



Anthony Droegge. *You Can't Judge a Book...*(detail). Oil on board, 33" × 47".  
Courtesy of Longstreth-Goldberg ART, Naples, Florida.

*Limited empirical research is available that focuses on the use of the Internet for health information among racial/ethnic populations and low literacy groups.*

# Internet Use for Cancer Information Among Racial/Ethnic Populations and Low Literacy Groups

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*Many Web sites on the Internet offer health information related to cancer and are increasingly being used by patients, caregivers, and those interested in cancer prevention and treatment. To comprehensively review the cancer literature regarding Internet health information use among those of racial/ethnic populations and low literacy groups, a comprehensive review of the MEDLINE/Pre-MEDLINE, LISA, PsycInfo, CINAHL, Embase, and Web of Science databases was conducted. Eight relevant articles were retrieved: seven are classified as content research and one as outcomes research.*

*Little empirical research exists on this topic of cancer Internet health information use among those of racial/ethnic populations and low literacy groups. This area of research is open for many unique contributions to the scientific literature.*

## Introduction

New technology in the form of Internet use has begun to impact the healthcare environment, as patients are increasingly using it for both a source of information and psychological support. As recent as

a few years ago, a 1997 survey in the United States found that nearly half of Internet users spent some time looking for health information on the Internet.<sup>1</sup> In 2000, 41 million individuals sought health information online,<sup>2</sup> while in July 2003, almost 125 million individuals in the United States accessed the Internet for general (ie, not exclusively health) use.<sup>3</sup>

A United States government report published in 2001<sup>4</sup> studied Internet users above 18 years old (n = 1,135) and concluded that African Americans and Hispanic Americans used the Internet less often than whites. Asian Americans, Pacific Islanders, American Indians, and other racial groups did not differ from whites regarding their Internet use. To the author's

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knowledge, no further government reports discuss this Internet use occurring over the past few years, while Internet use has increased among the overall United States population.

Cancer is one of the top three diseases about which the public seeks information on the Internet,<sup>5</sup> and 9.5 million individuals in the United States sought cancer information online in 2002.<sup>6</sup> Forums, chat groups, and listservs are proliferating with topics available for many types of cancers and other diseases. This is especially important for individuals who are seeking information and support regarding rare diseases. For example, the International Rare Disease Support Group Network offers numerous links for support groups on many rare diseases.<sup>7</sup> Also, organizations such as the W3C Web Accessibility Initiative<sup>8</sup> are trying several different approaches for content and design to facilitate access to Web sites for those with disabilities. Among a variety of cancer information sources sought by 654 prostate cancer patients, 45% (n = 295) used the Internet for their information.<sup>9</sup>

The Internet has the potential to provide psychological benefits, especially with regard to social support, to those who use it for health information. A recent report showed that breast cancer patients using the Internet for health information had greater social support and less loneliness than those who did not use the Internet for health information.<sup>10</sup> Recommending use of the Internet may be important for those clinicians who as part of their treatment goals focus on improving the social support of their patients.<sup>11</sup> From a healthcare perspective, survivorship<sup>12-14</sup> (because of the increased rates of mortality) and social support<sup>15-18</sup> (because of its impact on stress reduction and possibly survivorship) have been shown to be areas of great importance for racial/ethnic populations with cancer. Further, providing information that appeals to Internet users of varied literacy skills is key to ensuring that information is understood and has the potential to be utilized.

The Internet is clearly impacting the current healthcare environment, yet how does it relate to cancer information with regard to racial/ethnic populations and low literacy groups? This paper addresses these two categories above, and the comprehensive review will be applied to individuals using the Internet for cancer information, whether they or their loved ones currently have cancer or are seeking information for cancer prevention.

The main research question guiding this review is to determine if there is any empirical research on the topic of Internet cancer information use among those of racial/ethnic populations and low literacy groups. Some a priori questions of interest include the following: Are there empirical studies on the culturally relevant cancer information on the Internet?

Do cancer patients from racial/ethnic populations use the Internet? Do cancer patients with low literacy skills use the Internet? Does Internet information provide enhanced survivorship and/or social support to those from racial/ethnic populations and low literacy groups?

## Method

### *Inclusion and Exclusion Criteria*

All inclusion and exclusion criteria were done a priori before conducting the database searches. Studies were included if (1) they presented empirical data (either qualitative or quantitative methods) discussing Internet use of health information published on the World Wide Web among those of racial/ethnic population and low literacy groups in North America, (2) they contained information about cancer or prevention of cancer, or (3) they included World Wide Web materials for consumers/patients or for both consumers/patients and healthcare professionals.

Studies were excluded if (1) they were theoretical articles, (2) they contained anecdotal information, (3) they were from non-peer-reviewed journals, (4) they studied other Internet uses besides health information (eg, e-mail, list-servs), or (5) they contained Internet information intended for healthcare professionals (eg, training, continuing education).

### *Search Strategy*

On July 24, 2003, a variety of databases were searched for all of the relevant studies. The search strategy below consisting of three sets of terms was included in each search. All terms were searched in the subject heading and also as text words. The search strategy used was as follows: (Internet OR web OR www. OR www OR cyber\* OR cyber) AND (cancer OR neoplasms OR cancers OR neoplasm OR neoplast\* OR oncology OR metasta\* OR metastatic OR neoplastic OR neoplast) AND (culture OR ethnic OR race OR racial OR black OR blacks OR African OR Africans OR African American OR African Americans OR Hispanic OR Hispanics OR Hispanic American OR Hispanic Americans OR Latino OR Latinos OR Latina OR Latinas OR Asian OR Asians OR Asian American OR Asian Americans OR Indian OR Indians OR North American OR North Americans OR racial/ethnic OR literacy OR cultural diversity OR diverse OR cross-cultural OR cross-cultural comparison OR attitude to health/ethnology OR ethnology OR health behavior/ethnology).

Databases searched included MEDLINE and Pre-MEDLINE (1966-July 2003) using the PubMed inter-

Table 1. — Database Search Results for Cancer Internet Information Use Among Those of Racial/Ethnic Populations and Low Literacy Groups

Database	Hits	No. of Relevant Articles*	References
MEDLINE/Pre-MEDLINE	100	6	19-24
LISA	2	0	
PsycInfo	6	3	20, 22, 23
CINAHL	182	4	20, 22, 24, 25
Embase	36	3	20-22
Web of Science	70	5	20, 21-23, 26

\* Only 8 unique articles met the stated criteria.

face, LISA (Library and Information Science Abstracts Database; 1969-July 2003) using Webspirs, PsycInfo (1887-July 2003) using Ebsco, CINAHL (1982-July 2003) using Ebsco, Embase (1980-July 2003) using OVID, and Web of Science from the Institute for Scientific Information including searching all three databases of the Science Citation Index, Social Sciences Citation Index, and Arts and Humanities Citation Index (1945-July 2003). Finally, a search was done by reading the relevant articles to determine if there were any other significant articles of interest. No additional articles were found from this article review.

## Results

Table 1 shows the hits and final relevant article selections for each of the databases. A total of 396 titles were reviewed, with many of the titles being repetitions of the same reference from one or more of the other databases. MEDLINE/Pre-MEDLINE allowed for the most unique relevant hits of six articles.<sup>19-24</sup> In total, eight relevant articles were retrieved.<sup>19-26</sup> The high number of hits with a large number of irrelevant titles was a function of many abstracts containing an Internet reference to view the journal online (eg, www.bjcancer.com, referring to articles from the *British Journal of Cancer*).

Table 2 summarizes these studies conducted regarding Internet cancer health information use among individuals from racial/ethnic populations and low literacy groups. Overall, the reported racial/ethnic characteristics of the largest minority group in each of the studies were of equal frequency for both African Americans<sup>22,25</sup> and Hispanic Americans.<sup>23,26</sup> Two studies combined African Americans and Hispanic Americans for their analyses,<sup>19,20</sup> two studies had the second-largest minority group comprised of American Indians,<sup>23,26</sup> and one study had the largest racial/ethnic minority group comprised of Asian Americans.<sup>21</sup>

Table 2. — Summary of Empirical Studies of Cancer Internet Information Use Among Those of Racial/Ethnic Populations and Low Literacy Groups

Authors	Category*	Study Design	Results
Fogel et al <sup>19</sup>	Content	N = 188, breast cancer, cross sectional, quantitative	Internet users had higher income, more education, and a trend for non-whites to be less likely to use the Internet.
Monnier et al <sup>22</sup>	Content	N = 319, cancer patients and caregivers, cross sectional, quantitative	Differences in interest in Internet based cancer services between African Americans and whites on certain topics while no difference among other topics.
Buller et al <sup>23</sup>	Content	N = 200, New Mexico, United States community survey, quantitative; N = 43, qualitative	Survey and focus groups regarding implementing a Web-based nutrition program in primary prevention of cancer. Lower rate of Internet use among Hispanic Americans as compared to whites. Also, an existing Web site lacked cultural relevance to certain racial/ethnic groups.
Kahn et al <sup>25</sup>	Content	N = 15, adolescents, qualitative	Views about abnormal Papanicolaou smears where 2 adolescents thought that they could conduct their own research through the Internet.
Zimmerman et al <sup>26</sup>	Content	Study 1: N = 41, Study 2: N = 35, Study 3: N = 31, cross sectional, quantitative, qualitative	A series of three usability studies of a Web site for primary prevention of cancer. After the third usability study, most individuals rated it as very interesting, useful, and easy to read.
Kakai et al <sup>21</sup>	Content	N = 140, cancer patients, cross sectional, quantitative	Survey of health information used since cancer diagnosis. Association of Internet use for whites but not for Japanese Americans or non-Japanese Asian Americans and Pacific Islanders.
Fogel et al <sup>20</sup> **	Outcomes	N = 180, breast cancer, cross sectional, quantitative	Internet use among minorities was associated with greater overall, appraisal, and tangible social support.
Wilson et al <sup>24</sup>	Content	N = not applicable, cross sectional, quantitative	Web site of CancerNet had 12th-grade readability level. No culturally tailored content.

\* Categories are defined according to the approach of Bass.<sup>29</sup>  
 \*\* This study used the same sample as the study of Fogel et al.<sup>19</sup>

Fogel et al<sup>19</sup> studied the prevalence and predictors of 188 breast cancer patients using the Internet for breast health information. This sample included 21% (n = 37) non-whites of either African American or Hispanic American race/ethnicity and 79% (n = 143) whites; the Asian Americans (n = 7) and 1 “other” were not included in the race/ethnicity analyses. They found that 41.5% used the Internet, with sources of Internet use including the locations of home (53.7%), work (35.1%), a friend’s house (5.9%), and a library (5.3%). Internet users had higher income and more education, and non-whites had a trend to be less likely to use the Internet.

Monnier et al<sup>22</sup> studied 319 cancer patients and their caregivers regarding their interest in Internet-based cancer services. This sample included 25% African Americans (n = 79), 68% whites (n = 216), <1% Hispanic Americans (n = 1), and 7% “others” (n = 23). In their analyses, they only compared African Americans and whites. African Americans differed from whites in that they were less likely to use the Internet, less likely to have a family member who used the Internet, less likely to have home Internet access, less likely to know where else besides home they could access the Internet, and less likely to report desired use of the Internet for cancer-related services. They found no differences between African Americans and whites on scales measuring additional information on a variety of cancer topics, the likelihood to use the Internet to connect to a variety of professionals and/or a variety of peer support groups, and the likelihood to use the Internet for a variety of cancer healthcare services.

Buller et al<sup>23</sup> conducted surveys with 200 individuals comprised of 63% whites (n = 126), 30% Hispanic Americans (n = 60), 2% American Indians (n = 4), 1% African Americans (n = 2), 0.5% Asian Americans (n = 1), 1.5% other (n = 3), 2% who refused to answer (n = 4), and focus groups with 43 individuals comprised of 44% Hispanic Americans (n = 19), 33% American Indians (n = 14), and 23% mixed whites and Hispanic Americans (n = 10) regarding implementing a Web-based nutrition program for primary prevention of cancer. They found a lower rate of Internet use among Hispanic Americans (40%) compared with whites (58%), and they also reported that fewer Hispanic Americans owned a computer (32%) compared with whites (59%). In addition, they found that a nutrition Web site from another cancer prevention research group was not culturally relevant to American Indians as it did not include traditional American Indian foods and that it was not culturally relevant to Hispanic Americans whose primary language was Spanish, as it included only a minimal amount of Spanish language.

Kahn et al<sup>25</sup> used qualitative analysis consisting of focus groups and semi-structured interviews

with 15 adolescents comprised of 53.3% African Americans (n = 8), 13.3% Hispanic Americans (n = 2), and 33.3% whites (n = 5). They surveyed the views of the adolescents about Pap smears regarding perceived benefits, perceived barriers, perceived susceptibility to abnormal Pap smears/cervical cancer, and information seeking after an abnormal Pap smear. In response to the content area question regarding information seeking (“Where could Lisa go to get more information about her abnormal Pap smear?”), two of the 15 adolescents (ethnicity unknown) thought that they could conduct their own research regarding an abnormal Papanicolaou smear through information from the Internet and not need to use traditional healthcare services of physicians or nurses.

Zimmerman et al<sup>26</sup> conducted a series of three usability testing studies among mostly Hispanic Americans and American Indians in the states of New Mexico and Colorado in the United States for a Web site intended for primary prevention of cancer. After the third usability testing study comprised of 31 individuals, including 42% Hispanic Americans (n = 13), 35% American Indians (n = 11), and 23% whites (n = 7), 83% rated it as very interesting, 74% as useful, and 55% as easy to read. Reported difficulties even after the third usability testing study included unclear Web links, small text size, and the practice of placing a dead link as a temporary feature where a future featured link would be placed.

Kakai et al<sup>21</sup> surveyed 140 cancer patients comprised of 24% Japanese Americans (n = 35), 30% non-Japanese Asian Americans and Pacific Islanders (n = 30%), and 46% whites (n = 65) about the types of health information used since their cancer diagnosis. Using “correspondence analysis,” a technique similar to principal components analysis, they found an association of Internet health information use for whites but not for either Japanese Americans or non-Japanese Asian Americans and Pacific Islanders.

Fogel et al<sup>20</sup> studied 180 breast cancer patients using the Internet for breast health information. This was from the same sample described above in the study of Fogel et al<sup>19</sup> published in 2002. Internet use among racial/ethnic minorities was associated with greater overall, appraisal, and tangible social support. However, minority and white participants did not differ when examining their feelings of belonging or self-esteem social support. These perceived social support categories represent the following constructs<sup>27</sup>: the appraisal subscale measures the perceived availability of someone to talk to about one’s problems; the belonging subscale measures the perceived availability of people with whom one can do things; the self-esteem subscale measures the perceived availability of a positive comparison when

comparing oneself to others; and the tangible subscale measures the perceived availability of material aid. In addition, no differences were observed for stress, depressive symptoms, loneliness, or coping.

Only one study specifically addressed issues of literacy relating to the content of Internet information. Wilson et al<sup>24</sup> studied the readability and cultural aspects of information on CancerNet. Two researchers studied 49 documents retrieved from the “Patients and the Public” section of CancerNet. They found that it had an overall 12th grade readability level. The beginning paragraphs were easier to read than those in the middle or final portions of these documents. There was also an interaction of topic by paragraph position where beginning paragraphs from the “therapy” category were more difficult to read than beginning paragraphs from the “screening” category. In a separate subsample (n = 17) of documents titled with the word “ethnic,” a cultural relevance analysis was done. Although Spanish and English language options were offered, no culturally tailored content was provided. Although there were inquiries for racial categories, the individual information Web pages were the same for someone who indicated an Asian American

racial/ethnic category as were the individual information Web pages for someone who indicated a Hispanic American racial/ethnic category.

## Discussion

This review discusses cancer Internet information use for those from racial/ethnic populations and low literacy groups. Culturally sensitive Internet material is needed to encourage greater Internet information use for those from racial/ethnic populations. Some guidelines for this process for creating culturally sensitive material are available on the Internet for African Americans with cancer. It includes ensuring that the medical terms are understandable, the material is free from any possible stereotypical meaning, and the messages address cultural stereotypes and myths.<sup>28</sup> Additional guidelines for creating Internet information in consideration of literacy are needed to ensure that content is compatible with the user’s reading skills.

Fogel et al<sup>20</sup> suggest that the Internet may help reduce barriers to receiving care by providing racial/ethnic groups with an avenue to obtain infor-

Table 3. — Future Research Questions For Studying Those From Racial/Ethnic Populations and Low Literacy Groups Seeking Cancer Health Information on the Internet

Category*	Research Question
Content Research	<ol style="list-style-type: none"> <li>(1) Using an epidemiological framework, what are the characteristics, prevalence, and predictors of this Internet information use among those of racial/ethnic populations and low literacy groups?</li> <li>(2) What culturally sensitive measure can be created to measure the cultural appropriateness of cancer Web sites?</li> <li>(3) How does one effectively create a visually appealing Web site to interest those from racial/ethnic populations and low literacy groups?</li> <li>(4) How can one effectively measure the literacy level of Web sites created for racial/ethnic populations?</li> <li>(5) Do children and adolescents from racial/ethnic populations need different Web site cancer information content than those from non-racial/ethnic populations?</li> </ol>
Process Research	<ol style="list-style-type: none"> <li>(1) How do individuals from racial/ethnic populations and low literacy groups search cancer information Web sites?</li> <li>(2) What features in a Web site interest those from racial/ethnic populations and low literacy groups to choose that cancer information Web site as their favorite one?</li> <li>(3) What do those from racial/ethnic populations and low literacy groups do when they view a cancer Web site?</li> <li>(4) Which Web site features are easy to navigate for those from racial/ethnic populations and low literacy groups?</li> <li>(5) What interests those from racial/ethnic populations and low literacy groups to want to spend more time viewing one particular cancer Web site more than another cancer Web site(s)?</li> </ol>
Outcomes Research	<ol style="list-style-type: none"> <li>(1) What impact does Internet cancer information use have on survival of those with cancer from racial/ethnic populations and low literacy groups?</li> <li>(2) What impact does Internet cancer information use have on the caregivers of cancer patients among those from racial/ethnic populations and low literacy groups?</li> <li>(3) What impact does Internet cancer information use have on the quality of life of those with cancer from racial/ethnic populations and low literacy groups?</li> <li>(4) Is Internet cancer information use a successful method for primary prevention of cancer among those from racial/ethnic populations and low literacy groups?</li> <li>(5) Does Internet cancer information use relate to greater optimism and hope in coping with cancer among those from racial/ethnic populations and low literacy groups?</li> </ol>

\* Categories are defined according to the approach of Bass.<sup>29</sup>

mation and the knowledge of what to do about breast concerns. They state that the Internet may also provide individuals with the tangible support that they do not receive until very late in their diagnosis of breast cancer. Their research suggests that continuous Internet use may help prolong survival, just as the scientific literature suggests in the case of person-to-person formats of support groups and group psychotherapies. They recommend that not only should more Web sites focus on racial/ethnic groups and culturally sensitive themes related to health issues, but also breast surgeons should encourage patients to read reputable Web sites because this information may prolong their patients' survival.

In this comprehensive review, seven studies were retrieved regarding cancer Internet health information use among those of racial/ethnic populations, and only one study was retrieved that addressed low literacy groups. One can classify these studies according to the framework suggested by Bass<sup>29</sup> who suggests three classifications of Internet research. They are content research, process research, and outcomes research.

Content research involves studying the types of material available and the characteristics of those who use Web sites. In the studies reviewed above, almost all of them would be included as part of this category. This category includes the studies of Fogel et al,<sup>19</sup> Monnier et al,<sup>22</sup> Buller et al,<sup>23</sup> Kahn et al,<sup>25</sup> Kakai et al,<sup>21</sup> Zimmerman et al,<sup>26</sup> and Wilson et al.<sup>24</sup> Process research would include the processes used by individuals to use this Internet medium. None of the studies reviewed above are included in this category. Outcomes research would include the effects of Internet health information and/or treatments performed through the use of the Internet health information. In the studies reviewed above, only the study of Fogel et al<sup>20</sup> would be included in this category.

This comprehensive review has a number of limitations. As the Internet is a relatively new technology, there may be studies currently being conducted or accepted for publication but not yet published that were not included. The search terms used in this comprehensive review may not have captured all the relevant studies, as there may be terms that are more revealing or have other relevant subcategories. Thus, there may be previously published studies that were inadvertently omitted from this comprehensive review.

## Conclusions

The general intent of this paper was to review the empirical Internet cancer information use among those of racial/ethnic populations and low literacy

groups. With regard to the specific a-priori questions, there is a paucity of research to conclude whether Internet cancer information is culturally relevant. There are a few studies discussing cancer information Internet use among those of racial/ethnic populations but these studies do not focus on the varied cancer populations nor are they epidemiologically based. There is only one study regarding the psychosocial outcome of increase social support for cancer patient Internet information use and none on survivorship. In general, there are only a handful of empirical articles on how this new medium for information affects those from racial/ethnic populations. Only one study focused on literacy considerations of Internet health content. As most studies to date have focused on a few studies of content research, more research would be useful especially with regard to process research and outcomes research. This is a fertile area of research with the hope that Internet health information use will impact the psychosocial experience and also the survival of those experiencing cancer. Table 3 outlines a number of future questions to be studied on this topic. For those who study the effects of Internet use, the research field related to the study of cancer patients from among those of racial/ethnic populations and low literacy groups is open for many unique contributions to the scientific literature.

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