

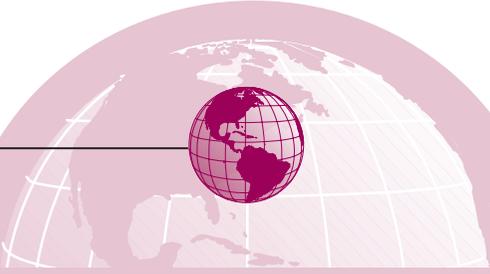
F E A T U R E

A R T I C L E

Creating Patient and Family Education Web Sites

Assuring Accessibility and Usability Standards

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This article gives details about the methods and processes used to ensure that usability and accessibility were achieved during development of the Home Parenteral Nutrition Family Caregivers Web site, an evidence-based health education Web site for the family members and caregivers of chronically ill patients. This article addresses comprehensive definitions of usability and accessibility and illustrates Web site development according to Section 508 standards and the national Health and Human Services' *Research-Based Web Design and Usability Guidelines* requirements.

KEY WORDS

Accessibility • Internet • Patient education • Usability

As the use of the Internet grows, so does its use for seeking online health information. According to the most recent Pew Internet and American Life Project report, approximately 61% of adults seek online health information.¹ More than 30 million American adults provide home caregiving, and approximately 80% of these caregivers seek health information online.^{1,2} Most caregivers managing chronic illnesses at home look to the Internet for detailed information about home care for their patients but are less likely to seek information about caring for themselves.³

Caregivers often neglect their own physical and mental health,^{4,5} with resulting fatigue, stress, and morbidities because of the conflicting demands of complex long-term caregiving, employment, family responsibilities, and increasing economic pressure.^{6,7} Caregivers must care for themselves because poor health may be detrimental to them and harmful to those for whom they care.⁸ There are many Web sites available to caregivers with general information about home care; yet, there are very few Web sites that provide evidence-based step-by-step guides to help caregivers manage their own health while providing complex home care such as home parenteral nutrition (HPN).

Home parenteral nutrition is used to treat lifelong malnutrition from intestinal failure due to underlying chronic diseases (eg, Crohn's disease), bowel loss due to surgery or abdominal trauma, or congenital or anatomical defects.⁹ Home parenteral nutrition therapy consists of nutrient solutions infused over 12 to 24 hours through

intravenous catheters that are surgically placed in the superior vena cava.¹⁰ The research-based HPN Family Caregivers Web site was designed specifically for HPN caregivers, conveniently providing step-by-step algorithm guides and HPN home care information while also providing information, activities, and algorithms for improving their own health.¹¹

To use the information, activities, and algorithms present on the HPN Family Caregivers Web site, users must be able to easily perform several tasks such as reading paragraphs, lists, success stories, and other Web pages; hyperlinking to other Web sites; downloading and printing checklist diaries; viewing graphics; opening, viewing, and downloading videos; downloading, saving, and/or

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listening to MP3s; and filling out success story forms. In order that all persons, including those with disabilities, are able perform these tasks, a Web site must be considered accessible and usable according to federal standards and national guidelines. To accomplish this, our Web site implemented Section 508 accessibility standards¹² and adhered to usability guidelines for user-centered Web site design provided by the US Department of Health and Human Services (USDHHS).¹³ Our Web site designers also noted two additional guidelines they found necessary specifically to our patient population. Our Web site was designed according to these standards and guidelines, then used and evaluated by caregivers. The implementation of Section 508 accessibility standards, *Research-Based Web Design and Usability Guidelines*, and our additional guidelines, as well as user satisfaction of the HPN Family Caregivers Web site will be described below.

SECTION 508

Section 508, an amendment to the United States Rehabilitation Act, mandates that electronic and information technology created or purchased by a federal agency must be accessible by people with disabilities.¹² While our Web site was not created or purchased by a federal agency, we still found Section 508 to be appropriate and necessary for our patient population. Our Web site was designed to comply with Section 508 by using hypertext markup language (HTML) and a cascading style sheet (CSS) layout. Text equivalents were included for all image, audio, and visual files.

The CSS layout guarantees that information is presented in a standard format across the WWW and allows the use of adaptive equipment and assistive technology to translate written, visual text to Braille or spoken words. Use of cascading style sheets allows adaptive equipment and assistive technology to differentiate recurring features of the Web site from unique content displayed on individual Web pages. Based on each user's preference (usually indicated by pressing a button), recurring content can be interpreted in written form such as Braille or verbally repeated each instance each Web page is viewed. If preferred, recurring information can be interpreted in writing or verbally when it is initially viewed, then skipped over as content on each new page is relayed. Examples of recurring content on the HPN Family Caregivers Web site included (1) the top margin containing the title of the Web site, (2) the left margin listing the menu of Web site contents, and (3) the bottom margin displaying the Health on the Net (HON) and World Wide Web Consortium (W3C) certifications, as well as the creating institution's information and the date the content was last updated.

Web sites can validate their compliance with Section 508 through the W3C online validation service for HTML and

CSS.¹³ The W3C online validation program provides immediate analysis and a detailed report. Our Web site was found to be in compliance with CSS level 2.1 of Section 508 via the W3C¹⁴ validation program.

RESEARCH-BASED WEB DESIGN AND USABILITY GUIDELINES

In addition to implementing Section 508 accessibility standards, Web sites should also be designed to enhance the user's ability to complete the tasks dictated by the Web site. The designers of the HPN Family Caregivers Web site followed the *Research-Based Web Design and Usability Guidelines* compiled by the USDHHS. These 18 guidelines for user-centered design are based on an extensive process of research and review.¹³

The *Research-Based Web Design and Usability Guidelines* include (1) design process and evaluation; (2) optimizing user experience; (3) accessibility; (4) hardware and software; (5) the home page; (6) page layout; (7) navigation; (8) headings, titles, and labels; (9) scrolling and paging; (10) text appearance; (11) lists; (12) screen-based controls (widgets); (13) links; (14) search capability; (15) graphics, images, and multimedia; (16) writing Web content; (17) content organization; and (18) usability testing. All of these guidelines were followed and are described below. Some of the guidelines will be described together because of overlapping or similar features within each guideline.

Design Process and Evaluation

Web site designers should set clear and concise goals and guidelines for their Web site before beginning its design. The International Usability Professionals' Association defines usability as "the degree to which something—software, hardware or anything else—is easy to use and a good fit for the people who use it."¹⁵ Therefore, a Web site must have a population-specific purposeful design, that is, a design with a clear purpose related to the needs of its prospective users.

The goal of the HPN Family Caregivers Web site was to provide caregivers with information about managing HPN without neglecting to care for themselves. To achieve this goal, our Web site designers included the most current and commonly accepted science-based principles and guidelines for home care, including (1) clinical standards for home care regimens; (2) prescribed medical and treatment-specific guidelines; (3) instruments, activities, and algorithms to help monitor patient and caregiver symptoms; and (4) guidelines to prevent or resolve home care problems with evidence-based information, algorithms, and activities.¹¹

Optimizing User Experience

To optimize the user experience, Web sites should “facilitate and encourage efficient and effective human-computer interactions.”¹³ This is achieved by (1) minimizing page-loading time, (2) having the ability to easily print information, and (3) not “pushing” unsolicited windows or graphics to users. Pushing refers to displaying distracting graphics or pop-ups that may deter users from focusing on a Web site’s primary content.

To minimize page-loading time and allow users to be able to quickly read, download, or perform other tasks, simple graphics were used sparingly and multimedia files were limited to MP3 and video files. This required less data to be uploaded to each page, thus increasing the speed of loading. All MP3 files could be played directly through the Web site or downloaded and saved to a computer hard drive or external device to be played without requiring the user to be online. Video files were optimized to stream in progressive download mode for quick viewing via browsers that supported video playback.

Additionally, all Web site pages were designed in print format so that information would print out exactly as seen on the computer screen. Using this format allowed any user to print a copy identical to the image on the Web page, regardless of their personal computer hardware, software, or printing device.

Also, users must be able to focus on the Web site’s content to fulfill the purpose of the site. Our Web site was designed to avoid unnecessary audio or visual information to ensure that users are not distracted from the essential aspects of the content. Therefore, no advertising was allowed within the Web site.

Accessibility

This USDHHS guideline states that Web sites should implement Section 508, allowing everyone, including those who have difficulty seeing, hearing, and making precise movements, to be able to use them. The creators of the HPN Family Caregivers Web site decided to implement and comply with Section 508 before becoming aware of this guideline.

Accessibility can also refer to a Web site’s availability. According to Princeton University, availability is “handiness: the quality of being at hand when needed.”¹⁶ While availability is not directly mentioned in the *Research-Based Web Design and Usability Guidelines*, our Web site designers thought it was important to ensure that accessibility was further fulfilled by making the information, activities, and algorithms on our Web site available to all persons at all times. Our Web site was available 24 hours a day, 7 days a week.

A usable Web site should be dependable and involve quick resolution of common problems (such as inabil-

ity to load pages or slow loading times), and any site closure due to maintenance should be kept at a minimum.¹⁷ The HPN Family Caregivers Web site was never closed due to maintenance. All maintenance was completed offline, and any pages that required troubleshooting were replaced with the pages completed offline.

Hardware and Software

Usability also refers to access to the hardware (computer type, speed) and software (operating system, Internet speed, Internet browser) necessary for getting online.¹⁸ While many patients and family members have computers in their home, Internet access for those who lack home computers can be a challenge.¹⁹ Users who reported having no home computer were directed to a local library or other facility with publicly available computers. Because there is no confidential patient information found on the HPN Family Caregivers Web site, access to the site in public areas did not pose a threat to patient confidentiality. However, if patients were not comfortable viewing this information in a public area, or if they had no means of access to publicly available computers, they were given a home computer on a temporary basis. A Web site User Guide containing detailed training on how to set up and use the computer and the Internet was offered to all participants, although most stated they did not need such a guide.

The Home Page

The home page provides the first impression of the Web site and therefore should be well-designed to clearly communicate the rationale of the site. The purpose the HPN Family Caregivers Web site was to provide evidence-based educational materials to caregivers on how to manage HPN at home without neglecting their own health.^{11,20}

Web site users were made aware that all evidence-based information, activities, and algorithms were to be used as an adjunct to the guidance and directives provided by the patient’s primary healthcare team. The home page featured the following statement: “The information provided on this Website is designed to support, not replace, the relationship that exists between a patient or family member and his or her physician.”

Additionally, all Web site content was accessible from the home page. A table of contents located in the left margin of the page included links to each of the five Web site sections: (1) Caring for Yourself, (2) Managing HPN, (3) Success Stories, (4) Other Resources, and (5) Our History. Also present on the home page were links to the HON and W3C certifications.¹¹

Page Layout

To enhance usability, all Web page designs should list the most important items first. The statement advising users that the information, activities, and algorithms found on the Web sites were only to be used in conjunction with their physician's orders was deemed the most important and placed at the top of the home page.

Furthermore, designers must decide whether to consistently use longer lines with more text (more information per line) or shorter lines with fewer words (less information per line). Most users prefer shorter line lengths as it facilitates scanning.¹³ Therefore, this Web site was designed with shorter, succinct lines and the ability to expand certain lines when more information was desired. Additionally, the site was designed so that all pages followed the same format, because usability is enhanced when the format of each page is consistent.¹³

Navigation, Headings, Titles, and Labels

A well-designed Web site must also have simple navigation with clear headings, titles, and labels to maximize usability. Our Web site was designed for users who might not be familiar with navigating Web sites. A user-friendly link on the home page labeled "click here for tips on moving around these websites" took users directly to a page with navigation tips in laymen's terms understandable by an Internet novice (see Figure 1).

Navigation of this Web site was designed to have specific links open in the current window and others open in a new, separate window. All patient and family education information, activities, and algorithms opened

in the current window, allowing users to click the "back" button to return to the previous page. Because usability is enhanced when users know where they are on a Web site and how to return to the home page, users were able to link back to the home page from any page within the Web site.¹³

Any links to external resources created by other institutions (eg, American Academy of Family Physicians, US National Library of Medicine, US Department of Health and Human Services) opened in a separate window so that the users were not distracted from the primary content of the site. Closing the separate window only closed the external information and not the HPN Family Caregivers Web site.

Web pages should have a table of contents accessible through the home page and subsequent pages.¹³ Our design allowed for easy access to each major content section via a table of contents on the left margin of each page.¹¹ Users could click on a labeled link to view the details within major content sections. Each of these sections had page titles, page headings, and labels named to correspond to its specific content. The page title refers to the text visible in the top left margin of the Internet browser. The page heading is the text located at the top of the page (within the Web page), and label refers to the hyperlink text present on the link which a user clicks (see Figure 2). The use of consistent terminology for the title, heading, and label enhances usability as it decreases ambiguity and allows users to identify exactly which section topic is being viewed. All of our headings, titles, and labels contained the same terms so that users were able to effectively and efficiently locate and link to destination pages.

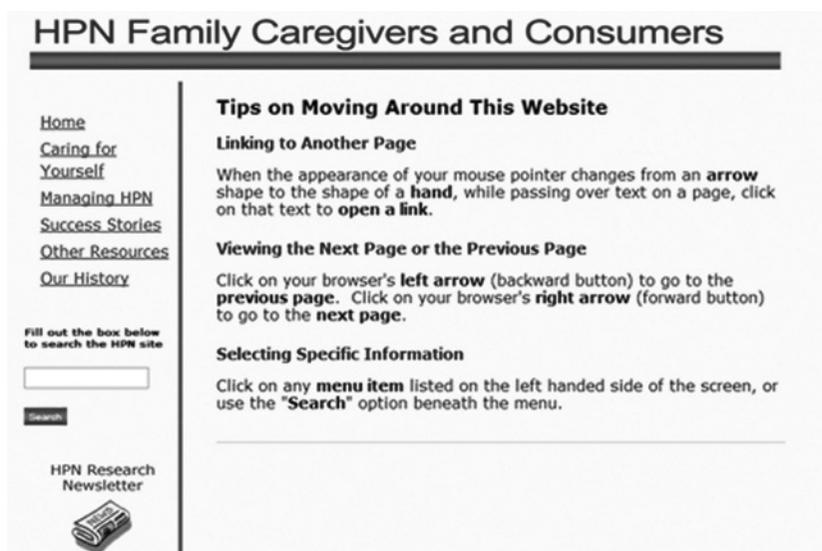


FIGURE 1. This figure shows the type of information that should be viewable when a user clicks a link for tips on navigating around a particular Web site. The information should be similar to this but vary slightly depending on the Web site.

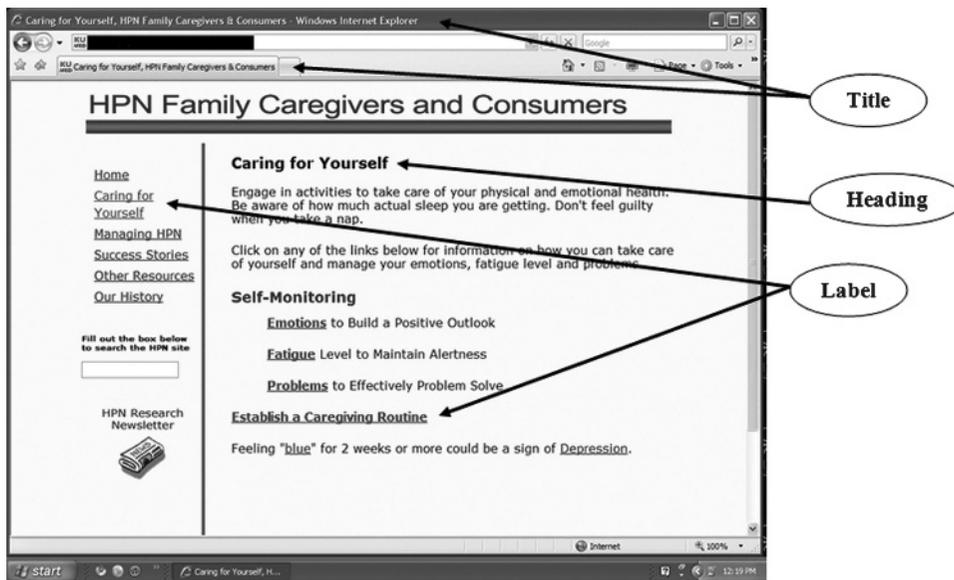


FIGURE 2. The title, heading, and label of a “Caring for Yourself” Web page.

Users often scan all Web site information first and then decide which sections to read. For this reason, designers should create specific descriptive titles that will allow users to select the content that best fits their needs. For example, one major content section of the HPN Family Caregivers Web site is Caring for Yourself. This section provides caregivers with myriad evidence-based information, activities, and algorithms designed to help them care for themselves (such as self-monitoring emotions and fatigue) while managing a patient requiring HPN.¹¹ Each page within the section repeated the heading and title Caring for Yourself, so users would know which content they were viewing (see Figure 2).

Scrolling and Paging

The scrolling and paging criterion suggests that Web site designers should decide whether to design a few long pages with lots of information on each page or several pages with less information. There are benefits to each of these designs. Fewer pages result in less navigation, making it less likely that a user will lose his/her place on the site. However, this requires a user to scroll up and down on a page to find information. More pages with less information on each page require more navigation, referred to as paging. Paging is beneficial in that all information can be viewed within one screen shot, and users do not have to scroll up or down to view information on a page.¹³

Ease of use is greatly enhanced when a user is not required to scroll up and down or side to side to view information.¹³ Therefore, the HPN Family Caregivers Web site was designed to have more pages with information captured in one screen shot.²¹ Pages with more

information than could be viewed within one screen shot were condensed into a list of links. If users decided they wanted more in-depth information on a particular topic, they could view the additional information by clicking the link. This also allowed the user experience to be optimized by creating faster page-loading times and allowing users to print screen shots exactly as seen on the computer monitor.

Text Appearance

Text appearance can make it easier for users to read information on Web pages, thus enhancing the usability of the site. National guidelines suggest applying familiar fonts that are at least 12 points in a dark color on a plain, high-contrast background.¹³ The HPN Family Caregivers Web site used Verdana as the default font. If users did not have Verdana on their machines, the closest sans serif font was applied (usually Arial or Helvetica). Font size ranged from 12- to 16-point type with letters mostly in dark blue or black and links a lighter shade of blue (the standard default color common to all browsers). The background was light yellow. No attention-attracting features (such as animation) that increase site-loading time and distract from Web site content were used.

Lists

Many Web sites contain lists. Usability guidelines suggest that lists should be clearly introduced and have a descriptive headline to facilitate the task of reading a list. Items on each list should be placed in order of importance with more important items at the top of the list. The HPN Family Caregivers Web site contained many

lists including, but not limited to, common health concerns, suggested activities, and external resources that might be helpful for caregivers managing HPN. Just as users scan pages for content, they often scan lists rather than read them word for word. On our Web site, list items were concise, with links available for information needing more in-depth explanations.

Screen-Based Controls (Widgets), Links, and Search Capability

Interactive Web sites require the use of screen-based controls. These include links, pushbuttons, radio buttons, check boxes, drop-down lists, and entry fields. Screen-based controls, often called widgets, enhance usability as they facilitate navigation and use of Web site information, activities, and algorithms.¹³

The widgets created for our Web site were simple. They included links, pushbuttons, and entry fields. Links were found on every Web site page for ease of navigation within and between major content sections. Links allow users to open new pages containing new content. Link labels should be meaningful and consistent with their target pages and should also indicate when they have been clicked. Our link labels were titled to correspond to the title of the target page. Links were initially displayed in blue text and then changed to purple after they had been clicked for viewing. This is the standard default for most Internet browsers.

Pushbuttons were applied to audio and video files. Familiar symbols commonly found on audio and video players were used to identify “play,” “pause,” “fast forward,” “rewind,” “stop,” and volume controls.

An entry field, or search box, was used for the Web site search function. The search criterion states that “each page of a website should allow users to conduct a search.”¹³ Entering one or more key words in an entry field should allow users to find any pages within a Web site containing those key words. Our Web site pages contained an internal search bar allowing users to search for specific information throughout the entire Web site, therefore enhancing usability. In addition, the search function was not case-sensitive, which provided flexibility within the search domain.

Graphics, Images, and Multimedia

The appropriate use of graphics can facilitate learning; however, graphics can also cause an increase in the time required to load a page. Therefore, graphics were limited to study logos (with which participants were familiar) and images for certifications for compliance with HON (a set of principles developed to ensure that Web sites contain

trustworthy health information)²² and W3C (a validation service confirming our Web sites adhere to Section 508 of the Rehabilitation Act).¹³

Users who are familiar with the Internet and Web pages often ignore graphics they consider to be advertising.¹³ Although this largely depends on the content and specific user preferences, our Web site was careful to create and place images in such a way that they would not be mistaken for advertisements.

Writing and Organizing Web Content

Content is the most important aspect of any Web site. A Web site that does not provide the information needed by users will be of little value no matter how easy it is to read information, play audio and video files, and so forth. Web site content should be written with familiar words and avoid jargon that may be confusing to some users.¹³ The HPN Family Caregivers Web site defined all acronyms and abbreviations and was designed to be succinct by limiting the number of words in each sentence, as well as the number of sentences in each paragraph. Content was also presented with critical information at the top of each page and all related content grouped together within its appropriate section on the same page.

Usability Testing

The HPN Family Caregivers Web site underwent extensive usability testing. Given the variety of choices for computer hardware and software available across the study setting (the United States and Canada), it was important to ensure accessibility and usability for all users.^{13,18,23} A variety of computers were selected to test access to all pages of our Web sites to emulate users’ experiences. Graduate students, research team staff members, nurse content experts, and Internet development specialists tested our Web site to ensure accessibility and ease of use with computers of various ages, speeds, monitor sizes, video output definitions (eg, high definition and standard definition), Web browsers, plug-ins, and Internet service providers. These pre-site testers verified that all pages loaded with ease and also provided feedback on ways to improve site appearance, function, and clarity. Most suggestions focused on word choice, suggesting replacing words that might be seen as jargon with more common lay terms.

■ ADDITIONAL GUIDELINES

In addition to following Section 508 and the USDHHS *Research-Based Web Design and Usability Guidelines*,

two additional guidelines were determined to be necessary for our patient population. These included (1) scientific relevance and (2) compatibility with mobile devices.

Scientific Relevance

The HPN Family Caregivers Web site contained evidence-based content obtained from previous research. This Web site provided a centralized repository of credible and current information tailored to fulfill the specialized needs of individuals managing HPN home care regimens.¹¹ With education as the primary purpose of this Web site, it was important to focus on the scientific rationale for the featured information using reference citations to verify the content's scientific relevance. Each featured scientific theme included links to a peer-reviewed journal publication validating the presented content.

Compatibility With Mobile Devices

With the growing use of mobile devices and smart phones to view Web pages, our Web site creators decided that our pages should be designed to be viewable on mobile devices. The HPN Family Caregivers Web site was designed to present as much essential information as possible within one screen shot. Pages were set up to be readily viewed on a standard desk top monitor (see Figure 3) and on a mobile device with a screen measuring only 3.5 in. in diameter (see Figure 4). The content on each page was centered to allow for viewing on a variety of monitor sizes.

USER SATISFACTION

The Web Communications and New Media Division of the US Department of Health and Human Services defines usability as "how well users can learn and use a product to achieve their goals and how satisfied they are with that process."¹⁸ Usability has also been defined in recent years as the effectiveness, efficiency, and satisfaction with which users can use a Web site.²⁴ To determine if users were satisfied with the user-centered design and found the Web site to have acceptable usability and accessibility, each unique visitor who accessed the HPN Family Caregivers Web site ($n = 41$) was asked to rate his/her satisfaction with the site. Specifically, users were asked to complete a survey, answering questions with Likert-type responses, as well as an open-ended question asking them to list things they liked and did not like about the Web site.

Most users (56.1%) reported that they were not likely to use the Internet for HPN information before

receiving access to the HPN Family Caregivers Web site. Because most of our users were novices at finding HPN information on the Internet, it was important to ensure that they found our Web site to be usable. Users were given the statement "I had a hard time accessing this website" with Likert responses ranging from "1, strongly disagree" to "4, strongly agree." Seventy percent of participants disagreed, meaning they did not have difficulty accessing the Web site. Users who agreed with this statement were found to have difficulty accessing the site because they incorrectly typed the URL, their username, or password.

Users also responded to the statement, "This website was available any time I wanted to look at its information" with the same Likert responses. Eighty-five percent of participants agreed. Users who disagreed were the same participants who had difficulty accessing the Web site because of mistyping the URL, username, or password.

Approximately 73% of caregivers stated that they would be willing to pay for access to the Web site, with responses ranging from "less than \$10" to "more than \$25" per month. When asked about insurance covering access to the Web site, approximately 85% of participants thought insurance should pay for access.

Most of the responses to the open-ended question were specific to the content of the site. However, there were a few comments on usability, such as "the site was simple and easy to navigate" and "I like the website because I can access it at my own convenience."

DISCUSSION

Accessible and usable patient education Web sites are beneficial media that can efficiently keep patients informed of current developments in their healthcare regimens and can also provide the best possible Web-based information that serves as a supplemental healthcare resource. Using national standards and guidelines allowed users to be able to easily complete the tasks dictated by the Web site and therefore gain the maximum benefit from the site's information, activities, and algorithms.

Users were satisfied with the content and design of the education Web sites and found them to have acceptable usability. However, one limitation researchers discovered with the evaluation data was that its questions focused more on the Web site content and design than its usability and accessibility. If usability and accessibility are to be further examined in the future, questions focusing more precisely on usability and accessibility should be asked.

A major limitation of this Web site was that it was only available in English, as it was created for patients in a research studies with an inclusion criterion that all participants must be able to speak and read English. To



FIGURE 3. A screenshot of the HPN Family Caregivers home page on a standard desktop monitor.

make this Web site available to more diverse populations, it should be available in other languages.

Our Web site also used very few widgets, or screen-based controls. For the purposes of this Web site, the widgets used were adequate. However, future Web site design will likely need to focus on the use of more widgets because online or computerized data collection may be utilized more in future research and healthcare.

The HPN Family Caregivers Web site was also password protected, allowing only study participants with active user names and passwords provided by the Web site's creating institution to access the site. To increase accessibility of sites such as this, users must not be restricted

to those who have assigned user names and passwords. In the instances where it is necessary to protect access, users should be able to create their own user names and passwords on their personal computers or mobile devices.

Also, this Web site could not ensure the readability of all hyperlinked pages. Any federally created or owned Web sites to which the HPN Family Caregivers Web site linked were guaranteed to follow Section 508 legislation; however, not all of the sites were federally created or owned. This could be frustrating to users who wish to view other pages using adaptive equipment.

It also would have been beneficial to consider the task-technology fit model when determining how to create

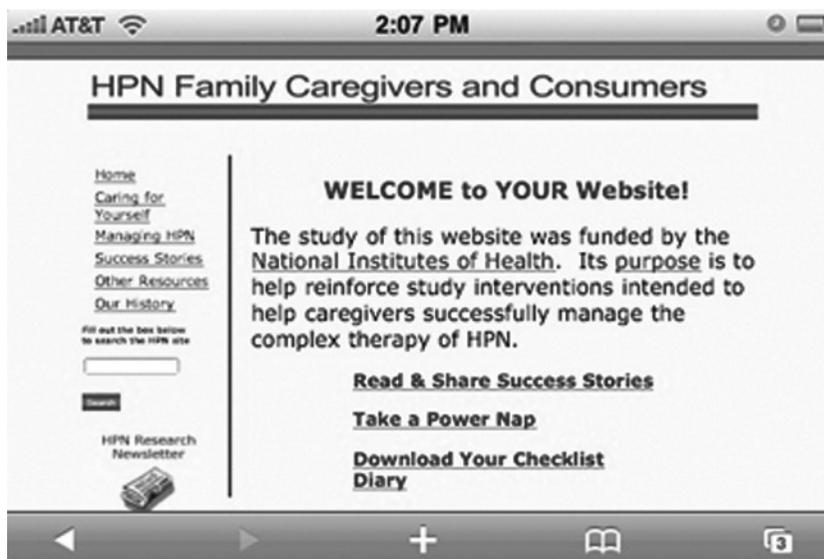


FIGURE 4. A screenshot of the HPN Family Caregivers home page on a mobile device measuring 3.5 in. in diameter.

a usable and accessible patient and family education Web site. Task-technology fit is defined as the degree to which technology assists an individual in performing tasks.^{25,26} Many aspects of this model can be found in the *Research-Based Web Design and Usability Guidelines* but should be further examined upon creation of future patient and family education Web sites.

CONCLUSION

When designing any Web site, national accessibility standards and usability guidelines should be followed, with special attention paid to the specific educational needs of the target population. Further research should focus on patients and family members with varying usability needs and populations where English is not the primary written or spoken language.

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