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Physician Evaluation of Internet Health Information on Proton Therapy for Prostate Cancer

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Abstract

Purpose—Many patients considering prostate cancer (PCa) treatment options report seeking proton beam therapy (PBT) based in part on information readily available on the Internet. There is, however, potential for considerable variation in Internet health information (IHI). We thus evaluated the characteristics, quality, and accuracy of IHI on PBT for PCa.

Methods and Materials—We undertook a qualitative research study using snowball-purposive sampling in which we evaluated the top 50 Google search results for “proton prostate cancer.” Quality was evaluated on a 5-point scale using the validated 15-question DISCERN instrument. Accuracy was evaluated by comparing IHI with the best available evidence.

Results—Thirty-seven IHI websites were included in the final sample. These websites most frequently were patient information/support resources (46%), were focused exclusively on PBT (51%), and had a commercial affiliation (38%). There was a significant difference in quality according to the type of IHI. Substantial inaccuracies were noted in the study sample compared with best available or contextual evidence.

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Conclusions—There are shortcomings in quality and accuracy in consumer-oriented IHI on PBT for PCa. Providers must be prepared to educate patients how to critically evaluate IHI related to PBT for PCa to best inform their treatment decisions.

Introduction

Nearly 80% of adults in the United States use the Internet, compared with 14% in 1995 (1). There has been a concomitant increase in Internet use to find health information. A 2010 survey found that 80% of Internet users (ie, 59% of all adults in the United States) searched online for health information (2), compared with 25% only a decade earlier (3). The emergence of the Internet as a source of health information underscores the importance of assessing the quality and accuracy of Internet health information (IHI) to better inform medical decision making.

Nearly 242,000 men in the United States will receive a diagnosis of prostate cancer (PCa) this year (4). The “treatment bazaar” (5) of options available to many men with localized PCa includes surgery, radiation, and expectant management (active surveillance or watchful waiting). Radiation therapy can include brachytherapy, x-ray therapy (such as intensity modulated radiation therapy [IMRT]), and proton beam therapy (PBT). PBT is becoming increasingly available in the United States: there are 10 operational PBT centers with another 7 in development (6). As such, PBT has attracted substantial national media attention in recent years for the treatment of PCa despite a scarcity of comparative effectiveness evidence (7).

Many patients considering PCa treatment report seeking PBT based in part on freely available IHI (8). Such information includes peer-reviewed scientific articles, blogs, discussion forums, and patient support sites. There is, however, potential for considerable variation and bias in IHI. We thus evaluated the characteristics, quality, and accuracy of IHI on PBT for PCa.

Methods and Materials

To emulate a patient searching the Internet, we undertook a qualitative research study using snowball-purposive sampling in which we evaluated the top 50 nonsponsored Google search results for “proton prostate cancer;” similar sampling strategies have been previously used to identify health-related websites (9). This sampling approach allowed for the evaluation of additional websites found to be referenced within the base study sample. The search was performed in a single session in March 2011. The results of a rereview of the final study sample in August 2012 suggested that most websites in our sample had not changed since their initial evaluation.

All 50 search results consisted of English-language websites. Two genitourinary radiation oncologists specializing in the treatment of PCa with PBT, x-ray therapy, and brachytherapy then independently evaluated each site over the same 5-day period. Raters were instructed to navigate domains freely and to add additional websites to the sample if they were frequently referenced in the initial sample. We excluded search results from the same domain (n=4), those requiring a login (n=7), nonfunctional URL (n=1), and IHI not containing information

on PBT for PCa (n=10); 22 websites were excluded in total. Available websites for operational PBT centers in the United States were added to the sample (n=6). Three additional websites were added to the initial sample using snowball sampling. Thirty-seven IHI websites were evaluated in the final sample (Appendix E1 and Appendix E2, available at www.redjournal.org).

Quality was evaluated on a 5-point scale using the validated 15-question DISCERN instrument (10). Reviewers discussed the definitions (10) of DISCERN questions during 2 sessions before rating the websites. An overall quality metric was assigned to each IHI source using a previously described algorithm based on the individual DISCERN ratings (11). Accuracy was evaluated by comparing IHI with the best available or contextual evidence. Websites were also evaluated for authorship, attribution, disclosures, and currency using a checklist known as the JAMA benchmarks (12).

Statistical analysis

Data were analyzed using Stata/IC 10.0 (Stata Corporation, College Station, TX) and MAXQDA 10 (VERBI Software, Marburg, Germany). Percent agreement was evaluated with Spearman's rho. Quality was compared with the Kruskal-Wallis 1-way analysis of variance with Bonferroni correction. $P < .05$ was considered statistically significant.

Results

As shown in Table 1, the websites in our sample most frequently were patient information/support resources (46%), were focused exclusively on PBT (51%), and had a commercial affiliation (38%). Table 2 depicts the evaluation of websites according to the JAMA benchmarks. Most websites did not clearly identify authorship (n=21, 57%) or attribution (n=24, 65%). A small fraction of websites (n=5, 14%) did not disclose ownership, most of which were blogs (4/5).

Individual quality scores for each reviewer and the percent agreement are reported in Table 3. There was high percent agreement (73.0%) on the overall quality metric (Spearman's rho 0.68, $P < .01$). Most websites addressed uncertainties related to PBT only "partially" at best. There was also infrequent discussion of the consequences of no treatment. There was a significant difference in quality according to the type of IHI ($P = .04$) (Table 4). There was no association between the JAMA benchmarks and overall quality. Similarly, there was no association between the type of IHI and the JAMA benchmarks.

Substantial inaccuracies were noted in the study sample; representative statements are depicted, together with best available or contextual evidence, in Table 5. Most inaccuracies centered on the comparison of PBT with conventional x-ray therapy for PCa. Many such inaccuracies were noted on the websites in the study sample.

Discussion

Our findings suggest that most IHI related to PBT for PCa lacked transparency with respect to authorship and attribution. We found that many IHI sources did not adequately address

what would happen if no treatment were used, especially given that expectant management is a reasonable treatment option for many men with low risk PCa. Furthermore, very few patient information sites and blogs acknowledged areas of uncertainty such as a lack of comparative evidence evaluating PBT versus conventional x-ray therapies, such as IMRT, for PCa (13).

Our study is consistent with and extends previous studies that have evaluated the quality and accuracy of IHI. Ragagopalam and colleagues found that Wikipedia, a freely modifiable Internet encyclopedia, was comparable in accuracy to the National Cancer Institute's Physician Data Query cancer database as a source of cancer information for patients (14). In comparison with other IHI websites in our study sample, we also found that Wikipedia was of relatively high quality and accuracy (15). However, a systematic review by Esyebach and colleagues found that a majority of studies in their sample concluded that the quality of included IHI sources was variable (16). Furthermore, depending on the standard of evidence used, 15.4% to 38.3% of IHI sources were deemed inaccurate (16). Recently, analyses of cancer-related IHI sources, including those related to PCa (17), have raised questions about the appropriateness of information available to patients.

Nonetheless, the Internet is an accessible resource for PCa patients to obtain information on their diagnosis, treatment options, and prognosis. In a study of men aged <50 years with localized PCa who decided to undergo radiation therapy, the Internet was cited by 11.8% as the most influential factor in their decision making (compared with 3.5% of men who decided to undergo surgery) (18). However, the impact of IHI on patients' decisions whether or not to undergo PBT for PCa has not been studied. In our anecdotal experience, whereas a substantial proportion of patients report reviewing IHI related to PBT before their consultation, many seek a greater appreciation of the risks (ie, side effects) of PBT for PCa from IHI. In our study, despite 72.3% agreement on whether or not websites described the risks of PBT for PCa, none were thought to thoroughly discuss the risks (ie, DISCERN rating = 5) by both raters. Other studies of IHI related to PCa have also found potentially misleading discussion of the relative benefits versus harms of emerging therapies: Mirkin and colleagues recently found that 42% of IHI about robotic prostatectomy did not address the risks associated with surgery (17).

We acknowledge several limitations of our study. Google search results are dynamic and vary according to time and location (19). Thus, a search of the same terms can yield different results. In addition, though all ratings were completed during the same 5-day period to minimize the possibility of changes in content, websites and their substance change frequently. However, a repeat search based on the same strategy in August 2012 yielded largely consistent results in both content and order. Second, it is possible that reviewers differed in their interpretation of the DISCERN instrument. Although there was high percent agreement for most individual questions and the overall quality metric, we noted limited agreement on some items; post hoc discussion of these questions among the investigators revealed differences in interpretation of questions. Third, we opted not to evaluate readability because this study was limited to physician reviewers, although this is an important metric to consider for patients. Fourth, we conducted a qualitative evaluation of

accuracy. A quantitative assessment was not performed. Last, it is possible, though unlikely (20), that patients look beyond the first 50 search results.

In conclusion, the emergence of the Internet as a source of health information is an opportunity for providers to educate patients how to critically evaluate IHI. This is especially true with respect to IHI related to PBT for PCa. By encouraging patients to find credible IHI, providers have the opportunity to better inform medical decision making and strengthen their relationships with patients. We hope that our article, particularly the accompanying appendix, can be used a resource for patients with prostate cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Characteristics of prostate cancer websites (n=37)

Characteristic	n (%)
Focus	
Proton therapy exclusively	19 (51)
Prostate cancer	18 (49)
Affiliation	
University	13 (35)
Commercial	14 (38)
Nonprofit	4 (11)
Unknown	6 (16)
Type	
Patient information site	17 (46)
Blog	7 (19)
Scientific article	3 (8)
Newspaper	4 (11)
Other information site	6 (16)

Table 2
Evaluation of JAMA benchmarks (n=37)

Characteristic	Yes (%)	No (%)
Authorship: "Authors and contributors, their affiliations, and relevant credentials should be provided"	16 (43)	21 (57)
Attribution: "References and sources for all content should be listed clearly, and all relevant copyright information noted"	13 (35)	24 (65)
Disclosure: "Web site 'ownership' should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support, or potential conflicts of interest. This includes arrangements in which links to other sites are posted as a result of financial considerations. Similar standards should hold in discussion forums"	32 (86)	5 (14)
Currency: "Dates that content was posted and updated should be indicated"	22 (59)	15 (41)

Benchmark definitions adopted from Silberg et al (12).

Table 3
Evaluation of quality

Question	Reviewer A, median (IQR)	Reviewer B, median (IQR)	Agreement (%)
Are the aims clear?	4 (3, 5)	4 (3, 5)	79.7
Does it achieve its aims?	4 (3, 4)	3 (3, 4)	81.1
Is it relevant?	4 (3, 4)	4 (3, 5)	83.1
Is it clear what sources of information were used to compile the publication (other than the author or producer)?	3 (2, 4)	3 (2, 5)	78.4
Is it clear when the information used or reported in the publication was produced?	4 (3, 4)	4 (2, 5)	74.3
Is it balanced and unbiased?	4 (2, 5)	4 (2, 4)	81.8
Does it provide details of additional sources of support and information?	4 (3, 4)	3 (1, 4)	66.9
Does it refer to areas of uncertainty?	3 (2, 4)	1 (1, 3)	73.7
Does it describe how each treatment works?	4 (3, 5)	3 (1, 4)	64.9
Does it describe the benefits of each treatment?	4 (4, 4)	3 (3, 3)	68.2
Does it describe the risks of each treatment?	4 (3, 4)	2 (2, 3)	72.3
Does it describe what would happen if no treatment is used?	2 (1, 3)	1 (1, 3)	85.1
Does it describe how the treatment choices affect overall quality of life?	3 (3, 4)	2 (1, 3)	66.9
Is it clear that there may be more than 1 possible treatment choice?	4 (3, 5)	3 (1, 5)	68.2
Does it provide support for shared decision-making?	3 (2, 4)	1 (1, 1)	54.5
5-star DISCERN quality rating (11)	4 (3, 4)	3 (2, 3)	73.0

Abbreviation: IQR = interquartile range.

Evaluation according to DISCERN (10).

Table 4
Quality comparison by type of IHI (n=37)

Item	Overall quality <4 stars n (%)	Overall quality 4 stars n (%)	
Patient information/support website	12 (71)*	5 (29)	
Blog	7 (100)	0 (0)	
Scientific article	0 (0)	3 (100)	
Newspaper/magazine	3 (75)	1 (25)	
Other news/information website	4 (67)	2 (33)	
Total	26 (70)	11 (30)	<i>P</i> =.04

Abbreviation: IHI = Internet health information.

* Row percentages are depicted.

Comparison by DISCERN 5-star rating (11).

Table 5
Examples of accuracy comparison of IHI (limited to Google search results) versus published best available evidence

Google page rank	URL	Statement from cited Internet health information website	Best available evidence
1	http://www.prostateblog.com/?cat=1&paged=4	"I believe that a comparison randomized clinical trials after 50,000 or so have already been treated worldwide with protons, is simply a political decision with the heat coming from those doctors who do not have the proton capability or have a treatment stake driven in other treatments and do not want buy this capability."	Multiple organizations, such as the Agency for Healthcare Research and Quality, National Cancer Institute, Centers for Medicare & Medicaid Services, and Institute of Medicine have encouraged a randomized controlled trial to evaluate the relative benefits versus harms of PBT for PCa.
2	http://www.protons.com/proton-therapy/conditions-treated/prostate-cancer/advantages.html	"Proton therapy for prostate cancer differs from other popular cancer treatment options in that it is... more accurate than other kinds of radiation, allowing the physician to deliver full or higher doses while sparing surrounding healthy tissues and organs"	Uncertainties in proton range and PBT planning and delivery are important to appreciate and may impact PBT accuracy. As with other forms of radiation therapy, PBT is associated with side effects related to damage to healthy tissues and organs. For example, PBT for PCa is associated with urinary, bowel, and sexual side effects.
14	http://www.ewhow.com/way_5498703_proton-prostate-cancer-treatments.html	"Since 2001, proton therapy has proven to be the most effective treatment available for prostate cancer that has not metastasized"	Randomized trials have yet to compare surgery, IMRT, PBT, brachytherapy or expectant management for prostate cancer; therefore, no treatment has been proven to be more effective.
44	http://enidnews.com/localnews/x636374092/Waukomis-man-conquers-prostate-cancer-using-proton-therapy-in-OKC	"A highly sophisticated form of radiation therapy, proton therapy is so precise to the exact target area—that damage to	Both PBT and standard radiation therapy (ie, with x-rays) entail beams of radiation traversing normal, healthy tissue. Consequently, as with other forms of radiation therapy, PBT is associated with side effects

<http://www.floridaprostate.com/protonbeam.html>

Abbreviations: IHI = Internet health information; PBT = proton beam therapy; PCa = prostate cancer; URL = uniform resource locator.