Title
Satisfaction with prostate cancer care

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Factors associated with satisfaction with prostate cancer care: results from Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE)

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Abstract

- To evaluate the impact of demographic, clinical, treatment and patient-reported parameters on satisfaction with prostate cancer care.
- Despite the significant worldwide impact of prostate cancer, few data are available specifically addressing satisfaction with treatment-related care.
- CaPSURE comprises participants from 40 US sites who were monitored during and after their treatment course.
- Participants who were diagnosed with clinically localized prostate cancer after 1999 underwent radical prostatectomy, radiation therapy or primary androgen deprivation, and those who also completed the satisfaction questionnaire within 2 years of treatment were included in the present study.
- Satisfaction was measured using a validated instrument that assesses contact with providers, confidence in providers, communication skills, humanness and overall satisfaction.
- Multivariable linear regression analysis were performed to evaluate the independent
- relationships between demographic, clinical, treatment and patient-reported parameters
- and satisfaction.
- Of the 3056 participants, 1927 (63%) were treated with radical prostatectomy, 843 (28%) were treated with radiation therapy and 286 (9%) were treated with primary androgen deprivation.
- Multivariable analysis showed that multiple patient-reported factors were independently associated with satisfaction, whereas clinical, demographic and treatment parameters were not.

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- Baseline health-related quality of life, measured by the 36-item short-form health survey, baseline fear of cancer recurrence (all $P < 0.01$) and declines in the sexual ($P = 0.03$), urinary ($P < 0.01$) and bowel ($P = 0.02$) function domains of the University of California Los Angeles Prostate Cancer Index were all independently associated with satisfaction.
- Patient-reported outcomes were more strongly associated with satisfaction in the low-risk subgroup.
- Patient-reported factors such as health-related quality of life and fear of cancer recurrence are independently associated with satisfaction with care
- Pretreatment parameters should be used to identify populations at-risk for dissatisfaction to allow for intervention and/or incorporation into treatment decision-making

Keywords

prostate cancer; quality of care; quality of life; satisfaction

Introduction

Although numerous studies have evaluated changes in health-related quality of life (HRQoL) after prostate cancer treatment [1–4], less attention has been paid to satisfaction with prostate cancer care. Patient satisfaction has been described by Donabedian [5] as ‘indispensable to assessments of quality as to the design and management of health care systems’. Although HRQoL measures are essential elements in the evaluation of patient-reported outcomes, satisfaction provides a comprehensive assessment that incorporates elements of structure, process and outcome [6]. Considering that the degree of satisfaction reflects a patient’s overall interaction with the healthcare system, attention must be paid to satisfaction as an indicator of care quality [7]. Given the considerable policy and reimbursement implications of healthcare quality, measurement of patient satisfaction will become increasingly important as a quality indicator in high-cost illnesses such as cancer [8]. Accurate assessment of patient satisfaction will be particularly valuable in prostate cancer considering the relative lack of comparative effectiveness research that is available to guide patients and clinicians in treatment decision-making. Historically, clinical and treatment-related characteristics were largely implicated in predicting satisfaction. The growing body of literature surrounding HRQoL after cancer treatment, however, has raised a number of questions surrounding the contribution of both baseline and change in HRQoL to satisfaction with care (SC). The magnitude of the interaction between HRQoL and satisfaction remains poorly characterized.

The present study aimed to evaluate demographic, clinical, treatment and HRQoL-related covariates in the prediction of satisfaction with prostate cancer care in the Cancer of the Prostate Strategic Urologic Research Endeavor (CaPSURE) database, comprising a large, prospective observational disease registry of men with prostate cancer.

Patients and methods

Study participants

Study participants were enrolled in the CaPSURE database, comprising an observational registry of men with biopsy-proven prostate cancer. Initiated in 1995, CaPSURE includes 40 community-based, academic and Veteran’s Affairs urology practices across the USA that prospectively collect demographic, clinical, treatment, survival, HRQoL patient satisfaction and resource utilization data from men with prostate cancer. Institutional Review Board approval is obtained at each participating CaPSURE practice site. Patients complete HRQoL

questionnaires at the time of enrollment and at regular intervals after treatment. More detailed reviews of CaPSURE methodologies have been reported previously [9,10].

To be included in the present study, participants were diagnosed from 1999 to 2007 and enrolled in CaPSURE within 6 months of diagnosis. Patients had clinically localized or locregional disease (cT1–3) and underwent therapy with either radical prostatectomy (RP), radiation therapy (RT) or primary androgen deprivation therapy (PADT). Furthermore, patients were followed in CaPSURE for at least 1 year after enrollment and completed both a baseline and at least one follow-up SC survey.

Patient-reported measures

General HRQoL was measured using the RAND 36-item short-form health survey (SF-36), which assesses physical function and vitality, emotional and social function, bodily pain, and general health. For the present study, two composite summary scales were used: the Mental Component Summary (MCS) and the Physical Component Summary (PCS) [11,12]. Scores range from 0 to 100. For all instruments used in the analysis, 0 represents the least favourable, and 100 represents the most favourable HRQoL. Disease-specific HRQoL was measured using the University of California Los Angeles Prostate Cancer Index (PCI), a validated instrument that assesses urinary, sexual and bowel function [13]. PCI scores also range from 0 to 100. Fear of cancer recurrence (FCR) was measured using a validated five-question instrument that evaluates patient beliefs and anxieties over disease recurrence [14,15]. Patients completed the surveys at baseline and 1–2 years after treatment. A clinically meaningful decline in HRQoL for each score was defined as a decrease of at least 1 SD from before to after treatment. We employed a conservative definition of a decline in HRQoL after treatment (using a decline of 1 SD as opposed to 0.5 SD) to ensure that these declines were indeed clinically significant [16,17].

Outcome measure

SC was measured using a validated instrument with nine questions concerning contact with providers, confidence in providers, communication skills, humanness and overall SC [18]. SC scores were transformed into a 0–100 point scale, with higher scores representing more favourable satisfaction [19], to be consistent with the other measures. Patients completed the SC questionnaire before treatment and between 1 and 2 years after treatment. Assessments were carried out before any salvage treatment for recurrence.

Analysis

We postulated that sociodemographic characteristics (age, race/ethnicity, education, relationship/marital status), clinical characteristics at diagnosis (PSA level, Gleason grade, T-stage), treatment variables (type, receipt of neoadjuvant treatment, time from diagnosis to treatment, type of clinical facility) and patient-reported parameters were associated with SC. Data were described with frequency tables for categorical variables and means for continuous variables. Pretreatment clinical risk was defined using the validated groupings of the UCSF Cancer of the Prostate Risk Assessment (CAPRA) score [20]: low- (0–2), intermediate- (3–5) and high- (6–10) risk disease.

Linear regression analysis was used to determine the independent association of each of these variables with post-treatment SC. Preliminary correlations of sociodemographics, clinical data and HRQoL scores were used to identify relationships between them. Based on those results, a separate multivariate model was run for each block of covariates aiming to avoid collinearity between covariates. The final model included all covariates to show associations for the complete set of patient factors.

Results

Of 6393 CaPSURE participants who met the inclusion criteria for the present study, 3056 completed HRQoL questionnaires before and after treatment. Patients were predominantly Caucasian (92%) and married or partnered (82%), with a median (range) age of 65 (41–91) years (Table 1). In total, 90% of these patients were treated in a community setting. At diagnosis, the median PSA level was 5.70 ng/mL and 1804 (59%) men presented with low-risk disease, 956 (31%) with intermediate-risk disease and 266 (9%) with-high risk disease, as defined by the CAPRA score. Overall, 1927 (63%) patients underwent RP, 843 (28%) patients underwent RT and 286 (9%) patients underwent PADT. In addition, 744 (24%) patients received neoadjuvant or adjuvant treatment (Table 1).

SC remained consistent from pretreatment to 2 years after treatment. The mean (SD) overall satisfaction score pretreatment was 77.5 (16.19) and the mean (SD) post-treatment score at 2 years was 78.2 (15.36). The same consistency between pre- and post-treatment satisfaction was seen in each of the satisfaction subscales measuring provider contact, competence of providers, communication skills and humaneness/sensitivity of care (Table 2).

Several factors were associated with overall satisfaction with prostate cancer care in limited multivariable models incorporating correlated variables within similar constructs. With regard to demographic covariates, those with a college degree reported higher SC than those who only attended high school ($P = 0.04$). Additionally, Asian and Pacific Islander patients reported lower SC than Caucasian patients ($P < 0.01$). Clinically, patients with higher pretreatment PSA were less satisfied with their care ($P < 0.01$). There was less favourable SC in those undergoing PADT ($P < 0.01$) and a trend towards less favourable SC in those undergoing RT compared to those patients undergoing RP ($P = 0.06$). Evaluation of relationships between HRQoL-related covariates showed that higher baseline SF-36 MCS ($P < 0.01$) and PCS ($P < 0.01$) were associated with higher SC. Higher (worse) FCR was inversely associated with SC ($P < 0.01$). Declines in University of California Los Angeles PCI sexual function ($P = 0.02$), urinary function ($P < 0.01$) and bowel function ($P = 0.02$) domains were also associated with less favourable SC (Table 3).

When demographic, clinical, treatment and HRQoL covariates were combined into a single model, only the patient-reported variables remained strongly associated with satisfaction. A one-point increase in FCR, again indicating more severe cancer-related anxiety, was associated with a 16% decrease in satisfaction ($P < 0.01$). One-point improvements in SF-36 MCS and PCS were associated with 14% and 13% improvements in satisfaction, respectively (both $P < 0.01$). Declines in sexual function ($P = 0.04$), urinary function ($P = 0.02$) and bowel function ($P < 0.01$) were each associated with a two-fold lower post-treatment satisfaction (Table 4).

Within the high-risk subgroup, no significant predictors of post-treatment satisfaction were identified. Within the intermediate-risk subgroup, a one-point decrease/improvement in FCR was associated with a 12% improvement in satisfaction ($P < 0.01$) and a severe decline in urinary function after treatment was associated with a more than threefold decrease in satisfaction ($P = 0.03$). There was significant clustering of HRQoL-associated covariates in the low-risk subgroup. Specifically, a one-point increase in baseline MCS was associated with a 17% improvement in satisfaction ($P < 0.01$) and a one-point increase/improvement in PCS was associated with a 20% improvement in satisfaction ($P < 0.01$). FCR remained inversely associated with satisfaction in the low-risk subgroup, with a one-point decrease in FCR associated with a 17% improvement in satisfaction ($P < 0.01$). Finally, a severe decline in bowel function after treatment was associated with a threefold decrease in SC (Table 4).

Discussion

Given the ageing population and both the current and future worldwide burden of prostate cancer, satisfaction will become an increasingly important quality indicator that reflects the structure, process and outcome of the care delivered. Data from CaPSURE show that both baseline and treatment-related HRQoL parameters are strongly associated with overall SC, whereas demographic, clinical or treatment parameters are not. When stratified by the CAPRA score, multivariable modelling showed a clustering of HRQoL parameters in the low-risk cohort. These data suggest that these predictors may be used to counsel individual low-risk patients during treatment decision-making or be incorporated into interventions for populations at risk for poor satisfaction outcomes. If a low-risk patient with a high-risk of post-treatment dissatisfaction were to be identified, active surveillance could be considered as a therapeutic strategy as opposed to immediate active treatment. Attempts at improving post-treatment HRQoL must be undertaken through attention to urinary, sexual and bowel complaints. However, the data obtained in the present study suggest that patients with poor overall and prostate cancer-specific pretreatment HRQoL are at high risk for post-treatment dissatisfaction. Accordingly, assessment of pretreatment MCS, PCS and FCR should be performed, and efforts should be made to improve pretreatment HRQoL by addressing urologic, general medical, psychological and functional deficits before undertaking therapy for prostate cancer. Specific interventions, including treatment of erectile dysfunction, urinary symptoms and bowel complaints, should be undertaken by the treating urologist. Additionally, pretreatment referral to psychiatry and/or psychology services to address emotional disturbances may improve post-treatment satisfaction. Careful assessment of each patient's support network and specific treatment-related concerns is essential to optimize post-treatment satisfaction. Finally, the physician and his/her staff may change practices when treating such patients by reducing waiting times, ensuring that calls are returned promptly and spending more face-to-face time with this group of patients. Furthermore, satisfaction may be a useful outcome measure in comparative effectiveness research. Pre- and post-treatment predictors of satisfaction offer both patients and providers important non-clinical distinctions between treatment modalities.

A modifiable parameter in any therapeutic algorithm for prostate cancer is treatment choice. Past research findings are varied regarding satisfaction based upon treatment choice. Jayadevappa *et al.* [6] found that RP was associated with a 7.9% improvement in satisfaction compared to RT. By contrast, the Prostate Cancer Outcomes Study (PCOS) found that those patients undergoing RT showed higher satisfaction scores than those undergoing RP [21]. However, these studies did not control for changes in HRQoL or FCR. The present study shows that, on univariate analysis, those who receive PADT were significantly less satisfied than those who underwent RP. Furthermore, there was a trend towards less favourable satisfaction in those patients undergoing RT compared to those undergoing RP. These relationships, however, fail to achieve significance in multivariable models. Patient-specific decisions regarding treatment choice for localized prostate cancer remain complex and multifactorial. Accordingly, the interaction between treatment modality with satisfaction remains vague, with the available data reflecting the heterogeneity of both the cohorts studied and the methodology employed.

Although it could be assumed that functional outcomes are closely linked with overall satisfaction with prostate cancer care, few data are available specifically addressing this association. In a prospective study comprising both patients and partners, Sanda *et al.* [4] reported changes in HRQoL measures up to 24 months after treatment. The investigators found that sexual function, hormonal function and urinary symptoms were all independently associated with satisfaction regarding treatment outcome. Interestingly, Sanda *et al.* [4] found that African-American patients were significantly less satisfied with their overall

treatment outcome than patients of other racial backgrounds. In the present study, there was a trend towards less favourable satisfaction among African-American patients, although this relationship failed to achieve significance. In addition to the multicentre study conducted by Sanda *et al.* [4], satisfaction was evaluated in the large, multicentre, PCOS cohort. Similar to the findings obtained in the study by Sanda *et al.* [4], PCOS investigators determined that maintaining urinary and bowel control and satisfactory erectile function were all associated with improvements in satisfaction. Although these and others groups have documented the direct relationship between absolute post-treatment HRQoL and SC [21–24], few have evaluated pretreatment HRQoL or change from baseline as predictors of post-treatment SC.

Although the widespread implementation of screening PSA levels has resulted in improvements in disease detection, it has also generated significant concern over prostate cancer overtreatment. Accordingly, active surveillance has become a reasonable therapeutic option for selected men and is supported by the most recent National Comprehensive Cancer Network Clinical Practice Guidelines [25]. The present study showed that patients with less favourable baseline SF-36 PCS and SF-36 MCS and higher FCR had less favourable post-treatment satisfaction. These relationships were evident in both the overall and low-risk cohorts (CAPRA 0–2). Although the present study did not specifically address SC in patients undergoing active surveillance, other CaPSURE research has shown that many low-risk patients who qualify for active surveillance still opt for active treatment [26]. Baseline care that is more tailored to an individual's HRQoL and FCR may allow for more appropriate treatment decision-making with lower treatment-related morbidity.

The present study has a number of strengths and limitations. CaPSURE comprises patients from 36 community-based, three academic and three Veteran's Affairs practice sites throughout the USA. The composition of the CaPSURE database mirrors the pattern of care delivery in the USA. Nonetheless, the preponderance of Caucasian men in the present study (92%) limits generalizability to diverse ethnic groups. Treatment choice was not randomly assigned, thereby introducing some element of selection bias into the present study. Furthermore, the study cohort was limited to those participants who completed pre- and post-treatment satisfaction questionnaires. Most of the excluded cohort did not regularly complete patient questionnaires or withdrew from the CaPSURE study altogether. The exclusion of patients who did not meet these criteria may also introduce some element of selection bias into the present study. The satisfaction instrument used in the present study is weighted towards an assessment of satisfaction with healthcare providers and is limited by the absence of specific domains for satisfaction with treatment choice and satisfaction with outcome. Identifying a clinically significant difference is essential for our understanding of the true relevance of changes in patient-reported outcomes over time. More work must be carried with this instrument, as well as others, aiming to identify what constitutes clinically significant change. Although our proposed multivariable model controlled for burden of comorbid disease and treatment choice, prostate cancer treatment decision-making is complex. Given the multifactorial nature of treatment decision-making, there is most certainly an element of unmeasured confounding in the analyses conducted in the present study. We analyzed patients who were treated for prostate cancer using surgery, radiation or PADT only. The exclusion of men who did not receive immediate curative treatments may have biased the present study towards a higher satisfaction than that seen on a population-based level [21]. Additionally, the study cohort included relatively few CAPRA high-risk patients, thereby potentially limiting the risk-stratified subgroup analysis.

In conclusion, the results from CaPSURE indicate that patient-reported factors including HRQoL and FCR are independently associated with SC, whereas demographic, clinical and treatment factors are not. Given the importance of satisfaction in measuring structure, process and outcome elements of healthcare, efforts should be undertaken to optimize

satisfaction. Accordingly, efforts to improve SC in prostate cancer should not focus on specific treatment groups but, instead, on certain subgroups of patients who may have differing HRQoL or FCR profiles.

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Abbreviations

CAPRA	Cancer of the Prostate Risk Assessment
CaPSURE	Cancer of the Prostate Strategic Urologic Research Endeavor
FCR	fear of cancer recurrence
HRQoL	health-related quality of life
PADT	primary androgen deprivation therapy
PCI	Prostate Cancer Index
PCOS	Prostate Cancer Outcomes Study
RP	radical prostatectomy
RT	radiation therapy
SC	satisfaction with care
SF-36	36-item short-form health survey

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TABLE 1

Clinical, demographic and pathological data

Variable	*n*	(%)
Age at diagnosis (years)		
< 55	363	(12)
55–59	514	(17)
60–64	583	(19)
> 64	1596	(52)
Ethnicity		
Asian	21	(1)
Latino	34	(1)
African American	142	(5)
Caucasian	2822	(92)
Unknown/other	37	(1)
Education		
High school	269	(9)
High school degree	680	(22)
College	555	(18)
College degree	1248	(41)
Missing	304	(10)
PSA level (ng/mL)		
≤ 4	515	(17)
4.1–10	1943	(64)
10.1–20	364	(12)
> 20	133	(4)
Missing	101	(3)
Biopsy Gleason score		
≤ 6	2043	(67)
7	776	(25)
≥ 8	198	(6)
Missing	39	(1)
CAPRA risk group		
Low (0–2)	1804	(59)
Intermediate (3–5)	956	(31)
High (6–10)	266	(9)
Missing	30	(1)
Primary treatment		
RP	1927	(63)
RT	843	(28)
PADT	286	(9)
Neoadjuvant treatment		
No	2312	(76)

Variable	*n*	(%)
Yes	744	(24)
Pathological Gleason score (RP only)		
≤ 6	1024	(53)
7	745	(39)
≥ 8	106	(6)

CAPRA, Cancer of the Prostate Risk Assessment; PADT, primary androgen deprivation therapy; RP, radical prostatectomy; RT, radiation therapy.

TABLE 2

Health-related quality of life and satisfaction with prostate cancer care

Variable	Value
Baseline quality of life pretreatment, mean (SD)	
SF-36 MCS	52.5 (8.96)
SF-36 PCS	51.3 (8.96)
Fear of cancer recurrence	36 (17.79)
Decline in quality of life at 1–2 years after treatment, *n* (%)	
PCI sexual function	1086 (55)
PCI bowel function	484 (24)
PCI urinary function	918 (46)
Satisfaction with care pretreatment, mean (SD)	
Overall satisfaction with care	77.5 (16.19)
Amount of contact	74.7 (21.16)
Communication	78.5 (18.07)
Humanness	81.8 (17.83)
Competence	82.9 (18.77)
Satisfaction with care at 1–2 years after treatment, mean (SD)	
Overall satisfaction with care	78.2 (15.36)
Amount of contact	77.7 (18.97)
Communication	76.6 (19.18)
Humanness	82.5 (16.65)
Competence	82.4 (17.55)

* Defined as decline > 1 SD from baseline.

MCS, Mental Component Summary; PCI, Prostate Cancer Index; PCS, Physical Component Summary; SF-36, 36-item short-form health survey.

TABLE 3

Overall multivariable linear regression model

Covariate	Coefficient	*P*
Age at diagnosis (years)	0.02	0.74
Education		
College degree vs high school	1.04	0.49
High school degree vs high school	1.45	0.36
College vs high school	−0.22	0.9
Race/ethnicity		
African American vs Caucasian	−4.36	0.07
Asian/Pacific Islander vs Caucasian	−4.39	0.33
Latino vs Caucasian	−4.77	0.2
Other/unknown vs Caucasian	0.83	0.81
Married/partnered (yes vs no)	−0.99	0.53
PSA level at diagnosis (ng/mL)	0.03	0.52
Biopsy Gleason grade		
7 (3+4) vs 2–6	−1.03	0.38
7 (4+3) vs 2–6	1.29	0.45
8–10 vs 2–6	1.96	0.32
Clinical T-stage		
cT2 vs cT1	−0.27	0.76
cT3 vs cT1	2.76	0.64
Primary treatment		
PADT vs RP	−2.47	0.27
RT vs RP	−0.58	0.65
Any neoadjuvant/adjuvant treatment	−1.28	0.33
Time from diagnosis to treatment (months)	0.1	0.75
Baseline body mass index	0.01	0.95
Baseline number of comorbidities	−0.73	0.04
Baseline SF-36 MCS	0.14	< 0.01
Baseline SF-36 PCS	0.13	0.02
Baseline fear of cancer recurrence	−0.16	< 0.01
PCI sexual function decline	−1.81	0.04
PCI bowel function decline	−2.84	< 0.01
PCI urinary function decline	−2.15	0.02

MCS, Mental Component Summary; PADT, primary androgen deprivation therapy; PCI, Prostate Cancer Index; PCS, Physical Component Summary; RP, radical prostatectomy; RT, radiation therapy; SF-36, 36-item short-form health survey.

TABLE 4

Risk stratified linear regression models *

Covariate	Overall cohort (*n* = 3056)		CAPRA low risk (*n* = 1804)		CAPRA intermediate risk (*n* = 956)		CAPRA high risk (*n* = 266)	
	Coefficient	*P*	Coefficient	*P*	Coefficient	*P*	Coefficient	*P*
Number of comorbidities	−0.73	0.04	−0.67	0.13	−1.08	0.06	0.16	0.9
SF-36 MCS	0.14	< 0.01	0.17	< 0.01	0.15	0.14	0.1	0.59
SF-36 PCS	0.13	0.02	0.2	< 0.01	0.14	0.11	0.05	0.8
FCR	−0.16	< 0.01	−0.17	< 0.01	−0.12	< 0.01	−0.14	0.19
PCI SF decline	−1.81	0.04	−1.83	0.11	−1.16	0.45	−4.61	0.17
PCI UF decline	−2.84	< 0.01	−2.92	0.02	−2.39	0.16	−0.57	0.87
PCI BF decline	−2.15	0.02	−1.83	0.09	−3.27	0.03	−0.13	0.97

* Adjusted for age, education, ethnicity, relationship status, treatment type, number of office visits per year, time to treatment, type of clinical facility and body mass index.

BF, bowel function; CAPRA, Cancer of the Prostate Risk Assessment; FCR, fear of cancer recurrence; MCS, Mental Component Summary; PCI, Prostate Cancer Index; PCS, Physical Component Summary; SF, sexual function; SF-36, 36-item short-form health survey; UF, urinary function.