Executive Summary

The National Association for Proton Therapy (NAPT) commissioned Dobson DaVanzo & Associates, LLC (Dobson | DaVanzo) to investigate outcomes and patient satisfaction associated with the use of proton therapy in treating prostate cancer. Close to 2,000 patients who were treated for prostate cancer with proton therapy from 1991 to 2010 completed a survey distributed by the Brotherhood of the Balloon (BOB), which examined satisfaction with care, quality of life, emotional and physical health limitations, urinary function, sexual function, bladder function, and bowel function. These 2,000 patients represent approximately 20 percent of all patients who had received proton therapy for prostate cancer prior to 2010.

Background

The BOB survey incorporates the Expanded Prostate Cancer Index Composite (EPIC), a validated instrument developed by the University of Michigan and UCLA that measures health related quality of life (HRQOL), specifically among men with prostate cancer. EPIC assesses a patient’s Health Related Quality of Life (HRQOL) in urinary, sexual, bowel, and hormonal domains. In addition, EPIC derives subscales for each category, which examine function and bother for each HRQOL category. Urinary scores also contain subcategories related to incontinence and irritation/obstruction. The BOB survey also incorporated the American Urological Association (AUA) symptom index, which provides a clinical context for urinary measures, and a Medical Outcomes Study SF-12 score which is a patient’s report of physical and mental health status.

Methodology

We first calculated descriptive statistics to examine patient demographics and treatment characteristics. EPIC scores were then calculated at the summary and sublevel categories for each respondent using this methodology to examine the prostate cancer patients’ post-treatment condition. An AUA symptom index, and Medical Outcomes Study SF-12 score was also calculated for each patient. These measures were then cross-tabulated by treatment modality (whether the patient received proton therapy only or proton plus another type of therapy: hormone or photon therapy), by time elapsed since the completion of treatment, and by whether the patient had reported problems associated with sexual, urinary, or bowel function prior to treatment. Differences were tested using Chi-square and t-tests.

1 Dobson DaVanzo & Associates, LLC is a health economics and policy consulting firm based in the Washington, D.C. metropolitan area. The analytic work of our principals has influenced the design of demonstrations and many public policy decisions, and appears in numerous instances in legislation and regulation.
2 Function scores measure habits associated with the category
3 Bothers scores measure annoyance associated with symptoms related to the category
4 Incontinence scores measure loss of bladder control
5 Irritation/obstruction scores measure pain or bleeding associated with urination
6 THE SF-12 is a validated measure of General Health Function developed by RAND. It examines physical and mental HRQOL, and provides both a physical and mental HRQOL score.
Key Findings

- Approximately 99 percent of respondents stated that they believed they made the best treatment decision for themselves, and 98 percent reported that they had recommended proton therapy to others.

- Approximately 96 percent of patients were satisfied or extremely satisfied with proton therapy.

- Ninety-two percent of patients reported that their quality of life was better or the same today than it was before their treatment, and only 8 percent stated that their quality of life was worse.

- Ninety-two percent of respondents reported that physical health or emotional problems did not interfere, or interfered very little, with their social activities.

- Those who completed proton therapy for the treatment of prostate cancer had similar urinary, bowel, and hormonal HRQOL measures compared to healthy individuals. Lower sexual HRQOL measures were mostly associated with those patients that received hormone therapy in addition to proton therapy. When looking at patients who received only proton therapy for the treatment of prostate cancer (did not receive hormone or photon therapy), proton therapy patients reported lower HRQOL than healthy individuals in only one HRQOL category (“Sexual Bother”).

- Respondents who were treated with photon therapy in addition to proton therapy had lower bowel, sexual, and hormonal HRQOL scores, while those who received hormone therapy in addition to proton therapy had lower sexual and hormonal HRQOL scores. Those receiving photon or hormone therapy in addition to proton therapy also reported lower SF-12 PCS scores compared to those only receiving proton therapy, indicating a lower physical HRQOL.

About NAPT and BOB

The National Association for Proton Therapy (NAPT) is a non-profit organization supported by proton center members and is the “Voice of the Proton Community.” The NAPT promotes education and public awareness for the clinical benefits of proton beam radiation therapy. Founded in 1990, NAPT is a strong advocate for the advancement of proton therapy. It serves as a resource center for patients, physicians and health care providers, universities, academic medical centers, hospitals, cancer centers, the Centers for Medicare and Medicaid Services (CMS) and other health care agencies, the U.S. Congress and staff, and the news media. NAPT’s goal is increased patient awareness and accessibility to proton therapy as the most advanced form of radiation treatment available to treat cancerous tumors resulting in less morbidity and minimum to no side effects.

The Brotherhood of the Balloon was founded in 2000 by Robert Marckini. The group consists of 6,400 men who received proton therapy, or proton therapy in combination with other therapies, for prostate cancer. Members are from all 50 US states and 33 countries. They represent all ten U.S. proton centers as well as three proton centers in Europe and Asia.

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7 Patients rating of the level of annoyance associated with their sexual symptoms