One Size Does Not Fit All: Using Qualitative Methods to Inform the Development of an Internet Portal for Multiple Sclerosis Patients

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ABSTRACT

Disabled and elderly populations are the fastest growing segment of Internet usage. However, these people face an “Inverse Information law”- access to appropriate information is particularly difficult to those who need it the most. Our tertiary care Multiple Sclerosis (MS) center received funding to develop a MS specific patient portal linked to web messaging system so as to empower patients to become more active participants in their health care. In order to design an effective portal, we conducted a qualitative study using focus groups and direct observation techniques. The study explores the perceptions, expectations and interactions of MS patients with the portal and underscores the many challenges MS patients face in getting quality health information on the Internet. Many of the patient barriers were due to inappropriate font sizes, low contrast, cluttering of web page and use of dynamic and flashing objects. Some of these issues are not addressed by Section 508 accessibility guidelines. We believe that any future patient portal or health information web site needs to address these issues and educate the patients about accessibility options to enhance utilization and user satisfaction.

INTRODUCTION

Multiple Sclerosis (MS) is a progressive disease of the central nervous system, without known cause or cure, that affects an estimated 250,000 to 350,000 patients in the United States (U.S.). The majority of patients with MS accumulate significant disability within 15 years of diagnosis, and consequently live with chronic disability for many decades. This leads to significantly more direct and indirect health care costs in comparison to the general U.S. population. Traditional face-to-face interventions are impeded by MS patients’ physical and cognitive problems, which limit their ability to attend clinic visits and recollection of details about their clinical encounters. Because of such disabilities and special care needs, MS can serve as an excellent model for innovative care delivery improvements including web-based disease management and telehealth interventions.

Our tertiary care MS treatment and research center (the Mellen Center, Cleveland Clinic Foundation) has received federal funding to develop and test a system that empowers patients to become more active participants in their health care. The proposed system called Mellen Center Care On-Line (MCCO) provides for an Internet-based secure patient portal to address a wide variety of clinical concerns, enhance patient-physician secure communication, provide links to MS symptom specific health information, and allows patients to monitor changes in disease status and prepare for upcoming health care visits.

This study resulted from the authors’ experience of designing the MCCO system. Since the literature on optimal web designs for MS patients is scarce, we explored MS patients’ health seeking behavior and experience with Internet so as to inform the development of the portal. We hypothesized that MS related impairments such as visual disturbance, incapacitating fatigue as well as cognitive problems, and memory would affect patients’ perceptions, experience and usage of the portal. The aims of this study were threefold: (1) to explore perceptions and beliefs about the Internet among MS patients, (2) to identify MS specific barriers to Internet usage, and (3) to analyze strategies that can help them make more effective use of the web and patient portals.
METHODS

We used multiple methods of data collection that are commonly used in studies of human computer interactions, combining focus groups with direct observation of consumers searching the Internet. Participants in the focus groups and the observational study were MS patients who were recruited voluntarily from the Mellon Center Patient database. Since Mellon Center is a tertiary care center with a wide patient referral base, the selection of patients for the study was limited to those who resided in the adjoining counties. Patients were excluded if they were unable to participate in an interview as a result of any significant comorbidity or if they were unable to give informed consent because of cognitive defects. Patient volunteers were recruited by the study co-coordinator using an interview script and standard procedures were employed for obtaining informed consent.

Two groups of patients participated in the study. The first group (Group 1) consisted of patients who had experience using our legacy patient portal which had online messaging capability but no self-evaluation or appointment preparation component. This group consisted of 10 individuals with 6 females. One female was African-American; all others were Caucasian. Two males used manual wheel chairs for mobility. Average age of the group was 46.3 years with a range of 32-60. The second group (Group 2) comprised of patients who had no prior experience with our legacy system. This group included five participants: four females (one of whom used a power scooter) and 1 male. All were Caucasian. Average age was 47.4 years with a range of 43 to 57 years.

A trained facilitator (AA) convened and chaired the two focus group sessions, each lasting about two to three hours. An interview guide was pilot tested to refine question wording and sequence. We audiotaped, videotaped, and transcribed the focus group sessions, which were also observed by other project team members behind a one-way mirror. Verification of the accuracy of the transcriptions was achieved by randomly crosschecking the transcripts against the tapes. The coding template was agreed upon by two researchers (AA, NM) and applied to transcripts and focus group notes using ANSWR 5.0 (CDC, Atlanta). AA and NM then independently analyzed transcripts with the framework analysis approach. The benefit of Framework Analysis is that it allows for the inclusion of a priori as well as emergent concepts. Categories and themes were identified in the final phase of analysis. Summary data was presented to the co-facilitator and a sample of participants for a modified member's check.

We then used the focus group findings to develop and refine our MCCO system. We then tested the system by direct observation of a sample of patients from the focus groups. We gave 2-3 tasks individually to six participants from the focus groups and observed them with one or two observers sitting in the background and taking field notes. We assigned tasks such as requesting a prescription refill, reporting new MS symptoms and filling out appointment expectation forms.

RESULTS

The results are presented in four sections that represent the main themes that arose from the analysis. These sections are Internet usage, health information seeking behavior, expectations for a web-based communication system and barriers related to web system usage.

1) Internet usage

All of the participants had access to the Internet either at home or at work, and many both at home and at work. Searching Internet for health reasons was among the top 5 reasons for a majority of participants. Participants liked the features such as shopping, prescription filling etc, which saved them from traveling. 12 out of 17 participants felt that they were using the Internet more than their peers or significant others who did not have MS. This was especially true if they feel sick. For example “I use Internet especially as I get sicker and become more disabled in terms of my ability to read or talk to other people.”

2) Health-Information seeking behavior

Using the Internet for health reasons was found invaluable by most of the participants; for example “I found the Internet in a health way the most useful because the numbers of years, the numbers of doctors, the numbers of diagnosis, and the numbers of the things I was told I had or didn’t have.” A majority of participants preferred using a search engine to find information;
however, they felt it was tough to get precise information on the Internet. In the words of one participant “You look for numbness, but you find [out] about paralysis. You just want to find out about numbness. You don't want to get freaked out about paralysis.” Participants were also much more likely to look for information before and after a visit to their doctor; “after seeing the doctor certain words or diagnosis, things when I get my labs… I have no idea what these various words mean, so I want to know. So I look up words.”

When asked about trusting information on the Internet, the group felt that, in general, it provided value but the information cannot be trusted to the extent that it allows patients to make health decisions on their own; for example “It’s a piece of information that you can take it to a doctor’s office and say… but it certainly isn’t something that you’re going to change your medicine or change the way you do things.”

3) Expectation for a web-based patient portal and communication system
The majority of participants felt that a patient portal could provide a valuable service to them, especially if it allows for timely communication with clinicians. The other features thought to be valuable were ability to self-monitor MS symptoms, receive updates on latest MS research, request prescription renewals, access laboratory results and get trustworthy online patient education. They felt that the success of such a system depends a lot on the extent of participation by the clinicians; for example “I think the easy part is putting together the Web site and all this information. The onus really is going to be on the doctors to be able to respond.” Surprisingly, some participants expected this system would address urgent health issues or concerns despite being told that the portal is to be utilized for non-urgent issues only. For example “Usually, if we’re calling we have a problem with symptoms and/or drug problems. It’s urgent. It’s immediate…we don’t want to wait and talk to a receptionist”

4) Barriers to web system usage
The group felt that there were unique barriers to Internet usage for MS patients (Table 1.). Though some of these such as “red desaturation” have been described in the literature, it seemed that participants had more problems secondary to inappropriate font size, contrast and cluttering. In general, the group felt strongly that readability of text and content mattered much more than glossy design. Except for one participant, no one in the group was aware of the accessibility options available to enhance their Internet experience. Participants were even unaware of simple browser options to increase text size. In fact this discussion generated so much interest, that the group wanted the moderator to demonstrate all the accessibility options. In the words of one participant, “How about hearing about these options tonight?”

<table>
<thead>
<tr>
<th>Intfont</th>
<th>For me, large font just really says it all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intcontrast</td>
<td>The first thing I would do when I get on the Internet is to try to get rid of colors because it is a lot easier to read white letters on a black background and vice versa.</td>
</tr>
<tr>
<td>Intclutter</td>
<td>I would say spacing it on the page. For me things are, I think if you don’t cram the page, a larger font with double spaced. Have it not too overwhelming and too busy</td>
</tr>
<tr>
<td>Intnavigation</td>
<td>You have to remember there could be trouble with focusing in general, not to mention on a screen with words and something flashing over there.</td>
</tr>
<tr>
<td>Intcolor</td>
<td>Oh, the color! Yes, red is very washed out.</td>
</tr>
<tr>
<td>Intmotor</td>
<td>Sometimes we would not be able to work with mouse, sometime with keyboard. We need options</td>
</tr>
<tr>
<td>Intaccessibility</td>
<td>I know there is a way to do it (increase font size), I don’t know how to do it.</td>
</tr>
<tr>
<td>Intmemory</td>
<td>I often forget passwords. There should be way to get the password. We often forget things, so you may have to explain browser options again and again till we get it.</td>
</tr>
<tr>
<td>Intworkaround</td>
<td>I will cut and paste because I write things in Word with big fonts and then make fonts smaller and cut and paste.</td>
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Table 1: Quotes from focus groups regarding barriers to accessing information on the Internet
Figure 1 displays some of the accessibility features which were added based on the discussion in the focus groups. The new portal was then tested by directly observing a sample of the participants perform common portal specific tasks such as prescription refill. There was a general agreement among the sample participants that the changes made to the MCCO system reflected the recommendations made in the focus group discussion.

DISCUSSION

Presently, more than 60% of the US population has access to the Internet and as much as 25-30% of these people have used the Internet for health reasons. Although eHealth is gaining ground among all patients, its impact and the growth of that impact could be most pronounced among patients who are sicker and who take the greatest number of prescription drugs.\(^{12, 13}\) Unfortunately, this is the group that continue to face the most barriers to access health information on the Internet.\(^{14, 15}\)

Our study revealed that many of the web-related perceptions of MS patients are similar to patients without any disability, such as the need for better health information, beliefs on trustworthiness of online health content and excessive reliance on search engines to search health-related information on the Internet.\(^{16}\) We also found that many of the barriers such as low contrast, inappropriate font size, poor navigational design etc. are similar to those faced by elderly.\(^{17, 18, 19}\)

At the same time, our study identified unique barriers not previously reported or covered in Section 508 accessibility guidelines such as problems with flashing and moving objects, crowded or cluttered screens and difficulty seeing the color red. These traits could be attributed to optic neuritis related visual issues resulting in problems with focusing and red desaturation.\(^{20}\)

Unfortunately, many patient education sites on the Internet fail to address common barriers faced by elderly and MS patients.\(^{21}\) More worrisome is the fact that our group of MS patients faced problems while browsing sites specifically designed for the MS population. The need to decrease web page cluttering is especially intriguing. The web-designers will have to balance the need for extremely simple design with less clutter for elderly and disabled with need for appeal and interactivity for the average patient population. One of the possible
solutions could be to develop customizable web sites using scripting language which can allow users to switch between different style sheets and dramatically alter the appearance of a web page layout (such as the one used in MCCO with user-defined options for font size, contrast etc). It remains to be seen if this approach would become a standard feature for the display of health related information on the web for disabled and the elderly.

We found that there is a lot of unmet need for health information among MS patients, especially the need to timely communicate with physicians. However, our discussion also revealed that many patients had unrealistic expectations from such a system, especially the need to use this system for urgent or emergent health care needs. Hence, we believe that expectation of patients for any kind of web application should be addressed prior to enrolling patients to use such portals. Furthermore, we suggest that efforts to identify and track usage that can lead to patient harm be continued even after application deployment as a continuous quality initiative (CQI).

CONCLUSIONS

This study underscores the many challenges MS patients face in getting quality health information on the Internet. Furthermore, most of them are unaware of additional accessibility features to help them navigate these sites. Hence, special emphasis should be paid on the need to educate patients about some common accessibility options. More research is needed to determine whether or not use of multiple style sheets is an optimum way to display health information targeted to both disabled and non-disabled population.

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