

## Misinformation on the Internet regarding Ablative Therapies for Prostate Cancer



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### OBJECTIVE

To evaluate the quality of web-based information on ablative therapies for prostate cancer.

### METHODS

The 2 most common search engines (Google and Bing) were queried for the following terms: “prostate cancer” + “HIFU” and “cryotherapy,” respectively. The top 50 websites for each were obtained. Websites were characterized and analyzed regarding their accuracy and completeness of information using criteria determined a priori. Academic papers were excluded.

### RESULTS

Of “HIFU” search results, 17% were advertisements, 13% and 29% were academic and private practice websites, respectively. Erroneous information on oncological efficacy was presented in 15% and 41% of academic and private practice websites, respectively. Criteria for treatment were mentioned in 31% and 66% of academic and private practice websites, respectively. Of “cryotherapy” search results, 18% were advertisements, 15% academic sites, and 11% private practices. Erroneous information was presented in 73% of both academic and private practice websites. Criteria for treatment were mentioned in 27% and 18% of these sites, respectively. Seventy eight percent and 75% of HIFU and cryotherapy sites, respectively, mentioned general side effects.

### CONCLUSION

There is substantial inaccurate and incomplete information on the Internet regarding ablative treatments for prostate cancer from academic and private practice websites. Selection criteria are uncommonly discussed. More attention to accuracy of information is needed to ensure patients are not misled about the data behind these treatments. UROLOGY 133: 182–186, 2019. © 2019 Elsevier Inc.

The Internet serves as a major source of medical information for the general public. A national telephone survey revealed that of the 74% of adults who use the Internet, 80% solicit medical information.<sup>1</sup> The quality or reliability of information on the web, however, varies widely. Urology has been susceptible to this problem—prior work has shown that there is substantial misinformation on the web regarding robotic prostatectomy and cystectomy.<sup>2,3</sup> This is problematic, as men may rely on electronic information to augment knowledge from their providers, or guide them to specialty providers in the first place. For men with newly diagnosed prostate cancer, this problem may be particularly significant given the lack of uniform standards of care and varied perspectives on best treatments.<sup>4,5</sup> This creates a space that the Internet can fill with information or misinformation.

Ablative treatments for prostate cancer have received increased recent attention due to a growing concern for side

effects of “radical therapy” and concern for overtreatment. High intensity focused ultrasound (HIFU) and cryotherapy are subtypes of focal therapies—HIFU involves concentrating strong ultrasound waves onto a discrete focal point, causing coagulative necrosis and tissue destruction,<sup>6,7</sup> while cryotherapy utilizes freezing to cause coagulative necrosis through cell rupture, apoptosis, and ischemia.<sup>8,9</sup> HIFU received Food and Drug Administration approval for prostate tissue ablation (not cancer specifically) in October 2017 through 2 companies, SonaCare Medical (Sonoblate 450) and EDAP TMS (Ablatherm technology).<sup>4,10</sup> Focal cryotherapy also remains investigational, although there is an approved indication for whole gland cryotherapy.<sup>4,11-13</sup> It is important to note that the Food and Drug Administration approves technologies for certain indications, but does not regulate the use of focal therapy in general, as this is considered more the practice of medicine, which is outside of their scope. American Urological Association (AUA) Guidelines state that cryotherapy might be considered for low risk disease, and HIFU and focal therapies should only be considered within clinical trials.<sup>4</sup> Notably, low risk patients are a shrinking subcategory of diagnosed patients given less screening and more stringent criteria for biopsy.<sup>14</sup> Another focal tissue ablative therapy utilized for prostate

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cancer is the Nanoknife, an irreversible electroporation method which uses pulsed, low energy direct current, leading to cell apoptosis by the formation of nanopores within the cell membrane.<sup>15</sup> The Nanoknife is used for the ablation of several other cancer types as well.<sup>15</sup> In a prospective study by Valerio et al, genitourinary functional preservation appeared to be high with the Nanoknife, although disease control appeared to be lower compared to thermal ablative methods.<sup>15</sup> Focal laser ablation or laser interstitial thermal therapy, is another ablative therapy that locally heats the prostate via a fiber coupled infrared laser.<sup>16,17</sup> This technology removes tissue through coagulative necrosis and can be performed without general anesthesia.<sup>17</sup>

In the clinic, we have noted both increasing interest in ablative therapies for prostate cancer, and also incomplete or misinformation obtained by patients through personal research, including on the Internet. Thus, we sought to evaluate the accuracy of web-based information on HIFU and cryosurgery, with the hypothesis that a substantial amount would be inaccurate or misleading.

## METHODS

In August 2018, the 2 most common search engines (Google and Bing) were queried for “prostate cancer” + “HIFU” as well as “prostate cancer” + “cryotherapy.” The top 50 websites for each paired search were obtained. Each search was performed on a single day by one of 3 researchers. Websites were characterized according to source type: advertisement, provider site, academic center, private practice, patient support group, medical news site, society meeting, or industry. A rubric for evaluating completeness and accuracy was created prior to review of websites. Accuracy was determined by comparison to AUA Guidelines and existing peer reviewed data. Accuracy was also assessed in 3 domains: oncological, functional outcomes, and other morbidity. Completeness was measured by the mention of specific side effects, and indications for ablation. Search results that linked to academic papers were excluded.

## RESULTS

Table 1 summarizes the type of websites each search yielded on the Google and Bing platforms, respectively. Among HIFU results, 17% were advertisements, 13% and 29% were academic and private practice websites, respectively, and 24% were patient support websites. Among cryotherapy results, 18% were advertisements, 15% and 11% were

academic and private practice websites, respectively, and 10% patient support websites.

Among HIFU searches, erroneous information related to oncological efficacy was presented in 15% and 41% of academic and private practice websites, respectively. Selection criteria for treatment were mentioned in 31% and 66% of academic and private practice websites. Among cryotherapy searches, erroneous information was presented in 73% of both academic and private practice websites. Selection criteria for treatment were mentioned in 27% and 18% of academic and private websites, respectively. Some false/misleading statements from websites included the following:

*“In general, cryotherapy is suitable for patients with disease severity ranging from low, intermediate to high risk.”*

*“Cryotherapy predictably preserves urinary continence and erectile function.”*

*“Studies show cryotherapy is effective alternative to surgery and RT especially for patients in their 60s and 70s.”*

*“All side effects are temporary.”*

*“Cryosurgery is as effective as surgery or radiation for low-risk, early-stage prostate cancer.”*

Although cryotherapy and HIFU are available alternatives for prostate cancer treatment in select patients, few websites discussed the fact that these focal therapies are not standard of care options due to the lack of comparative evidence against standard of care options.

Table 2 summarizes the disclosure of side effects for each ablative therapy. Side effects were mentioned at relatively high, similar rates for HIFU and cryotherapy, respectively. 25%-30% of sites did not mention the potential morbidity of treatment.

There was distinction between whole gland and partial ablation/focal therapy in 61% of the sites. Among cryotherapy search results, 18% were advertisements. Twenty five percent of the cryotherapy searches mentioned partial ablation. Seventeen percent of the HIFU searches were advertisements. Thirty nine percent of the HIFU searches mentioned partial ablation. Figure 1 in the appendix outlines the various criteria used to grade each website. Our team, using statements made in the AUA guidelines as a benchmark, developed the grading rubric.

## DISCUSSION

There has been longstanding interest in understanding how the public utilizes health information on the Internet. In 2001, the National Cancer Institute initiated the

**Table 1.** Characterization of websites for HIFU and cryotherapy search terms

Search Term	Search Engine	Ad	Academic Center	Private Practice	Patient Support Site	Medical News Site	Society Meeting	Industry	Other
“Cryotherapy”	Google	9	5	6	5	4	0	5	19
	Bing	9	10	5	5	1	0	5	12
	Total	18	15	11	10	5	0	10	31
	Final %	18%	15%	11%	10%	5%	0%	10%	31%
	“HIFU”	Google	10	8	9	7	5	2	6
	Bing	7	5	20	9	3	2	4	1
	Total	17	13	29	16	8	4	5	3
	Final %	17%	13%	29%	16%	8%	4%	10%	3%

**Table 2.** Side effects of HIFU and cryotherapy on Internet searches

	HIFU	Cryotherapy
General side effects*	78%	75%
Urinary morbidity	78%	70%
Erectile dysfunction	77%	74%

\* Side effects included erectile dysfunction, rectal pain, urinary incontinence, and urinary retention.

biannual Health Information National Trends Survey including over 6000 respondents, that revealed that 64% seek medical information online, even if they view their physicians as trusted sources.<sup>18,19</sup> Diaz et al, in a study of about 1000 patients, showed that more than 50% used the Internet for medical information, with a majority feeling that this information was “the same as” or “better than” information from their doctors.<sup>20</sup> Finally, Baker et al reported, in a national survey of about 60,000 patients, that 40% of respondents used the Internet for health information, and this information influenced medical decision making for about one-third.<sup>21</sup> Further evidence shows that the Internet is a significant source of cancer-related information; in 1 study, the Internet was the first choice for cancer information in 38.9% of persons aged 18-34 and 46.6% in those aged 35-64.<sup>19</sup> Overall, only 10.9% of people reported going to their physicians as the first source of information.<sup>19</sup> Smith et al reported that 32% of prostate cancer patients utilized the Internet as a source of information gathering.<sup>22</sup>

	Advertisement	Academic	Private Practice	Provider site	Patient support site	Total
<b>Website Type</b>						

	Medical news site	Society meeting	Industry	Other	Total
<b>Website Type</b>					

	Mention patient selection by risk level	Mention use as primary treatment	Mention of use as salvage treatment	Mention partial ablation	Mention of clinical trials	Total
<b>Patient Selection</b>						

<b>Accuracy of Technology Information</b>	Evidence Based Only	Erroneous Only	Both Evidence Based and Erroneous information presented	Total
<b>Oncologic Functional Morbidity</b>				

	Mention side effects generally	Mention Erectile Dysfunction	Mention urinary morbidity (e.g. retention, irritative symptoms)
<b>Side Effects</b>			

**Figure 1.** Grading rubric for websites. “0” for no, “1” for yes.

Against this backdrop, we evaluated the accuracy and completeness of information obtained via web searches for HIFU and cryotherapy. While these therapies have been available for some time, there has been a recent surge of interest based on concern for the side effects of “radical therapies.” We have anecdotally observed more frequent queries regarding ablation, and patients often present or share information obtained on the Internet. We have observed that patients typically do not understand that these interventions are generally considered investigational (HIFU) or not first line (cryotherapy) for treatment of prostate cancer in the United States, and furthermore might be applied only to a subset of cancers.<sup>4</sup> This provoked our interest in evaluating information on the Internet that is available to men and their families in their informal research.

We confirmed our hypothesis that there was considerable misinformation regarding the role of ablative therapies. It was uncommon for websites to indicate that these should be considered for low risk disease, and in that HIFU is investigational for treatment of prostate cancer. Furthermore, there was inaccurate information regarding oncological effectiveness, which risks giving patients false expectations. We did find that there was a relatively common discussion of side effects, which was encouraging. Overall, our findings demonstrate that patients are likely to encounter misinformation, which can set unrealistic expectations and potentially encourage inappropriate care.

It is important to acknowledge that ablative therapies are not necessarily ineffective or inappropriate, but at present have narrow indications. AUA guidelines for treatment of localized disease synthesized the evidence for ablative therapies and reported the following: For low and very low risk prostate cancer, whole gland cryosurgery has not shown survival benefits compared to active surveillance; also, focal therapy or HIFU are not considered standard of care due to lack of comparative outcome evidence.<sup>23</sup> For intermediate risk prostate cancer, select patients may consider cryosurgery as a conditional recommendation; focal therapy or HIFU are not standard care options. Finally, the aforementioned therapies are not recommended for men with high-risk localized prostate cancer outside of a clinical trial.<sup>23</sup> Further research into the role of these treatments is worthwhile, to determine if a subset of men with lower risk disease may benefit. However, substantial work is needed to clarify appropriate oncological outcomes, and follow men more longitudinally. There is sufficient evidence to propel this type of study forward, for example, some evidence of long term “cancer control” in men with low and intermediate risk prostate cancer undergoing HIFU.<sup>7,24</sup> There is also data that selected men achieve similar long-term survival with cryotherapy vs other treatments for varied risk levels of prostate cancer.<sup>11,12</sup> However, declarative statements of the effectiveness of these treatments and lack of acknowledgment of uncertainties and alternative options are inappropriate at this time.

In addition to the expected search results from academic and private practice group, 18% and 10% of results

included advertisements and industry-direct to consumers, respectively, for cryotherapy. Similarly, 17% and 10% of results were advertisement and industry-direct to consumers, respectively, for HIFU. These results were often at the top or bottom of the search results, in an apparent effort to draw attention. We noticed that it may be hard to distinguish a clinical site from an industry-sponsored site, and this may influence the nature of the content that people view.

Surprisingly, there was a relatively high rate of reporting side effects of therapy, including urinary retention, erectile dysfunction, stress incontinence, and rectal pain.<sup>7,25,26</sup> There was a similar rate of discussion of these risks for both HIFU and cryotherapy. These findings were encouraging, though approximately one in 4 sites did not mention morbidity.

## LIMITATIONS

There are several limitations to our study. Search engines typically gather “hits” based on geographic location. Therefore, as the searches in this study were completed in New York City, results may differ from searches in other parts of the United States. Local medical resources also vary across the country, which may drive the presence of websites and advertising in different geographic regions. Also, those searching for these therapies may link to other websites through other search terms, or use other search engines, that may yield different results. Finally, these websites typically serve as an initial or as supplemental resources for men contemplating options, which may in the clinical setting receive actual shared decision-making. However, as this may not happen, and as first impressions can linger, we do believe that the quality of information on the Internet needs to improve.

## CONCLUSION

There is substantial inaccurate and incomplete information on the Internet regarding criteria for and outcomes of ablative therapies for prostate cancer. More attention to accuracy and completeness of information is needed to ensure patients are not confused and misled about the data behind and their eligibility for these treatments. As urologists and healthcare providers, we should continue to counsel our patients accordingly so as to decrease the burden of ineligible patients in the healthcare system.

## SUPPLEMENTARY MATERIALS

Supplementary material associated with this article can be found in the online version at <https://doi.org/10.1016/j.urology.2018.12.050>.

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## EDITORIAL COMMENT



The Internet is a go-to resource for most Americans. Based on the findings of the Pew Internet Project, looking up health information is the third most common use of the Internet following e-mail and search engine use.<sup>1</sup> While there are many advantages of the Internet as a source of health information, health-related websites may also be misleading or misinterpreted, which can compromise health behaviors and health outcomes, or result in inappropriate requests for clinical interventions, which can reduce time efficiency and strain the physician-patient relationship.<sup>2</sup> This study reported that erroneous information on the oncological efficacy and criteria for treatment of both high intensity focused ultrasound and cryotherapy for the treatment of prostate cancer was prevalent in both academic and private practice websites. What is particularly alarming about these websites is they are assumed to be endorsed by medical professionals and they are thereby relied on as trusted sources of information not only by patients, but also other health care professionals who may not be knowledgeable about the particular subject matter, thus perpetuating further confusion.

Although the motivations of the creators and owners of these websites vary, it is assumed that one reason is to advertise that a practice offers an alternative treatment option for prostate cancer. If one of the primary aims of this type of direct to consumer advertising campaigns is to increase market share and profit rather than enhance well-being,<sup>3</sup> these sites may cause a patient to fail to consider all available treatment options or fail to provide a patient with comprehensive information on potential

adverse effects. Furthermore, this can have implications on value-based care as current health care strategies are interested in treatments that promote the best patient outcomes while driving down costs.

High-quality health care involves core commitments to safety, effectiveness, patient-centeredness, and equity,<sup>4</sup> which are linked to the basic ethical principles of respect for persons, beneficence, nonmaleficence, and justice. Another important ethical consideration is the need for disclosing conflicts of interest as the lack thereof can intentionally or unintentionally introduce bias into information disclosed to the public. Providers of online health information should ensure their websites adhere to ethical standards. As health care professionals, we have an ethical obligation to share accurate health information, promptly correct false or misleading health information, and direct people to reliable sources of health information. The National Institutes of Health has compiled some useful questions that can be asked to help assess credibility and accuracy of a website (ie, Who is responsible for the content on the site? Who/What pays for the site? Is there research to support information on the site? When was the material written or compiled?).<sup>5</sup>

Given the large number of health-related websites, the ease with which sites can be created and assessed and the high number of those who rely and trust such information, the medical community needs to come up with ways to further improve the quality of online health information.

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