

Recognizing Symptom Burden in Advanced Prostate Cancer: A Global Patient and Caregiver Survey

Lawrence Drudge-Coates,¹ William K. Oh,² Bertrand Tombal,³ Anthony Delacruz,⁴ Brian Tomlinson,⁵ Aimee Vella Ripley,⁶ Ken Mastris,⁷ Joe M. O'Sullivan,⁸ Neal D. Shore⁹

Abstract

An international survey was conducted in 927 men with advanced prostate cancer (aPC) and 400 caregivers to assess symptom communication. Patients with aPC often ignore pain and pain-related symptoms, do not discuss pain with their physician, and have difficulty discussing symptoms. Effective communication among patients, caregivers, and health care providers may improve symptom and disease management and patient quality of life.

Background: Bone metastases in men with prostate cancer are often initially asymptomatic, resulting in delayed identification, diagnosis, and appropriate treatment. To assess how patients with advanced prostate cancer (aPC) communicate symptoms to health care providers, an international patient survey was conducted. **Methods:** An online and phone survey was conducted by Harris Poll in 11 countries (Brazil, France, Germany, Japan, Italy, Netherlands, Singapore, Spain, Taiwan, United Kingdom, United States) from February 12 to October 27, 2015, in men with aPC (ie, those who reported as having PC beyond the prostate [metastatic]) and their caregivers. Cell weighting was used to ensure equal weight of data across countries. Percentages are based on weighted n values. **Results:** A total of 927 men with aPC (weighted n = 664) and 400 caregivers completed the survey. Most commonly reported symptoms were fatigue (73%), urinary symptoms (63%), sexual function symptoms (62%), and bone pain (52%). Of 568 patients with bone metastases (weighted n = 421), most (73%) noticed pain before receiving a diagnosis of metastatic PC. Most patients with aPC (56%) were uncertain if their pain was cancer related, 55% felt they had to live with daily pain, 45% sometimes ignored pain, and 39% had difficulty talking about pain. Patients who had a caregiver were more likely than those without to discuss pain at every visit (45% vs. 32%, $P < .05$). **Conclusions:** Disease symptoms in aPC are often underrecognized. Tools encouraging effective communication among patients, caregivers, and health care providers on early symptom reporting may lead to enhanced symptom and disease management.

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Introduction

Prostate cancer (PC) is the second most common malignancy in men worldwide, with an estimated 1.1 million men across the world diagnosed in 2012, and the fifth leading cause of cancer-related

death in men, with 307,000 deaths reported worldwide in 2012.¹ PC is an androgen-dependent disease that initially responds to androgen-deprivation therapy (ie, chemical or surgical castration). However, most men will become resistant to androgen-deprivation

¹King's College Hospital NHS Foundation Trust, London, UK

²Tisch Cancer Institute-Icahn School of Medicine at Mount Sinai, New York, NY

³Institut de Recherche Clinique, Université Catholique de Louvain, Louvain-la-Neuve, Belgium

⁴Memorial Sloan-Kettering Cancer Center, New York, NY

⁵CancerCare, New York, NY

⁶Harris Poll, New York, NY

⁷Europa Uomo, The European Prostate Cancer Coalition, Essex, UK

⁸Queen's University School of Medicine, Belfast, UK

⁹Carolina Urologic Research Center, Myrtle Beach, SC

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Address for correspondence: Lawrence Drudge-Coates, MSc, Urological Oncology Clinical Nurse Specialist and Honorary Lecturer, King's College Hospital NHS Foundation Trust, Denmark Hill, London, UK SE5 9RS
E-mail contact: ldrudge-coates@nhs.net

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therapy over time, developing nonmetastatic castration-resistant PC (CRPC), in which a rise in prostate-specific antigen is often the first detectable sign.²⁻⁴ For some men, nonmetastatic CRPC will progress to metastatic CRPC, which is still uniformly incurable, although several new treatment options have been shown to significantly improve survival, including traditional taxane chemotherapy (docetaxel), new androgen-receptor pathway antagonists (enzalutamide, abiraterone), novel taxanes (cabazitaxel), immunotherapy (sipuleucel-T), and targeted alpha therapy (radium-223).^{5,6}

A large majority of men with metastatic CRPC (90%) will develop bone metastases, which are often initially asymptomatic.^{6,7} Although a small proportion of patients are de novo diagnosed with metastatic disease, most bone metastases develop in patients who have failed local treatment and progress under androgen-deprivation therapy. Bone metastases are strongly associated with increased mortality in men with metastatic CRPC, and the risk of death is even higher in men with skeletal-related events.^{8,9} In addition to increased mortality, bone metastases are a major cause of disability, bone pain, impaired quality of life (QoL), and excessive treatment costs.^{6,10} Pain is the most common symptom, occurring in 75% of symptomatic patients with metastatic PC,⁷ whereas spinal cord compression occurs in up to 12% of patients and may be the first sign of bone metastases.¹¹

To better understand the symptoms associated with advanced PC (aPC) and the impact of symptoms on the lives of patients and their caregivers, an international survey was commissioned by the International Prostate Cancer Coalition. The goals of the survey were to describe the disease burden, highlight barriers that prevent men from discussing symptoms, explore the patient-caregiver dynamic, and raise awareness of the importance of discussing symptoms with health care providers.

Patients and Methods

This survey (see [Supplemental Figure 1](#) for full survey questionnaire) was conducted online and by phone by the Harris Poll in Brazil, Europe (France, Germany, Italy, the Netherlands, Spain, and the United Kingdom), Asia-Pacific region (APAC; Japan, Singapore, and Taiwan), and the United States from February 12, 2015, to October 27, 2015. The survey was provided to respondents in the following local languages: American English, British English, German, French (France and Belgium), Italian, Spanish, Dutch (Netherlands and Belgium), Japanese, Traditional Chinese (Taiwan), and Portuguese (Brazil). After the surveys were translated from the US English version to the local language by local translators, the surveys were then reviewed by in-country representatives familiar with the survey topic to ensure that the meaning of the questions would be understood in the same way across the different countries.

Survey respondents were selected from among individuals who had agreed to participate in surveys through the Harris Poll and their partners or were recruited to participate by patient advocacy organizations. Sampling methods included a convenience sample from patient advocacy organizations. Respondents were included in the survey if they lived in 1 of the 11 participating countries, were aged ≥ 18 years, and had a diagnosis of aPC (respondents reported having PC in locations other than the prostate). A caregiver was defined as someone who had provided unpaid care to a

friend or family member diagnosed with aPC. Patient care may have included providing support or assistance to a friend or family member; however, this definition did not include care provided by a health care professional or someone with formal volunteering experience. Eligible caregivers were aged ≥ 18 years, were caring for someone with aPC, and lived in the same country in which the patient lived. Informed consent was obtained at the start of the online survey.

Demographic information was obtained from all respondents. Questions included in the survey assessed general health, concerns about personal health, symptoms, challenges faced living with aPC, and comfort level when speaking with health care providers.

The sample was based on the individuals who agreed to participate in panels or advocacy groups; therefore, it was not possible to estimate a theoretical sampling error. Because sample sizes varied between countries, the findings were adjusted to ensure that data from all countries received an equal weight in global and regional data analyses. Country-level data were unweighted. Data were analyzed using descriptive statistics, cross-tabulations, and correlations. Between-group differences were analyzed using a standard *t* test at the 95% confidence level ($P < .05$). Because of the small base size, comparisons versus APAC and Brazil are directional in nature and should be interpreted with caution.

Results

The study sample consisted of 927 men with aPC (weighted $n = 664$) and 400 caregivers who responded to the survey and met eligibility requirements; the overall weighted n value of 664 or the weighted n values by country, as indicated later in this article, were used to calculate the reported percentages. Overall, the mean patient age was 65.7 years, and 86% ($n = 570$) of patients had a caregiver. Patients from the United States and Europe were similar in age (mean, 67.9 and 67.8 years, respectively), as were patients from the APAC and Brazil (61.7 and 62.6 years) ([Table 1](#)).

In the total population, 84% of the men had been diagnosed with PC for longer than 12 months ([Table 1](#)). Among patients with aPC, the bone compartment was the most observed site for metastases, followed by lymph node involvement. Most patients in all regions had confirmed bone metastases ([Table 1](#)).

Most patients had caregivers, with the proportion somewhat greater in the APAC and Brazil compared with Europe and the United States ([Table 1](#)). Of the caregiver respondents in the United States, 63% (60/95) were patients' spouses or partners compared with 49% (179/362) in Europe and 43% (17/40) in Brazil. In contrast, caregivers in the APAC were primarily patients' offspring (126/181, 70%). Most caregivers were women ($n = 520$, 78%) with a mean age of 52 years. Differences in employment status were apparent between patients and caregivers. More patients were retired compared with caregivers ($n = 325$, 49% vs. $n = 160$, 24%), with more than twice as many caregivers working full- or part-time ($n = 199$, 30%) compared with patients ($n = 86$, 13%). Patients were accompanied by caregivers to 70% of their physician visits on average, and 50% ($n = 330$) of patients relied on a spouse or caregiver to ask the most important questions about their PC issues.

Nearly all patients reported facing challenges related to their PC, the most common of which was a decreasing ability to maintain

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