95% CI 2.35–10.01). Men who lived more than 45 km from the clinic had lower odds of participation compared to those who lived less than 15 km away (OR 0.34, 95% CI 0.16–0.72). Unlike the relationship with registration, ADT was not associated with lower odds of participation. Furthermore, we observed no relationship between income quintile and program participation.

Kaplan-Meier curves

Among those who participated in the program, the median time from diagnosis to registration was 68 days (mean 185, standard error (SE) 241). Median time from registration to participation was 38 days (mean 19, SE 74). For 3-, 6-, and 12-month and 2-year following diagnoses, PCSC program

Table 1 Cohort demographics, number (column %)

	Non-registrants $N = 703$ (52.4%)	Registrants $N = 638$ (47.6%)		Total ($N = 1341$)
		Participants $N = 546$ (85.6%)	Non-participants $N = 92$ (14.4%)	
Age (mean (SD))[1,2]	69.0 (8.8)	66.6 (7.3)	66.5 (7.2)	67.8 (8.2)
< 60	91 (12.9)	87 (15.9)	12 (13.0)	190 (14.2)
60− < 70	292 (41.5)	265 (48.5)	49 (53.3)	606 (45.2)
70+	320 (45.5)	194 (35.5)	31 (33.7)	545 (40.6)
Age at diagnosis (in years)[2]	66.9 (8.7)	63.8 (7.2)	64.4 (7.4)	65.5 (8.1)
Gleason Grade[3]				
< 7	187 (26.7)	107 (19.6)	32 (34.8)	326 (24.5)
3 + 4	166 (23.7)	200 (36.6)	23 (25.0)	389 (29.1)
4 + 3	94 (13.4)	90 (16.5)	12 (13.0)	196 (14.6)
8	95 (13.6)	63 (11.5)	12 (13.4)	170 (12.7)
9–10	159 (22.7)	86 (15.8)	13 (14.1)	258 (19.3)
Primary treatment				
RP[4]				
Yes	354 (50.4)	392 (72.5)	48 (52.8)	794 (59.5)
No	349 (49.6)	149 (27.5)	43 (47.2)	541 (40.5)
EBRT, BT, or BT adjuvant to RP[5]				
Yes	96 (13.7)	53 (9.8)	5 (5.5)	154 (11.5)
No	607 (86.3)	487 (90.2)	86 (94.5)	1180 (88.5)
ADT (continuous or intermittent)[6]				
Yes	149 (21.2)	14 (2.8)	3 (3.8)	166 (13.0)
No	553 (78.8)	479 (97.2)	77 (96.2)	1109 (87.0)
Active surveillance[7]				
Yes	167 (23.8)	85 (15.7)	20 (22.0)	272 (20.4)
No	536 (76.2)	455 (84.3)	71 (78.0)	1062 (79.6)
Median distance to clinic[8]	25.5 km (723.8)	15.2 km (356.9)	28.8 km (377.4)	18.5 km (598.4)
Income quintile[9]				
1	125 (17.8)	60 (12.0)	10 (15.9)	195 (15.4)
2	120 (17.1)	72 (14.4)	8 (12.7)	200 (15.8)
3	140 (20.0)	83 (16.6)	10 (15.9)	233 (18.4)
4	135 (19.3)	134 (26.8)	14 (22.2)	283 (22.4)
5	181 (25.8)	152 (30.3)	21 (33.3)	354 (28.0)

[1] $F = 15.2$, $p < 0.0001$

[2] $F = 17.4$, $p < 0.0001$

[3] Chi-square = 841.1, $p < 0.0001$ ($N = 2$ missing)

[4] Chi-square = 63.8, $p < 0.0001$ ($N = 6$ missing)

[5] Chi-square = 7.9 $p = 0.02$ ($N = 6$ missing)

[6] Chi-square = 12.2 $p = 0.002$ ($N = 7$ missing)

[7] Chi-square = 92.9 $p < 0.0001$ ($N = 6$ missing)

[8] Chi-square = 20.0, $p < 0.0001$ ($N = 76$ missing)

[9] Chi-square = 22.8, $p = 0.01$ ($N = 76$ missing)

attendance probabilities among those who registered were 39.7% (SE 2.0), 52.1% (SE 2.0), 68.2% (SE 2.0), and 85.4% (SE 1.5) respectively (Fig. 1a). The Kaplan-Meier curves varied significantly by treatment modality and Gleason Grade but not by age, age at diagnosis, income, or distance to clinic. The median time from diagnosis to participation is 362 days (mean 508, SE 41) for men with Gleason < 7, and 113 days (mean 271, SE 33) for men with Gleason 9 or 10 (Fig. 1b). Also, men with the lowest Gleason Grade had the highest rates of non-participation: 23.0% over the study

Table 2 Binary logistic regression modelling†

	Model 1: program registration ($N = 1341$) Odds ratio (95% CI)	Model 2: program participation ($N = 638$) Odds ratio (95% CI)
Age group		
< 60	1 (reference)	1 (reference)
60– < 70	1.12 (0.77–1.63)	1.04 (0.46–2.35)
70+	0.69 (0.46–1.03)	0.91 (0.37–2.23)
Gleason Grade		
< 7	1 (reference)	1 (reference)
3 + 4	1.26 (0.81–1.95)	2.32 (0.96–5.61)
4 + 3	0.86 (0.52–1.45)	2.29 (0.77–6.77)
8	0.79 (0.46–1.37)	2.26 (0.67–7.64)
9–10	0.72 (0.42–1.25)	2.60 (0.75–8.98)
Primary treatment		
RP		
Yes	2.19 (1.52–3.16)***	4.85 (2.35–10.01)***
No	1 (reference)	1 (reference)
EBRT, BT, or BT adjuvant to RP		
Yes	1.16 (0.67–2.01)	11.79 (1.40–97.59)*
No	1 (reference)	1 (reference)
ADT (continuous/intermittent)		
Yes	0.11 (0.05–0.22)***	1.94 (0.20–18.60)
No	1 (reference)	1 (reference)
Active surveillance		
Yes	0.62 (0.38–1.02)	1.90 (0.71–5.06)
No	1 (reference)	1 (reference)
Distance to clinic		
< 15 km	1 (reference)	1 (reference)
15– < 30 km	1.03 (0.71–1.50)	0.64 (0.29–1.40)
30– < 45	1.11 (0.77–1.63)	0.90 (0.33–2.44)
> 45 km	0.30 (0.22–0.41)***	0.34 (0.16–0.72)*
Income quintile		
1	1 (reference)	1 (reference)
2	1.01 (0.64–1.61)	0.69 (0.23–2.12)
3	0.97 (0.62–1.53)	0.90 (0.33–2.44)
4	1.76 (1.15–2.69)**	1.05 (0.38–2.92)
5	1.65 (1.09–2.47)*	0.84 (0.32–2.19)

$^{*}p < 0.05$; $^{**}p < 0.001$; $^{***}p < 0.0001$

† Model 1 uses the complete study sample ($N = 1341$). Model 2 uses the subset of the sample who registered for the program ($N = 638$) since registration is required in order to participate

period, compared to between 10.3 and 16.0% for men with higher-grade disease. Active surveillance also affected the timing of program participation (Fig. 1c) since these men were not seen as frequently as those who had definitive therapy (median time follow-up 404 days and 131 days respectively) and therefore had fewer opportunities to be exposed to the program. Lastly, men who received EBRT, RP, or radiotherapy adjuvant to RP had a median of 53 days from diagnosis to participation compared to 180 days for men not treated with any (Fig. 1d). We observed no difference in the timing of program participation based on whether or not men received surgical treatment or ADT, nor by age, distance to clinic, or income quintile (data not shown).

Intensity of program participation

Ninety-two (14.42%) program registrants never subsequently attended any PCSC program education sessions or clinic appointments. Two-hundred thirty-one (36.21%) attended one or two, 111 (17.4%) attended three or four, and 204 (32.0%) attended five or more sessions or clinic appointments. Unadjusted, the intensity of participation varied significantly

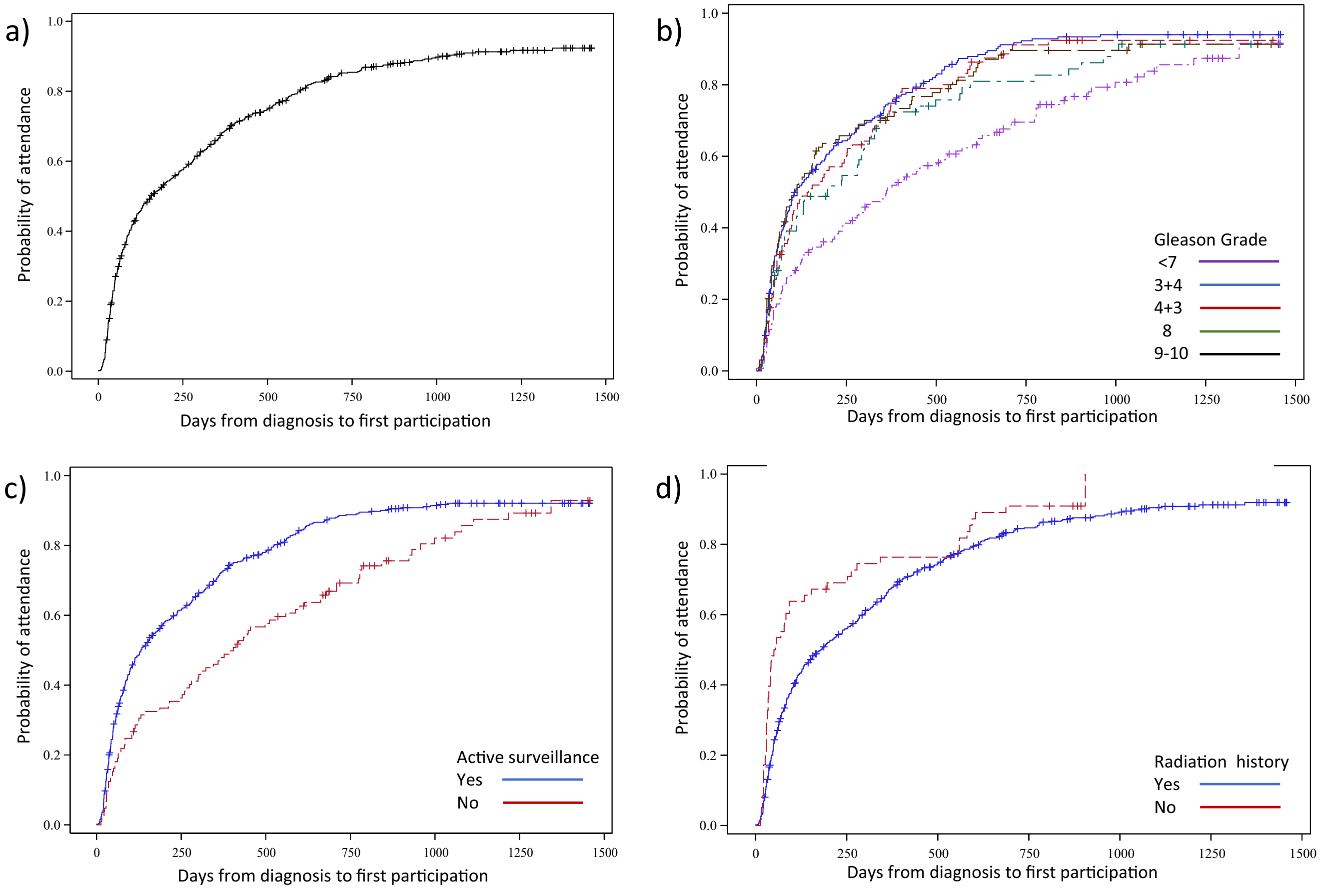

Fig. 1 Kaplan-Meier curves estimating probability of attending one or more PCSC education sessions or clinics among program registrants ($N = 638$). Maximum possible follow-up of 4 years (1460 days). **a** Overall, unstratified participation curve. **b** Gleason Grade ($p < 0.0001$). **c** Active surveillance ($p < 0.0001$). **d** Radiation history (EBRT, BT, or BT adjuvant to RP ($p = 0.0066$)). No difference in attendance over time by other factors examined

by Gleason Grade (chi-square = 21.6, $p = 0.04$) and surgical treatment (chi-square 64.1, $p < 0.0001$) (Table 3). We found no difference in intensity of participation by age, distance to clinic, socioeconomic quintile, or other treatment variables.

Ordinal logistic regression results suggest that controlling for other clinical and sociodemographic characteristics receiving either an RP or some form of radiation (EBRT, BT, or BT adjuvant to RP) were associated with higher levels of participation in the program (prostatectomy: OR 5.48, 95% CI 3.35–8.95; radiation: OR 2.57, 95% CI 1.20–5.52) (Table 4). In contrast, intermittent or continuous ADT treatment was associated with lower levels of participation (OR 0.25, 95% CI 0.07–0.95). Living more than 45 km from the clinic similarly reduced the odds of higher levels of participation (OR 0.47, 95% CI 0.30–0.73).

Discussion

To the authors' knowledge, this is the first paper that assesses registration and attendance at supportive care services within a population of men with PC. The PCSC program offers a comprehensive set of services for men facing the physical and mental health effects of the disease and its treatment and is offered free of charge to all patients and family members. Despite this, almost 15% of the men who initially registered for the program did not end up using any services and an additional 23% attended only one education session or clinic appointment.

Whether or not men undergo PC treatment and the specific treatment modality they chose appear to be the primary predictors of whether, when, and how much they interact with the program. We found that men who underwent an RP had higher odds of both registration and participation compared to all men who did not; however, RP did not appear to affect participation timing. Men who were exposed to a radiation-based treatment also had higher odds of participation and tended to participate earlier compared to those not treated with RT or EBRT. Treatment with ADT lowered the odds of program registration, but once registered did not appear to affect the timing or degree of participation. This is concerning because the program offers a module that is specifically intended

Table 3 Intensity of program participation, number (row %) ($N = 638$)[†]

	Total	Sessions/clinic visits attended			
		0	1–2	3–4	5+
Total program participants	638	92 (14.4)	231 (36.2)	111 (17.4)	204 (32.0)
Age group[1]					
< 60	99	12 (12.1)	31 (31.3)	19 (19.2)	37 (37.4)
60– < 70	314	49 (15.6)	108 (34.4)	54 (17.2)	103 (32.8)
70+	225	31 (13.8)	92 (40.9)	38 (16.9)	64 (28.4)
Gleason score (average)[2*]					
< 7	139	32 (23.0)	50 (36.0)	23 (16.5)	34 (24.5)
3 + 4	223	23 (10.3)	81 (36.3)	36 (16.1)	83 (37.2)
4 + 3	102	12 (11.8)	37 (36.3)	23 (22.5)	30 (29.4)
8	75	12 (16.0)	21 (28.0)	12 (16.0)	30 (40.0)
9–10	99	32 (32.3)	50 (50.5)	23 (23.2)	34 (34.3)
Primary treatment					
RP[3]					
Yes	440	48 (10.9)	128 (29.1)	87 (19.8)	177 (40.2)
No	192	43 (22.4)	99 (51.6)	23 (12.0)	27 (14.1)
EBRT, BT, or BT adjuvant to RP[4]					
Yes	58	5 (8.6)	29 (50.0)	10 (17.2)	14 (24.1)
No	573	86 (15.0)	198 (34.6)	99 (17.3)	190 (33.2)
ADT (continuous/intermittent)[5]					
Yes	17	3 (17.6)	5 (29.4)	5 (29.4)	4 (23.5)
No	556	77 (13.8)	196 (35.3)	100 (18.0)	183 (32.9)
Active surveillance[6]					
Yes	105	20 (19.0)	43 (41.0)	18 (17.1)	24 (22.9)
No	525	71 (13.5)	184 (35.0)	91 (17.3)	180 (34.3)
Distance to clinic[7]					
< 15 km	343	53 (15.5)	124 (36.2)	57 (16.6)	109 (31.8)
15– < 30 km	108	12 (11.1)	41 (38.0)	23 (21.3)	32 (29.6)
30– < 45	77	6 (7.8)	28 (36.4)	14 (18.2)	29 (37.7)
> 45 km	110	21 (19.1)	38 (34.5)	17 (15.5)	34 (30.9)
Income quintile[8]					
1	70	10 (14.3)	32 (45.7)	11 (15.7)	17 (24.3)
2	80	8 (10.0)	26 (32.5)	15 (18.8)	31 (38.8)
3	93	10 (10.8)	30 (32.3)	15 (16.1)	38 (40.9)
4	148	14 (9.5)	47 (31.8)	33 (22.3)	54 (36.5)
5	173	21 (12.1)	56 (32.4)	33 (19.1)	63 (36.4)

[†] Sample for Table 3 is all men who registered for the program, $N = 638$ (40.7% of the total study sample)

[1] Chi-square = 5.1, $p = 0.53$

[2] Chi-square = 21.6, $p = 0.04$

[3] Chi-square = 64.1, $p < 0.0001$ ($N = 6$ missing)

[4] Chi-square = 6.3, $p = 0.10$ ($N = 7$ missing)[5] Chi-square = 2.0, $p = 0.58$ ($N = 65$ missing)

[6] Chi-square = 6.2, $p = 0.10$ ($N = 7$ missing)

[7] Chi-square = 7.6, $p = 0.57$

[8] Chi-square = 9.7, $p = 0.64$ ($N = 74$ missing)

for PC survivors being treated with ADT. Lastly, while protocols of AS did not appear to affect the propensity to register or participate, participation was significantly delayed as a result.

Taken together, these results suggest that men who have undergone treatment and are therefore more likely to be experiencing deleterious side effects are more likely to engage

Table 4 Ordinal logistic regression and program participation ($N = 546$)[†]

	Odds ratio (95% CI)
Age group[1]	
< 60	1 (reference)
60– < 70	0.90 (0.56–1.41)
70+	0.80 (0.48–1.3)
Gleason score (average)[2*]	
< 7	1 (reference)
3 + 4	1.61 (0.95–2.7)
4 + 3	1.31 (0.75–2.28)
8	1.74 (0.87–3.47)
9–10	1.43(0.72–2.87)
Primary treatment	
Prostatectomy[3]	
Yes	5.48 (3.35–8.95)***
No	1 (reference)
EBRT, BT, or BT adjuvant to RP [4]	
Yes	2.57 (1.20–5.52)*
No	1 (reference)
ADT (continuous/intermittent)[5]	
Yes	0.26 (0.07–0.95)*
No	1 (reference)
Active surveillance[6]	
Yes	1.43 (0.80–2.55)
No	1 (reference)
Distance to clinic[7]	
< 15 km	1 (reference)
15– < 30 km	0.72 (0.46–1.11)
30– < 45	0.74 (0.44–1.22)
> 45 km	0.47 (0.30–0.73)*
Income quintile[8]	
1	1 (reference)
2	1.21 (0.64–2.30)
3	1.46 (0.75–2.70)
4	1.31 (0.75–2.28)
5	1.39 (0.81–2.39)

[†] Sample for Table 4 is all men who registered for the program, $N = 546$ (85.6% of those who registered, and 40.7% of the total study sample)

$^{*}p < 0.05$; $^{**}p < 0.001$; $^{***}p < 0.0001$

with the PCSC program. On the surface, this finding should not be surprising; however, it is a concern given that many components of the program—and indeed much of what is recommended as necessary survivorship/supportive care for men with PC [19]—are recommended for all survivors and not just those who are already experiencing the deleterious effect treatment. For example, providing evidence-based information on diagnosis and treatment, services for promoting a healthy lifestyle (e.g. nutrition education and counselling, exercise programs), and psychological services to assist with coping with cancer diagnosis could be beneficial to all PC survivors, not just those who have already undergone treatment for their disease. Connecting patients to appropriate physical activity is increasingly recommended as part of the standard treatment pathway [31]. Exercise and nutrition prescription and programming, psychological support, and the provision of evidence-based information on treatment are all currently provided within the PCSC program. Furthermore, there is specific evidence suggesting that there are benefits derived from attending lifestyle modification programs in the absence of or prior to treatment in terms of slowing the progression of early, low-grade PC [32], improving social and physical quality of life [33], and generating feelings of hope and optimism [34].

We also found that being in a lower-income quintile adversely affected the odds of registering for the program, but that relationship did not hold for either the intensity or timing of participation. Poorer socioeconomic status has previously been associated with lower access to health services (even within a publicly financed system with legislatively mandated equity of access) [35, 36]. It also influences the extent of PC at initial presentation, the choice of treatment [37], and overall cancer mortality [38, 39].

Lower levels of health literacy have been suggested as one possible moderating factor in these relationships [40, 41]. It is possible that men in lower-income quintiles are more likely to underestimate their potential need for supportive care services, or to delay using them, due to misconceptions about cancer treatment and side effects, or because of lower levels of health literacy more generally. Existing research suggests that individuals in lower-income categories do tend to have lower levels of health literacy and higher odds of having misconceptions about cancer and its treatment [42]. The explicit link between health literacy and the use of supportive care services will be investigated in a future study.

Lastly, travel distance is also a barrier to accessing supportive care, with men who live further from the clinic having lower odds of both registering and participating in the PCSC program. Online and telehealth resources may be useful program delivery options that could assist in addressing this barrier, and have been used successfully to help address distress and fatigue, provide social support, and improve quality of life [43–45]. These delivery options could also be useful in cases where patients are unable to come to clinic for health reasons, such as advanced disease, or when there are a limited number of appropriate medical professions to deliver the program in a particular region. The PCSC program is actively developing online and telehealth resources for men who are physically unable to come to our clinic, whether due to transportation costs, infirmity, or travel distance. This is particularly relevant for those who live in remote areas of the province.

Limitations

Although the PCSC Program office is located in the same hallway as the urology clinic and fliers for the program are displayed in the waiting areas, the chief limitation of this study is the fact that we cannot be confident that those who did not register were aware of the program. As a result, we cannot distinguish between those who chose not to register and those who were never made aware of the program in the first place. Reasons that physicians might choose or choose not to refer a patient to PC supportive care should be explored in future research.

We did not examine whether participation in the program occurred prior to or following treatment and do not assess the effect of the program on treatment choice. This will be investigated in a follow-up study. A related limitation is the under-representation of men who had not undergone an RP relative to published rates of treatment [46]. This may be caused by the fact that the program is nested within a urology clinic, and the majority of program registrants are referred by their urologist. Furthermore, we excluded men who were not patients of the VPC from our analysis (which would include men treated elsewhere, or who learned about the program from their family physician, the PCSC website, or other means) because we had incomplete clinical data for many of these men. Taken together, these limitations suggest that our results may not reflect the "average" population of PC survivors because of weighting towards surgically treated patients and away from those who are untreated, or who undergo radiation-based treatments.

Our Kaplan-Meier estimates do not adjust for baseline characteristics. Unmeasured differences at baseline may drive some of the differences we observed in terms of timing and intensity of follow-up with the program. Also, there are some key sociodemographic variables we suspect may also influence men's decisions to register and participate in supportive care but that we were unable to measure. Chief among those is relationship status, which is of particular relevance because the PCSC program is designed to support both patients and their partners as they navigate the complex PC trajectory. Education level, a direct measure of health literacy, and employment status would also have added to our understanding of factors that contribute to or dissuade access and use of supportive care in this population. These data are now being routinely collected by the program for use in future research.

Lastly, with our dataset we are unable to explore the reasons that patients might choose to register for the program but then subsequently chose not to participate in any services, nor does it directly inform solutions to the underuse of the program. A follow-up study that involves semi-structured interviews with non-participants in an attempt to better understand their decision not to participate is ongoing, and to support the development of strategies to inform opportunities to enhance program participation in future. We are also assessing the level of out-of-pocket cost borne by patients attending the program, and whether these costs are a deterrent to attendance. Additional research is also necessary to establish the effectiveness of each of the six PCSC program modules, and the elements of PC supportive care more broadly. These evaluations will be instrumental in the development of evidence-based best practices for supportive care in this population.

Conclusions

Primary treatment modality, low income, and long travel distance all have a significant impact on whether or not men choose to register for supportive care. While the majority who register do go on to use the services provided, almost 1 in 6 men do not despite the fact that the program is offered without charge. Additional research is needed to better understand the barriers and facilitators of access to and participation in supportive care, whether in person or online, as well as to gauge the success of these programs in addressing the physiological and psychological needs of PC survivors and their families.

Funding This study was funded by the Michael Smith Foundation for Health Research (grant number 16605), and Prostate Cancer Canada (grant number PDF2016-1270). The PCSC program is funded by the Specialist Services Committee, the BC Ministry of Health, the Prostate Cancer Foundation of BC, and philanthropic donors. Vancouver Coastal Health Research Institute and the University of British Columbia provide institutional support.

Compliance with ethical standards

Conflict of interest Dr. Higano has received research grants from Aptevo, Aragon, Astellas, AstraZeneca, Bayer, Dendreon, Emergent, Genentech, Hoffman-La Roche, Medivation, Millenium, Sanofi, and Pfizer. She has served on the advisory board or in a consultancy role for Aptevo, Asana, Astellas, Bayer, Blue Earth Diagnostics, Churchill, Clovis, Dendreon, Endocyte, Ferring, Janssen, Medivation, MorphoSys, Orion, and Pfizer.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. For this type of study, formal consent is not required. Ethics approval for this retrospective analysis was obtained from the University of British Columbia's Clinical Research Ethics Board (H16-03296).

References

1. Cancer Research UK. Prostate Cancer Statistics [Internet]. 2015 [cited 2017 Jun 22]. Available from: http://www.cancer.ca/en/cancer-information/cancer-type/prostate/statistics/?region=sk
2. National Cancer Institute. SEER cancer stat facts: prostate cancer [Internet]. Cancer Stat Facts. 2018 [cited 2018 Mar 4]. Available from: https://seer.cancer.gov/statfacts/html/prost.html

3. Burt LM, Shrieve DC, Tward JD. Factors influencing prostate cancer patterns of care: an analysis of treatment variation using the SEER database. Adv Radiat Oncol [Internet]. 2018 Jan [cited 2018 Mar 4];3(2):170–80. Available from: http://linkinghub.elsevier.com/retrieve/pii/S2452109417302403
4. Lu-Yao GL, Albertsen PC, Moore DF, Shih W, Lin Y, DiPaola RS, Barry MJ, Zietman A, O'Leary M, Walker-Corkery E, Yao SL Outcomes of localized prostate cancer following conservative management. JAMA [Internet]. 2009 Sep 16 [cited 2018 Mar 4];302(11):1202. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19755699
5. Albertsen PC, Hanley JA, Fine J. 20-Year outcomes following conservative management of clinically localized prostate cancer. J Am Med Assoc [Internet]. 2005 May 4 [cited 2018 Mar 4];293(17): 2095–101. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15870412
6. Cornford P, Bellmunt J, Bolla M, Briers E, De Santis M, Gross T, et al. EAU-ESTRO-SIOG guidelines on prostate cancer. Part II: treatment of relapsing, metastatic, and castration-resistant prostate cancer. Eur Urol [Internet]. 2017 [cited 2018 Mar 4];71(4):630–42. Available from: http://www.europeanurology.com/article/S0302-2838(16)30469-9/abstract
7. Nam RK, Cheung P, Herschorn S, Saskin R, Su J, Klotz LH, Chang M, Kulkarni GS, Lee Y, Kodama RT, Narod SA Incidence of complications other than urinary incontinence or erectile dysfunction after radical prostatectomy or radiotherapy for prostate cancer: a population-based cohort study. Lancet Oncol [Internet]. 2014 Feb [cited 2018 Mar 4];15(2):223–31. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24440474
8. Resnick MJ, Koyama T, Fan K-H, Albertsen PC, Goodman M, Hamilton AS, Hoffman RM, Potosky AL, Stanford JL, Stroup AM, van Horn RL, Penson DF Long-term functional outcomes after treatment for localized prostate cancer. N Engl J Med [Internet]. 2013 Jan 31 [cited 2018 Mar 4];368(5):436–45. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23363497
9. Taylor KL, Luta G, Miller AB, Church TR, Kelly SP, Muenz LR, Davis KM, Dawson DL, Edmond S, Reding D, Mabie JE, Riley TL Long-term disease-specific functioning among prostate cancer survivors and noncancer controls in the prostate, lung, colorectal, and ovarian cancer screening trial. J Clin Oncol [Internet]. 2012 Aug 1 [cited 2018 Mar 4];30(22):2768–75. Available from: http://www.ncbi.nlm.nih.gov/pubmed/22734029
10. Alicikus ZA, Yamada Y, Zhang Z, Pei X, Hunt M, Kollmeier M, Cox B, Zelefsky MJ Ten-year outcomes of high-dose, intensity-modulated radiotherapy for localized prostate cancer. Cancer [Internet]. 2011 Apr 1 [cited 2018 Mar 4];117(7):1429–37. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21425143
11. Galvão DA, Spry NA, Taaffe DR, Newton RU, Stanley J, Shannon T, Rowling C, Prince R Changes in muscle, fat and bone mass after 36 weeks of maximal androgen blockade for prostate cancer. BJU Int [Internet]. 2008 Jul [cited 2016 Jan 18];102(1):44–7. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18336606
12. Smith MR. Changes in fat and lean body mass during androgen-deprivation therapy for prostate cancer. Urology [Internet]. 2004 Apr [cited 2016 Jan 18];63(4):742–5. Available from: http://www.sciencedirect.com/science/article/pii/S0090429503012147
13. Wadhwa VK, Weston R, Mistry R, Parr NJ. Long-term changes in bone mineral density and predicted fracture risk in patients receiving androgen-deprivation therapy for prostate cancer, with stratification of treatment based on presenting values. BJU Int [Internet]. 2009 Sep [cited 2018 Mar 4];104(6):800–5. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19338564
14. Saylor PJ, Smith MR. Metabolic complications of androgen deprivation therapy for prostate cancer. J Urol [Internet] 2013 Jan [cited 2018 Mar 4];189(1 SUPPL):S34–44. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23234628
15. Roth AJ, Weinberger MI, Nelson CJ. Prostate cancer: psychosocial implications and management. Futur Oncol [Internet]. 2008 Aug [cited 2015 Dec 15];4(4):561–8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18684066
16. Couper J, Bloch S, Love A, Macvean M, Duchesne GM, Kissane D. Psychosocial adjustment of female partners of men with prostate cancer: a review of the literature. Psychooncology [Internet]. 2006 Nov [cited 2016 Jan 21];15(11):937–53. Available from: http://www.ncbi.nlm.nih.gov/pubmed/16521081
17. Lehto U-S, Aromaa A, Tammela TL. Experiences and psychological distress of spouses of prostate cancer patients at time of diagnosis and primary treatment. Eur J Cancer Care (Engl) [Internet]. 2018 Jan 1 [cited 2018 Mar 4];27(1):e12729. Available from: http://doi.wiley.com/10.1111/ecc.12729
18. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ (2009) What are the unmet supportive care needs of people with cancer? A systematic review. Support Care Cancer 17(8):1117–1128
19. Skolarus TA, Wolf AMD, Erb NL, Brooks DD, Rivers BM, Underwood W, et al. American Cancer Society prostate cancer survivorship care guidelines. CA Cancer J Clin [Internet] 2014 Jul [cited 2018 Mar 4];64(4):225–49. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24916760
20. Ream E, Quennell A, Fincham L, Faithfull S, Khoo V, Wilson-Barnett J, Richardson A Supportive care needs of men living with prostate cancer in England: a survey. Br J Cancer [Internet]. 2008;98(12):1903–9. Available from: http://www.nature.com/doifinder/10.1038/sj.bjc.6604406
21. Lintz K, Moynihan C, Steginga S, Norman A, Eeles R, Huddart R, Dearnaley D, Watson M Prostate cancer patients' support and psychological care needs: survey from a non-surgical oncology clinic. Psychooncology [Internet]. 2003 Dec [cited 2017 Jun 19];12(8): 769–83. Available from: http://www.ncbi.nlm.nih.gov/pubmed/14681951
22. Smith DP, Supramaniam R, King MT, Ward J, Berry M, Armstrong BK. Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer. J Clin Oncol [Internet]. 2007 Jun 20 [cited 2016 Jan 14];25(18):2560–6. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17577034
23. Steginga SK, Occhipinti S, Gardiner RA (Frank., Yaxley J, Heathcote P. Prospective study of men's psychological and decision-related adjustment after treatment for localized prostate cancer. Urology [Internet]. 2004 Apr [cited 2017 Jun 19];63(4): 751–6. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15072894
24. Resnick MJ, Lacchetti C, Bergman J, Hauke RJ, Hoffman KE, Kungel TM, Morgans AK, Penson DF (2015) Prostate cancer survivorship care guideline: American Society of Clinical Oncology clinical practice guideline endorsement. J Clin Oncol 33:1078–1085
25. Spiegel D, Kraemer HC, Bloom JR, Gottheil E (1989) Effect of psychosocial treatment on survival of patients with metastatic breast cancer. Lancet. 334:888–891
26. Stanton AL (2006) Psychosocial concerns and interventions for cancer survivors. J Clin Oncol 24:5132–5137
27. Hedden L, Wassersug R, Mahovlich S, Pollock P, Sundar M, Bell RH, Goldenberg L, Higano CS Evaluating an educational intervention to alleviate distress amongst men with newly diagnosed prostate cancer and their partners. BJU Int [Internet]. 2017 May 17 [cited 2017 Jun 2]; Available from: http://doi.wiley.com/10.1111/bju.13885
28. Hedden L, Pollock P, Elliot S, Bossio JA, Weller S, Van Patten CL et al (2018) Development, implementation & evaluation of a PCa supportive care program. J Community Support Oncol (6):16
29. Zheng DJ, Sint K, Mitchell H-R, Kadan-Lottick NS. Patterns and predictors of survivorship clinic attendance in a population-based sample of pediatric and young adult childhood cancer survivors. J

Cancer Surviv [Internet]. 2016 Jun 16 [cited 2016 Dec 7];10(3): 505–13. Available from: http://link.springer.com/10.1007/s11764-015-0493-4

30. Statistics Canada (2013) Postal code conversion file plus (PCCF +) version 6A, reference guide
31. Santa Mina D, Sabiston CM, Au D, Fong AJ, Copozzi LC, Langelier D et al (2018) Connecting people with cancer to physical activity and exercise programs: a pathways to create accessibility and engagement. Curr Oncol 25(2):149–162
32. Ornish D, Weidner G, Fair WR, Marlin R, Pettengil EB, Raisin CJ, et al. Intensive lifestyle changes may affect the progression of prostate cancer. J Urol [Internet]. 2005 Sep 1 [cited 2018 Mar 6];174(3): 1065–70. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0022534701685185
33. Keogh JWL, MacLeod RD. Body composition, physical fitness, functional performance, quality of life, and fatigue benefits of exercise for prostate cancer patients: a systematic review. J Pain Symptom Manag [Internet]. 2012 Jan 1 [cited 2017 Jun 21];43(1): 96–110. Available from: http://linkinghub.elsevier.com/retrieve/pii/S0885392411002077
34. Kronenwetter C, Weidner G, Pettengill E, Marlin R, Crutchfield L, McCormac P, et al. A qualitative analysis of interviews of men with early stage prostate cancer: the Prostate Cancer Lifestyle Trial. Cancer Nurs [Internet]. 2005 [cited 2018 Mar 6];28(2):99–107. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15815179
35. Maddison AR, Asada Y, Urquhart R. Inequity in access to cancer care: a review of the Canadian literature. Cancer Causes Control [Internet]. 2011 Mar 8 [cited 2018 Mar 6];22(3):359–66. Available from: http://link.springer.com/10.1007/s10552-010-9722-3
36. Asada Y, Kephart G. Equity in health services use and intensity of use in Canada. BMC Health Serv Res [Internet]. 2007 Dec 11 [cited 2018 Mar 6];7(1):41. Available from: http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-7-41
37. Krupski TL, Kwan L, Afifi AA, Litwin MS. Geographic and socioeconomic variation in the treatment of prostate cancer. J Clin Oncol [Internet]. 2005 Nov 1 [cited 2018 Mar 6];23(31):7881–8. Available from: http://ascopubs.org/doi/10.1200/JCO.2005.08.755
38. Cella DF, Orav EJ, Kornblith AB, Holland JC, Silberfarb PM, Lee KW, Comis RL, Perry M, Cooper R, Maurer LH Socioeconomic status and cancer survival. J Clin Oncol [Internet]. 1991 Aug 22 [cited 2018 Mar 6];9(8):1500–9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/2072149
39. Byers TE, Wolf HJ, Bauer KR, Bolick-Aldrich S, Chen VW, Finch JL, Fulton JP, Schymura MJ, Shen T, van Heest S, Yin X, for the Patterns of Care Study Group The impact of socioeconomic status on survival after cancer in the United States: findings from the National Program of Cancer Registries patterns of care study. Cancer [Internet]. 2008 Aug 1 [cited 2018 Mar 6];113(3):582–91. Available from: http://doi.wiley.com/10.1002/cncr.23567
40. Paasche-Orlow MK, Wolf MS. The causal pathways linking health literacy to health outcomes. [cited 2018 Mar 4]; Available from: http://www.ingentaconnect.com/content/png/ajhb/2007/00000031/A00100s1/art00004
41. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review [Internet]. Vol. 155, Annals of Internal Medicine. American College of Physicians; 2011 [cited 2018 Mar 4]. p. 97–107. Available from: http://annals.org/article.aspx?doi=10.7326/0003-4819-155-2-201107190-00005
42. Gansler T, Henley SJ, Stein K, Nehl EJ, Smigal C, Slaughter E. Sociodemographic determinants of cancer treatment health literacy. Cancer [Internet]. 2005 Aug 1 [cited 2018 Mar 6];104(3):653–60. Available from: http://doi.wiley.com/10.1002/cncr.21194
43. Agboola SO, Ju W, Elfiky A, Kvedar JC, Jethwani K. The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials. J Med Internet Res [Internet] 2015 [cited 2017 Mar 17];17(3):e65. Available from: http://www.jmir.org/2015/3/e65/?utm_source=TrendMD&utm_medium=cpc&utm_campaign=JMIR_TrendMD_0
44. Bouma G, Admiraal JM, de Vries EGE, Schröder CP, Walenkamp AME, Reyners AKL. Internet-based support programs to alleviate psychosocial and physical symptoms in cancer patients: a literature analysis [Internet]. Vol. 95, Critical Reviews in Oncology/Hematology. 2015 [cited 2017 Mar 17]. p. 26–37. Available from: http://linkinghub.elsevier.com/retrieve/pii/S1040842815000141
45. Dickinson R, Hall S, Sinclair JE, Bond C, Murchie P. Using technology to deliver cancer follow-up: a systematic review. BMC Cancer [Internet] 2014 Dec 3 [cited 2017 Mar 16];14(1):311. Available from: http://bmccancer.biomedcentral.com/articles/10.1186/1471-2407-14-311
46. Miller KD, Siegel RL, Lin CC, Mariotto AB, Kramer JL, Rowland JH, et al. Cancer treatment and survivorship statistics, 2016. CA Cancer J Clin [Internet]. 2016 Jul 1 [cited 2018 Mar 4];66(4):271–89. Available from: http://doi.wiley.com/10.3322/caac.21349