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Complementary and Alternative Medicine and Supportive Care at Leading Cancer Centers: A Systematic Analysis of Websites

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Abstract

Background: With increasing frequency, patients with cancer and their family members are turning to the Internet to educate themselves about their disease and treatment options, including complementary and alternative medicine (CAM) and supportive care. However, very little is known about how national leading cancer centers represent these therapies via their websites.

Methods: Simulating the perspective of an information-seeking patient or family member, we performed a systematic analysis of the websites of 41 National Cancer Institute designated comprehensive cancer centers. Two researchers independently evaluated websites, recorded CAM information, and rated quality of the websites using a 4-item Likert scale (overall, information, presentation, and navigation) with Cronbach's $\alpha = 0.97$. Rating was adequately correlated between the two raters (correlation coefficient 0.8).

Results: Of 41 centers, 12 (29%) did not have functional websites with regard to information related to CAM. The most common CAM approaches mentioned were: acupuncture (59%), meditation/nutrition/spiritual support/yoga (56% for each), massage therapy (54%), and music therapy (51%). Twenty-three (23; 56%) presented information on support groups, 19 (46%) on patient seminars, 18 (44%) on survivorship effort, and 17 (41%) on symptom management clinics. Twenty-nine (29) (71%) of these websites had a telephone number available, 22 (54%) mentioned at least one ongoing research opportunity, and 19 (46%) provided links to the National Center for Complementary and Alternative Medicine website. Median rating of the quality of websites was 50 of 100, with only 7 (17%) of centers receiving a composite score 80 (excellent) or better.

Conclusions: While a growing number of leading cancer centers provide information about CAM and supportive oncology information for patients via their websites, the quality and ease of navigation of these sites remain highly variable. Effective development and redesign of many of the websites is needed to better inform and empower patients and families seeking CAM and supportive care information.

Introduction

Patients with cancer use complementary and alternative medicine (CAM) extensively.[1] Such use is often associated with experiencing greater symptom distress, a desire for spiritual transformation, or unfulfilled needs from the existing health care system.[2,3] Although limited, several types of CAM approaches such as acupuncture, massage, and mind–body medicine have found to be beneficial for these patients in terms of symptom management and quality of life.

The Internet, an important aspect of modern life, has become a powerful tool utilized by patients in search of medical information. Existing literature suggests that available CAM information on the web is often inaccurate and may even be fraudulent.[4] One study found that 41 inaccurate statements were made on 18 popular breast cancer web pages.[5] Additionally, it has been demonstrated that 25% of 150

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herbal information websites contained information that could lead to direct physical harm if acted upon.[4] In a specific examination of breast cancer information websites, it was noted that those that had CAM information were more likely to contain inaccurate information.[6] Thus, providing accurate Internet resources for CAM is necessary for effective utilization of these therapies and to safeguard patients from potential harm and financial exploitation.

In response to increasing patient demand, a growing number of cancer centers have developed an integrative oncology initiative. The formation of the Society for Integrative Oncology further brings academicians, researchers, and clinicians of both CAM and conventional medicine together to integrate their practice of medicine.[7] Despite this effort, no study in the existing literature has examined how cancer centers, specifically via their websites, are addressing cancer patients' interest in CAM. Thus, we conducted a systematic analysis of all of the National Cancer Institutes (NCI) designated cancer centers, with the following goals in mind: To determine the frequency of specific CAM services and educational activities described and to evaluate the specific and overall quality of website information, presentation, and navigation.

Methods

We conducted a systematic analysis of websites of the 41 NCI-designated cancer centers to evaluate the type of CAM content and services provided at these centers between January 2008 and September 2008. Two researchers (J.B. and A.E.) independently evaluated these websites. Five (5) cancer centers were chosen as pilots to check for inter-rater reliability. Differences in rating were then discussed among J.B., A.E., and J.M. to reach consensus. J.B. and A.E. then independently rated all the cancer centers with an inter-rater reliability of 0.80. We recognize that the websites are regularly being updated and upgraded, and that these sites were evaluated over three different time frames within a 6-month period (February 2008–August 2008). Any changes in the interim were updated in the final database for analysis.

Criteria for evaluation of content

We approached this study from the perspective of an information-seeking patient or family member attempting to access CAM services or learn about educational opportunities at a particular cancer center. Evaluation included accessibility (is there a CAM website, and if so, is there a telephone number available to access such services?). Also, given that the National Center for Complementary and Alternative Medicine (NCCAM) and NCI's Office of Cancer Complementary and Alternative Medicine (OCCAM) are recognized government entities for dissemination of authoritative information on CAM services and products, we sought to determine whether cancer center websites provided a direct link to these two websites.

Specific types of CAM services searched for were identified based on published literature and well-known integrative oncology centers. In addition, we included conventional supportive oncology approaches such as symptom palliation, support groups, and survivorship programs in our search. Last, we attempted to identify academic pursuits of these centers via evidence of ongoing research as well as educational opportunities for patients.

Rating of websites

We used a 5-point Likert scale (1 poor, 5 outstanding) to rate the websites. Those without websites received a 0 for all categories. Websites were rated for overall quality, as well as the quality of information, presentation, and navigation. The arithmetic mean of the scores was calculated and then converted to a 100-point scale. The average scores of the two raters were used as the final rating.

Analyses

We performed appropriate descriptive analyses such as distribution, median, mean, and proportion. We conducted bivariable analyses to explore whether the overall ranking of the cancer center or geographic location of these centers were related to the quality of the websites; however, we did not find any significant findings and thus, the results are not included in this report.

Results

Of the 41 NCI-designated comprehensive cancer centers, 12 (29%) did not have functional websites with regard to CAM information. Nineteen (46%) websites provided links to the NCCAM site, while 5 (12%) websites provided links to the NCI's OCCAM site. Telephone numbers were available on 29 (71%) of these websites. Twenty-two (22; 54%) mentioned at least one ongoing research opportunity, and 19 (46%) provided patient educational seminars. Conventional supportive oncology approaches mentioned on the websites included support groups (56%), survivorship efforts (44%), and symptom management clinics (42%).

The specific CAM therapies mentioned on these websites included the following: acupuncture (59%), meditation/nutrition/yoga/spiritual counseling (56% for each), biofeedback/massage (54% for each), music therapy (51%), art/exercise (46% for each), guided imagery/herbs (44% for each), dietary supplements (42%), *t'ai chi* (38%), Reiki (37%), hypnosis (32%), Ayurveda/healing touch (29% for each), and *qigong*/dance (27% for each) (Table 1).

Median rating of the quality of websites was 50 of 100, with only 7 (17%) of the centers achieving a score of 80 (excellent) or above in the composite score. In specific categories, a greater number of centers received a score of "excellent" or better: 15(37%) for navigation, 12 (29%) for information, and10 (24%) for presentation.

Discussion

The growing use of the Internet as a tool for patient research requires the establishment of a standard of quality for the medical web information provided. This is particularly important and relevant for CAM in patients with cancer and their care. Although studies have examined popular websites and other reliable Internet resources for CAM,[8,9] to the best of our knowledge, our study is a novel endeavor to offer insight into how cancer centers provide information on CAM

Table 1. Complementary Therapies Mentioned on the Websites ($N = 41$)

Complementary therapies	N	*(%)*
Whole medical systems		
Ayurveda	12	(29.3%)
Acupuncture	25	(58.6%)
Biological		
Dietary supplements	17	(41.5%)
Herbs	18	(43.9%)
Nutrition	23	(56.1%)
Mind–body		
Hypnosis	13	(31.7%)
T'ai chi	15	(37.5%)
Guided imagery	18	(43.9%)
Biofeedback	22	(53.7%)
Meditation	23	(56.1%)
Yoga	23	(56.1%)
Manipulative		
Massage	22	(53.7%)
Energy		
Qigong	11	(26.8%)
Healing touch	12	(29.3%)
Reiki	15	(36.6%)
Other		
Dance	11	(26.8%)
Art	19	(46.3%)
Exercise	19	(46.3%)
Music	21	(51.2%)
Spiritual counseling	23	(56.1%)

therapies for their patients through their websites. The 41 NCI-designated comprehensive cancer centers offer information of extremely variable quality, and nearly a third do not contain any CAM-related information at all.

Previously published data have shown that anywhere from 8% to 50% of patients with cancer use the Internet to learn about cancer therapies.[10] Unfortunately, too often they have negative experiences in doing so. A survey study of patients with breast cancer found that 31.7% of respondents expressed negative opinions about websites they visited, compared to 23.8% positive opinions.[11] In particular, these patients found it difficult to process the detailed medical information provided, and second, they found that the sites were not particularly easy to navigate. Our findings support these concerns, with only 37%, 29%, and 24% of the websites we reviewed receiving a score of "excellent" or better for navigation, information, and presentation, respectively.

The 41 NCI-designated comprehensive cancer centers are considered leading cancer centers in the United States and as such are expected to provide the highest quality of care and outreach to their patients. This should be extended to include offerings available at the centers as well as online, and include conventional as well as CAM modalities. These leading centers are to serve as examples for other national and local cancer centers, and have been selected for review in our study for this purpose. However, our study found a high degree of variability in the quality of information provided. Furthermore, close to a third of such centers did not have functional websites, which could have made their patients' efforts to obtain information particularly challenging and frustrating.

It is important to acknowledge the limitations of this study. The Internet is a constantly evolving environment, and therefore we are only reporting on the existing status of web information at the time of evaluation, not necessarily by the time of publication of this report. Although we intended to approach our research from a patient's perspective, we are not patients. A follow-up study using real patients of diverse socioeconomic and cultural backgrounds may help gain further insight and perspective. Our research focuses on the arrangement and provision of information. We acknowledge the subjectivity involved in this aspect of evaluation, and it is possible that some centers do provide beneficial services that are not reflected via their websites. Still others have user-friendly websites but lacked concrete clinical or educational programs for their patients. Last, we were likely to spend more time and effort in search of information during this research process than that of an average patient with cancer or their family, and therefore may have found information that would not be discovered during a more cursory search.

Even with acknowledging these limitations, we still found that almost a third of leading U.S. cancer centers do not have functional websites related to CAM, and only a small proportion of the centers had websites independently judged to be excellent. Developing reliable and user-friendly Internet resources is critical in providing information and guidance for the safe and effective use of CAM among patients with cancer.

Disclosure Statement

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