

THE INTERNET, MINORITIES, AND PATIENT EDUCATION

A community-based education project

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ABSTRACT

Background: With the increase of accessibility and information on the internet, it becomes incumbent on health care providers to examine at how the internet can be used as an adjunct to helping patients make proper health-related and lifestyle decisions. In the Bronx community alone, studies have found that about 64% of patients have internet access. Studies conducted at the national level have shown that anywhere between 40-78% of patients are using the internet to acquire health information with about 68% searching for information on nutrition and diet. With the rise in obesity and obesity-related diseases in the Bronx (24% of the Bronx community are obese), the use of the internet by patients to learn how to combat obesity (self education) and its possible sequelae can be a powerful community-based education tool.

Objectives: 1) To create a community-based health information website that patients can access from their home, in order to find high quality information on a broad range of health topics

related to obesity and nutrition and exercise. 2) To educate patients about basic information regarding obesity, nutrition and exercise, and then to teach them how to use the internet, in particular the community-based website, to find information to answer their obesity and nutrition related questions. The overall goal is to help empower the Bronx community to feel comfortable using the internet in seeking out health information resulting in better health-related decisions.

Project Description, Setting, and Participants: The project incorporated both weekly didactics and the development of the website. The didactic portion was held weekly at the Health Center at Tremont and was attended by clinic patients enrolled by Dr. Jose Rodriguez. The weekly sessions averaged an attendance of approximately 10 patients, with more than half attending regularly.. The demographics of the participants were: ages 40-60, African American or Hispanic, obese- many had at least one obesity-related disease, i.e. diabetes and/or hypertension), and low-income/low educational status. The classes taught the participants about basic nutrition and exercise information and methods to modify their current habits to achieve behavior change. Participants were then taught how to obtain health information on the internet related to the class discussion and in particular accessing the newly created program website (healthnotcosmetics.250free.com/HealthNotCosmetics/index.htm). The website was designed using education materials obtained from prior work on the Health Not Cosmetics project, feedback from class participants on what the content of the website should be, and from research conducted to find articles and tools from other health-related websites. The Health Not Cosmetics project and the related website are partially funded by a grant from AETNA .

Outcomes and Future Research/Application: The primary outcome of this project was to teach patients some basic nutrition, obesity and exercise information they could use, with a special emphasis on holiday eating. In addition they were introduced to the Internet as a source of health information, in particular the Health Not Cosmetics website. Because this is a work in progress, future research should focus on how using the Health Not Cosmetics website and

attending the clinic classes impact behavior change and promote a decrease in obesity, as measured by BMI, and obesity-related diseases in the clinic population. Future research can also focus on providing specific data on internet use in low income, low education, minority populations, and the demographics of those seeking health information online. This research should also analyze whether patients are differentiating the quality of the health information they are gathering from the internet. Also, the impact of internet use on the doctor-patient relationship can be examined. Based on grant funding, the class and WWW education model can be brought to the larger Bronx community.

INTRODUCTION

With the rise of the internet as a source of information on a vast amount of topics, it is also becoming an increasingly sought after source of health information. Using the internet patients can find information on specific conditions and their management, prescription drugs, and a host of sites on nutrition, diet, exercise, and other lifestyle modification topics. In order for patients to utilize the internet as a health education resource, they must have access to 1) a computer and 2) internet access. According to a large U.S. survey on internet use, fifty-two million adults (or 55% of all those online) use the internet to obtain health or medical information¹. By 2005, the number of people using the internet for health information will rise to about 88.5 million². This increase in computer and internet access is also prevalent within the Bronx community. A recent study showed that within the Bronx community, 64% of people had at least one in-home computer, and of those, 92.6% reported internet access³.

For the past year, the Health Not Cosmetic project, pioneered by Dr. Jose Rodriguez at the Health Center at East Tremont clinic, has sought to provide patients with the tools and information necessary to initiate behavior modification, specifically focused on reducing obesity and achieving diabetes control. This has been accomplished through weekly classes conducted

by both Dr. Rodriguez and medical students. Given that obesity related diseases are more prevalent in the Bronx community, compared to other areas in NYC, and that a large number of people in the community have access to both computers and the internet as stated above, the development of a web-based educational tool that patients may access on their own would be an extremely useful adjunct to the limited current patient education e received at primary care clinics. Before investing in developing such an educational website, it is imperative to search the current literature and analyze the data supporting the effectiveness of the internet as a patient educational tool and whether there is evidence to support its use in urban, minority populations similar to the Bronx communities.

THE INTERNET AS A SOURCE OF HEALTH INFORMATION

There is considerable evidence in the literature that shows that the internet is being used by patients to access health information. Two recent studies were conducted to evaluate the use of the internet by patients for health care information. The first study⁴ was a self-administered survey that was mailed to 1,000 patients randomly selected from a primary care internal medicine private practice in Providence , RI . Of the 1,000 patients, 512 returned a completed survey (56.2%) which asked about internet use for medical reasons (i.e. specific conditions, medications) and the frequency of use, the usefulness of the internet, perceptions on the quality of the information found, and how they judged the reliability of the information. Fifty-three percent of the respondents stated that they used the internet for health information. Interestingly, of these respondents 68% stated that they used the internet to find information about nutrition or diet. Sixty-two percent of respondents rated the quality of the information as “excellent” or “very good” while none of those responding rated the information as “poor.” This is disconcerting given that the quality of health information on the web is not all good^{5,6} and patients seem to not be able to differentiate high from poor quality information. The major problem with this study was that the majority of respondents were higher income, higher educated, and white,

unrepresentative of our community. There was no stratification for these factors. Nevertheless, and as will be seen later, the internet is still a significant source of health education.

A second study published in May 2003, *Journal of American Medical Association*⁷, measured the extent of Internet use via a survey sent to 12,878 individuals who agreed to participate from 60,000 individuals asked to participate via random digit dialing. Of the 12,878 individuals, 8,935 responded (69.4%). The respondents were stratified on age, sex, race, education, region, metropolitan residence, and veteran status in efforts to match known distributions of the US population. Only the data collected on 4,764 respondents was used because these respondents had used the internet prior to the study (which provided everyone with WebTV hookups). Seventy-nine percent of respondents lived in urban areas similar to our Bronx population. Forty percent of respondents stated they used the internet for acquiring health information over the past year. The use of the internet for health information was infrequent with most saying they used it every 2-3 months. The study also found that there was stronger relationship between educational level and use of the internet than that between income and use of the internet (something not seen in the previous study). Although the use of the internet for gathering health information was infrequent, it does not belittle the fact that 40% of the respondents were using the internet for health information. The authors of the paper mention in their discussion that this infrequent use may be more a product of sample bias and wording of questions in the survey than an actual representation of the US population's frequency of use of the internet for health information.

Benefits, Risks, and Challenges of the Internet as a Patient Education Tool

In a review article that examines the effect of the internet in promoting both health and illness, the authors focus on those factors of online communication that produce positive health outcomes and also the potential for health risk. Some of the benefits that were found by the

review include: more proactive patients in their personal care, stronger partnerships between patients and doctors, decreased doctor visits for minor maladies, online support groups and community-building capabilities (both of which contribute significantly to empowerment). On the flip side, the review also found that the internet may also be a new health-risk environment. A growing concern is over internet “addiction”, which can have many serious consequences if it affects offline behavior. The internet is also a portal through which people can solicit sex-partners, so it represents a new high-risk environment in terms of STD’s and HIV/AIDS. It can also be used to acquire illegal drugs, acquire prescription drugs, and to gamble. But despite any risks(which need to be addressed and limited) , the widespread use of the internet for health related information will make it indispensable in addressing health promotion and disease prevention, on which our project is focusing⁸.

The use of the internet as a health tool also creates certain challenges. Some of these challenges include clearly defining the roles and responsibilities of the patient/provider relationship, disseminating quality information, ensuring privacy and confidentiality, and ensuring greater accessibility. ⁸ For example, a recent study has shown that many health information websites offer incomplete or misleading information, while others “blur the distinction between advertising and medical advice”⁹.

Internet Use In Primary Care-Underserved Populations

Previous research has established a significant number in our community with internet access (64%)³. However, before becoming content with this number, it is imperative to assess the demographics, or the internet usage patterns of family medicine patients in a similar population. In a study done at the University of Texas Health Science center, they surveyed 824 university based family practice patients, >18 years old, over a 2 week period in November 1999 with a response rate of 72.2%. The survey assessed availability of a home computer, internet access, and

intended use of a health website. Their mean and median age was 44 and 45.7 respectively, similar to our target audience in our HealthNotCosmetic class. Patients were asked if they would use a free health information Web Site provided by the university. Close to 40% claimed a home computer, and 32% claimed internet access. Of those, about 50% said they would use the free website to acquire health information. Having internet access at home considerably enhanced the likelihood of using the website (OR=5.62, 95% CI=2.83-11.18;P<.001). There were several limitations to this study. First of all, it was dealing with intended use and not actual measured use. The survey was self reported, with no way of verifying the information reported. Importantly, in order to maximize patient response, they elected not to ask about potentially sensitive information such as race/ethnicity, education level, and income¹⁰. Hence, patient demographics is limited, but what is clear is that in this population, increasing access suggests more use.

There was a study done in 1999 that actually did survey its population about race, income, and education within the overall question of access and internet use for obtaining health information. In a nationally representative, random, telephone survey of 1237 people between 18 and 60, with addition of 301 African-Americans for more detailed subgroup analyses, questions about home computer, internet access, and use of the internet to get health information were asked. The results were very interesting: Lower incomes and lower education were associated with a significantly less likelihood of having/using a computer, having internet access, and using that access to obtain health information compared to their high income, high level of education counterparts. (less than 30,000—at least 2X less likely to have internet access and use it to access health information than those making more than \$50,000. Similar numbers in terms of education level. All p values < .001) Gaps between Blacks and Whites were similarly pronounced. When corrected for income (which home computer, internet access, and accessing health information may all directly correlated) these gaps tended to disappear. The study also asked specific questions as to what those online were looking up. Once people were on the internet, its use at

home to get health information is similar across income, education, race, and age¹¹. These glaring statistics point to access to the internet as the key to accessing health information not dependent on any other variable. Since there are significant numbers in our community with internet access, this lends itself to a community based web service for accessing health information. There were some limitations to the study however. The telephone survey is itself a bias because it will miss surveying those lower income families without a phone. If they don't have a phone, they don't have access.

Another recent study was designed to determine whether access to health information via internet can positively influence "empowerment" among residents of a low-income urban community. Empowerment refers to the ability to make the most informed decisions and have control over ones' personal life. It is characterized by a "sense of perceived control, competence, and goal internalization." In-home internet access and some training were provided to volunteers (people who had already worked for the community i.e., from those on the community board) in a low income urban community in Chicago . They were taught to reach and search a community specific health-oriented web page. There was also a comparison group, randomly chosen from the volunteers same street block (a secondary goal looking at opinion/leader effect). The study consisted of a monthly telephone survey asking about internet usage and for what purpose. The study found that at baseline the intervention group was similar to the comparison group in terms of empowerment. After receiving internet access and some basic training, empowerment related to health-decision making improved significantly in the intervention group, while similar changes did not occur in the comparison group (all p values <.05 between baseline and 1 year). Also, perceptions about internet and technology, as well as mere comfort with them, significantly improved in the intervention group, which adds an additional element of empowerment. The study failed to give any p values to determine the significant difference between the two groups' demographic characteristics. There were definitely a larger number of more educated people in

the intervention group, for example. Also, the intervention group was chosen on the basis of their previous community involvement or leadership, ie: already shown to be motivated, and may not be representative of the community as a whole. Either way, it was found that internet access to the community health web page and to just general health information leads to a greater sense of empowerment and appreciation of information technology¹². The idea of this study embodies our goals of starting a community based health oriented web page and teach our community to access, search, and empower themselves to make better health-related and lifestyle decisions.

CONCLUSION

After analyzing the above literature, it seems clear that 1) the internet is an increasingly used tool for gathering information including health-related topics, 2) independent of any variables (i.e., sex, age, race, socioeconomic status), access to the internet is the rate-limiting factor in using the internet as a patient education tool, 3) there are many benefits (i.e., greater patient empowerment and proactivity) and risks/challenges (i.e., poor quality of information, illegal purchase of prescription and illegal drugs, access to the internet), and 4) despite the amount of literature about the use of the internet for obtaining health information, the number of studies on lower income/minority populations in urban centers are few.

Future research and outcomes should focus on how using the Health Not Cosmetics website and attending the classes impacted actual behavior modification and hopefully promoted a decrease in obesity and obesity-related diseases in our community. Future research should also focus on providing more data on internet use in low income, low education, minority populations, especially those seeking health information from the internet and the demographics of those using the internet (especially our website). This research should also examine whether patients are differentiating the quality of the health information they are gathering from the internet, and the impact of internet use in our community on the doctor-patient relationship. It is obvious that

further research and application of findings must occur in order for increased utilization of the internet as a patient education tool. With time websites like ours and others will change the face of how patients get their health information.

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