# *Proton therapy for prostate cancer online: patient education or marketing?*

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***Introduction:*** *Proton therapy (PT) for prostate cancer is an expensive treatment with limited evidence of benefit over conventional radiotherapy. We sought to study whether online information on PT for prostate cancer was balanced and whether the website source influenced the content presented.*

***Materials and methods:*** *We applied a systematic search process to identify 270 weblinks associated with PT for prostate cancer, categorized the websites by source, and filtered the results to 50 websites using predetermined criteria. We then used a customized version of the DISCERN instrument, a validated tool for assessing the quality of consumer health information, to evaluate the remaining websites for balance of content and description of risks, benefits and uncertainty.*

***Results:*** *Depending on the search engine and key word used, proton center websites (PCWs) made up 10%-47% of the first 30 encountered links. In comparison, websites from academic and nonacademic medical centers without ownership stake in proton centers appeared much less frequently as a search result (0%-3%). PCWs scored lower on DISCERN questions compared to other sources for being balanced/unbiased ($p < 0.001$), mentioning areas of uncertainty ($p < 0.001$), and describing risks of PT ($p < 0.001$). PCWs scored higher for describing the benefits of treatment ($p = 0.003$).*

***Conclusions:*** *Patients should be aware that online information regarding PT for prostate cancer may represent marketing by proton centers rather than comprehensive and unbiased patient education. An awareness of these results will also better prepare clinicians to address the potential biases of patients with prostate cancer who search the Internet for health information.*

**Key Words:** consumer health information, internet, marketing of health services, prostatic neoplasms, proton therapy, prostate cancer, radiation therapy

## Introduction

Proton therapy (PT) is an increasingly popular treatment option for prostate cancer but costs significantly more than conventional intensity-modulated radiation therapy (IMRT). The median Medicare reimbursement for PT in 2008-2009 was $32,428, which is 75% more than that of IMRT.[1]

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Protons boast a better dose distribution profile that provides better precision when targeting a tumor.[2] This characteristic allows for increased doses of radiation that would theoretically improve cancer cure rates while causing fewer side effects by limiting the dose to nearby organs at risk. However, few studies have compared PT to other treatment options. Those studies that do exist have failed to demonstrate PT is a superior treatment for prostate cancer with regard to increased overall survival, cancer-specific survival, or fewer long term side effects.[1,3]

Two studies in 2012 evaluating PT for prostate cancer highlighted these issues and made the treatment option a topic of public discourse, garnering considerable media attention. First, a study by Sheets

et al revealed a surprising increase in gastrointestinal toxicity with PT compared to IMRT.[4] Subsequently, Yu and colleagues showed that although PT afforded a reduction in genitourinary toxicity at 6 months, this benefit was transient and there was no difference at 12 months for any toxicities.[1]

Despite these results, there has been continued growth in the use of PT for prostate cancer. The number of Medicare beneficiaries receiving PT for treatment of prostate cancer increased 68% from 2006 to 2009.[5] There has also been a steady increase in the number of proton treatment centers over the past two decades. According to the Particle Therapy Co-Operative Group, there are 37 proton centers in operation today worldwide. An additional 34 centers are currently under construction or development.[6]

Patients with prostate cancer often seek further information on PT as a treatment option, and many of them turn to the Internet as a resource. A recent survey found that 59% of all American adults went online for health information in the past year. Among them, 77% began at a search engine such as Google, Yahoo, or Bing.[7] The quality of online health information resources is critical for patients to make well-informed decisions. However, the majority of research evaluating these consumer health information sources has concluded that quality is a problem.[8] Previous studies have judged the quality of such resources for urological topics range from good with noted shortcomings[9-11] to variable[12-15] to poor.[16-19]

In addition to health information, the Internet can serve as a venue for marketing of treatment options. An analysis of websites describing robot-assisted laparoscopic prostatectomy revealed that many of the sites claimed benefits that were not supported by evidence and that almost half of the sites did not mention risks.[20] Furthermore, new and developing technologies often attract more media coverage than the standard therapy. This disparity in available information may create an inherent bias in favor of the new treatment for patients when researching treatment options online. One study showed that direct-to-consumer advertising and media coverage was significantly greater for robotic prostatectomy compared to conventional surgical options online.[21]

Shah and colleagues described the landscape of internet health information on PT for prostate cancer. The study revealed a difference in quality when comparing the sources of information and highlighted inaccuracies by providing representative statements from various websites compared to best available evidence to date.[12]

The present study seeks to further analyze online information on PT as a treatment option for prostate cancer. Specifically, we evaluate the frequency of websites derived from proton centers that patients may encounter when searching online. We also analyze whether health information provided on proton center websites (PCWs) contains bias and has an unbalanced presentation of risks versus benefits when describing PT as a treatment option.

## Materials and methods

We first identified the most popular key words used to search for PT for prostate cancer online. Using the Google Key Word Tool on December 14, 2012, we performed queries with the terms "proton therapy for prostate," "proton beam therapy," and "proton radiation for prostate cancer." We then selected the top five key words related specifically to PT. The terms "proton beam," "beam therapy," and "proton beam therapy" were deemed to have significant overlap and thus used as one key word. We agreed that "prostate cancer" would be added to each of the key word searches in order to focus the results.

Based on rankings developed by Experian Hitwise, we determined the three search engines with the highest volume in December 2012 were Google, Yahoo, and Bing. The search terms "proton therapy and prostate cancer," "proton beam therapy and prostate cancer," and "proton radiation and prostate cancer" were used with each of the search engines. One physician searcher in Chicago, IL systematically used the selected search terms and search engines to identify the first 30 links for each term using each search engine on December 28, 2012. We considered this a sufficient number of links as a previous study reported that 75% of Internet users only look at the first two web pages displayed for each search term.[22]

We only included organic search results, which are links that are returned based on the natural indexing of the search engine. Advertisements and sites that were non-English or not primarily text (e.g., YouTube videos) were excluded. Sites without full content accessible or that did not discuss PT for prostate cancer were considered irrelevant and also excluded. The remaining sites were categorized by source (government, academic medical center [nonowner], nonacademic medical center [nonowner], proton center, nonprofit, news, health website, and other). Sites categorized as "other" included general information sites such as Wikipedia.com and Ehow.com, stand-alone blogs, or those with no obvious source. As part of our initial analysis, we studied the sources of all search results for each search engine and key word. We then filtered the websites to obtain a unique set of websites and removed sites that were irrelevant and/or duplicated.

Our method of website appraisal was based upon directly evaluating the page from which the search results took us. We were able to freely click links to information on prostate cancer, but once we landed there, a one-click limit was in place. A similar method has been used previously.[20] We used the DISCERN instrument to assess the quality of information presented on the websites. DISCERN is a brief questionnaire that provides users with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem[23] and has been widely used to assess the quality of health information on the web.[12,13,18,19] We created a customized DISCERN instrument with scoring criteria appropriate for PT for prostate cancer (available upon author request), intended to improve reproducibility of results. The seven questions in the customized instrument allowed us to focus our analysis on the objective of determining the presence of marketing in the sites. Two investigators independently analyzed each of the unique websites. Interrater reliability was assessed, and the mean score between the two investigators was used for analysis.

MedCalc version 12.5 (Belgium) was used for statistical analysis with a significance level of $p < 0.05$. The one-way analysis of variance was used to compare mean DISCERN scores between source groups for each question. Agreement between raters was calculated using kappa with quadratic weights, in which different weights are assigned to disagreements according to the magnitude of the discrepancy. Weighted kappa is appropriate for ordinal data and recommended by the creators of DISCERN.[23]

## Results

We initially identified 270 sites using our search process (30 websites per key word per search engine) and categorized these search results by source. We studied each group of 30 weblinks and found that websites developed by news sources and proton centers were the most frequent links to appear in the search results. Depending on the search engine and key word used, news sources made up 13%-47% of the results; websites developed by proton centers represented 10%-47%; and nonprofit websites amounted to 3%-13% of search results (however, the most frequent nonprofit seen was the National Association for Proton Therapy.) Websites developed by academic and nonacademic medical centers that did not have ownership stake in proton centers appeared much less frequently as a search result (0%-3%). The compilation of search results according to the three search engines is displayed in Figure 1.

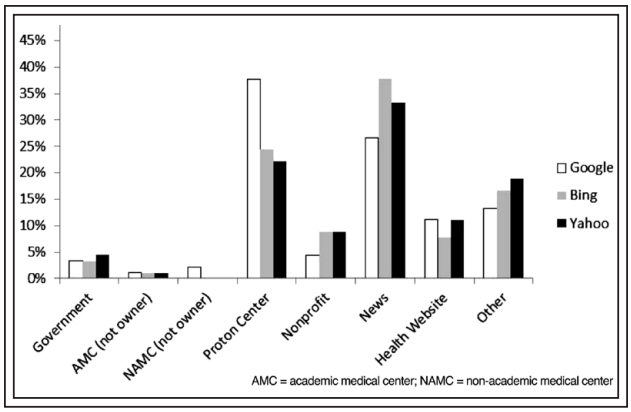


**Figure 1.** Source distribution of combined first 90 web results for each search engine (30 websites per key word searched).

Of the 270 websites, 212 were duplicated sites, subpages of parent sites, or deemed irrelevant and excluded. Within the news source category, an additional eight websites that simply reposted information from another site that was already in the study were removed. A total of 50 sites remained for the final analysis. We found that 11 of the unique sites were PCWs and 13 from news sources. Table 1 displays the number of websites from each of the source categories included in the final analysis.

When we evaluated our unique sources using the DISCERN instrument, we found that the average DISCERN rating was 18.3, out of a possible total score of 35. Sources were grouped into three categories to include proton centers, news, and others. The average DISCERN scores according to these three source categories for each question are displayed in Table 2. PCWs scored lower on DISCERN questions compared to the news and other sources for being balanced/unbiased ($p < 0.001$), mentioning areas of uncertainty ($p < 0.001$), and describing risks of PT ($p < 0.001$). PCWs scored higher for describing the benefits of treatment ($p = 0.003$). The ratios of risks to benefits using the average DISCERN scores for the sources were 0.35 for PCWs, 1.2 for news, and 1.0 for others. The weighted kappa statistic for interrater reliability was 0.59.

The five websites with the highest total DISCERN scores from the study are listed in Table 3.

## Discussion

While PT is continuing to rise in popularity as a radiation treatment for prostate cancer, there is a lack of evidence supporting it as a superior treatment option

TABLE 1. **Source categories of websites**

| Source category | Number of sites, n | DISCERN score, mean ± SD (35 total possible) |
|---|---|---|
| Proton center | 11 | 15.1 ± 3.6 |
| News | 13 | 18.5 ± 3.0 |
| Nonacademic medical center | 1 | 20.0 ± 0.0 |
| Nonprofit organization | 5 | 22.9 ± 5.4 |
| Health website | 9 | 19.4 ± 3.1 |
| Other | 11 | 18.1 ± 5.3 |
| **Total** | **50** | **18.3 ± 4.4** |

"Other" category includes general information sites, blogs, and sites not otherwise classified

TABLE 2. **Source categories with DISCERN scores**

| Source | Is it balanced and unbiased? | Does it provide details of additional sources of support and information? | Does it refer to areas of uncertainty? | Does it describe the benefits of each treatment? | Does it describe the risks of each treatment? | Is it clear that there may be more than one possible treatment choice? | Does it provide support for shared decision-making? |
|---|---|---|---|---|---|---|---|
| | mean ± SD | mean ± SD | mean ± SD | mean ± SD | mean ± SD | mean ± SD | mean ± SD |
| Proton center (n = 11) | 1.1 ± 0.2 | 2.9 ± 1.3 | 1.0 ± 0.0 | 4.3 ± 0.6 | 1.5 ± 0.7 | 3.2 ± 1.4 | 1.2 ± 0.6 |
| News (n = 13) | 3.6 ± 0.5 | 2.0 ± 1.5 | 3.4 ± 1.1 | 2.8 ± 0.8 | 3.3 ± 1.0 | 2.4 ± 0.6 | 1.1 ± 0.2 |
| Others (n = 26) | 3.0 ± 1.4 | 2.8 ± 1.4 | 2.5 ± 1.3 | 3.1 ± 1.4 | 3.1 ± 1.4 | 3.2 ± 1.1 | 1.8 ± 1.1 |
| p value | < 0.001 | 0.191 | < 0.001 | 0.003 | < 0.001 | 0.108 | 0.020 |

"Others" include nonacademic medical center (n = 1), nonprofit organization (n = 5), health website (n = 9), and other (n = 11)

TABLE 3. **Top five websites**

| Website URL | Source category | DISCERN score (35 total possible) |
|---|---|---|
| http://en.wikipedia.org/wiki/Proton_therapy | Other | 29.5 |
| http://www.cancer.org/cancer/prostatecancer/detailedguide/prostate-cancer-treating-radiation-therapy | Nonprofit organization | 29 |
| http://www.radiologyinfo.org/en/info.cfm? pg=pros_cancer | Nonprofit organization | 28.5 |
| http://www.hisprostatecancer.com/proton-therapy-for-prostate-cancer.html | Other | 25.5 |
| http://www.livestrong.com/article/216043-about-proton-beam-therapy-and-prostate-cancer/ | Health website | 25 |

compared to IMRT. The content of some websites marketing PT, however, may contribute to the growing demand for this more expensive option. The purpose of this study was to evaluate whether the content of websites discussing PT for prostate cancer provides balanced patient education or marketing. Our analysis found that PCWs were frequently encountered while searching online for information on the topic. These websites presented unbalanced information and were more likely to emphasize benefits over risks compared to news and other sources. This unbalanced representation of PT may represent marketing rather than comprehensive patient education.

In one Google search of our key words, approximately half of the results were links to PCWs. In fact, links for proton centers were more prevalent in all of the searches with Google compared to the other two search engines. Google uses intricate algorithms to determine relevancy and rank order search results. Their set of algorithms relies on over 200 unique components, many of which are kept private for the sake of competition and preventing spam.[24]

The average total DISCERN score was lowest for proton centers and highest for nonprofit organization sources. This discrepancy supports our hypothesis that PCWs are more of a venue for marketing. Proton centers have a financial interest to increase the number of patients using their facility, while most nonprofit organizations do not have a direct financial gain in promoting PT. The average risk-benefit ratio for the websites may also suggest the amount of marketing present in each of the source categories. The ratios for news and other sources were at or above 1, while that of proton centers was nearly 1:3. An emphasis on benefits and omission of risks suggest the source is not intended for balanced patient education.

The interrater reliability for scoring was satisfactory. A weighted kappa statistic ≥ 0.40 is considered an acceptable level of agreement for the DISCERN instrument.[23] DISCERN is a valid and reliable tool, but there is a degree of subjectivity inherent in the scoring of health information with it. The investigators established specific scoring criteria and discussed practice cases prior to formal analysis in order to diminish this bias.

The DISCERN scores from our analysis generally agree with a previous study by Shah and colleagues assessing PT online.[12] Disagreement was only noted in the questions on being balanced/unbiased and if more than one treatment option was mentioned, in which our scores were lower for both. This difference in scoring may be from the specific criteria we applied in our customized DISCERN instrument. The present study adds to their work by comparing the frequency of websites encountered and content quality according to source category, with a specific focus on proton centers.

Our study is timely in that PT for prostate cancer has gained considerable media attention over the past year after two research studies were published.[1,4] Although the benefits of PT for prostate cancer are still investigational, it is covered by many health insurance plans, including Medicare, and there is patient demand for it. The topic of health care costs and medical technology will likely become even more relevant in the national discourse as health care reforms expand. The results of the present study provide insight into one possible source of increased consumer demand for a new medical therapy. A similar phenomenon was seen with the rapid expansion of robotic surgery due to direct-to-consumer marketing.[20,21] This study also draws physician attention to the fact that patients researching PT as a treatment option for prostate cancer online often encounter unbalanced information.

We acknowledge several limitations with our study. First, our methods intended to mimic the information seeking behavior of patients searching for information on PT for prostate cancer. However, we do not know if all patients use search engines, or if patients use the key words we used in our study. It is also unclear whether patients click on organic search results or if they are diverted to videos and sponsored advertisements. Second, as noted above, the timing of our online search took place soon after research by Yu and colleagues was reported by Reuters and The Wall Street Journal. Consequently, search engines produced a disproportionate number of results that included these two news articles. This specific example highlights the broader limitation of a website search being performed at one point in time. Online content is constantly changing, and the results rendered from search engines are similarly in continuous flux. However, this fluidity of Internet content also mirrors the reality of what patients experience while seeking information at different times.

## Conclusions

Our analysis found that PCWs are frequently encountered when searching online for terms related to PT for prostate cancer. PCWs appear preferentially biased towards the benefits of PT, which may represent marketing by proton centers instead of patient education. Patients should be aware of these findings when searching online for information on PT for prostate cancer. An awareness of these results will better prepare clinicians to address the potential biases of patients with prostate cancer who search the Internet for health information. □

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