Mini-review

Online cancer communication: Meeting the literacy, cultural and linguistic needs of diverse audiences

Linda Neuhauser [a,*], Gary L. Kreps [b]

[a] *School of Public Health, 50 University Hall MC 7360, University of California, Berkeley, CA 94720-7360, USA*
[b] *George Mason University, Fairfax, VA, USA*

Abstract

Objective: This article provides an analysis of issues and empirical evidence related to literacy, cultural, and linguistic factors in online health and cancer communication, and recommendations to improve cancer communication for diverse audiences.

Methods: We examined English-language online literature and selected books and policy documents related to literacy, cultural, and linguistic factors in health and cancer communication.

Results: Studies about literacy, cultural, and linguistic factors in online cancer communication for diverse audiences are limited, but have increased during the past 15 years. Empirical evidence and theoretical guidance describe the critical importance of these factors, significant unmet needs among low-literate, multicultural and non-English-speaking populations, and strategies to improve communication.

Conclusion: Overall, online cancer communication has not met the literacy, cultural, and linguistic needs of diverse populations. The literature offers valuable recommendations about enhancing research, practice, and policy for better cancer communication.

Practice implications: Practitioners should understand the strengths and weaknesses of online cancer communication for vulnerable groups, guide patients to better Websites, and supplement that information with oral and tailored communication.

© 2008 Elsevier Ireland Ltd. All rights reserved.

Keywords: Cancer communication; Online communication; Cancer disparities; Health communication; Interactive health communication; Internet communication; Health literacy; Language; Diverse audiences; Cultural communication; Multicultural communication; Review

1. Background

1.1. Cancer and cancer disparities

Current advances in knowledge and practice have tremendous potential to reduce the international burden of cancer, but this is an elusive goal for many vulnerable populations who have limited access to relevant and motivating health information about evidence-based cancer prevention and control [1–4]. Cancer remains a leading cause of death and suffering throughout the world [5–7]. In 2004, an estimated 554,000 Americans died of cancer [5], and in 2005 an estimated 1.7 million people died of cancer in 38 countries of Europe [6]. Cancer has been the leading cause of death in Japan since 1981 [7]. Beginning in 1990, age-adjusted US cancer deaths have been continuously decreasing for

the first time since 1900, and the incidence of many cancers has also declined [2,8]. Favorable mortality trends have also been observed for many cancers in Europe [9–11]. The World Health Organization estimated that, worldwide, 22 million people were living with cancer in 2003 [12]. In the US, an estimated 9.8 million people were living with cancer in 2001 [13].

However, cancer disparities are widening among subpopulations that differ by literacy level, race/ethnicity, language, or other characteristics [5,14–22]. In 1999, the US Institute of Medicine released "The Unequal Burden of Cancer" report that documented the increasing disparities of cancer incidence and mortality among US populations [23]. The report noted that although incidence for all cancers has been declining for most age groups, for both men and women and for most ethnic groups, cancer rates continued to increase for black men. A 2007 study of cancer among US Asian and Pacific Islanders showed unfavorable patterns of the stage of diagnosis for colorectal, breast, cervical, and prostate cancers in some of these groups [24].

---

* Corresponding author. Tel.: +1 510 643 9177; fax: +1 510 642 9792.
E-mail address: lindan@berkeley.edu (L. Neuhauser).

In the US, African American men have the highest death rates for lung, colon, and prostate cancer, and black women have the highest death rates for colon and breast cancer [5]. The disparity in breast cancer mortality rates between whites and African Americans increased progressively from 1980 to 2000, when the age-standardized death rate was 32% higher in African Americans [21]. During 1999–2003, African American men and women had significantly high incidence of cancer than white men and women [5]. During that period, African American women had significantly higher death rates from 14 cancers than white women [5]. Cancer is the leading cause of death among Asian Americans [29], and Vietnamese women have the highest incidence of cervical cancer in the US [20,25].

In New Zealand, cancer death rates have increased for Māori and Pacific people, but decreased for European subgroups [26]. Māori and Pacific people have twice the mortality of European groups. Breast cancer mortality rates for European subgroups decreased during the 1980s and 1990s compared to increasing rates among Māori and Pacific women. By the late 1990s, Māori and Pacific females in New Zealand had 1.5–2 times higher cancer mortality rates than European subgroups [26]. Cultural, educational, and language barriers to prevention, screening, and treatment are thought to be significant factors in cancer disparities [9,15,20–22,27–29].

1.2. Engaging people to control cancer

Human and social factors are estimated to account for 50–75% of cancer mortality [30]. Along the continuum of cancer prevention, treatment and survivorship, there are many points at which people's behaviors can make a difference. There is strong evidence that reductions in cancer mortality are linked with changes in behavioral risk factors, such as smoking, diet, and adherence to cancer screening tests [2,15,28,31].

Some researchers estimate that if people were to follow currently available recommendations for cancer prevention and early detection, US national cancer mortality could be reduced by as much as 60% [32–33]. Even assuming more modest projections – that prevention could reduce cancer incidence by 19% and deaths by 29% – would result in a yearly reduction of cancer cases by 100,000 and deaths by 60,000 by 2015 [34]. It is clear, however, that even with the important accomplishments that have been made to date, we are still far from achieving the level of behavior change called for in national health goals [35,36]. For example, helping the 24% of adults who smoke cigarettes discontinue their habit and preventing youth from adopting the habit is estimated to save more lives than all the benefits of screening and treatment combined [37].

The US Institute of Medicine report "Fulfilling the Potential of Cancer Prevention and Early Detection" [17] provided estimates that appropriate use of screening could reduce the rate of mortality from colorectal cancer by 30–80% among adults 50 and older, reduce the rate of mortality from breast cancer by 25–30% among women 50 and older, and reduce the rate of mortality from cervical cancer by 20–60% among women 18 and older. For example, 5-year cervical cancer survival rates are 90% if patients are diagnosed at stage I, but drop precipitously

to 50% and 10% for diagnoses at stages II and III, respectively [20]. Unfortunately, cancer is often poorly understood and screening rates are low among many minority groups [15,21,22,27,29,38]. A 2005 national population-based US study found that over 25% of Hispanics and 18% of African Americans (compared with 14% of whites) believed there was nothing they could do to reduce their risk of cancer [39]. The same survey reported that 74% of Hispanics and 59% of African Americans (compared with 35% of whites) could not think of a test that would detect colon cancer. In one study of Vietnamese-American women and cervical cancer, three-quarters of the women did not know the purpose of a Pap test and believed their risk of cancer was low [40]. A population-based survey of Asian Americans found that non-English-speakers were more likely to believe that cancer screening was unnecessary if there were no medical symptoms [41]. It is critical to find successful interventions that will engage vulnerable populations in cancer control and reduce preventable suffering and deaths.

1.3. Cancer and communication

Communication to patients and the public has been the central approach to engage people in cancer control. Kreps and Viswanath [42] define *cancer communication* as

The study and application of the use of strategically designed messages delivered through selected media, to convey relevant health information to targeted audiences (such as health care consumers, cancer survivors, health care providers, researchers, patients and at-risk populations) to promote cancer prevention and control, enhance cancer screening and early detection, reduce cancer morbidity and mortality, and enhance quality of life (p. ix).

A variety of conceptual frameworks, such as "stages of change" [43], "social ecological" [44], "diffusion of innovation" [45], "online social support" [46], "ecological model for cancer communication" [47], mediated consumer-provider communication in cancer care" [48], and "knowledge integration" [49] provide theoretical support to the notion that communication strategies are essential to help people understand ways to prevent and manage cancer. Increasingly, guidance emphasizes that communication be relevant to people's personal needs and social contexts.

Communication strategies for cancer control have focused on smoking cessation, increased consumption of fruits and vegetables, increased exercise, early and regular cancer screenings, compliance with treatment protocols, and psychological and social support during and after treatment. Behavioral interventions to affect cancer have shown some positive outcomes and are thought to have substantially contributed to the downturn in age-adjusted cancer incidence and mortality [2,9,17,28].

Cancer communication research has documented important prevention and cancer control outcomes—especially through behavior change [1,3,4,15,28,50–52]. The most successful approaches have used multiple communication methods or

media channels, and/or had strong linkages at health care or community levels [17].

However, the results of cancer communication interventions are sometimes disappointing, especially for vulnerable groups. For example, in the US, the state of California's "5-a-Day for Better Health! Campaign" seeks to increase people's consumption of fruits and vegetables to decrease the risk of cancer and other diseases. After 5 years, study results showed that the intensive statewide campaign significantly increased people's knowledge, but found no overall positive impact on changing consumption [53]. Disturbingly, consumption of fruits and vegetables decreased substantially for African Americans and Hispanics. Pinto et al. [54] reviewed studies of interventions intended to improve people's smoking, dietary, or physical activity behaviors after cancer diagnoses. They said there was not enough evidence to determine if self-help communication interventions (without intensive interpersonal support) would be effective with cancer populations. Likewise, it is obvious that past communication efforts have not effectively closed the gap in cancer screening levels for minority populations.

Concerns about the effectiveness of health and cancer communication for vulnerable groups have prompted intense debate during the past decade. The emerging view is that traditional health communication is frequently insufficient to engage people to change behavior within the complex contexts of their lives [28,55]. Generic messages to "stop smoking," "eat 5 a day," or "get a mammogram" are not adequately customized to the needs of diverse populations to motivate or sustain behavioral changes. This is a particular problem for people who face communication barriers related to literacy, culture, language, or other factors [9,15,20–22,26–29,56–58]. Information must become "personalized" so that it fits into people's family and community situations. Further, it is important to understand the information sources that diverse groups use to access health communication [59].

Recommendations have been offered to improve health communication interventions: (1) construct better models that reflect a deeper understanding of dynamic social processes and take into account the great diversity of subcultures; (2) design communication that is more "contextual" and "tailored"; (3) create communication that has the reach of mass media and the impact of interpersonal media; and (4) improve the interactivity of communication through the use of multiple and new media [55,58].

1.4. The potential and challenges of online cancer communication

Online cancer communication is thought to have particular promise to overcome the weaknesses of traditional communication through broad reach, 24-h availability, interactivity, social networking, multimedia capacities, anonymity, and potential for targeting to groups and tailoring for individuals [15,58,60–62]. The public has rapidly and enthusiastically embraced the Internet (accessed via computers, phones, and other electronic devices) as a source of health information.

Global Reach [63] estimated that in 2004, over 729 million people worldwide had online access. Miniwatts Marketing Group (http://www.internetworldstats.com/stats.htm) [64] estimated that in 2007, 20% of global populations (1.3 billion people) used the Internet, including 43% of Europeans, 13% of Asians, 4.7% of Africans, and 22% of people in Latin America and the Caribbean. A telephone survey in 7 European countries found that 44% of the respondents (71% of the Internet users) had used the Internet for health purposes [65]. A Taiwanese study [66] estimated that 73% of those living in Taipei used the Internet in 2002, of whom about 52% had accessed health Websites. As of May 2006, Pew and the American Internet Project findings indicated that 80% of 113 million American adult Internet users searched for online health information, and about half of them searched for information related to a medical diagnosis [67]. Cancer is one of the top three diseases for which the public seeks information on the Internet [68].

During the past 15 years, many Internet health information and support programs have been established to help health care consumers and providers cope with cancer [15,28,55,58, 60,69,70,71]. Initial evidence shows that online communication can greatly enhance our efforts to reach diverse audiences with personalized and engaging cancer information, and can improve knowledge and behaviors. For example, in an area relevant to cancer control, computer tailored messages improved fruit and vegetable intake [73]. Although it is beyond the scope of this paper to describe general results of online communication, we suggest the following reviews: Kreps [15]; Eysenbach [1]; Kreps et al. [71]; Neuhauser and Kreps [58]; Neuhauser and Kreps [55]; Revere and Dunbar [72]; Marcus et al. [73]; Krishna et al. [74]; and Balas et al. [75].

Despite such positive results, researchers and practitioners question whether online cancer communication is reaching the public and is adequate to meet the literacy, cultural, and linguistic needs of vulnerable populations [15,28,55,58,60,76]. Is it sufficiently powerful to reduce cancer disparities?

In this paper, we will (1) examine usage of online cancer communication, (2) review issues and empirical evidence about online cancer communication to meet the public's literacy, linguistic, and cultural needs, and (3) identify recommendations to improve cancer communication for these groups.

2. Methods

2.1. Databases searched

We conducted key-word searches on the following English language databases: PubMed (1950 to December, 2007), Medline Plus, LEXIS-NEXIS (1970 to December 2007), PsychINFO (1967-December 2007), ERIC (1966 to December 2007), Expanded Academic ASAP (1980 to December 2007), and from the SAGE Full-Text Collections, we searched the research databases in Communication Studies, Health Sciences, and Psychology. We also conducted key-word searches using the Google Web browser.

2.2. Key-words searched

Searches included the following terms and combinations of them: online cancer communication, Internet usage, digital divide, Internet cancer communication, online patient information, online health communication, interactive health communication, electronic media, multimedia cancer communication, cancer, oncology, oncology communication, readability, Internet usability, Internet navigation, literacy, health literacy, intercultural, intercultural communication, cross-cultural communication, language (also: Spanish, Chinese, Vietnamese, Korean), race/racial, ethnicity/ethnic, African-American, Hispanic, Latino, Asian (also: Chinese, Korean, Vietnamese) minority, and culture.

2.3. Paper selection

Titles and abstracts of publications were read to identify papers that covered issues and/or empirical studies of online cancer communication with an emphasis on those that related to the literacy, cultural, and linguistic needs of diverse or vulnerable populations. With regard to literacy, selected papers were limited to those addressing the readability and usability of online communication. Selected reviews of more general online health communication were also reviewed. Papers meeting these criteria were read completely. Additional papers were identified from "related links" provided during the database searches, and from reference lists in selected articles.

2.4. Additional publications reviewed

Selected books and policy documents related to cancer communication, online cancer communication and online health communication – especially those related to low-literate, minority racial/ethnic groups, and non-English-speaking audiences – were reviewed.

3. Results

Of the thousands of articles identified from key-word searches, about 300 were considered relevant to the specific focus of this paper. Similar to Fogel's experience [77], we found that searching by key words was not an efficient or effective way to identify relevant literature about online cancer communication for diverse groups. Checking referred links and article reference lists yielded a significant portion of the literature in this review.

3.1. Use of online cancer communication

We did not find population-based studies of online cancer communication usage outside of the US. Eysenbach [1], in a review of 24 studies, estimated that in the industrialized world in 2003 about 39% of people with cancer used the Internet, and another 15–20% of people with cancer used the Internet "indirectly" through family or friends. The US National Cancer Institute's "Health Information National Trends Survey" (HINTS) is the most comprehensive, nationally representative study available on use of the Internet for health and cancer communication [78,79]. HINTS findings estimated that 59.5% of respondents reported looking for health or medical communication online in 2005, and 28.2% of them (up from 20.5% in 2003) reported looking for cancer information on the Internet [39]. A striking HINTS finding was that a significant majority of Americans went to the Internet *first*, rather than to a health provider, to seek cancer information [79]. People's preferences for the Internet as a source of cancer information far outstripped that for going to books, brochures, family/friends, libraries, or magazines.

Non-population-based studies have also examined the use of online cancer communication, with overall estimates ranging from 39 to 58% [1,69,80–83]. A review by Basch et al. [69] found that usage estimates ranged from 42 to 49% for patients with breast cancer [81,84–86], from 32 to 45% among patients with prostate cancer [87,88], and from 16 to 18% among patients with lung or head and neck cancer [89,90]. For example, Satterlund et al.'s study [81] of women with breast cancer found that 49% reported using the Internet for information and support after diagnosis, and 40% used it for up to 16 months. In a small study of ethnically diverse respondents, Pecchioni and Sparks [59] found that caregivers had higher use of online cancer information than did the patients.

3.2. Literacy factors in online cancer communication

Given significantly higher cancer morbidity and mortality among lower-educated populations [5] and their lower participation in cancer prevention and control programs [91,92], literacy has become a major issue in cancer communication [93–95]. "Literacy" is defined by the 2003 US National Assessment of Adult Literacy as "using printed and written information to function in society, to achieve one's goals, and to develop one's knowledge and potential" [96]. In 2003, an estimated 43% of US adults had "basic" or "below basic" prose literacy skills—the lowest of four levels. Most US adults with a high school education or less – 47% of the adult population [97] – and 13% of those with a college degree tested at these lower literacy levels. The International Adult Literacy Survey, conducted in 25 countries, shows that low literacy is a worldwide problem [98]. Survey results indicate that average reading levels in Canada are between grade 8 and 9 [99].

Because of these limitations, communication experts recommend matching text readability and usability more closely to audience levels [100–103]. In the US, high school graduates' reading levels are estimated to be between 7th and 9th grade [95,104–106]. Further, 20% of American adults are estimated to read at or below the 5th-grade [95]. Hence the US National Work Group on Cancer and Literacy recommended that cancer information be written at a 5th grade reading level or below [105].

Health information, with its scientific terminology and frequently complex recommendations, is considered to pose additional literacy requirements beyond general reading comprehension [106]. These specialized abilities are embodied

in the concept of "health literacy," defined by the World Health Organization as "the cognitive and social skills and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [107], and by the US Institute of Medicine [108] as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions."

During the past two decades, health literacy has become an issue of global concern. Researchers in this emerging field are documenting that low literacy can make it difficult for people to understand preventive actions, screening information, and treatment options [91,92]. A US Institute of Medicine report [108] concluded that low health literacy is strongly associated with increased cancer disparities. For example, a study of men in the US Veterans Affairs' health system found that despite equal screening access, those who read below a 6th-grade level were 69% more likely to be diagnosed with late-stage prostate cancer [109].

A growing literature describes issues and empirical studies of health literacy. The vast majority of studies are from the US and Canada. Kondilis et al. [110] found few articles related to health literacy in Europe in their search of the Medline database for 1985–2005. One barrier, cited by Baron-Epel et al. [111], is that health literacy measurement tools exist in only a few languages. A national survey in Canada [112] concluded that health literacy abilities were low: an estimated 60% of Canadian adults lack the capacity to obtain health information and make appropriate health decisions on their own. Results of the International Adult Literacy Survey also showed low levels of health literacy [98]. Health literacy levels are especially low among older adults, who experience 70% of all cancers [56]. For general background on health literacy issues, measurement, and implications for health, we refer readers to: Swartzberg et al. [93]; Doak et al. [95]; OECD and Statistics, Canada [98]; Health Literacy in Canada [112]; Kickbusch et al. [113]; Zarcadoolas [114]; and Doak et al. [115].

Although some concepts of "health literacy" have been expanded to include a broad range of factors that may affect or complement online cancer communication – such as consumer numeracy (quantitative abilities), psychographic variables, and patient-practitioner oral communication – we limited our review to readability and usability.

3.2.1. Readability and usability of online cancer communication

An extensive literature – approximately 800 studies – documents that most health information is written at levels exceeding that of the average high-school graduate [112]. In 2000, one study estimated that only 1% of Websites were judged to be usable by people with low-literacy skills [116]. Limited, but increasing, research indicates that the same is true for online cancer content. In analyzing patient information on the US National Cancer Institute's CancerNet site in 2000, Wilson et al. [117] found an overall readability level of 12th grade. In a 2001 study of Internet health communication, Berland et al. [118] found that 100% of the English Websites

and 86% of the Spanish sites they assessed required at least a high school reading level. Doak et al. [115] estimated the average reading level of cancer communication to range from 10th grade to college level. Average readability was at a college level on 39 Websites providing information about clinical trials in cancer centers [119].

Friedman et al. [120] analyzed readability of 100 cancer information Websites. Reading levels were grade 12.9 and 10.7 for SMOG and Flesch-Kinkaid tests, respectively, and scored "difficult" on the Flesch Reading Ease test. In another study of 55 popular breast, prostate, and colorectal cancer Websites, these authors [121] found a mean readability of 13.7 (SMOG) and 10.9 (Flesch-Kinkaid). A study of 70 Websites about prostate cancer found a mean readability level of 12.9 [122]. When Kaphingst et al. [123] conducted SMOG tests on Website content about colorectal cancer screening, they found an average reading level of grade 12.9. An analysis of MyPyramid.gov, the US government's primary Website for healthy eating and physical activity (important for cancer prevention), found that the average readability of consumer content was between grade 8.8 and 10.8—lower than that of many other cancer-relevant sites, but higher than the site's intended 7–8th grade level [103]. Cheh et al. [124] found that the content in 16 of 30 smoking cessation Websites exceeded the 8th grade level. All these studies found notable reading level variability within and among content on the sites. A systematic review of Web-based decision aids for cancer screening found that 74% averaged readability at grade 10–13, 22% at grade 9, and 4% at grade 8 [125].

Researchers caution that in addition to readability, there are additional literacy requirements for people who use Websites, including abilities to locate and search sites, spell terms, navigate content, and link to other sites [94,103]. Such factors are often combined into the concept of "usability" [113,126–129]. Our search found increasing guidance about usability factors and testing that can improve online health and cancer communication. For example, the US Department of Health and Human Services publishes the "Research-Based Web Design & Usability Guidelines" online at http://www.usabil-ity.gov/pdfs/guidelines.html, and the US National Cancer Institute provides a usability site for cancer information http://www.usability.gov/.

We found little empirical research on usability of cancer-relevant sites. In their assessment of smoking cessation Websites, Cheh et al. [124] found that only 40% provided a search mechanism. Neuhauser et al. [103] proposed modifications to the usability criteria recommended by the US Department of Health and Human Services and the US National Cancer Institute to make them more relevant to the needs of lower-literate populations. They assessed the resulting 20 usability factors for a national nutrition Website and found that the consumer portion met only half the criteria. Thomson and Hoffman-Goetz's systematic study of 83 cancer decision aids found that none allowed key-word searches [125]. Kaphingst et al. [123] documented multiple text, layout, graphic and interactivity weaknesses on Websites about colorectal cancer. Monaco and Krills [119] found several Web navigation problems in their

analysis of Websites advising consumers about cancer clinical trials.

We found little empirical research about the impact of interventions intended to improve readability and usability of online cancer communication. Holmes-Rovner et al. [130] found that a simplified Internet decision aid for prostate cancer improved patients' awareness of radiation side effects and their intentions to take a more active role in their treatment decisions. Zimmerman et al. [131] tested three stages of usability improvements for a primary cancer prevention Website. Although consumer satisfaction with the site's usefulness was high after the third-stage improvements, only 55% said it was easy to read.

3.3. Language factors in online cancer communication

Language issues identified in this search included availability and use of language-relevant sites, language quality and readability, and cultural targeting and tailoring.

Language can be considered "the lowest common denominator of cultural sensitivity" [132] and presents an obvious barrier to the accessibility of online cancer communication within and across nations. Internet World Stats (http://www.internetworldstats.com/stats7.htm) provided estimates that in 2007, 30.1% of Internet users were English speakers. Although the majority of Websites are in English, the non-English-speaking Internet population is rapidly growing (especially Chinese and Arabic speakers). According to the 2000 US Census, 47 million people (18% of the population) spoke a language other than English at home, and more than 300 languages were spoken [133]. More than 22 million Americans had limited English proficiency [133].

Our search did not identify a comprehensive analysis of language content on the Internet. Singh and colleagues [134] examined language query patterns of users in 227 countries who searched for health and food information via the Google browser. They estimated that 80–90% of the searched Websites did not translate their information into multiple languages. However, there was a strong preference for content in local languages: only 1% of searches from users in non-English-speaking countries were in English. In the US, Spanish-language online searches for sample health topics occurred at less than 1% of the English rate, although 12% of the US population is Hispanic. In 2000, Lazaras and Mora [116] estimated that only an estimated 2% of Websites used a language other than English.

Some of the health literacy research and most of the cultural relevance research cited in this paper included mention of language issues in online health and cancer communication. However, we found few empirical studies. As noted earlier, Berland et al. [118] found that 86% of a sample of Spanish-language health sites had college-level readability. Rai-Chaudhuri and Hogan [135] described the language challenges of developing an online cancer discussion list in India. An online nutrition program for cancer prevention, assessed by Buller et al. [136], was not accessible to monolingual Hispanics. In our review, most of the issues related to language

had been inferred from studies focusing on cultural factors. For example, Friedman et al. [137] described how Hispanic cancer survivors and caregivers found and used online cancer communication in Spanish. The authors recommended that doctors direct more Hispanic caregivers to such information.

Although health and cancer educators generally agree that communication should be provided in peoples' native languages when possible, there is no consensus on standards for the translation process. Literal translations may not be effective at communicating complex health concepts and motivating behavior change among diverse linguistic audiences [78,91]. Even among speakers of one language, there are often regional linguistic variations and cultural nuances (i.e., Spanish from Cuba, Mexico, and Spain). For this reason, there is increasing guidance that health content be linguistically and culturally adapted, rather than literally translated, to meet the needs of the intended audience [138]. Massett [139] recommends that those involved in adapting materials understand the regional and cultural variations of the target language, and the literacy levels of the intended users. It is critical to involve users in the design and testing of adapted content [58,103,140].

3.4. Cultural factors in online cancer communication

The significant racial and ethnic disparities in cancer morbidity, mortality, and participation in cancer prevention, screening, and treatment have prompted increasing research about whether online cancer communication is accessible to and culturally appropriate for minority groups. In addition to communication that meets users' linguistic and literacy requirements, research is increasingly identifying values, beliefs, risk perceptions, norms, practices, motivations, family and community relationships, and many other cultural factors that may affect the acceptance and use of cancer communication among diverse racial/ethnic groups [15,141,142]. For example, "fear of discovering cancer" appears to be an important contributor to lower breast cancer screening rates among older African American women [143]. Shouten and Meeuwesen [141] suggest that such factors are likely to vary widely across cultures and countries. Tu et al. [144] found that Cambodian women were less likely to have breast screening if done by a male physician. It is beyond the scope of this review to summarize the literature on cultural factors related to cancer communication. This section focuses on research about the use of online cancer communication by racial/ethnic groups, and the cultural relevance of Internet cancer sites.

3.4.1. Online cancer communication among minority populations

The "digital divide" has been a critical issue since the beginning of the e-health era, when Internet users were primarily white, highly educated, and middle- or upper-income. During the past two decades, accessibility gaps have greatly narrowed in the US and some other countries (http://dccps.nci.nih.gov/cancer_resources-digdivide.html), but remain a global concern [145–149].

Little population-based data exists about use of the Internet for cancer communication by minority racial/ethnic populations. In a 2003 search of six research databases, Fogel [77] found only seven empirical studies of Internet use among these groups and commented on the difficulty of finding such studies using key-word searches. We had similar difficulties, and many of the studies cited in this section were accessed through database links to "related studies" (such as on Medline), or citations in other articles. The vast majority of studies were from the US.

As we noted earlier, the most comprehensive, nationally representative study available on Internet use for cancer communication is the US National Cancer Institute's "Health Information National Trends Survey" (HINTS) [78,79]. In a 2005 sample, 46.9% of African Americans, 25.1% of Hispanics, and 49% of "Non-Hispanic Other" groups (includes Asian Americans), compared with 54.6% of whites, reported seeking cancer information [39]. Of groups seeking cancer information, 43.2% of African Americans, 36.3% of Hispanics, and 48.2% of non-Hispanic other groups searched for it on the Internet, compared with 49.6% of whites [39]. Internet searches far surpassed searches of printed materials for cancer information. Only 14% of African Americans, 21.6% of Hispanics, 17.2% of non-Hispanic other groups, and 14.8% of whites reported searching printed materials [39]. Similarly, Internet searches greatly exceeded inquiries to health care providers. Only 27.1% of African Americans, 22.6% of Hispanics, 19% of non-Hispanic other groups, and 26.9% of whites reported seeking such information from providers [39]. However, the same survey found that a majority of respondents from these racial/ethnic groups (55.9% African American; 65.7% Hispanic; 53.7% non-Hispanic other groups; 52.9% white) would have *preferred* to receive cancer information from a health care provider. The Internet was a preferred source of cancer information for 29% of African Americans, 20.5% of Hispanics, 28.8% of non-Hispanic other groups, and 33.4% of whites. Members of all groups who searched for online cancer information rated the information as "useful" to "very useful." Minority groups had similar levels of trust in health and medical information from the Internet: 25.8% of African Americans, 25.4% of Hispanics, and 21.3% of non-Hispanic other groups reported "a lot" of trust in this source, compared with 17.5% of whites.

Although not specific to online cancer communication, other HINTS 2005 findings [39] are relevant to group perceptions about cancer information. The groups had different levels of confidence in cancer advice or information: 28.5% of African Americans, 40.5% of Hispanics, 30.1% of non-Hispanic other groups, and 27.2% of whites reported that they were only "somewhat" or "a little" confident that they could get such advice. Groups also reported differing perceptions about the difficulty of obtaining cancer information: 41.8% of African Americans, 52.6% of Hispanics, 49.8% of non-Hispanic other groups, and 33.4% of whites reported that it took a "lot of effort" to find this information. Likewise, comprehension of information was most difficult for Hispanics: 23.7% of African Americans, 36.1% of Hispanics, 26.3% of non-Hispanic other groups, and 21.5% of whites thought the cancer information was "too hard to understand."

Other studies based on smaller samples have examined minorities' use of online cancer communication. Nguyen et al. [150] tested the content of two nonprofit organizations' cancer Websites in a small multiethnic sample. The groups they sampled reported having similar online access. Although the vast majority of participants in all groups considered the information easy to understand, over 60% (especially Spanish speakers) said they would prefer to have the information in a printed pamphlet, rather than online. Friedman et al. [137] studied Internet use by conducting focus groups with Hispanic cancer patients and caregivers. Findings showed patients used the Internet mainly for entertainment and stress reduction, and preferred to receive cancer information from their physicians. Caregivers were more likely to search for online health information.

In multiple analyses of a study of breast cancer patients who used the Internet, Fogel et al. [84,85,142] found that although the minority groups (African Americans, Hispanics, and Asian Americans) showed a trend toward less Internet use, their Internet use was associated with greater ability to talk to someone about problems and increased tangible social support—effects suggested to improve cancer survival. Minority women did not differ from white women on feelings of belonging, self-esteem, or social support. Levels of stress, depression, loneliness, and coping with cancer were not significantly different between minority and white women. In a study of patient and caregiver interest in Internet-based cancer services, Monnier et al. [83] found that although Hispanics and African Americans were less likely than whites to use the Internet, have online access, or report that they would use the Internet for cancer-related services, they had similar levels of interest in learning about cancer topics.

In Kakai et al.'s [151] survey of cancer patients, Internet use for health information was notable among whites but not among Japanese-American and non-Japanese-American Asian and Pacific Islander groups. Buller et al. [136] surveyed a multiethnic sample of 200 people (Hispanics, American Indians, African Americans, and whites about developing a nutrition Website for cancer prevention. They found significantly lower computer ownership and Internet use among Hispanics (40%) compared with whites (58%). Wei et al. [152] found that only 11% of people registering on a clinical trials database for colorectal cancer were minorities (3.4% were African American and 2.3% were Hispanic).

The Comprehensive Health Enhancement Support System (CHESS) project has explored online cancer communication use and outcomes among minority and low-income groups during the past two decades [153–156]. Researchers found that low-income African American women used the system as frequently as did affluent white women. They also reported that compared to non-minority groups, African Americans used online CHESS services more for information and less for interactive features, such as discussion groups. The CHESS program has demonstrated positive quality-of-life outcomes, reduced ambulatory care visits and shorter hospitalizations for minority women [156].

We found several studies that examined use of online cancer support groups among minority groups. Shaw et al. [157] studied CHESS peer support-group outcomes for African American and white women with breast cancer and found limited psychological benefits. Lieberman [158] attempted to replicate their methods in a study with only white participants. When he found increased psychological benefits, he suggested it could be related to differential interest in online psychological support between white and African American women.

3.4.2. Cultural relevance of online cancer communication

In his 2003 review [77], Fogel concluded that there is little research about the cultural relevance of Internet cancer information for racial/ethnic groups. For example, as cited earlier, Buller et al.'s study [136] found that an existing nutrition Website for cancer prevention was not appropriate for American Indians because their traditional foods were not included. Zimmerman et al. [131] commented on the difficulty of developing a cancer prevention Website that Hispanic Americans and American Indians would find easy to use. Birru et al. [102] found that cultural references in the US National Cancer Institute's CancerNet Website were not adequately specific to the ethnic groups targeted. They commented that Websites like that of the American Cancer Society with African American-focused web pages may have links that are difficult to access for people with low literacy. Changrani and Gany [159] found that a cancer Website lacked adequate tailoring for Caribbean women immigrants.

Recent studies are using more comprehensive measures of cultural relevance. Thomson and Hoffman-Goetz [125] used the Cultural Sensitivity Assessment Tool (CSAT) Internet to assess 23 Web-based cancer decision aids. The CSAT scale [160] provides a numeric assessment of variables related to the "cultural sensitivity" of information formats, messages and graphics. Scores range from 4 ("highly cultural sensitive") to 1 ("culturally insensitive"), with 2.5 as the cut point. The Web decision aids averaged 2.78, or "culturally sensitive." Friedman and Kao [122] used the CSAT to measure the cultural relevance of Internet sites for African American, Hispanic, Asian, and white men with prostate cancer, and found a mean score of 2.78—"culturally sensitive." However, because the researchers were concerned that the CSAT had not been validated in the literature, had not been tested on Web-based cancer information, and was not developed for minority groups other than African Americans, they also tested the online information with a checklist of additional cultural criteria and found weaknesses: the tested information neglected to mention perceptions of cultural risk by racial/ethnic group, or cultural beliefs about cancer.

Neuhauser et al. [103] studied the cultural relevance of national nutrition Website useful for cancer prevention by assessing criteria related to graphic representation, textual references, personalization of interactive features, and social support references to racial/ethnic groups, as well as participatory design of the site with targeted cultural groups. Results showed that despite good personalization features and participation of multiple cultural groups in the design, the graphics and text lacked cultural relevance.

Because developing culturally sensitive information is complex and knowledge about these factors is limited, it is critical to involve the target groups in the design and testing of online content [58,78,103,140,161,162].

4. Discussion and conclusion

4.1. Discussion

Cancer survivorship is increasing, but the alarming and sometimes increasing disparities among diverse groups pose a global challenge. People with low literacy and members of racial/ethnic minority groups have significantly lower awareness of cancer risks, and less involvement with actions that can help prevent, detect, or treat cancer [2,15,21,28,29,38,39,41]. Communication, the central strategy to engage people with cancer control, has traditionally been less effective among people who face barriers related to literacy, culture, or language. Research shows that such communication has often been overly generic, passively delivered, and not sufficiently relevant to diverse people's lives [15,28,56,58,115].

Online cancer communication, through features of personalization, interactivity, convenience, and broad extension throughout societal networks, is thought to have great promise to overcome many of the limitations of past interventions [15,58,60–62]. During the past two decades, increasing empirical evidence has shown that online communication can reduce cancer risks, improve screening, and enhance patient care [1,15,55,58,71–75].

However, it is evident from this review that we face significant challenges in taking full advantage of the e-health environment. Substantial numbers of people in underserved groups worldwide still lack access to the Web and to information that meets their linguistic, cultural, or literacy needs or other preferences. Reading levels of online content significantly exceed the average person's reading level, and many sites are not easy to navigate. The majority of Internet sites are English-only, although English speakers are less than a third of the world's population. Research is just beginning to identify the many cultural factors that may be essential to engage and motivate diverse groups to participate more fully in cancer control.

Fortunately, researchers, practitioners, and policymakers are increasingly cognizant of these issues and are taking steps to translate valuable research knowledge into more effective standards and interventions for online health and cancer communication [2,17]. The Commission of the European Communities brought together Internet and health experts and consumers to define quality criteria for health-related Websites, including standards for readability, usability, translation, and cultural adaptation [163]. At the 8th European Health Policy Forum, international experts discussed efforts to improve health literacy for European citizens [113]. In the US, the National Cancer Institute established a Center to Reduce Cancer Health Disparities in 2001 [20].

There are limitations to this review. As noted earlier, keyword searching was not an efficient way to locate the studies

cited in this paper; many were identified through "related links," references listed in papers and reports, and from other sources. For this reason, there are likely to be relevant studies not included here. Referenced studies are in English only, and do not include research published in other languages.

4.2. Conclusion

The initial outcomes of online cancer communication show encouraging results for vulnerable groups. As worldwide Internet access increases, our challenge is to link researchers, practitioners, policymakers and, most importantly, diverse consumers to leverage the potential of cancer communication—so that all groups will benefit equally from cancer research.

4.3. Practice implications

We recommend that practitioners become familiar with the strengths and weaknesses of online cancer communication by exploring the literature in this review in more depth. Understanding the importance of literacy, linguistic, and cultural factors is essential to guide patients and client groups to the best use of cancer information on the Internet. Practitioners may also find that knowing more about these barriers can help them judge where online information fits within overall communication options, such as oral communication, printed materials, and video/DVD. Practitioners who develop communication content can access the US Department of Health and Human Services Quick Guide to Health Literacy at http://www.health.gov/communication/literacy/quickguide/, and the American Medical Association health literacy Website: http://www.ama-assn.org/ama/pub/category/8115.html.

Practitioners can learn more about designing and testing easier-to-use Websites from "Research-Based Web Design & Usability Guidelines" at http://www.usability.gov/pdfs/guidelines.html. The US National Cancer Institute also provides a usability site for cancer information at http://www.usability.gov/. Finally, we believe the most powerful approach is to involve diverse groups in cancer communication design and testing.

Acknowledgments

Conflict of interest

There is no conflict of interest related to the information in this paper.

References

[1] Eysenbach G. The impact of the Internet on cancer outcomes. CA Cancer J Clin 2003;53:356–71.

[2] Hiatt RA, Rimer BK. A new strategy for cancer control research. Cancer Epidemiol Biomarkers Prev 1999;8:957–64.

[3] Kreps GL, Chapelsky MD. Cancer communications research and health outcomes: review and challenge. Commun Stud 2002;53:318–36.

[4] Viswanath K. Science and society: the communications revolution and cancer control. Nat Rev Cancer 2005;5:828–35.

[5] US Cancer Statistics Working Group. United States cancer statistics: 2004 incidence and mortality. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2007.

[6] Cancer in Europe: facts and figures January 2005. European Cancer Leagues; 2007. Report accessed online November 2007 at: http://www.europeancancerleagues.org/ecl/Modules/_Content/FileAttach/cancer%20in%20europe.pdf.

[7] Editorial Board of the Cancer Statistics in Japan. Cancer statistics in Japan: 2007. Tokyo: Foundation for the Promotion of Cancer Research; 2007.

[8] Klausner RD. Statement on the unequal burden of cancer: NCI response to a report by the Institute of Medicine. Testimony before the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies; January 21 1999.

[9] Levi F, Bosetti C, Lucchini F, Negri E, La Vecchia C. Monitoring the decrease in breast cancer mortality in Europe. Eur J Cancer Prev 2005;14:497–502.

[10] Levi F, Lucchini F, Negri E, La Vecchia C. The recent decline in gallbladder cancer mortality in Europe. Eur J Cancer Prev 2003;12: 265–7.

[11] Levi F, La Vecchia C, Lucchini F, Negri E. Worldwide trends in cancer mortality in the elderly, 1955–1992. Eur J Cancer 1996;32A:652–72.

[12] Stewart BW, Kleihues P. World cancer report. Geneva: World Health Organisation; 2003.

[13] Rowland J, Mariotto A, Aziz N, Tesauro G, Feuer EJ, Blackman D, et al. Centers for Disease Control and Prevention. Cancer survivorship—United States, 1971–2001. MMWR Morb Mortal Wkly Rep June 25, 2004;53(24):526–9.

[14] Burgess DJ, Fu SS, van Ryn M. Why do providers contribute to disparities and what can be done about it? J Gen Intern Med 2004;19: 1154–9.

[15] Kreps GL. Communication and racial inequities in health care. Am Behav Sci 2006;49:760–74.

[16] Freeman HP. Poverty, culture, and social injustice: determinants of cancer disparities. CA Cancer J Clin 2004;54:72–7.

[17] Institute of Medicine. Fulfilling the potential of cancer prevention and early detection.. Washington: National Academies Press; 2003.

[18] Prothrow-Stith D, Gibbs B, Allen A. Reducing health disparities: from theory to practice. Cancer Epidemiol Biomarkers Prev 2003;12: 256S–60S.

[19] Smedley BD, Stith AY, Nelson AR, editors. Unequal treatment: confronting racial and ethnic disparities in healthcare. Institute of Medicine. Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. Washington: National Academies Press; 2003. Available at: http://fermat.nap.edu/books/030908265X/html/R1.html.

[20] Garner EIO. Cervical cancer: disparities in screening, treatment and survival. Cancer Epidemiol Biomarkers Prev 2003;12:242S–7S.

[21] Ghafoor A, Jemal A, Ward E, Cokkinides V, Smith R, Thun M. Trends in breast cancer by race and ethnicity. CA Cancer J Clin 2003;53:342. doi:10.3322/canjclin.53.6.342.

[22] Hiatt RA, Pasick RJ, Stewart S, Bloom J, Davis P, Gardiner P, et al. Community-based cancer screening for underserved women: design and baseline findings from the Breast and Cervical Cancer Intervention Study. Prev Med 2001;33:190–203.

[23] Institute of Medicine. The unequal burden of cancer: an assessment of NIH research and programs for ethnic minorities and the medically underserved. Washington: National Academies Press; 1999.

[24] Miller BA, Chu KC, Hankey BF, Ries BA. Cancer Causes Control 2007 (Nov 27 epub ahead of print).

[25] Miller BA, Kolonel LN, Bernstein L, Young Jr JL, Swanson GM, West D, et al., editors. Racial/ethnic patterns of cancer in the United States 1988–1992. Bethesda: National Cancer Institute. NIH Publication No. 96-4104; 1996.

[26] Blakely T, Robson B. Decades of disparity. Wellington, NZ: The Wellington School of Medicine and Health Sciences of the University of Otago and the Ministry of Health; July 2003.

[27] McCracken M, Olsen M, Chen Jr MS, Jemal A, Thun M, Cokkinides M, et al. Cancer incidence, mortality, and associated risk factors among Asian Americans of Chinese, Filipino, Vietnamese, Korean, and Japanese ethnicities. Cancer J Clin 2007;57:190–205.

[28] O'Hair D, Kreps GL, Sparks L, editors. Handbook of communication and cancer care. Cresskill, NJ: Hampton Press; 2007.

[29] Chen MS. Cancer health disparities among Asian Americans. Cancer 2005;104(S12):2895–902.

[30] McGinnis JM, Foege WH. Actual causes of death in the United States. J Am Med Assoc 1993;270:2207–12.

[31] Kerlikowske K, Grady D, Rubin SM, Sandrock C, Ernster VL. Efficacy of screening mammography. A meta-analysis. J Am Med Assoc 1995;273:149–54.

[32] Colditz G, DeJong W, Hunter D, Trichopoulos D, Willett W. Harvard report on cancer prevention: causes of human cancer. Cancer Causes Control 1996;1:1569–74.

[33] Willett W, Colditz G, Mueller N. Strategies for minimizing cancer risk. Sci Am 1996;275:58.325–33.

[34] Byers TE, Mouchawar J, Marks J, Cady B, Lins N, Swanson GM, et al. The American Cancer Society challenge goals. How far can cancer rates decline in the US by the year 2015? Cancer 1999;86:715–27.

[35] Keppel KG, Pearcy JN, Klein RJ. Measuring progress in healthy people 2010. Statistical Notes, no. 25. Hyattsville, Maryland: National Center for Health Statistics; September 2004. http://www.cdc.gov/nchs/data/statnt/statnt25.pdf.

[36] U.S. Department of Health and Human Services. Healthy people 2010. 2nd ed., 2 vols. With understanding and improving health and objectives for improving health. Washington, DC: U.S. Government Printing Office, November 2000.

[37] American Cancer Society. Cancer prevention and early detection: facts and figures 2002. Atlanta (GA): American Cancer Society; 2002, http://www.cancer.org/downloads/STT/CPED2002PWSecured.pdf.

[38] Kinney AY, Bloor LE, Martin C, Sandler RS. Social ties and colorectal cancer screening among blacks and whites in North Carolina. Cancer Epidemiol Biomarkers Prev 2005;14:182–9.

[39] Rutten LF, Moser RP, Beckjord EB, Hesse BW, Croyle RT. Cancer communication: Health Information National Trends Survey. Washington: National Cancer Institute. NIH Pub. No. 07-6214.

[40] Schulmeister L, Lifsey DS. Cervical cancer screening knowledge, behaviors and beliefs of Vietnamese women. Oncol Nurs Forum 1999;26:879–87.

[41] Kandula NR, Wen M, Jacobs EA, Lauderdale DS. Low rates of colorectal, cervical, and breast cancer screening in Asian Americans compared with non-Hispanic whites: cultural influences or access to care? Cancer 2006;107:184–92.

[42] Kreps GL, Viswanath K. Foreword. Communication interventions and cancer control: a review of the National Cancer Institute's Health Communication Intervention Research Initiative. Fam Commun Health 2001;24:ix–xiii.

[43] Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Health Promot 1997;12:38–48.

[44] Stokals D. The social ecological paradigm of wellness promotion. In: Jamner M, Stokals D, editors. Promoting human wellness: new frontiers for research, practice, and policy. Berkeley, Los Angeles, London: University of California Press; 2000. p. 21–37.

[45] Rogers EM. Diffusion of innovations, 4th ed., New York: Free Press; 1995.

[46] Lacoursiere SP. A theory of online social support. ANS Adv Nurs Sci 2001;24:60–77.

[47] Patrick K, Intille SS, Zabinski MF. An ecological framework for cancer communication: Implications for research. J Med Internet Res 2005;7:e23. doi: 10.2196/jmir.7.3.e23.

[48] Street RL. Mediated consumer-provider ommunication in cancer care: the empowering potential of new technologies. Patient Educ Couns 2003;50:99–104. doi: 10.1016/S0738-3991(03)00089-2.

[49] Best A, Hiatt RA, Norman C. Knowledge integration: Conceptualizing communications in cancer control. Patient Educ Couns 2008;71:319–27.

[50] Loerzel VW, Bushy A. Interventions that address cancer health disparities in women. Fam Commun Health 2005;28:79–89.

[51] Kreuter MW, Skinner CS, Steger-May K, Holt CL, Bucholtz DC, Clark EM, et al. Responses to behaviorally vs culturally tailored cancer communication among African American women. Am J Health Behav 2004;28:195–207.

[52] Snyder LB, Hamilton MA, Mitchell EW, Kiwanuka-Tondo J, Fleming-Milici F, Proctor D. A meta-analysis of the effect of mediated health communication campaigns on behavior change in the United States. J Health Commun 2004;9(S1):71–96.

[53] Foerster SB, Hudes M. California dietary practices survey: focus on fruits and vegetables, trends among adults, 1989–1993, topline report. Sacramento: California Department of Health Services and California Public Health Foundation; 1994.

[54] Pinto BM, Eakin E, Maruyama NC. Health behavior changes after a cancer diagnosis: what do we know and where do we go from here? Ann Behav Med 2000;22:38–52.

[55] Neuhauser L, Kreps GL. The advent of e-health: how interactive media are transforming health communication. Medien Kommunikationswissenschaft 2003;51:541–56.

[56] Sparks L, Nussbaum J. Health literacy and cancer communication with older men. Patient Educ Couns 2008;71:345–50.

[57] Zapka JG, Taplin SH, Solberg LI, Manos MM. A framework for improving the quality of cancer care: the case of breast and cervical cancer screening. Cancer Epidemiol Biomarkers Prev 2003;12:4–13.

[58] Neuhauser L, Kreps GL. Rethinking communication in the e-health era. J Health Psychol 2003;8:7–22.

[59] Pecchioni LL, Sparks L. Health information sources of individuals with cancer and their family members. Health Commun 2007;21:143–51. doi: 10.1080/10410230701307162.

[60] Kerr BJ. Cancer information on the Internet. In: O'Hair D, et al., editors. Handbook of communication and cancer care. Cresskill, NJ: Hampton Press; 2007.

[61] Chang BL, Bakken S, Brown SS, Houston TK, Kreps GL, Kukafka R, et al. Bridging the digital divide: reaching vulnerable populations. J Am Med Inform Assoc 2004;11:448–57.

[62] McCray AT. Promoting health literacy. J Am Med Inform Assoc 2005;12:152–63.

[63] Global Reach. Global Internet statistics (by language). http://global-reach.biz/globstats/index.php3. Accessed November 2007.

[64] Miniwatts Marketing Group. Internet World Stats. Bogota, Colombia: Miniwatts de Colombia Ltda., International Div.; November 2003. Available at: http://www.internetworldstats.com.

[65] Andreassen HK, Bujnowska-Fedak MM, Chronaki CE, Dumitru RC, Pudule I, Santana S, et al. European citizens' use of E-health services: a study of seven countries. BMC Public Health 2007;7:53. doi: 10.1186/1471-2458-7-53.

[66] Hsu LL. An exploratory study of Taiwanese consumers' experiences of using health-related websites. J Nurs Res 2005;13:129–40.

[67] Pew Internet &American Life Project. Online health search 2006. http://www.pewinternet.org/pdfs/PIP_Online_Health_2006.pdf. Accessed March 2008.

[68] Larkin M. Online support groups gaining credibility. Lancet 2000;355:1834.

[69] Basch EM, Thaler HT, Shi W, Yakren S, Schrag D. Use of information resources by patients with cancer and their companions. Am Cancer Soc 2004;100:2476–83. doi: 10.1002/cncr.20261.

[70] Harris LM, Kreps GL, Dresser C. Health communication technology and quality cancer care. In: O'Hair D, Kreps GL, Sparks L, editors. Handbook of communication and cancer care. Cresskill, NJ: Hampton Press; 2007.

[71] Kreps GL, Gustafson D, Salovey P, Perocchia R, Wilbright W, Bright M, et al. Using computer technologies to provide relevant cancer information to vulnerable populations: the NCI Digital Divide Pilot Projects. In: Whitten P, Cook D, editors. Understanding health communications

technologies: a case study approach. San Francisco: Jossey-Bass; 2004. p. 328–336].

[72] Revere D, Dunbar PJ. Review of computer-generated outpatient health behavior interventions: clinical encounters "in absentia". J Am Med Inform Assoc 2001;8:62–79.

[73] Marcus AC, Heimendinger J, Wolfe P, Rimer BK, Morra M, Cox D, et al. Increasing fruit and vegetable consumption among callers to the CIS: results from a randomized trial. Prev Med 1998;27:S16–8. doi: 10.1006/pmed.1998.0405.

[74] Krishna S, Balas EA, Spencer DC, Griffen JZ, Boren SA. Clinical trials of interactive computerized patient education: implications for family practice. J Fam Pract 1997;45:25–33.

[75] Balas EA, Jaffrey F, Kuperman GJ, Boren SA, Brown GD, Pinciroli F, et al. Electronic communication with patients. Evaluation of distance medicine technology. J Am Med Assoc 1997;278:152–9.

[76] Atkinson NL, Gold RS. The promise and challenge of ehealth interventions. Am J Public Health 2002;26:494–503.

[77] Fogel J. Internet use for cancer information among racial/ethnic populations and low literacy groups. Cancer Control 2003;10(S5):45–51.

[78] Hesse BW, Shneiderman B. eHealth research from the user's perspective. Am J Prev Med 2007;32:S97–103.

[79] Hesse BW, Nelson DE, Kreps GL, Croyle RT, Arora NK, Rimer BK, et al. Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. Arch Intern Med 2005;165:2618–24 [PMID: 16344419].

[80] Yakren S, Shi W, Thaler H, Agre P, Bach PB, Schrag D. Use of the Internet and other information resources among adult cancer patients and their companions. Proc Am Soc Clin Oncol 2001;20:398a [abstract 1589].

[81] Satterlund MJ, Mccaul KD, Sandgren AK. Information gathering over time by breast cancer patients. J Med Internet Res 2003;5:e15. doi: 10.2196/jmir.5.3.e15.

[82] Fleisher L, Bass S, Ruzek SB, McKeown-Conn N. Relationships among Internet health information use, patient behavior and self efficacy in newly diagnosed cancer patients who contact the National Cancer Institute's (NCI) Atlantic Region Cancer Information Service (CIS). Proc AMIA Symp 2002;1:260–4.

[83] Monnier J, Laken M, Carter CL. Patient and caregiver interest in Internet-based cancer services. Cancer Pract 2002;10:305–10.

[84] Fogel J, Albert SM, Schnabel F, Ditkoff BA, Neugut Al. Use of the Internet by women with breast cancer. J Med Internet Res 2002;4:E9.

[85] Fogel J, Albert SM, Schnabel F, Ditkoff BA, Neugut Al. Internet use and social support in women with breast cancer. Health Psychol 2002;21: 398–404.

[86] Ranson S, Morrow GR, Dakhil S, Wade JL, Fitch T, Roscoe J, et al. Internet use among 1020 cancer patients assessed in community practices: a URCC CCPO study. Proc Am Soc Clin Oncol 2003;22:534 [abstract 2149].

[87] Diefenbach MA, Dorsey J, Uzzo RG, Hanks GE, Greenberg RE, Horwitz E, et al. Decision-making strategies for patients with localized prostate cancer. Semin Urol Oncol 2002;20:55–62.

[88] Smith RP, Devine P, Jones H, DeNittis A, Wittington R, Metz JM. Internet use by patients with prostate cancer undergoing radiotherapy. Urology 2003;62:273–7.

[89] Metz JM, Devine P, DeNittis A, Jones H, Hampshire M, Goldwein J, et al. A multi-institutional study of Internet utilization by radiation oncology patients. Int J Radiat Oncol Biol Phys 2003;56:1201–5.

[90] Peterson MW, Fretz PC. Patient use of the Internet for information in a lung cancer clinic. Chest 2003;123:452–7.

[91] Davis TC, Williams MV, Marin E, Parker RM, Glass J. Health literacy and cancer communication. CA Cancer J Clin 2002;52:134–49.

[92] Michielutte R, Alciati MH, el-Arculli R. Cancer control research and literacy. J Health Care Poor Underserved 1999;10:281–97.

[93] Swartzberg JG, VanGeest JB, Wang CC. Understanding health literacy: implications for medicine and public health. Chicago: American Medical Association Press; 2005.

[94] Baur CE. Using the Internet to move beyond the brochure and improve health literacy. In: Swartzberg JG, VanGeest JB, Wang CC, editors. Understanding health literacy: implications for medicine and public health. Chicago: American Medical Association Press; 2005 p. 141–55.

[95] Doak L, Doak C, Meade C. Strategies to improve cancer education materials. Oncol Nurs Forum 1996;23:1305–12.

[96] Kutner M, Greenberg E, Baer J. National Assessment of Adult Literacy (NAAL). A first look at the literacy of America's adults in the 21st century. Washington: US Department of Education, Institute of Education Sciences; 2005 [NCES 2006470].

[97] US Census Bureau. Current population survey; 2005. http://www.census.gov/population/www/socdemo/education/cps2005.html. Accessed March 2008.

[98] OECD and Statistics Canada. Literacy in the information age: final report of the International Adult Literacy Survey. Paris and Ottawa; 2000.

[99] Centre for Literacy of Quebec. Background document on literacy and health. http://www.nald.ca/PROVINCE/QUE/litcent/health/finalsum/bd/bd3-sec1.html. Accessed December 2007.

[100] Meade CD, McKinney WP, Barnas GP. Educating patients with limited literacy skills: the effectiveness of printed and videotaped materials about colon cancer. Am J Public Health 1994;84:119–21.

[101] Osborne H. Health literacy from A to Z: practical ways to communicate your health message. Sudbury, MA: Jones and Bartlett Publishers; 2005

[102] Birru MS, Monaco VM, Charles L, Drew H, Njie V, Bierria T, et al. Internet usage by low-literacy adults seeking health information: an observational analysis. J Med Internet Res 2004;6:e25.

[103] Neuhauser L, Rothschild R, Rodriguez F. MyPyramid.gov: assessment of literacy, cultural and linguistic factors in the USDA Food Pyramid Web site. J Nutr Educ Behav 2007;39:219–25.

[104] Kirsch I, Jungeblut A, Jenkins L, Kolstad A. Adult literacy in America: a first look at the findings of the National Adult Literacy Survey. Washington: US Department of Education, Institute of Education Sciences; 1993 [NCES 1993-275].

[105] National Work Group on Literacy and Health. Communicating with patients who have limited literacy skills: report of the National Work Group on Literacy and Health. J Fam Pract 1998;46:168–76.

[106] Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. Health literacy: report of the Council on Scientific Affairs. J Am Med Assoc 1999;281: 552–7.

[107] World Health Organisation. Health promotion glossary. Geneva: WHO; 1998. p. 10. http://www.who.int/hpr/NPH/docs/hp_glossary_en.pdf.

[108] Institute of Medicine. Health literacy: a prescription to end confusion. Washington: National Academies Press; 2004.

[109] Bennett CL, Ferreira MR, Davis TC, Kaplan J, Weinberger M, Kuzel T, et al. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. J Clin Oncol 1998;16:3101–4.

[110] Kondilis BK, Soteriades ES, Falagas ME. Health literacy research in Europe: a snapshot. Eur J Public Health 2006;16:113. doi: 10.1093/eurpub/cki204.

[111] Baron-Epel O, Balin L, Daniely Z, Eidelman S. Validation of a Hebrew health literacy test. Patient Educ Couns 2007;67:235–9.

[112] Health literacy in Canada: initial results from the International Adult Literacy and Skills Survey 2007. Ottawa: Canadian Council on Learning; 2007.

[113] Kickbusch I, Wait S, Maag D, McGuire D. Navigating health: the role of health literacy. Gastein Healthy Choices Forum. European Public Health Centre. London UK: Alliance for Health and the Future. International Longevity Center-UK; 2005. http://ns1.siteground169.com/~healthan/healthandfuture/images/stories/Documents/navigating%20health%20-%20the%20role%20of%20health%20literacy.pdf. Accessed January 2008.

[114] Zarcadoolas C, Pleasant A, Greer DS. Understanding health literacy: an expanded model. Health Promot Int 2005;20:195–203.

[115] Doak CC, Doak LG, Friedell GH, Meade CD. Improving comprehension for cancer patients with low literacy skills: strategies for clinicians. CA Cancer J Clin 1998;48:151–62.

[116] Lazaras W, Mora F. Online content for low-income and underserved Americans: The digital divide's new frontier. Santa Monica and Washington: Children's Partnership; 2000. http://www.childrenspartner

ship.org/AM/Template.cfm?Section=Home&Template=/CM/Content Display.cfm&ContentFileID=1034. Accessed January 2008.

[117] Wilson FL, Baker LM, Brown-Syed C, Gollop C. An analysis of the readability and cultural sensitivity of information on the National Cancer Institute's web site: CancerNet. Oncol Nurs Forum 2000;27:1403–9.

[118] Berland GK, Eliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, et al. Health information on the Internet: accessibility, quality, and readability in English and Spanish. J Am Med Assoc 2001;285: 2612–21.

[119] Monaco V, Krills SK. On-line information about cancer clinical trials: evaluating the Web sites of comprehensive cancer centers. AMIA Annu Symp Proc 2003;470–4.

[120] Friedman DB, Hoffman-Goetz L, Arocha JF. Health literacy and the World Wide Web: comparing the readability of leading incident cancers on the Internet. Med Inform Internet Med 2006;31:67–87.

[121] Friedman DB, Hoffman-Goetz L, Arocha JF. Readability of cancer information on the Internet. J Cancer Educ 2004;19:117–22.

[122] Friedman DB, Kao EK. A comprehensive assessment of the difficulty level and cultural sensitivity of online cancer prevention resources for older minority men. Prev Chronic Dis 2008;5. http://www.cdc.gov/pcd/issues/2008/jan/07_0146.htm. Accessed January 2008.

[123] Kaphingst KA, Zanfini CJ, Emmons KM. Accessibility of web sites containing colorectal cancer information to adults with limited literacy (United States). Cancer Causes Control 2006;17:147–51.

[124] Cheh J, Ribisi KM, Wildemuth BM. An assessment of the quality and usability of smoking cessation information on the Internet. Health Promot Pract 2003;4:278–87.

[125] Thomson MD, Hoffman-Goetz L. Readability and cultural sensitivity of web-based patient decision aids for cancer screening and treatment: a systematic review. Med Inform Internet Med 2007;32:263–86.

[126] Nielsen J. Designing web usability. Indianapolis: New Riders Publishing; 2000.

[127] Whitten P, Kreps GL, Eastin MS. Creating a framework for online cancer services research to facilitate timely and interdisciplinary applications. J Med Internet Res 2005;7:e34.

[128] Swan K. Nonprint media and technology literacy standards for assessing technology integration. J Educ Comput Res 2000;23:85–100.

[129] Whitaker WA. Human navigation. In: Forsythe C, Grose E, Ratner J, editors. Human factors and web development. Mahwah, NJ: Lawrence Erlbaum Associates; 1998.

[130] Holmes-Rovner M, Stableford S, Fagerlin A, Wei JT. Evidence-based patient choice: a prostate cancer decision aid in plain language. BMC Med Inform Decis Mak 2005;5:16.

[131] Zimmerman D, Akerekrea CA, Buller D, Hau B, LeBlanc M. Integrating usability testing into the development of a 5-a-day nutrition website for at-risk populations in the American Southwest. J Health Psychol 2003;8:119–34.

[132] Rogler LH, Malgady RG, Costantino G, Blumenthal R. What do culturally sensitive mental health services mean? The case of Hispanics. Am Psychol 1987;42:565–70.

[133] Shin HB, Bruno R. Census Brief: language use and English speaking ability. Washington: US Department of Commerce, US Census Bureau; 2000.

[134] Singh PM, Wight CA, Sercinoglu O, Wilson DC, Boytsov A, Raizada MN. Language preferences on websites and in Google searches for human health and food information. J Med Internet Res 2007;9 (2):e18.

[135] Rai-Chaudhuri A, Hogan RH. The role of on-line cancer support groups in enhancing health care in developing countries-case study of a chronic myelogenous leukemia discussion list. Internet Health 2004;3:e2.

[136] Buller DB, Woodall WG, Zimmerman DE, Heimendinger J, Rogers EM, Slater MD, et al. Formative research activities to provide Web-based nutrition education to adults in the Upper Rio Grande Valley. Fam Community Health 2001;24:1–12.

[137] Friedman SH, Harvey CD, Rein A, Lopez RA. Internet use by Hispanics and its effect on doctor/patient communications. Proc Am Soc Clin Oncol 2002;21 (abstr 2804).

[138] COSSHMO. Delivering preventive health care to Hispanics: a manual for providers. Washington: National Coalition of Hispanic Health and Human Service Organizations; 1990.

[139] Massett HA. Appropriateness of Hispanic print materials: a content analysis. Health Educ Res 1996;11:231–42.

[140] Neuhauser L. Participatory design for better interactive health communication: a statewide model in the USA. Electron J Commun/La Revue Electronique de Commun 2001;11 [numbers 3 and 4].

[141] Shouten BC, Meeuwesen L. Cultural differences in medical communication: a review of the literature. Patient Educ Couns 2006;64:21–34.

[142] Fogel J, Albert SS, Schnabel F, Ditkoff BA, Neugut A. Racial/ethnic differences and potential psychological benefits in use of the Internet by women with breast cancer. Psychooncology 2003;12:107–17.

[143] King E, Rimer BK, Balshem A, Ross E, Seay J. Mammography-related beliefs of older women. A survey of an HMO population. J Aging Health 1993;5:82–100.

[144] Tu SP, Yasui Y, Kuniyuki A, Thompson B, Schwartz SM, Jackson JC, et al. Breast cancer screening among Cambodian American women. Cancer Detect Prev 2000;24:549–63.

[145] Balanskat A. Digital Divide. Policy briefings. Eur Schoolnet 2002. http://insight.eun.org/ww/en/pub/insight/policy/policy_briefings/archive/digital_divide.htm. Accessed March 2008.

[146] Cullen R. The digital divide: a global and national call to action. Electron Libr 2003;21:247–57.

[147] Rice MF. Information and communication technologies and the global digital divide: technology transfer, development, and least developing countries. Compar Technol Transf Soc 2003;1:72–88.

[148] Amiel G. What's new in cancer education research. J Cancer Educ 2005;20:133–5.

[149] World Internet Project. http://www.worldinternetproject.net. Accessed December 2007.

[150] Nguyen KD, Hara B, Chlebowski RT. Utility of two cancer organization websites for a multiethnic, public hospital oncology population: comparative cross-sectional survey. J Med Internet Res 2005;7:e28. doi:10.2196/jmir.7.3.e28.

[151] Kakai H, Maskarinec G, Shumay DM, Tatsumura Y, Tasaki K. Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. Soc Sci Med 2003;56:851–62.

[152] Wei SJ, Metz JM, Coyle C, Hampshire M, Jones HA, Markowitz S, et al. Recruitment of patients into an Internet-based clinical trials database: the experience of OncoLink and the National Colorectal Cancer Research Alliance. J Clin Oncol 2004;22:4730–6.

[153] Gustafson D, Wise M, McTavish F, Taylor JO, Wolberg W, Stewart J, et al. Development and pilot evaluation of a computer-based support system for women with breast cancer. J Psychosoc Oncol 1993;11:69–93. doi:10.1300/J077V11N04_05.

[154] Gustafson D, Hawkins R, Pingree S, McTavish F, Arora N, Salmer J, et al. Effect of computer support on younger women with breast cancer. Report. Madison: Center for Health Systems Research and Analysis, University of Wisconsin; 2000.

[155] Shaw BR, Han JY, Baker T, Witherly J, Hawkins RP, McTavish F, et al. How women with breast cancer learn using interactive cancer communication systems. Health Educ Res 2007;22:108–19.

[156] Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med 1999;16:1–9.

[157] Shaw BR, Hawkins R, McTavish F, Pingree S, Gustafson DH. Effects of insightful disclosure within computer mediated support groups on women with breast cancer. Health Commun 2006;19:133–42.

[158] Lieberman M. The role of insightful disclosure in outcomes for women in peer-directed breast cancer groups: a replication study. Psychooncology 2007;16:961–4.

[159] Changrani J, Gany F. Online cancer education and immigrants: effecting culturally appropriate websites. J Cancer Educ 2005;20:183–6.

[160] Guidry JJ, Larke P, Walker VD, Fagan P, McDowell T, Cormeaux S. Cancer prevention materials for African Americans: cultural sensitivity assessment tool manual.. College Station: Texas Cancer Council; 1996.

[161] Grama LM, Beckwith M, Bittinger W, Blais D, Lollar C, Middleswarth A, et al. The role of user input in shaping online information from the National Cancer Institute. J Med Internet Res 2005;7:e25. doi: 10.2196/jmir.7.3.e25.

[162] Kaplan B, Brennan PF. Consumer informatics supporting patients as co-producers of quality. J Am Med Inform Assoc 2001;8:309–16.

[163] eEurope 2002: Quality criteria for health related websites. J Med Internet Res 2002;4:e15. doi:10.2196/jmir.4.3.e15.