Prostate Cancer Specialty Registry Report 2017

What is the Prostate Cancer Specialty Registry?

Nearly 3 million men diagnosed with prostate cancer are alive today (American Cancer Society, 2017). The Prostate Cancer Specialty Registry, which began accepting participants in August 2015, documents the experiences of a cross-section of people living with prostate cancer. The Prostate Cancer Advisory Council—made up of prostate cancer specialists and other oncologists, behavioral scientists, patient advocates, and industry representatives—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at **www.cancersupportcommunity.org/RegistryIndexReport2017**).

CANCER SUPPORT COMMUNITY
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KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE PROSTATE CANCER EXPERIENCE. KEY FINDINGS INCLUDE:

QUALITY OF LIFE

58%

OF PROSTATE CANCER SURVIVORS RATE THEIR OVERALL HEALTH AS VERY GOOD OR EXCELLENT

20%

REPORT WORSE FATIGUE THAN THE NATIONAL AVERAGE

38%

ARE AT RISK FOR CLINICAL DEPRESSION

CANCER-RELATED DISTRESS

51%

ARE CONCERNED ABOUT SEXUAL INTIMACY AND FUNCTION

51%

ARE CONCERNED ABOUT EATING AND NUTRITION

45%

ARE CONCERNED ABOUT EXERCISING AND REMAINING PHYSICALLY ACTIVE

SEXUAL INTIMACY

24%

SAID THEY DID NOT FEEL COMFORTABLE SPEAKING WITH ANYONE ON THEIR HEALTH CARE TEAM ABOUT SEXUAL SIDE EFFECTS

65%

REPORTED THAT THEY DO NOT ENGAGE IN SEXUAL INTERCOURSE

50%

FELT THEY WERE NOT SUFFICIENTLY KNOWLEDGEABLE ABOUT ERECTILE DYSFUNCTION PRIOR TO TREATMENT

DOCTOR-PATIENT COMMUNICATION

WHILE **84%** WERE INVOLVED IN TREATMENT DECISION-MAKING, ONLY **48%** FELT FULLY PREPARED TO MAKE A DECISION

68%

WERE NOT SATISFIED WITH THEIR DOCTOR'S COMMUNICATION ABOUT THE COST OF CARE

ONLY **47%** WERE SATISFIED WITH THEIR CONVERSATIONS WITH THEIR DOCTOR ABOUT THE IMPACT OF CANCER ON WORK

Who is in the Registry?

This 2017 report presents analysis from 220 prostate cancer survivors who reside in the United States and completed survey questions from the opening of the Registry in August 2015 to December 31, 2016 (in the tables below, the number of responses is 220 unless otherwise noted).

FIGURE 1 **PROSTATE CANCER REGISTRY SURVEY DEMOGRAPHICS**

	NUMBER OF PARTICIPANTS (n)	*PERCENT*
AGE	(n = 140)	
Mean age	64.5 years, SD = 8.6	Range: 26 to 64
18-44	3	3%
45-64	65	46%
>=65	72	51%
GENDER	(n = 111)	
Male	111	100%
RACE	(n = 112)	
White	103	91%
NON-HISPANIC ETHNICITY	(n = 112)	
	103	92%
EDUCATION	(n = 112)	
High school or less	20	18%
Associate degree or some college	15	13%
Bachelor degree	31	28%
Graduate degree or higher	43	38%
REGION	(n = 129)	
Urban	36	28%
Suburban	65	50%
Rural	25	19%
EMPLOYMENT STATUS	(n = 107)	
Full-time	39	36%
Part-time	13	12%
Retired	41	38%
Not employed due to disability	8	8%
Not employed (reason not specified)	6	6%
ANNUAL INCOME	(n = 98)	
<$40K	19	19%
$40-59.9K	13	13%
$60-79.9K	7	7%
$80-99.9K	6	6%
$100K+	30	31%
Prefer not to share	23	24%

FIGURE 2 CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS

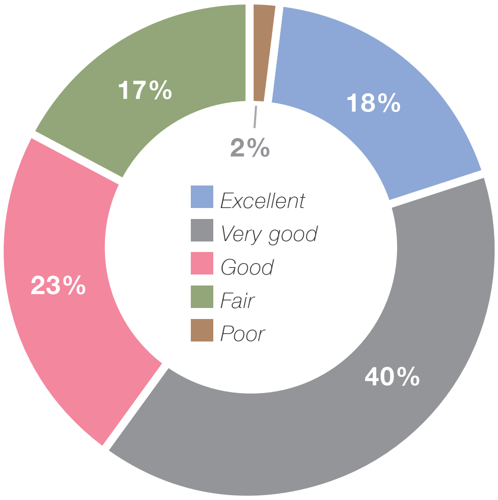
	NUMBER OF PARTICIPANTS (n)	*PERCENT*
STAGE AT DIAGNOSIS	(n = 93)	
Stage 0	2	2%
Stage I	19	20%
Stage II	17	18%
Stage III	15	16%
Stage IV	18	20%
I don't know	22	24%
TIME SINCE DIAGNOSIS	(n = 97)	
<1 year	11	11%
1–1.9 years	20	21%
2–4.9 years	32	33%
>=5 years	34	35%
METASTATIC	(n = 96)	
	30	31%
RECURRENCE	(n = 97)	
	22	23%

What are we learning?

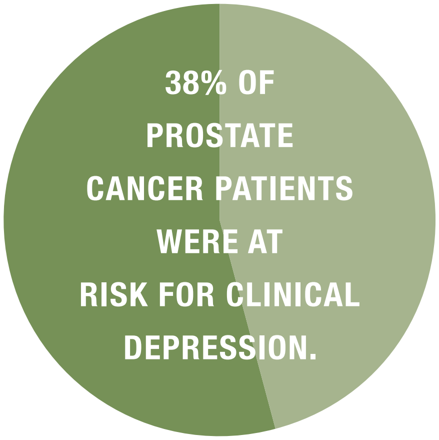
DIAGNOSTIC EXPERIENCE

For many men, prostate cancer is a slow-growing disease, and it is not uncommon for symptoms to be absent at the time of diagnosis. In fact, 66% of respondents reported that their diagnosis occurred after a routine or annual physical check-up, while only 29% exhibited symptoms at the time of diagnosis. The sooner the cancer is detected, the higher the probability of treating or curing it. Health care providers can perform simple early detection screening tests on men who may be at higher risk—because of age or family history, among other factors—for a diagnosis. An overwhelming majority (70%) of survey respondents indicated their doctor recommended a screening, either a prostate-specific antigen test (PSA) or digital rectal exam. Of those who asked for a screening, 18% said their spouse or partner encouraged them to do so. In the prostate cancer experience, partners often play an important role in decision-making.

FIGURE 3 SURVEY PARTICIPANTS' PERCEIVED OVERALL HEALTH



n = 60



PERCEPTIONS ABOUT HEALTH

In the survey, 58% described their health as either excellent or very good while 19% reported their overall health as fair or poor (Figure 3).

CANCER-RELATED DISTRESS

Treatment is not the only source of stress in a cancer patient's life. "Watch and Wait" observation can also produce elevated levels of worry and anxiety. It is important, then, to identify specific factors that cause distress. Figure 4 presents the 10 items that most respondents were moderately, seriously, or very seriously concerned about according to CancerSupportSource®, a validated distress screening instrument.[1]

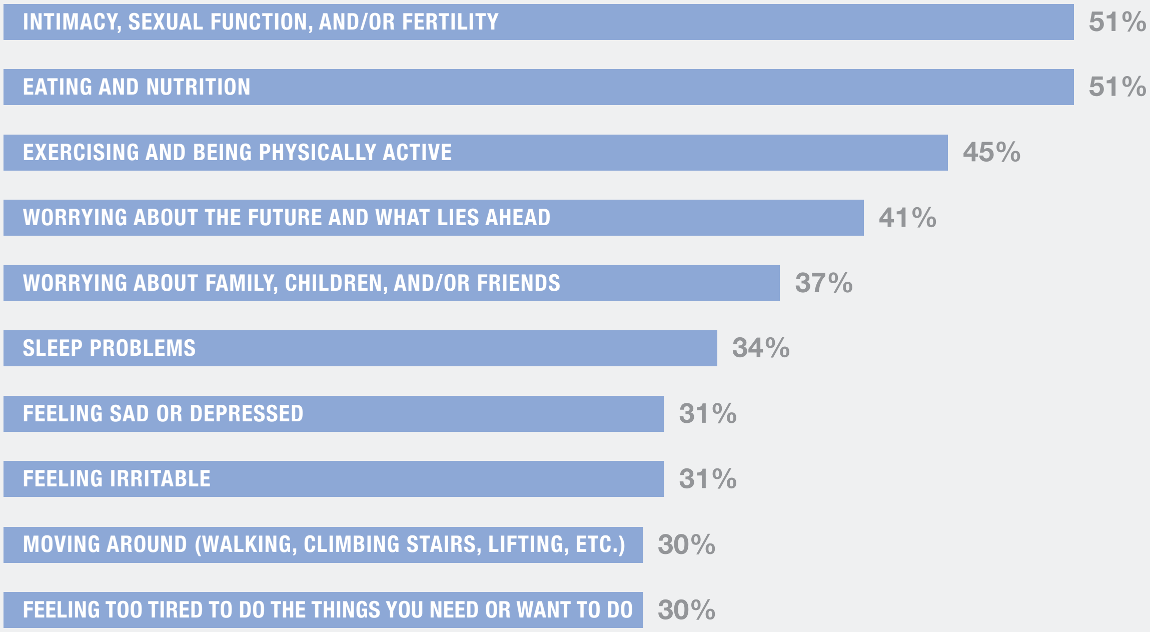
CancerSupportSource features a depression subscale, which demonstrated that 38% of prostate cancer patients were at risk for clinical depression.

Apart from CancerSupportSource data, the survey probed respondents for information about any additional concerns about their prostate cancer experience. Among them, 80% were at least somewhat concerned about their disease progression, 76% about recurrence, 70% about their quality of life, and 62% about side effects of treatment.

QUALITY OF LIFE

Patients describe cancer's impact on their quality of life in different ways, and quantifying quality of life

FIGURE 4 **TOP 10 CONCERNS ACROSS PROSTATE CANCER PARTICIPANTS**



Percent of Patients Moderately to Very Seriously Concerned

n = 88

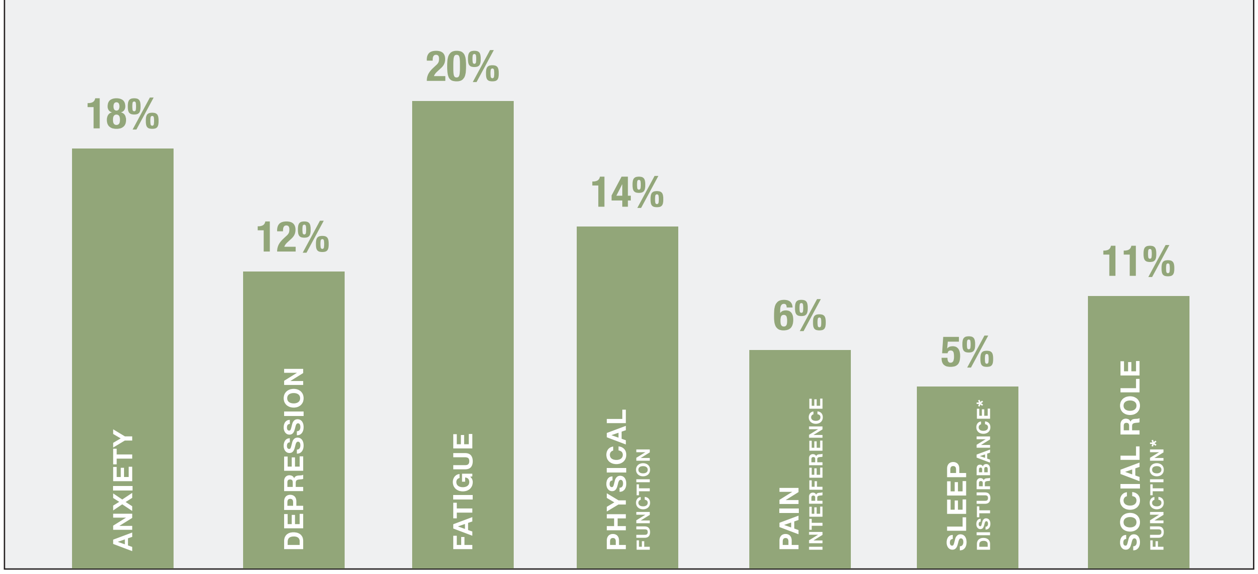
impairments among prostate cancer patients can go a long way toward addressing their emotional and psychosocial needs. The Prostate Cancer Specialty Registry incorporates the PROMIS-29, which compares how patients describe their quality of life to other U.S. population groups across seven different areas of life.[2] As Figure 5 illustrates, many prostate cancer patients reported substantially worse quality of life than the national average for fatigue (20% of respondents), anxiety (18%), physical functioning (14%), depression (12%), and social functioning (11%). In addition, 6% of respondents reported worse pain interference and 5% reported worse sleep disturbance.

While many people diagnosed with prostate cancer respond well to treatment and subsequently survive the disease, it can be easy for others to overlook its impact on the patient's quality of life. It is notable that 57% of respondents to the prostate cancer survey reported that their lives changed for the worse compared with their lives prior to diagnosis. This finding is crucially important for health care providers and counselors as they devise treatment plans and make attempts to address every patient's psychosocial needs.

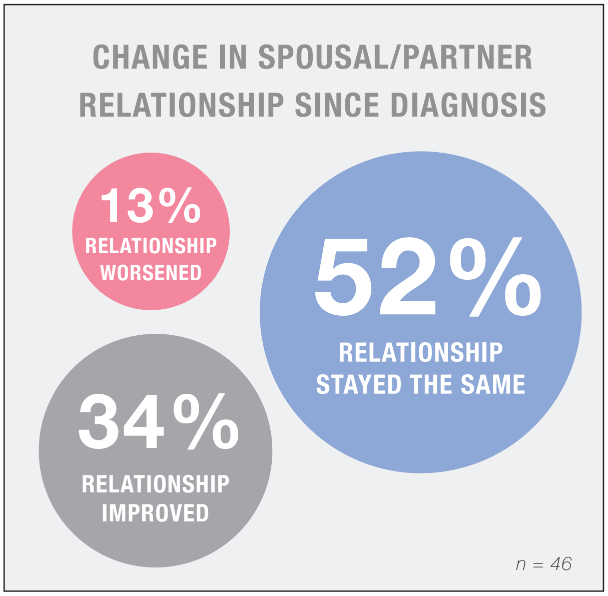
SEXUAL INTIMACY

Many treatments for prostate cancer are associated with sexual dysfunction, which can greatly impact self-image and social relationships, particularly with spouses or partners. Among respondents to the Prostate Cancer Specialty Registry, close to two-thirds (65%) reported that they do not engage in sexual intercourse, and 42% indicated they felt most comfortable discussing cancer-related intimacy issues with their spouse. Significantly, 24% said they did not feel comfortable speaking with anyone on their health care team about side effects related to sexual intimacy. Incontinence is a common byproduct of prostate cancer and often impacts sexual activity. Specifically, 37% of respondents reported experiencing a problem with urinary control in the four weeks prior to completing the survey. Twenty-four percent of survey respondents reported that incontinence led to intimacy issues, and 29% reported no history of incontinence.

FIGURE 5 **PERCENT OF PROSTATE CANCER SURVIVORS REPORTING WORSE QUALITY OF LIFE**



*Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.*



Erectile dysfunction (ED) is the most widely-known complication of prostate cancer—and, in fact, 73% of survey respondents reported an incidence of ED since their diagnosis. They were, by and large, optimistic about an effective treatment: 65% believed it was somewhat, quite a bit, or very much possible to treat ED. At the same time, 50% felt they were not sufficiently knowledgeable about ED prior to treatment.

SPOUSAL/PARTNER RELATIONS

Cancer-related sexual intimacy issues can lead to worsening communication, elevated emotional tension, and increased marital distress. Indeed, 21% of respondents reported being not at all comfortable sharing problems about ED with their spouse or partners, and 53% believed that ED has adversely impacted their relationship at least a little bit.

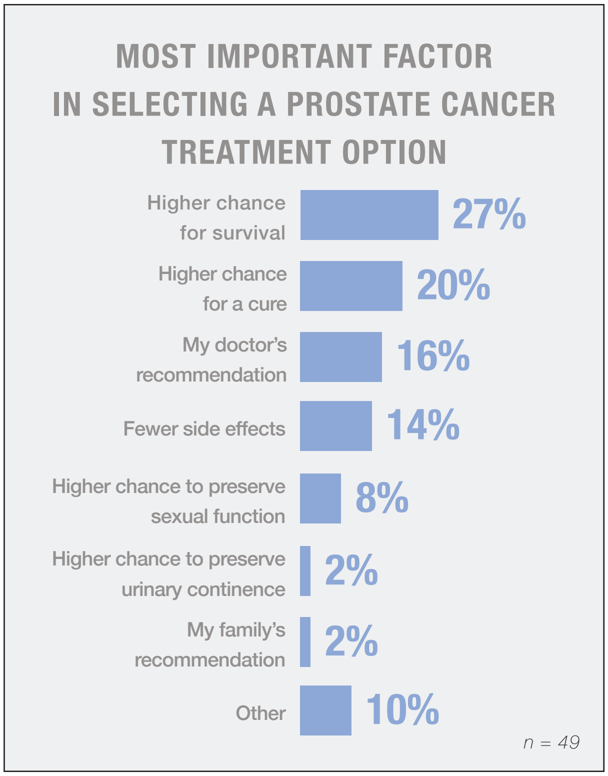
50% OF PROSTATE CANCER RESPONDENTS FELT THEY WERE NOT GIVEN ENOUGH INFORMATION ABOUT ED BEFORE TREATMENT

Further, an overwhelming majority (86%) reported that, in general, their cancer had put at least somewhat of an emotional strain on their spouse or significant other.

At the same time, many respondents indicated they make decisions about treatment with input and involvement from their spouse or partner: 44% made treatment decisions together, while 48% made decisions after consulting their spouse or partner.

TREATMENT DECISION-MAKING AND PLANNING

There are a variety of options when it comes to prostate cancer treatment, including "watch and wait," surgery, radiation therapy, vaccines, hormone therapy, chemotherapy, cryosurgery, and bone-directed treatment. Twenty-two percent of respondents reported that they were under active surveillance ("watch and wait"). An even larger percentage (36%) were post-treatment, while 5% had recently been diagnosed and were currently making a treatment decision. Apart from active surveillance, 31% reported a current treatment of hormone therapy such as androgen deprivation



therapy, 10% reported they had recent surgery, and 7% were undergoing chemotherapy.

Shared decision-making is a critical element of treatment, especially when patients have to make choices between multiple modes of therapy from multiple health care providers at multiple facilities. Although patients are very involved in treatment decision-making, they are far less likely to report feeling knowledgeable about treatment options or prepared to discuss treatment options with their doctor (Figure 6).

FIGURE 6 **TREATMENT DECISION-MAKING PROCESS: PROSTATE CANCER**

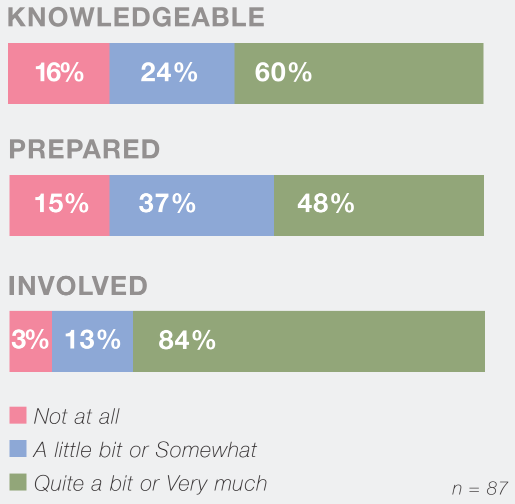


FIGURE 7 **SATISFACTION WITH DOCTOR'S COMMUNICATION**

47%	39%	32%
Impact of cancer and treatment on work	Social and emotional concerns (e.g., family, relationships, worry)	Cost of treatment

Percent of respondents indicating Somewhat to Very much

n = 48

DOCTOR-PATIENT RELATIONSHIP

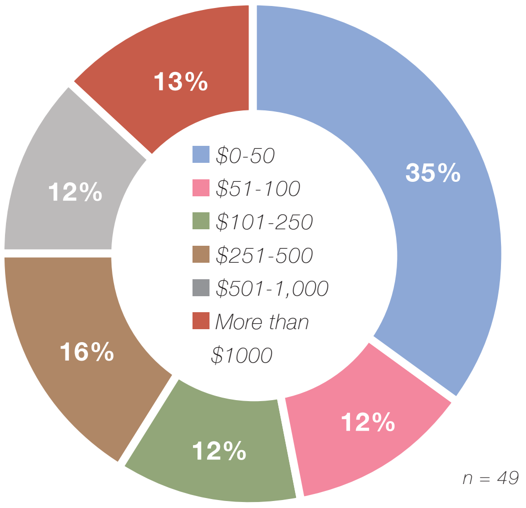
Choice in prostate cancer treatments is often driven by personal preference as much as other factors. Fifty-one percent of patients reported that they themselves made a treatment decision after considering their doctor's opinion, slightly more than the 35% who said they shared decision-making with their doctor. Figure 7 illustrates that only a subset of respondents were satisfied with how their health care provider communicated about a variety of issues. Notably, between a fifth to a third of survivors responding to these questions report that they did not discuss cost of treatment (35% of respondents), impact of cancer and treatment on work (38%), or social and emotional concerns (21%).

COST OF CARE

Insurance coverage can mask the monetary impact that prostate cancer patients experience on a regular basis. Many respondents were able to quantify monthly out-of-pocket costs related to their cancer (Figure 8).

The financial burden of cancer care is a common source of psychosocial distress, regardless of the cancer, treatment, or survival rate. Twenty-five percent of prostate cancer respondents reported significant levels of intrusive thoughts about their ability to manage costs of their cancer care, according to the Impact of Events Scale.[3]

FIGURE 8 **MONTHLY OUT-OF-POCKET COSTS**



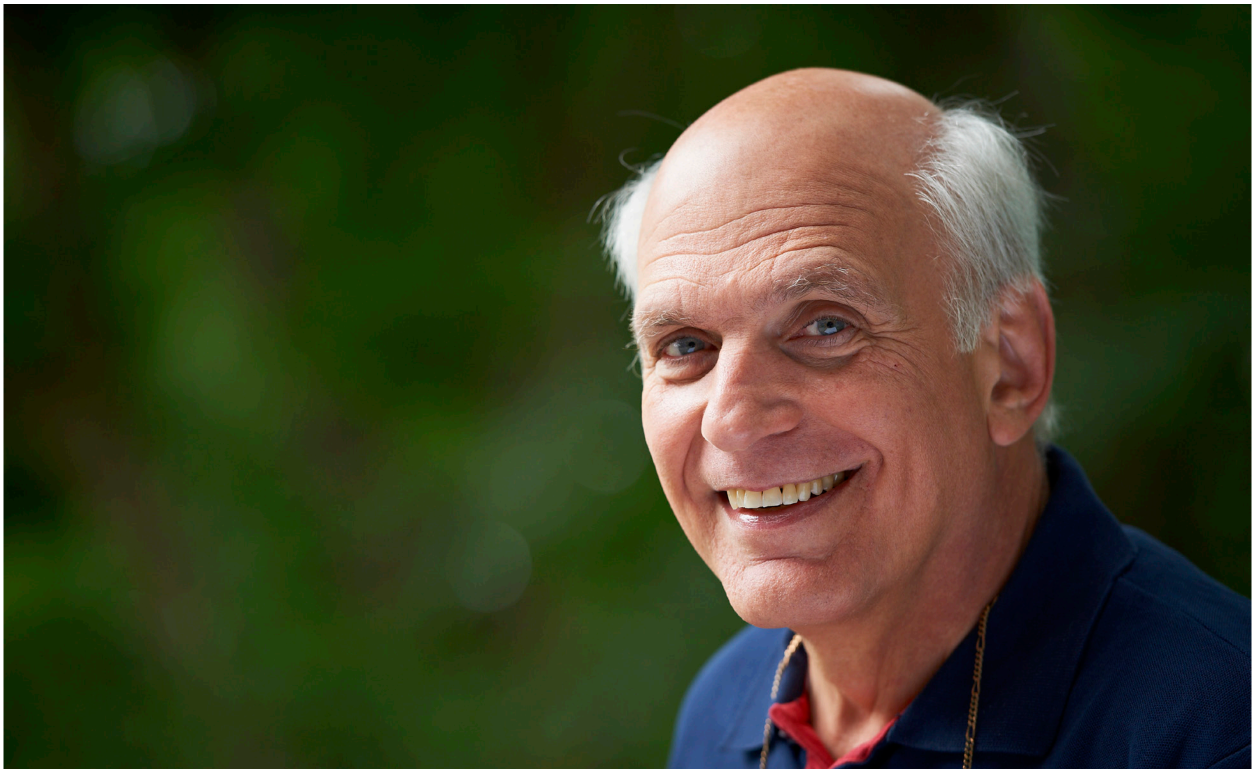
MARK, Prostate Cancer Patient

“I try to step back and look at this experience from afar and try to turn it into a positive. Cancer can control you and kill you. But instead, why not let us control the cancer, take it one day at a time, and enjoy those moments that you can.”

Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Caregiver Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Stomach Cancer Specialty Registry Report



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2. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,…Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient–Reported Outcomes Measurement Information System (PROMIS) network: 2005–2008. *Journal of Clinical Epidemiology*, *63*(11), 1179-94.

3. Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine*, *41*(3), 209-218.

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