



September 2013

The Advanced Prostate Cancer Patient and Caregiver Burden of Illness Survey Fact Sheet

Survey Overview¹

The Advanced Prostate Cancer Patient and Caregiver Burden of Illness Study was conducted online within the United States by Harris Interactive on behalf of Astellas Pharma US, Inc. and Medivation, Inc. between August 29, 2012 and March 15, 2013. A total of 91 men age 60+ with advanced prostate cancer completed the survey.² Separately, Harris Interactive surveyed 100 caregivers of advanced prostate cancer patients.³

Survey Results: The Patient Perspective

More than 50 percent of the patient survey respondents have been living with a prostate cancer diagnosis for at least six years. Nearly one-third (33 percent) reported living with a diagnosis for more than 10 years.

Physical and emotional impact of disease

- Patient respondents expressed the most concern around their ability to continue living their lives fully and about becoming a burden to those around them. Sixty-three percent of patients said they are “concerned” or “very concerned” about their ability to continue participating in the activities they enjoy, 62 percent are “concerned” or “very concerned” around the uncertainty of their future, and 59 percent express this same level of concern around becoming a burden to their family and friends.
 - In comparison, 43 percent said they are “concerned” or “very concerned” about dying.
- Forty-one percent of patients who participated in this survey indicated they do not feel like people understand what they are going through in terms of managing and treating their prostate cancer.
 - Of these patients, 78 percent said they wish people better understood the stress of coping with prostate cancer and 59 percent each, respectively, wish others understood the inconveniences caused by prostate cancer or the side effects of treatment.
- Nearly half of patients (45 percent) in the survey report they keep silent about their prostate cancer and their treatments.
- While many patient survey participants report feeling “hopeful” about their disease (58 percent), the greatest percentage say their disease makes them feel “uncertain” (62 percent). Among other responses, 33 percent say they feel fearful, 32 percent feel sad, and 20 percent feel “lonely or alone”.

¹ Survey data are not weighted, and thus are only representative of people who qualified for and completed the survey.

² For the purposes of this survey “advanced” disease was defined as prostate cancer that has been or is being treated with at least one course of hormone therapy and has continued to progress (i.e., castration-resistant prostate cancer [CRPC]).

³ “Caregivers” was defined as anyone in regular contact with qualified patients who assist with their care and/or help them make treatment decisions.

Education, information and support

- Among the 74 patient participants who reported troublesome feelings about their prostate cancer (uncertainty, fear, sadness, etc.), 74 percent said that talking to a medical professional has been helpful in coping with these feelings. Patients also reported other ways to help them cope, including staying busy (54 percent), talking to family members (41 percent) and talking to another man with prostate cancer (36 percent).
- Despite the older age of patients who participated in the survey, the Internet is an important source of information for them. After their doctors, websites specific to prostate cancer are the most frequently utilized sources of information for the patients and caregivers in this survey.
- Patient respondents are eager for information, but more than one-third of patients (35 percent) said there is too much information available about prostate cancer to understand it all.

Treatment priorities and gaps

- While 66 percent of patient respondents said that “the level of discomfort” experienced during treatment is “important” or “very important” when making decisions about their prostate cancer treatment, only 45 percent believe that this factor is “important” or “very important” to their physicians.
- Ninety-seven percent of patient respondents feel it is at least somewhat important for them to get information about potential treatments at this stage of their disease. Of these patients, 66 percent feel that information about treatment options that will be available to them in the future is among the most important for them.
- Three-quarters of patient survey participants said they are interested to learn more about new treatment options available over the past two years and ones that are expected to be approved within the next year, and 62 percent say these new treatment options make them hopeful.

Survey Results: The Caregiver Perspective

Caregivers who participated in the survey reported an average caregiving “duration” of nearly five years. Sixteen percent have been providing care for more than eight years. Thirty-eight percent of caregivers reported caring for a father, 23 percent are caring for a spouse/partner, 12 percent for a grandfather, 10 percent a father-in-law, nine percent a friend, and five percent another relative.

Physical and emotional impact of disease and caregiving

- Caregiver respondents – some of whom are elderly themselves (19 percent age 65 and over) or have full-time work/family responsibilities (55 percent) – expressed a high degree of stress associated with their roles and a desire for support.
 - Eight-five percent reported that caring for someone with prostate cancer creates stress/anxiety related to their patient’s well-being, 61 percent feel stress/anxiety related to their caregiving responsibilities, and 57 percent experience physical issues related to these responsibilities (e.g., fatigue, lack of sleep).
 - Seventy-three percent said they are very concerned or concerned about the ability to continue providing care over a long period of time.

- Among the 93 percent of caregiver respondents who report experiencing troublesome feelings as a result of caregiving (e.g., stress, sadness, fear, etc.), 58 percent indicate that they rely on family members to help relieve these feelings.

Education, information and support

- In terms of information priorities, 64 percent of caregiver respondents strongly agree that they would like more information about treatment options available, 53 percent want to know how to help their loved one cope with the physical side effects of treatment, and 51 percent want to understand how specific treatments work in his body.
- Caregivers demonstrated a clear need for additional support as well as guidance around where/how to find desired information:
 - Forty-seven percent of caregivers said there is too much information about prostate cancer to digest it all.
 - On the other hand, about nine out of 10 (86 percent) caregiver participants said they would like more information to be available to them.

Treatment priorities

- Eighty-three percent of caregiver respondents would be likely to encourage their loved one to start or try a new therapy if it extended survival and 76 percent would be likely to do so if the side effects are manageable.
- Caregivers who participated in the survey nearly universally place a high degree of importance on the patient's comfort during treatment: Ninety-five percent said the discomfort their loved one will experience during treatment and how his quality of life will be impacted are important or very important to them.

Survey Partners

Astellas Pharma US, Inc. and Medivation, Inc. commissioned the Advanced Prostate Cancer Patient and Caregiver Burden of Illness Survey through Harris Interactive, and sponsored four leading cancer advocacy and education organizations to collaborate on the initiative.

- *The Association of Oncology Social Work (AOSW)* is an international organization dedicated to the enhancement of psychosocial services to people with cancer and their families.
- *CancerCare* is the leading national organization committed to improving lives by providing professional oncology social work services to help people manage the emotional and financial challenges of cancer. *CancerCare* offers free telephone, online and in-person counseling and support groups, resource referrals, publications, education and financial and co-payment assistance.
- *The Prostate Health Education Network (PHEN)* aims to eliminate the African American prostate cancer disparity and to increase overall support and resources to find a cure for the benefit of all men.
- *Us TOO Prostate Cancer Education and Support Network* is a grassroots prostate cancer education and support network of 325 support group chapters worldwide, providing men and their families with free information, materials and peer-to-peer support so they can make informed choices on detection, treatment options and coping with ongoing survivorship.

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