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Health Promot Pract 2014 15: 664 originally published online 16 April 2014
DOI: 10.1177/1524839914530401

The online version of this article can be found at:
http://hpp.sagepub.com/content/15/5/664
Cultural Competence

Development of a Culturally Relevant Consumer Health Information Website for Harlem, New York

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BACKGROUND AND INTRODUCTION

The health status of the population in Harlem is among the poorest within the five boroughs of New York City (NYC). According to a search on the NYC Department of Health’s EpiQuery tool, a 2012 self-reported health status survey revealed that 26% of East and Central Harlem residents view their health as fair or poor in comparison to 16.1% of residents in Manhattan overall (NYC Department of Health and Mental Hygiene, 2012d). The same search shows a higher prevalence of obesity, diabetes, and high blood pressure in these Harlem communities as compared to Manhattan overall (NYC Department of Health and Mental Hygiene, 2012a, 2012b, 2012c). These disparities are highlighted in a 2010 report by the NYC Department of Health and Mental Hygiene showing that death rates in communities such as East and Central Harlem are between 743 and 927 per 100,000 residents, compared to 610 deaths per 100,000 in NYC overall (Myers, Kerker, Thorpe, Greene, & Farley, 2010). Such evidence underscores the importance of convenient access to relevant health information in order to assist in making better health decisions (Coulter & Ellins, 2007; Nutbeam, 2008).

Web-Based Health Education and the Digital Divide

When we began our research in 2004, the use of web-based information as a method of health promotion had gained traction in the health promotion field. However, the “digital divide” concept—the gap between

Keywords: web-based health education; health literacy; consumer education; health communication; Internet; technology; cultural relevance; tailored communications; community collaboration

Health Promotion Practice
September 2014 Vol. 15, No. (5) 664–674
DOI: 10.1177/1524839914530401
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those accessing/using computers and the web and those who are not—emerged, pointing out the tendency to “leave behind” certain sociodemographic populations, such as low-income, low-education, and racial/ethnic groups, including African Americans and Hispanics (Fox, 2011; Jackson et al., 2008). Although e-health may provide convenient consumer access to health information and support, multiple barriers hamper utilization of these sources, such as lack of physical access to computers and the Internet, the need to navigate through overwhelming amounts of information, and mistrust of the medical and health information found online (Anderson, 2004; Car, Lang, Colledge, Ung, & Majeed, 2011; Chang et al., 2004; Kreps, 2006; Sillence, Briggs, Fishwick, & Harris, 2004). Additional factors that reduce the use of the Internet especially in specific populations include difficulty navigating web pages and lack of digital literacy (Ginossar & Nelson, 2010; Car et al., 2011; Eshet-Alkali & Amichai-Hamburger, 2004; Kreps, 2006).

Many e-health sources exist online, but it is imperative that individuals find accurate, reliable, and comprehensive information that meets their specific needs, and that these resources recognize cultural influences and cater to various levels of health literacy (Hay, 2010) and digital literacy.

**Health Literacy**

Consequences of inadequate health literacy include higher rates of chronic illnesses, greater use of health care services, higher rates of hospitalization, lower use of screening and other procedures, and poorer understanding of disease processes and adherence to treatment regimens (McCray, 2005; Speros, 2005). Navigating today’s health care system carries with it a high health literacy burden. Consumers need to interact in a variety of health care settings and with a broad range of health-related information. In addition, consumers are increasingly asked to take greater responsibility for their own health care and disease management (McCray, 2005). Although there are a number of definitions for health literacy, the World Health Organization (1998) defines it as representing “the cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health” (p. 10). More than reading pamphlets and successfully making appointments, achievement of health literacy requires adequate support systems that ensure that vulnerable or disadvantaged populations are able to access, process, and respond to health information (Hay, 2010). Research shows that one out of five American adults reads at or below a fifth-grade reading level, but most health care materials are written above the tenth-grade level (Glassman, 2012).

Health literacy is a critical component of content on a health information website (Glassman, 2012). Medical or health information is often not relayed effectively to consumers due to technical jargon that is insufficiently translated for laymen. Research shows that barriers are not limited to cultural differences but also include socioeconomic status (SES) and scientific knowledge (Egbert & Nanna, 2009). As health care providers tend to have higher SES and greater exposure to biomedical information, it is crucial that they be attentive to health literacy in their practices in order to better communicate health information (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Speros, 2005).

**Cultural Competence**

Another related and critical component of a health information website is consumer-centric and culturally competent content (McCray, 2005). E-health resources are often designed without involving the community (Ginossar & Nelson, 2010). In 2004, The U.S. Department of Health and Human Services released a report that envisioned “a health care industry that is consumer-centric and information-rich, in which medical information follows the consumer, and information tools guide medical decisions” (Thompson & Brailer, 2004 p. a). Consumer-centric information, including health status–monitoring tools and customized prevention and self-care information, helps individuals manage their own wellness and assists with personal health care decisions (McCray, 2005).

Additional considerations in ensuring consumer-centric health information rest on research showing that ethnic and racial similarities between consumers and health care professionals can be critical to quality care. For example, the degree of sharing of “common life experiences and societal circumstances,” including issues of racial discrimination, creates either rapport or detachment between patients and providers (Saha et al., 2011). Differences in “perspectives, values, beliefs, biases, customs, and communication styles” breed barriers between patients and providers, whereas similarities may help nurture beneficial interactions between them (Saha et al., 2011). These findings suggest that consumers are more likely to trust and accept health care and information provided by someone from similar backgrounds, including ethnicity and race, a shared history, and societal conditions.

To better understand and serve the needs of specific populations, community-based participatory research...
(CBPR) methodologies are increasingly used in health research and intervention design. CBPR is a research paradigm designed to bridge the gap between science and practice through community engagement and social action to increase health equity (Buchanan, Miller, & Wallerstein, 2007; Wallerstein & Duran, 2010). CBPR intervention research is based on two primary assumptions for improving health outcomes and reducing disparities: that interventions can be strengthened if they benefit from community insight and that there is an added value to community participation in enhancing the community’s health (Wallerstein & Duran, 2010).

Health Behavior Theories

Health information websites as a form of intervention can be informed by behavior change theories. Theories provide a framework for addressing various determinants of individual behavior by examining a person’s psychosocial environment and interpersonal relationships, as well as the community-wide and policy structures that influence access to or actions on health-related matters (National Cancer Institute, 2005). According to several recent systematic reviews, some behavior theories used most frequently in the design of health interventions include the transtheoretical (stages of change) model, social cognitive theory (SCT), health belief model, theory of reasoned action/theory of planned behavior, and social networks/social support (Painter, Borba, Hynes, Mays, & Glanz, 2008). These theories primarily involve individual and interpersonal levels of behavior change. Our research focused on the transtheoretical model, SCT, and social networks/social support.

The transtheoretical model is based on an individual’s readiness to consider or engage in any particular behavior change (Glanz & Bishop, 2010; Glanz, Rimer, & Viswanath, 2008). The SCT posits that personal attitudes, in combination with a person’s social and physical environment, and the characteristics of the behavior itself all influence behavior change (Glanz et al., 2008; Langlois & Hallam, 2010). Social networks and social support examine relationships surrounding an individual, where social networks address the context of interpersonal relationships (intensity, reciprocity, homogeneity, etc.) and social support describes the content of those relationships (emotional, instrumental, informational, and appraisal; Glanz et al., 2008).

Web 2.0 Technology as a Social Support Mechanism

Health information websites that incorporate social support mechanisms have the potential to increase the likelihood of positive health behavior changes. Web 2.0 technology can encourage a more human approach to interactivity on the Web, support group interaction, and foster a greater sense of community (Kamel Boulos & Wheeler, 2007; Thackeray, Neiger, Hanson, & McKenzie, 2008).

With health literacy, cultural competence, theory, and Web 2.0 technology in mind, we developed GetHealthyHarlem.org (GHH) over a 5-year period using CBPR methods to incorporate continuous involvement of community partners and individuals.

METHOD

GetHealthyHarlem.org: A Health Literacy and Consumer-Centric Health Education Website

GHH is a unique, Internet-based health resource that addresses health literacy while tailoring content for the target audience, primarily consumers of color in Harlem, New York. Recognizing the need for a demographically relevant health information website, we aimed to minimize the cultural distance between health information and consumers in order to increase health literacy and the likelihood that consumers would trust and act on the information found. In collaboration with community groups and individuals, we focused website content on chronic illnesses prevalent in Harlem.

Community-Based Participatory Research

Using CBPR methodologies, we describe our experiences, thought processes, and efforts in engaging the Harlem community in the development of GHH.

Focus Groups. We first explored the viability of using web-based technology to promote health in Harlem by gathering information about what community members look for when seeking health information online. Our focus groups revealed discouragement with hard-to-understand content and disappointment in existing health websites that did not reflect their ethnic or cultural backgrounds. Respondents also indicated that colors and architecture of a website were keys to attracting attention and maintaining engagement. The methodology of these focus groups is provided elsewhere (Kukafka et al., 2007).

Landline Phone Survey. To better understand access to and use of computers and the Internet in Harlem, we conducted a landline random-digit dial survey. The survey sought to uncover perceived access to, barriers to, and future intent for computer and Internet use in...
this community. Attitudes toward the Internet as well as inadequate understanding and trust of information found online illuminated the need for and potential benefit of providing a web-based health information resource. Findings of this research show that the majority of respondents have access to computers and the Internet and that they use the Internet to find health information. Where previous research showed a substantial divide between racial/ethnic groups, our findings did not show any significant differences based on race/ethnicity. This is likely because our audience is primarily African American and Hispanic. Our research did find, however, that a digital divide exists between younger and older users and between those with higher SES versus lower SES (see Cohall et al., 2011, for detailed results).

Ongoing Community Input. Concurrent to developing the website, we established a core group of up to 10 community volunteers living or working in Harlem. This group helped direct all aspects of website development, including content, features, look and feel, and navigation. This group began meeting in 2007 and continues to meet monthly to create and critique the website as well as to determine outreach strategies and targets.

Website Development

Based on information gathered from the focus groups and landline survey, we involved key stakeholders and community members to develop a web-based health education “portal.” This static portal concept consisted of providing links to health-related websites and organizations that address issues and interests of the local community, mindful of including easy-to-understand and culturally appropriate health information. During our Internet search between 2006 and 2007 for such websites, we soon experienced firsthand the concerns voiced by community members. This led us to shift our focus from a static portal to a community health website where we create geographically tailored, culturally appropriate, and easy-to-understand health content, while allowing users to engage directly through features such as blogs and comments.

With the increased popularity of Web 2.0 platforms such as Facebook and Wikipedia, modifying the aforementioned static website (see Table 1) to include information-sharing technology enabled online users to become active members and contribute their own events, articles, and thoughts. This addressed part of the “wish list” of community members to be able to share information found online with others. This static content plus Web 2.0 technology resulted in a hybrid website.

RESULTS AND DISCUSSION

Website Content Development

The site offers tailored content to match the characteristics and needs of Harlem residents. Content focuses on chronic illnesses related to hypertension, such as obesity and diabetes, as research shows disproportionately high prevalence of these illnesses among Harlem residents. Focusing on health disparities specific to Harlem increases pertinence of the website to the community.

Original articles and other content are mindfully written for consumers at a sixth-grade reading level or below, minimizing “public health speak,” and with a nonacademic jargon. To further address the issue of health literacy, we developed two “dictionaries” on the website, Healthopedia and Pharmapedia, which provide easy-to-understand definitions of biomedical terms to help consumers understand information more completely.

Incorporating the transtheoretical model, GHH articles address individuals at any stage, with a particular focus on moving people from precontemplation to contemplation as well as moving those in contemplation to preparation and action (Glanz et al., 2008). We also consulted the SCT with special regard to skills building and modeling in order to increase self-efficacy in our target population. Articles were written with conscious attention to the target audience’s environment and any barriers that exist locally.

We developed three content types to deliver health information: (a) Harlem Word, (b) Profiles of Hope, and (c) Did You Know? Harlem Word includes interviews with local health professionals and experts who provide information on health issues disproportionately prevalent in this community. These articles increase awareness about various health topics (consciousness raising) while offering tips for dealing with obstacles, taking baby steps toward healthy behavior change, or finding appropriate resources (self-efficacy, skills training). The expertise of these health professionals who serve the community increases the website’s ability to address local health concerns. The interviews occasionally take a more personal route where the interviewees share their personal story about their own path to healthy behavior (modeling).

Profiles of Hope are interviews with Harlem community members who have dealt with a health problem. Anecdotes from individuals of similar ethnic
origins aim to establish a connection and inspire hope in consumers dealing with similar health problems (McAlister, 1995). These articles use modeling as a way to teach skills, demonstrating how a person from Harlem can overcome obstacles to achieve his or her health goals (skills training, modeling), while also intending to add to users’ virtual social network, covering concepts of homogeneity and instrumental and informational social support.

Did You Know? includes short articles on health issues concerning the community on topics related to fitness, food, spirit, and mind (mental health and relaxation), health information, and environment (e.g., air pollution and home environment). These articles provide information about a health topic and step-by-step instructions on accomplishing the behavior change (consciousness raising, skills training, and self-efficacy). All articles are based in Harlem and aim to increase website relevance to consumers through the content and people featured.

The website incorporates several means of social support, allowing users to receive and offer support to others through individual profiles to share personal experiences and resources. Users can post comments on all content, allowing them to share their thoughts on information found on the website. Details on the functionality on GHH are reported elsewhere (Khan, 2007, 2009).

In addition to posting comments, community involvement and interaction are further fostered through the “Events” and “Around Harlem” features. Events is a calendar of local health-related events and activities. Around Harlem includes profiles of healthful resources with contact information and hours of operation. Together, these offer opportunities for community members to participate in local events, locate places to exercise and eat healthfully, find health information, and seek medical and social support.

### Website Design Development

The look and feel of GHH took many years to develop with constant feedback from community members (Figure 1). The theme color (orange) and logo of the final website came after three major iterations (see Figures 2 through 4) between 2007 and 2008. Here, we briefly describe the changes, with figures of each version providing additional detail.

The first version of the website (Figure 2) provided our team and community members with a general idea of the concept for the site, including introducing its basic layout and ideas for section names. The section names (“Get Moving,” “Get Food,” etc.) were intended to provide catchy identification of the major topics covered on the site, such as physical activity, healthy food, and the like. However, feedback from our monthly meetings with community members revealed that they did not connect with the names of the sections, stating that although the names of the sections were catchy, they were not helpful in determining the purpose of each section.

With this feedback in mind, the second version of GHH used icons, designed by art students, to accompany the titles (Figure 3). This second version also added graphics, a new color scheme (blue), and logo options to make the website more appealing to visitors.
Logo options were shared with community members through on-the-street interviews and our regularly occurring monthly meetings. Figure 3 shows one option for the logo.

Even with the new icons to assist in understanding section names of the site, community members did not feel that the sections were easy to understand on first glance. They shared that the images could be interpreted in various ways or that the icons were too abstract. By the final version of the website design (Figure 4), the titles were replaced by simple, descriptive words indicative of the section topic.

Throughout our collaboration with community members, the importance of geographic and cultural relevance was made clear. Community members expressed that colors such as orange, red, black, and green represented Harlem. In addition, community members wanted to see local areas featured in photos on the site. Figure 4 shows an example of how these recommendations were implemented. Every article includes a picture of the person featured or an image related to a topic in order to increase visual interest.

In addition to the logo, theme color, and section names, a major change between the website designs is in the display of the events (community) calendar. Over time, it became clear that listing the actual event names and dates made it more likely that community members would know what they wanted to learn more about and click on the specific event. This was more effective than an image of a calendar with no information attached (Figures 2 and 3).

To highlight the social networking component of the hybrid website, the “New Members” area on the bottom right-hand side of the site (Figure 4) shows avatars or photos of people who have registered with the website. By including this information on the home page, we
sought to address the social support needs highlighted in earlier conversations as well as demonstrate the presence of other similar individuals in this online community.

All items on the page are simplified and spaced to include white space and minimize clutter of the site content.

Finally, research from other studies raised “concerns about dangerous or biased information on the Internet.” Internet information has different characteristics e.g. . . . ease with which anyone can publish information on the web” (Childs, 2004). The lack of moderation in health information available on the Internet troubles consumers and develops mistrust in the information. To address these concerns, GHH is Health on the Net Foundation (HON; 2010) certified, demonstrating its aim to provide a safe, virtual environment. According to the HON website (http://debussy.hon.ch/cgi-bin/find?1+submit), there are 67,547 health websites, out of which only 239 are HON certified. Other HON certified websites include the U.S. Food and Drug Administration, American Cancer Society, and National Center for Complementary and Alternative Medicine.

Public Launch of GetHealthyHarlem.org

The website launched in November 2008 as part of a community forum to introduce community members to the site. Workshop topics highlighted different sections of the website and other topics such as living well on a budget. Workshops were led by Harlem Word interviewees to feature site content and demonstrate that interview subjects are real people working in their community.

CHALLENGES AND LIMITATIONS

We experienced several challenges and limitations over the course of developing and promoting GHH.
Financial Capacity

As a nonprofit, grant-funded research institution, our Center at times faces challenges in providing the best, current, and relevant information through the website.

Upkeep of Site. GHH is hosted and maintained by a consultant agency specializing in website development and maintenance. To continue running the site, several costs must be met, including those for paying the consultant, maintaining the URL, hosting and securing the server on which it resides, and addressing technical problems as they arise. Keeping the site fresh requires working with the web developer to review current features and develop additional features as necessary. Given the current financial climate, sustainability is also an issue, with the constant threat that grant funds will diminish to the point where we are unable to maintain the site financially.

Staffing. At present, two full-time staff members manage the site, and there is no paid staff member fully tasked with coordinating and implementing an outreach plan. As such, outreach activities are carried out by interns with limited amounts of time. This presents a challenge for maintaining visibility with community organizations and members. To build partnerships and trust in the community, a consistent image is important.

Content Development

To encourage frequent site usage, we strive to maintain a constant flow of new content. The process of completing one article, including interviewing/research, transcription, and writing, is time-consuming, often taking 6 weeks or more from start to finish. Interns develop content, which undergoes multiple revisions with staff members and advisory board members, who vet the information for medical accuracy.
Interns are largely master’s of public health students in the process of learning public health concepts such as structural barriers to good health, health literacy, and health behavior change theories. Staff members actively teach interns to use their academic skills in a real-life environment where student work is published on a live website. Our challenge is to provide this essential training while maintaining an active and growing website.

**Spam**

While we have active site users, we have encountered spam problems. When the site first launched, the amount of spam was overwhelming. We continue to work at eliminating user profiles and content generated by automated users in an attempt to control spam, while still encouraging community involvement.

**CONCLUSION**

Our experience in establishing this site highlights the importance of ongoing community collaboration and flexibility. Health behavior theory and community engagement remain key foundations in ensuring relevance of health information online. Furthermore, our work in developing and implementing this geographically tailored, consumer health information website has allowed us to expand its use in additional Center programming, including a randomized control trial of health education materials in hypertension reduction.

Our next steps in this process include promoting the website to increase its use and then evaluating use among website visitors. Given the highly competitive, fast-paced, and dynamic environment of online communication, including photo-based, instant sharing,
and mobile devices, we will also need to identify feasible updates to the website’s capabilities in order to remain current while being cognizant of community needs and wants. Our experience proposes that public health professionals and organizations develop long-term advisory relationships with members of the priority population to determine what methods best serve community needs while also considering their own capacity for building and managing online interventions, which involves revising and publishing content quickly while simultaneously nurturing off-line and online relationships.

Additional research regarding the process of theoretically based online interventions from conception to design, implementation, and evaluation could provide insight into best methods for achieving health behavior change at the individual level in various communities. Higher level interventions would also be an interesting topic of exploration with the increased influence of online communication modalities at community and policy levels. Increasing the availability and variety of evidence-based online intervention programming will provide practitioners with the necessary tools to provide effective and efficient services to their target populations.

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