

C O N T I N U I N G

E D U C A T I O N



Creating Patient and Family Education Web Sites

Design and Content of the Home Parenteral Nutrition Family Caregivers Web Site

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According to the Pew Internet and American Life Project's 2009 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 due to the conflicting demands of complex long-term caregiving, employment, family responsibilities, and increasing economic pressure.^{6,7} To reduce caregiving stress, caregivers must be taught to care for themselves because poor health among caregivers is not only detrimental to them but may also be harmful to those for whom they care.⁸ There are many Web sites available to caregivers with general information about how to perform 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 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 disease), bowel loss due to surgery or

When managing chronic illnesses, caregivers repeatedly seek online information about providing complex, long-term care but often neglect to find information about how to care for themselves. Poor health among caregivers is not only detrimental to their own well-being but may also result in harm to those for whom they care. For this reason, caregivers need access to information and activities about caring for themselves in addition to the information about managing home care they are already likely to seek. The HPN Family Caregivers Web site was developed to guide caregivers through the process of caring for themselves by establishing a caregiving routine, self-monitoring their mental and physical health, and practicing good sleep hygiene, while also managing the complexities of home care. While Web site information, activities, and algorithms for managing chronic illnesses need to be specific to each population, the content guiding caregivers to care for their own health is universal.

KEY WORDS

Caregivers • Caregiving • Chronic illness • Internet

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 into the superior vena cava.¹⁰ The HPN Family Caregivers Web site was designed specifically for HPN caregivers, conveniently providing step-by-step algorithm guides and home care information for providing care for a patient

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on HPN as well as providing activities that can improve their own health. This article describes the content and rationale for each section of the HPN Family Caregivers Web site.

HPN FAMILY CAREGIVERS WEB SITE

The HPN Family Caregivers Web site consists of comprehensive information on pages that provide interactive nursing interventions for HPN caregivers. These interventions, or evidence-based activities, information, and guidelines, have been shown to improve the quality of life of caregivers as well as the successful management of HPN home care.¹¹⁻¹⁶ The HPN Family Caregivers Web site provides scientifically based algorithms with step-by-step instructions for practicing the most common self-care procedures and resolving HPN home care problems. While the Web site content about managing HPN is specific to this patient population, the information guiding caregivers to care for their own health can be generalized to other caregivers who provide similar complex home care for other illnesses.^{8,11,17-19}

Home Page

All Web site content is accessible from the home page (Figure 1). A table of contents located in the left margin

of the page includes 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. Each of these sections is composed of multiple Web pages containing content specific to the section. These will be fully described below.

The home page includes additional information that caregivers are encouraged to review prior to accessing the five sections. These include (1) a prominent notification cautioning that the information provided on the Web site is designed to be used by patients and caregivers only in conjunction with their primary care physicians; (2) a link to tips on how to navigate the Web site; (3) contact information for the creators of the Web site; (4) Health on the Net certification (Figure 2), a set of principles developed for health and medical Web site certification via repeated reviews that use stringent ethical and technical criteria²⁰; (5) links to national guidelines teaching laypersons how to evaluate whether a health Web site has reputable, reliable, and quality health information; (6) links to the most popular and frequently used information (ie, success stories, power naps, checklist diary) as indicated by previous research^{11,13}; (7) a search field providing easy access to all online content; and (8) World Wide Web Consortium validation,²¹ which confirms that all Web site information can be interpreted by audio or Braille software, complying with section 508 of the Rehabilitation Act.

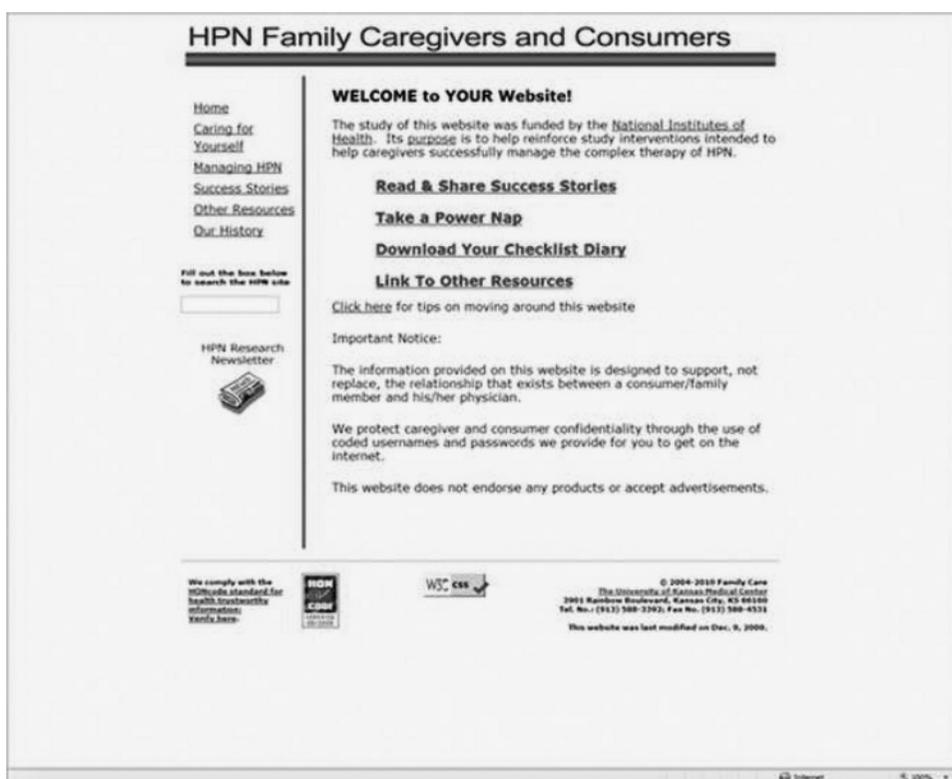


FIGURE 1. A snapshot of the HPN Family Caregivers Web site home page as it appears immediately after log-in.

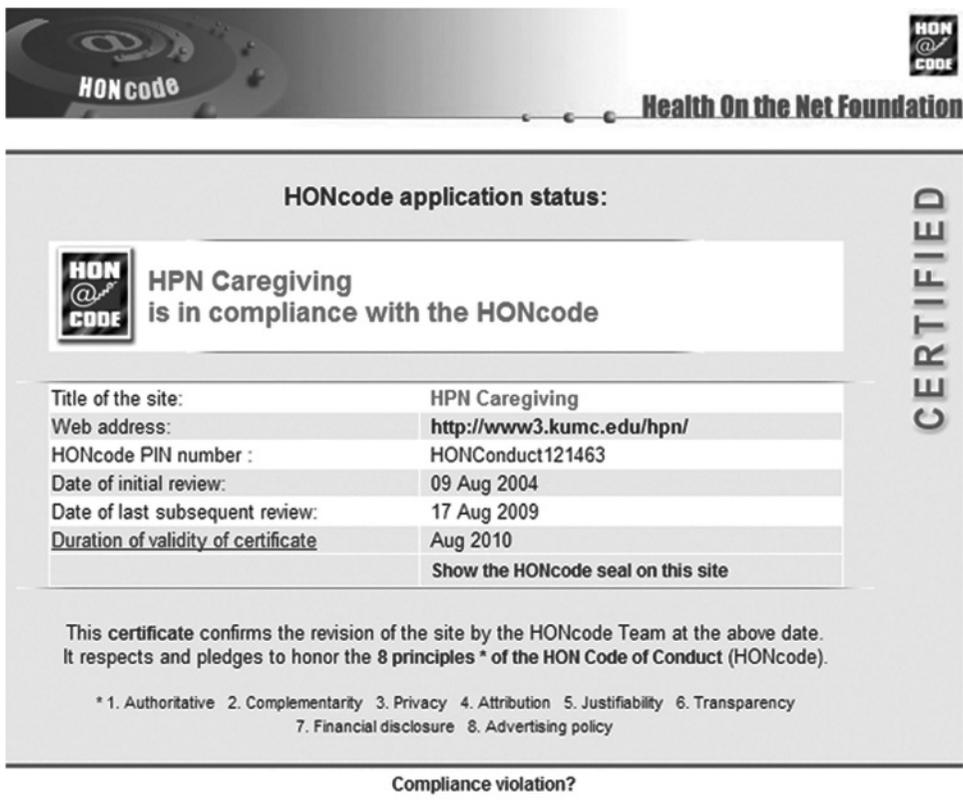


FIGURE 2. A snapshot of the HPN Web site Health on the Net code certification.

Caregivers are encouraged to view all Web site content, as it has all been found effective in improving their health and the health of the patient for whom they care. However, because of the demands of HPN home care, caregivers may not have the time or energy to view all content. They are therefore asked to focus on the first two sections: (1) caring for yourself, which provides caregivers with information and activities for their own health needs and (2) managing HPN, which provides caregivers with specific and detailed information about HPN home care procedures. Providing these two distinct sections side-by-side on the same Web site allows caregivers to easily access key information about caring for a patient on HPN while also caring for themselves.

Caring for Yourself Web Pages

The Caring for Yourself section features access to a variety of content about caregivers' physical and mental health needs, self-assessments, and algorithmic activities that encourage establishing a caregiving routine (Figure 3). Establishing a caregiving routine has multiple benefits because it empowers caregivers to take control of their own routines and activities while adhering to rigorous home caregiving treatments for their HPN patient.

A diary checklist is available on the Web site allowing patients and caregivers to record their daily routines. This

checklist prompts caregivers to develop a habit of health assessments while maintaining daily routines for monitoring home care. The checklist has been validated as accurate, sensitive, and specific for self-monitoring emotions, fatigue, and caregiving-related problems.^{22,23}

Self-monitoring Emotions

Caregivers have been found to have frequent and recurring episodes of reactive or situational depression, as diagnosed by the *Diagnostic and Statistical Manual for Mental Disorders, Fourth Edition*,²⁴ because of the many strains and frustrations often associated with caring for others.^{16,25} Persons with reactive depression sleep poorly, ignore their health, obtain less social support, and are at a higher risk for comorbidities.²⁶ However, previous research has found that caregivers with increased depression are responsive to telehealth or online nursing interventions.^{11,14,17,27}

The Web site links in this section guide caregivers to assess their own levels of depression and that of the HPN patient. For example, they are told that feeling "blue" for 2 weeks or more could be a sign of depression. If they have felt this way, they are encouraged to use the interactive links to depression management algorithms that are aligned with national standards established by the National Institutes of Health.^{7,28-30} These step-by-step algorithm links guide the caregiver through evidence-based activities

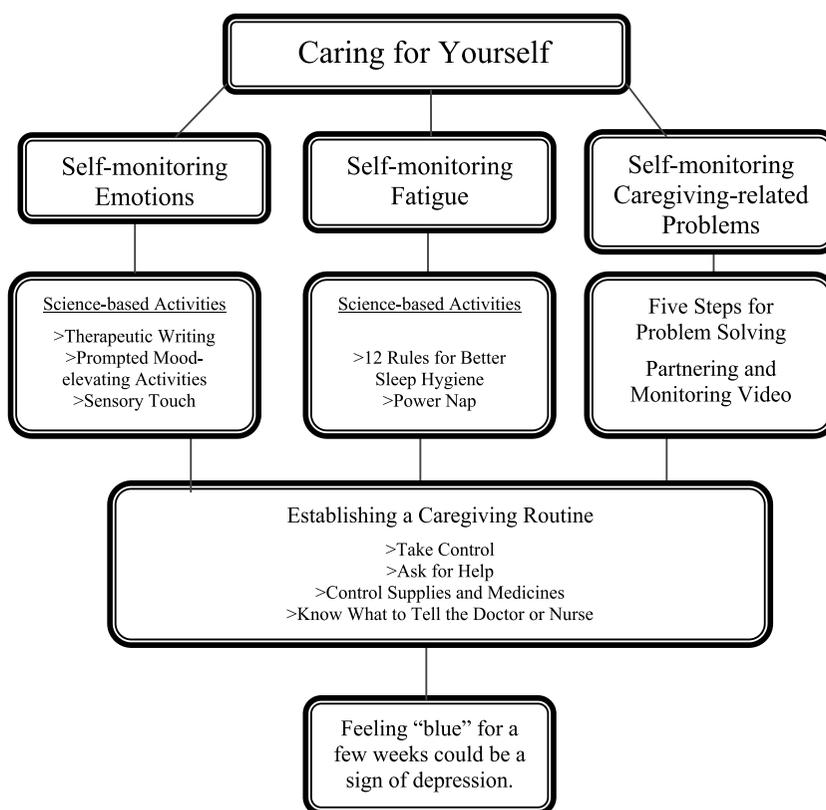


FIGURE 3. A flow chart outlining the content in the Caring for Yourself Web site section.

known to reduce depression. These activities and guides include therapeutic writing, prompted mood-elevating activities, and sensory touch.^{14,16,31}

Therapeutic writing about emotions has been reported to increase positive outlook, enhance the body’s immune system and avoid infection, manage depression and maintain quality of life.^{14,16,29} Caregivers are encouraged to write about their feelings twice during the week and once on the weekend either in their checklist diaries found on the Web site or in a personal journal. Writing can also lead to self-disclosure, identification of problems, recognition of emotional reactions, and improved cognitive processing about challenges.³² The consistent research findings of Pennebaker et al^{33–36} confirm that writing about experiences in as little as 15 minutes for at least 3 days a week brings about robust health improvements. These findings have been replicated across various age, ethnic and chronically ill groups, and both sexes.

Prompted mood-elevating activities are provided for caregivers when they have low self-assessment ratings of their emotions on the diary checklist or any time caregivers feel “sad, blue, or discouraged.” These mood-elevating activities include calling a friend or relative to talk, working on hobby, joining a club, listening to favorite music, watching TV, reading a book, and writing about feelings and emotions. Performing enjoyable activities has been shown to help moods become positive. This

can improve physical and mental health as well as provide a positive atmosphere for caregivers and their HPN patients.^{11,16}

Sensory touch, or firm skin contact creating gentle pressure for 5 to 10 seconds, enhances relaxation and decreases depression as it stimulates sensation throughout the nervous system. Like therapeutic writing, sensory touch increases positive outlook and enhances the body’s immune system.³⁷ A list of suggested science-based activities that stimulate relaxation is provided, such as using a rolling-back massager, hugging a small pillow, rubbing the back of the neck, holding hands or hugging another person, or petting an animal.^{8,11,14} Caregivers are encouraged to perform any of these activities whenever they feel sad, blue, or discouraged.

Self-monitoring Fatigue

Lack of sleep can also negatively impact mood and alertness, and the effects of chronic fatigue can be cumulative. A recent review found that HPN caregivers have daily distress and fatigue due to managing complex HPN care, disrupted social activities, and lost employment.³⁸ Sleep deprivation is a pervasive problem for family caregivers of patients on HPN because of the nightly sleep interruptions necessitated by HPN home care.^{9,39} Sleep deprivation, even if only intermittent, is

a risk to safety because of its effect on brain function, such as increased attention lapses, cognitive deficits, memory loss, and involuntarily falling asleep.¹² Long-term clinical consequences of sleep deprivation include numerous chronic illnesses and other mood disorders and injuries from fatigue-related activities. The HPN Family Caregivers Web site features science-based activities for self-monitoring fatigue and drowsiness. These include (1) 12 rules for practicing better sleep hygiene and (2) taking “power naps.”

The 12 rules for better sleep hygiene advise caregivers to get the proper amount of sleep to reduce the chronic fatigue often associated with caregiving. Examples of ways to improve sleep hygiene include (1) sleeping as much as needed to feel refreshed, (2) keeping routine hours for going to bed and waking up, (3) engaging in daily exercise, and (4) avoiding caffeine and alcohol close to bedtime.⁴⁰

Power naps, or afternoon naps of less than 30 minutes (even those as brief as 10 minutes), restore wakefulness, promote performance and learning, and improve cognitive task performances such as attention to intravenous procedures.^{12,13,41,42} Sleeping longer than 30 minutes can increase the risk of waking up feeling groggy and affect the ability to fall asleep at bedtime. A short, 10-minute power nap is recommended to restore alertness and memory as well as relieve stress and fatigue without disrupting nighttime sleep cycles.^{43,44} Power naps promote focused imagery of restful sleep that features a gradually slowing musical tempo with lyrics that guide deep breathing, muscle group relaxation, and synchronization with a resting heart rate cadence.¹²

Caregivers are given links to audio files guiding them through power naps. These files are available in five different musical genres: classical, soft rock, spiritual, country, and easy listening. Files are available directly through the Web site or downloaded to a CD or mobile device, such as an MP3 player or cell phone with MP3 capabilities. This popular and frequently used is linked from the home page or through the Caring for Yourself section.

Self-monitoring Problems Related to Caregiving

Caregivers often use the Internet to help solve a home care problem.⁴⁵ A Web site similar to this used for specific chronic illness home care problems was tested in 2005. It was found that the 202 caregivers and patients who used the Web site had significantly more problem-solving confidence and engagement with healthcare professionals than the control group.⁴⁶

Managing long-term complex home care may directly impact the physical and mental health of caregivers, often causing new illnesses or triggering an exacerbation of current comorbidities. Several Web pages are dedicated to self-monitoring the most common problems, such as frustration with coordinating multiple service agencies,

managing technology problems, and coping with financial strain of the high cost of caregiving.^{16,47} A video entitled “Partnering and Monitoring” addresses these issues. Other pages in this section include prompts for helping caregivers obtain resources and overcome barriers to health promotion activities and provide scripted guides to help those who may be reluctant about contacting their healthcare providers with questions.^{48,49} Also included are links to the five steps for problem solving: (1) identifying the exact problem(s); (2) talking about everyone’s feelings and emotional reactions to the problem(s), such as fear of infection, worry over healthcare bills, and so on; (3) listing quick fixes and long-term solutions; (4) identifying solution options and partners available to help; and (5) trying the “best” solution. Use of these five steps has been scientifically shown to improve caregiver logical problem solving and confidence with complex home care.¹⁴

Managing HPN Web Pages

The Managing HPN section is dedicated to information and illustrations about how to provide the daily caregiving procedures required for successful HPN home care (Figure 4). HPN home care requires these procedures to be completed at least twice daily. Treatment includes dressing changes and intravenous infusions through an indwelling chest wall central venous catheter that must be done in a specific sequence with stringent aseptic technique.^{9,10,50} Previous research describes the caregivers’ demanding schedules of 12- to 24-hour HPN infusions often performed throughout the night with frequent awakenings from pump alarms for fluid, electrolyte, and blood glucose monitoring⁵¹ and for daily maintenance, cleaning, assembly, and troubleshooting of the electric pump.¹³ The cognitive complexity of HPN care includes distress over the numerous and commonly recurring home care problems (ie, infusion problems, catheter contamination, insertion site leakage, etc) that patients and caregivers must recognize as well as problems coordinating care with multiple healthcare professionals, service providers, and insurers.^{51,52}

The HPN Family Caregivers Web site provides automated algorithms based on national HPN clinical care guidelines and education designed to assist in managing complex and recurring HPN home care problems.^{17,53} Caregivers are shown how to make HPN management a part of their daily caregiving routines. They may use the same diary checklist they use to monitor their own health to monitor the health of their HPN patients, as the checklist has also been shown to be effective in reducing home care infection rates.⁵⁴ Caregivers can link to Web pages that include science-based information, activities, and algorithms about living with HPN; infection

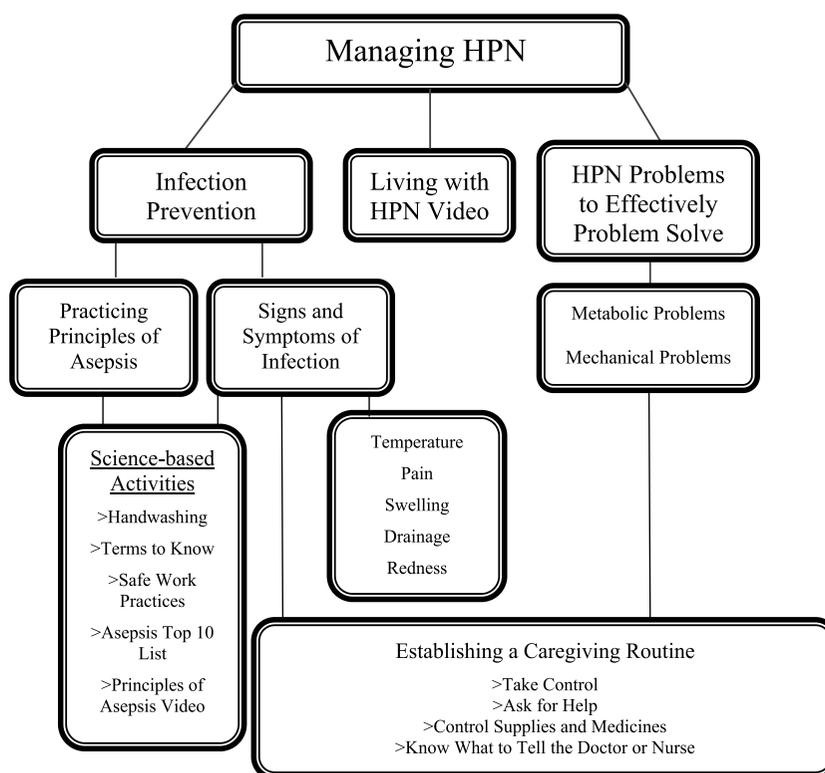


FIGURE 4. A flow chart outlining the content in the Managing HPN Web site section.

prevention; and problem-solving skills for common problems often associated with HPN.

A video entitled “Living With HPN” illustrates caregivers’ home care concerns and coping skills. This video includes information from healthcare professionals and personal stories from HPN patients and their caregivers. In controlled studies, caregivers who view video recordings of others managing similar situations have successfully adjusted to managing complex HPN home care^{55–57} and have had greater positive patient and caregiver outcomes.⁵⁸

In order to prevent infection, caregivers have access to information about practicing principles of asepsis and recognizing signs and symptoms of infection. Caregivers and patients are guided through the following science-based activities and information shown to be effective in reducing catheter-related infections: (1) hand washing, (the Centers for Disease Control and Prevention [CDC] indicates that hand washing is the first line of defense against disease-producing microorganisms and prevents the spread of pathogens)^{12,59}; (2) terms to know, such as “aseptic technique,” “clean,” and “sterile”; (3) safe work practices, such as preparing the HPN work station and handling sterile supplies; (4) asepsis top 10 list that includes infection prevention principles of which anyone managing HPN should be aware, compiled from other caregivers and patients managing HPN and the CDC; and (5) principles of asepsis video, which illustrates

techniques to help prevent HPN-related infections and guides caregivers in practicing the science-based activities for the principles of asepsis, such as hand washing and safe work practices.

Decision-making steps of the HPN Infusion Problem Monitoring and Solving Web pages are guided by the Oley Foundation’s Complication Chart, which lists the commonly repeating and serious problems that may occur with HPN. The Oley Foundation is a nonprofit 501(C) organization that provides information and psychosocial support to families managing HPN.⁶⁰ The Oley Complication Chart provides information about potential metabolic problems (systemic infection, hyperglycemia, hypoglycemia, and/or dehydration) and mechanical problems (air embolisms, cracking, catheter tearing or clotting, inflammation, and/or pump or power failure) often associated with HPN. The Web site emphasizes that this chart is to be used as a reference guide, not to replace the advice of the healthcare professional. A direct link to Oley Foundation’s Web site is provided.

Success Stories Web Pages

Social connection is an important component of this Web site, as social isolation among caregivers can be common and recurring.⁶¹ Research has found that 47% of HPN patients and caregivers rated their own peers as an

important source of health information and felt that information shared by people in similar situations is trustworthy.^{62,63} In this section, caregivers are encouraged to submit stories they feel would benefit others in the areas of self-care, problem solving, and overcoming challenges. These stories are edited by Web site staff to remove identifying information and protect the confidentiality of the author.

Other Resources Web Pages

There are more than 70 000 Web sites devoted to health information, and many of them have not been validated as having accurate and reliable information, thus exposing patients to misinformation.⁶⁴ Because of the amount of unreliable online health information, Healthy People 2010 includes a health communication objective for quality criteria for Internet health information sources.⁶⁵ To support this objective, the HPN Family Caregiving Web site provides links to other reliable Web sites found to meet quality criteria on topics such as (1) caregiving, (2) HPN, (3) medical/health information, (4) paying for healthcare, (5) clinical trials, (6) grief and bereavement, and (7) using and evaluating the Web for health information. Specific links include the Family Caregiver Alliance, the National Family Caregiver Support Program, the American Academy of Family Physicians, the Drug and Medical Device Alerts section of the Food and Drug Administration, the Centers for Disease Control, Medicare and Medicaid via the US Department of Health and Human Services, COBRA via the US Department of Labor, and clinical trial information and information about using the Web for reliable health information via the National Institutes of Health, to name a few. These resources were carefully chosen because the topics related to the learning needs, information queries, and support sought by caregivers managing HPN at home.

Our History Web Pages

It is important that caregivers feel a sense of connection with the individuals who provide them with health information.⁶³ In order to provide this sense of connection, the section entitled Our History offers myriad information about the Web site author and the research team that helped develop and maintain the Web site and how to contact these people. Also included is information about confidentiality, prior research findings, and the Web site staff's gratitude toward all previous and current caregivers who contributed to this Web site.

The Our History section also provides credibility and content validity of the Web site information to assuring users that Web site content and relevant information were

provided by researchers who are experts in this area. These pages also illustrate the partnership between researchers and caregivers who shared their real-life experiences and helped develop the content. The HPN Family Caregivers Web site was created by a Web site specialist in our university information technology (IT) department and reviewed by non-IT research staff and caregivers to ensure that the terms would be understandable to the lay public.

DISCUSSION

As with any growing discipline, there are negative aspects of online health information to consider. The current popularity of social media tools such as Twitter, Facebook, and weblogs provides the opportunity for quick dissemination of health information. However, this information is seldom deidentified and can often be inaccurate if not provided by a health professional.⁶² Furthermore, social media blurs the boundaries between nurses and patients, as online socializing with patients and/or their caregivers may damage nurse-patient relationships.⁶⁶

For these reasons, it is important that online health information be presented in a professional, nonsocial media format, as it is on the HPN Family Caregivers Web site, until further development can ensure privacy and accuracy of information disseminated through social media tools.

IMPLICATIONS FOR FURTHER RESEARCH

Because the Caring for Yourself information, activities, and algorithms are generalizable, they can be provided to and tested among caregivers of other chronic illnesses. If information specific to managing other chronic illnesses can be found to be effective when placed online, additional sections about providing home care for specific illnesses (eg, Managing Heart Failure, or Managing Chronic Obstructive Pulmonary Disease, etc) could be added to this Web site and tested.

CONCLUSION

The HPN Family Caregivers Web site was designed to provide caregivers with content about caring for themselves and their patients on HPN. The Managing HPN content is specific to this patient population, but the Caring for Yourself content is applicable to caregivers of patients with any chronic illness. The HPN Family Caregiving Web site was evaluated by external experts

as well as Web site users as a quality, science-based, reliable, and valid site providing caregivers with specific information to manage their own health while providing complex HPN home care.

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